

# **Transitioning from Home to Residential Care and its Impact on the Psychosocial State of Older Adults and Family Caregivers: A Scoping Review**

by

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## Declaration of Committee

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## Abstract

**Background:** Transitions to long-term care (LTC) homes at older age are occurring more often due to the escalation of complex health care needs at more advanced ages, increasing the demand for palliative care services and LTC homes that provide appropriate care. The lack of understanding and knowledge on transition and admission processes to LTC homes may impact the psychosocial state of older adults and family caregivers that accompany them. Moreover, healthcare staff and frontline LTC staff often lack access to organizational tools, understanding about transitioning experiences, peer support and must learn the appropriate knowledge to aid in the transition experience. The unique older adult and family caregiver transition experiences from the home to LTC have yet to be further explored.

**Methods:** To address the gap in literature, a scoping review of the global literature on the transitioning experiences of older adults and family caregivers from the home to LTC was conducted. The PRISMA-Scoping Review guidelines and the five step framework by Levac and colleagues were followed. Multiple databases were analyzed through narrative synthesis, the creation of infographics and informational tables.

**Results:** Twenty-one studies met the inclusion criteria. Transitioning experiences of both older adults and family caregivers were individually organized into three sections, with each of their respective subsections. 1) Pre-move experiences, 2) Move experiences, and 3) Post-move experiences.

**Discussion:** Identifying experiences and barriers and facilitators on the transition experience from the home to LTC offers more in-depth information and supported evidence on the need to develop and offer inclusive transition support programs to combat the grief, stress and other psychosocial factors that may arise throughout for both older adults and family caregivers, as well as the need for guidance when considering the move to LTC.

**Conclusion:** Future research is needed to implement policy, cultural and practice changes to enhance older adult's transition to LTC, the dissemination of information about transitions throughout the care continuum, admission processes and transition programs for families to benefit from.

**Keywords:** Family caregivers; Long-term care; Health care staff; Person-centered care; Transitions

## Dedication

This project is dedicated to my grandparents. Growing up in Spain I learned what it really meant to be taken care of deeply and wholeheartedly by spending my summers with them, living together and learning innumerable life lessons. To my grandmother **María Rivera**, you forgot about life before you left it, and every day I intend to honor you through my lifetime devotion of working with seniors. Your joyous infectious smile, empathic and loving heart, happy dancing moments and the love and kindness you had for people will forever be ingrained in me. You are the reason why I wanted to pursue this career and I hope wherever you are that you know that. I could not have done this without the revelations I had when visiting you and befriending other seniors at the long-term care home, where I learned about the need to provide better quality of life for the older adult population. To my grandparents **Pura (Puri, Purita) and Jesús (Sr. Gutiérrez) Gutierrez Pascual**, every summer was the best summer when I got to spend it with you. Every year, going for walks around your small town of roughly 300 people, and watching other seniors enjoy the shade on a hot evening from their chairs outside their homes would ask me the famous “y tú de quién eres?” (who are you from?), to which I would proudly answer “Del Sr. Gutiérrez y de la Puri!”. I will forever remember the continuous snacking, bantering during those hot evenings, and peeking out the curtains without being noticed to see who was walking by.

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## List of Acronyms

ADCs	Adult Day Centres
ADLs	Activities of Daily Living
IADLs	Instrumental Activities of Daily Living
BC	British Columbia
BCMoH	British Columbia Ministry of Health
CINAHL	Cumulative Index of Nursing and Allied Health Literature
COVID-19	Coronavirus Disease of 2019
HCP	Health Care Professionals
HCW	Health Care Worker
LTC	Long-Term Care
MEDLINE	Medical Literature Analysis and Retrieval System Online
PCP	Primary Care Provider
PRISMA	
PCC	Person-Centered Care
PSW	Personal Support Worker
PsycINFO	Psychological Information
PLWD	Persons(s) Living with Dementia
RQ	Research Questions
SW	Social Worker

# Chapter 1.

## Introduction

Transitioning to long term care (LTC) is a complex and emotionally taxing experience for both older adults and family caregivers. Transitions may often be preceded by a prolonged period of complex physical and/or mental health comorbidities that become incredibly challenging for family caregivers to manage effectively and efficiently (Fabbri et al., 2015; Stolee et al., 2019). Acute health conditions have also shown to lead to hospitalization, followed by transfer to LTC (Graneheim et al., 2014; SoS, 2015; Sussman and Dupuis, 2012;). These patterns have been exacerbated by increased demand for LTC due to population aging and availability of beds (Chateau et al., 2012; Marier, 2021). Research has shown that the transition to LTC occurs as a last resort due to values of independence, concerns related to care quality in LTCs, and resident safety (Sussman & Dupuis, 2012). Furthermore, the Covid-19 pandemic has significantly increased these concerns (Scopetti et al., 2021), which has made LTC transitions even more problematic.

Transitioning experiences from home to LTC, and the need for transition support services for both family caregivers and older adults, are a growing topic of interest, especially in the face of loss of control and choice over LTC placement options and complicated regulatory policies (Nolan & Davies, 2004). Furthermore, distress of transitioning a family member or friend into LTC can be heightened by access to limited information about navigating the relocation. For example, application procedures, payment, and selection of a LTC home, pressure for a premature move for older adults and family caregivers to feel ready (Lee et al., 2022; Reuss, Dupuis et al. 2015). Still, older adults and family members have felt unprepared and unsupported by the limited help from staff throughout the transition experience (Eika et al., 2013; Martz & Morse, 2017). There is a lack of coherent synthesis of recent studies that encapsulate experiences in transitioning processes by older adults and family caregivers. Thus, this scoping review specifically explores the experiences of older adults transitioning into LTC and the support of family

caregivers accompanying them in the transition. Moreover, barriers and facilitators related to this experience are included to synthesize a knowledge base of strategies that aim to explain the complex emotions they may experience when moving from a familiar, secure and homelike environment to unknown and new living conditions.

## **1.1. Key Terminology**

Long term care (LTC) is one of several terms that denote different levels of intensive residential care. The Government of Canada defines long-term based care as the care that “provides living accommodation for people that require 24 hour, 7 days a week delivery of supervised care, which include professional health services, personal care and services such as meals, laundry and housekeeping” (Government of Canada, 2004). However, it is not used in a consistent manner, given many other overlapping terms, such as residential care, retirement homes, nursing homes, etc. Part of this issue entails provincial and country differences since health is legislated differently. For the purpose and scope of this scoping review, we have decided to use LTC, which is the most used term among the current literature. However, other overlapping terms will be used in the key word search to scope the literature on this topic.

## **1.2. Background**

According to Statistics Canada, the population of older adults has increased to almost one in five Canadians (7.02 million people), representing about 19 per cent of the total population (Arriagada, 2020). 2021 marks an important year, as it was the year that the baby boomers, Canada’s largest cohort, began turning 75 (Canadian Medical Association, 2021). As older adults in this group move into older age with higher health care needs, so will the rapid growth of the demand for LTC services increase. Demand for LTC is expected to reach 606,000 older adults in 2031 with a cost of care of \$58.5 billion, compared to the 380,000 older adults in 2019, with a cost of \$29.7 billion (Canadian Medical Association, 2021). Even though the use of LTC

services have been on a downward trend in recent years due to preference and support of home care services, the cost for such limit access and affordability for families. Due to limited funding and availability of home care services for older adults, LTC services are seen as the last respite option for family caregivers to provide older adults appropriate and safe services in a supervised environment, matching the varying health care needs of older adults.

According to Statistics Canada, 7.8 million Canadians (25% of the population) were caregivers in 2018, with 51.35% of those aged 45 to 64 providing care for a parent (Arriagada, 2020). Previous studies have shown that women are 42% more likely than men to provide care for older adults in Canada (Arriagada 2020; Cranswick & Dosman 2008; Sinha 2013), with the biggest gender gap being throughout the ages of 45 to 64, yet decreasing substantially in older age groups (Arriagada, 2020). LTC home transitions have been identified as highly stressful, burdensome, and dissatisfying as the timing, pace, lack of resources, support, and accumulating responsibilities among others, may complicate the transition of aiding in the move into LTC home for the older adult (Adekpedjou et al., 2018; Muller et al., 2017). The transition to LTC includes decision-making, planning and preparation for the older adult and family members that may be part of the move and partake in subsequent care (Lee et al., 2013; Marshall et al., 2022). Moreover, deciding to move into LTC may often be reflected in terms of personal safety at home and worsening health, with varying levels of control over when and where to relocate is viable (Lee et al., 2013).

Prior scoping reviews and meta-synthesis have focused on the transition to illustrate the lived in experiences of older adults and family caregivers such as the ones from Sullivan and Williams (2017) or the one from Egan et al., (2023), which share distinct experiences and the importance of the decision-making process respectively. The sub-sections that follow this introduction will illustrate previous existing literature, giving an overall understanding of the diverse topics that will be covered throughout the findings including: The decision-making process for older adults and family

caregivers; the transition process; Family caregiver experiences in the transferring process into LTC; older adult experiences in the transferring process into LTC; and supporting transitions to LTC.

The decision-making process that encompasses the transition to move into LTC may include adult children, other relatives, friends, and relevant professionals to help them navigate the move from their private residence into the LTC home. The decision by family caregivers to move a parent from a non-residential care living arrangement into a LTC home has arguably been identified as one of the most difficult decisions for families to make (Gill & Morgan, 2011). Research has extensively highlighted the decision to move from one home to a LTC home as an emotionally taxing moment, with complex factors to take into consideration, emphasizing the older adult's loss of independence, the struggle between paternalism and autonomy, and the ambiguity the transition may bring regarding relational roles between the older adult and next of kin (Moilanen et al., 2021). Goldberg (2004) suggested that as families are coping with recent changes in their family member's health and/or independence, transition and health care decisions become even more complex. The support that next of kin provide to their parents demands for the attention to juggle many other responsibilities in their day to day lives, including child-rearing, personal interests, social affiliations, and employment, to which the demand of admission into LTC may be experienced as rushed and forced (Merla et al., 2018). Researchers have found that a crisis event, such as acute illness, fall, or an injury that leads to admission to the hospital may be a precursor for the decision to transfer an older adult into LTC (Horner et al., 2021; Merla et al., 2018). In addition, factors such as cognitive impairment, incontinence, wandering behaviors, loneliness or increased pressure on their partner/carer also serve as predictors and influence in the decision of LTC placement (Cepoiu-Martin et al., 2016; Merla et al., 2018).

The transitioning experience is impacted by many factors, including whether the transition, decision-making and home admission was unplanned and not discussed with older adults, creating feelings of loneliness, rejection, and isolation (Bowers, Nolet, & Jacobson, 2015; Brownie et al., 2014).

Research surrounding the decision-making processes on relocation has highlighted that older adults rarely take action in the decision to relocate to LTC, relying instead on the decisions and choices from family members, professionals, or both to decide when relocation will be needed (Fraher & Coffey, 2011; Johnson & Bibbo, 2014; Serrano-Gemes et al., 2020). Therefore, the degree to which older adults have control over their decision to move, stay or choose alternative care options that fit their needs, may cause emotional distress and personal loss in choice and autonomy, shaping their relocation experience (Fraher & Coffey, 2011; Lee et al., 2013; Zamanzadeh et al., 2016). In addition, personal emotional states throughout important life transitions have shown to be either disruptive, destructive, or empowering and regenerative (Almeida & Wong, 2009). Qualitative research included in this scoping review will expand on the evidence that shows the effects of leaving one's home behind to move into LTC and the behavioral responses that may arise from such change from both older adults and family caregivers, as well as which factors may empower a positive change and consolidation of the move, or a troublesome reaction.

Various theoretical models have been proposed to describe the decision of transitioning into a LTC home as a process involving several stages. Ducharme and colleagues (2012), proposed that the process begins when a caregiver, healthcare professional or at times the older adult, introduces the idea of the placement. The suggestion of a potential move is then evaluated in terms of the current living situation and future outcomes, weighing the pros and cons of a potential placement, which may result in the cessation about the move (which may later be resumed) or a final decision for placement into a LTC home. Bridges (2020) developed a transition model which begins with *endings*, wherein a person leaves a social and/or physical system they were previously embedded in, being a residential situation in this case. Next comes a *neutral zone*, where the individual finds themselves in between old systems and commitments but without a clear presence of a new beginning (Bridges, 2020). According to the transition model developed by Bridges (2020), most of the internal restructuring occurs in this phase, considered to be the foundation for personal growth in the next phase known



as *beginnings*, where the individual is met with new roles and relationships, as well as a new sense of purpose and sense of identity. Throughout this stage, individuals are challenged to develop alternative ways to view their surrounding world and the new experiences, a concept known as *reconstructing*, which may prompt the individual to respond creatively to their new reality (Ellis, 2010). Theoretical models such as the ones previously stated denote and guide the transitioning experience throughout this scoping review, exemplifying participants' unique experiences. In addition to theoretical research, this scoping review will comprise facilitators and barriers that may arise throughout the transition from previous qualitative evidence from older adults and family caregivers with different backgrounds and conditions, amplifying the understanding of the transition process.

Research has found that family caregivers may consider LTC placement as a final resort to meet the needs of their aging members, hoping to keep the older adult at home for as long as possible (Caldwell et al., 2014). Postponing transition when it is needed may lead to a crisis, with family caregivers finding themselves under pressure by health care professionals (HCP) to make important decisions about the older adult's care (Caldwell et al., 2014). Previous research using qualitative methods has found that for some family members, the transition of moving a relative into LTC may negatively impact their mental health (Cottrell et al., 2020). Moreover, the transition experience can be associated with feelings of self-doubt in family members and blame about not being able to provide the quality of care, resulting in feelings of loneliness in the care of their loved one; feeling isolated from other social circles and responsibilities due to care demands; ashamed about making the decision of going against their loved one's wishes; and powerlessness of not being able to meet the care needs of their loved one (Afram et al., 2015; Gaugler 2014).

Relationship standards between older adults and their family caregivers such as with next of kin, act as a primary source of emotional and instrumental support, which typically remains constant in quality across the lifespan relationship, with the quality of such impacting throughout salient

transitions (Carstensen 1992; Kwak et al., 2012; Meyer et al., 2022; Tough et al., 2022). Even though parents and next of kin may provide reciprocal care, conflict is present, with such closeness and unique relationship dynamics carrying more ambivalence than with other interpersonal relationships (Fingerman & Hay, 2004; Kwak et al., 2012). Role transitions within the relationship between older parents and next of kin as parents age may sharpen the struggle to negotiate and navigate each other's concerns that may appear and be enhanced in older age, with both closeness and concern present throughout (Hogerbrugge & Silverstein, 2015; Torabian et al., 2022).

Adult children caring for their parents and aiding in the transition process may experience conflicting emotions, as they weigh both positive and negative outcomes that may result from either working to either maintain their independence or acting paternalistically. Moreover, situational hardships and decision-making processes may cause adult children to wrestle with the roles of being their child and the primary caregiver to their parents, with responsibilities that relate to parental authority while also keeping their parents safe from harm due to declining health (Charenkova et al., 2023; Silverstein & Giarrusso, 2010). Such role transitions that may occur throughout the move to LTC and the responsibilities from family caregivers may heighten ambivalence, as the behavioral norms during this time period may be uncertain (Fingerman et al., 2006; Merla et al., 2018; Ornstein et al., 2017).

Extensive research within this field has argued that older adults can be especially unwilling to move into a LTC home (Robinson and Fisher, 2024). The widespread negative stigma throughout the media and public understanding surrounding residential care and LTC quality of life (QoL) have highlighted the ongoing belief of poor practice, non-homelike environments, elder abuse and neglect, impacting the willingness for older adults to move into LTC. In addition, the stigma and lack of control over the public understanding of LTC homes and working procedures have failed to highlight the innovative high-quality person-centered care (PCC) practices and the enhancement of the built environment. Furthermore, older adults may fear

that they will be forgotten once they move into a LTC home away from their immediate family, which adds to evasion and denial behavioral responses about moving into LTC (Boamah et al., 2021; Gaugler et al., 2014). Highlighting the improvement in care and QoL would enhance the self-actualization that is needed for a positive reception of the public about the developments taking place at present.

Older adults may respond to the relocation experience in distinct ways. For some, there may be a sense of relief and security in moving to a setting with supervised care provision from professional health care staff. This reassurance would reinforce the acknowledgement that their health deterioration may put them at risk if their care needs are not met and that living at home may not be a good person-environment fit (Davison et al., 2019; Koppitz et al., 2017). For others, moving into LTC may create a discrepancy in the meaning of home, expressing a desire to leave after several months (Davison et al., 2019; Koppitz et al., 2017).

The personal meaning and connection to the home is key for one's sense of identity, health, and well-being, as the home provides the individual with basic living needs (National Board of Health and Welfare, 2011; Rowles & Bernard, 2013). Ryan and Mackenna (2015) established that familiarity emerged as the core theme influencing relocation experience in the placement of an older relative in LTC. Literature has extensively covered the meaning of home, the stages in which this happens, and the diverse living conditions that may hinder the meaning-making process, including family homes (Bigonnesse et al., 2014; Molony et al., 2011; Oswald and Wahl 2005), assisted living homes (Cutler 2007; Lewinson et al., 2012), and LTC homes (Eijkelenboom et al., 2017; Johnson and Bibbo, 2014; Rijnaard et al., 2016), with each of these having their own distinct meaning-making processes. Creating meaning of one's surroundings, occurs by one's interpretation of the cultural and social world that surrounds individuals, with such meanings defining and reflecting older adults' relationships to their environment (Allen et al., 2021; Chaudhury & Oswald, 2019; Kaufman, 1981).

Older adults transitioning to LTC may choose to allocate personal meaning and sources of familiarity within the new space they move into. Previous studies have shown that the home is viewed as both a place and a quality that develops over time through the personal, social, and physical domains (Molony, 2010). In addition, older adults' self-identity and personal history have been found to be intertwined with dwellings and personal possessions, which may be transferred to their new residential environment, serving as a source of familiarity (Shenk, Kuwahara, & Zablotsky, 2004). At times, one's possessions, attachment to the home, feelings of belonging, autonomy and previous lived experience in the community are left behind, causing a feeling of disconnect from their self-identity, making it a difficult transition for older adults.

As the need for professional healthcare services for older adults increases over time, the accumulated financial, social, psychological, and physiological effects of family caregiving intensify (Pinquart & Sorensen, 2003). Supportive measures throughout the transitioning process have been found to reduce caregiver burden and depressive symptoms among family caregivers by providing enhanced counseling (Gaugler et al., 2008). Recent research has shown that the continued involvement of relatives in care and on the impact of admission to LTC can lower their own level of stress and mental health effects of the transition of their family member (Gaugler & Mitchell, 2022; Tornatore & Grant, 2002; Schulz et al., 2004). In addition, meta-analyses and multisite, randomized, controlled studies have demonstrated that psychosocial interventions for caregivers such as skills training, education, therapeutic counseling, and information-based services are generally effective in improving psychological well-being (Sorensen, Pinquart, Habil et al., 2002; Sorensen, Duberstein, Gill et al. 2006; Zarit et al., 2008).

### **1.3. Research Contribution**

This scoping review will map and illustrate the existing empirical literature that have examined the transitioning process from the home to residential care, specifically LTC homes among community-dwelling older

adults and family caregivers. From current knowledge throughout the time of data collection, no scoping review has summarized and compiled literature on the transitioning experience that include the pre-move, move, and post-move experiences as a continuous process with distinct stages and each of their identifiable sub-themes. Specifically, this scoping review will encapsulate the overall transition experiences of older adults and family caregivers, which contrasts with other reviews that only review older adults or distinct sub-types of transitions (e.g., dementia or immigrants) (Afram et al., 2015; Lee et al., 2022; Young et al., 2019). This will fill a gap in the knowledge base related to this topic, since it will focus on the home to LTC transition experiences of the dyad, both together and individually. Three research questions guide this scoping review: 1) What are the most common pathways by which older adults and family caregivers experience transitions from home to LTC? 2) What are the most prevalent barriers and facilitators that are experienced by older adults and their family caregivers during these transitions? 3) What transitioning support (community and long-term care) is available for older adults and their caregivers moving into residential care to maximize integration and wellbeing?

The scarcity of recorded transition experiences surrounding this topic have proved for a scoping review to be an appropriate choice, compared to other systematic and iterative approaches such as with a meta-analysis. Meta-analysis is described as a quantitative, formal, epidemiological study design used to systematically assess previous research studies to derive conclusions about a body of research (Haidich, 2010). For the purpose of this study, quantitative research has not been the main focus to exhibit the literature. Regarding this topic, qualitative research provides a more detailed description about the transitioning experiences that cannot be fully expressed into numbers to understand human experience and everyday realities throughout the move to LTC. In addition, compared to the purpose of providing a consolidated and quantitative review of large, complex interactions of diverse bodies of literature, this scoping review will incorporate themes collated from the findings to enhance the understanding of the transitioning experiences instead of scales explaining the resulting behavior of an

interaction. In addition, conducting a scoping review provides detailed reflection on the empirical and unique experience of individuals and the recounting of such that include their own understanding on their behavior related to moving, the meaning of home, grief, relief, sadness and loss.

## **Chapter 2.**

### **Methods**

To identify transitioning experiences of older adults and family caregivers from the home to a LTC home, this scoping review of related existing literature incorporated the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) guidelines (Tricco et al., 2018). By using a systematic and iterative approach, a scoping review identifies and synthesizes an existing or emerging body of literature on a given topic to examine the evidence and identify the gaps in literature and research questions that need to be addressed (Mak and Thomas, 2022; Tricco et al., 2018). In addition, the methodological framework developed by Arksey and O'Malley (2005) is used to achieve in-depth and comprehensive results to identify all relevant literature, regardless of the study design.

The five steps developed in the methodological framework by Arksey and O'Malley (2005) are as follows: 1) identifying the research question, 2) identifying relevant studies, 3) study selection, 4) charting the data, 5) collating, summarizing and reporting the results. This scoping review summarizes transitioning experiences of older adults and family caregivers transitioning to a LTC home and the current gaps in research that need to be addressed in future research to fully understand the experience, potential solutions and recommendations from the existing literature. Throughout this scoping review, supervisory committee consultation was present. A protocol and research strategies for the scoping review were developed, defended and approved, which were required as part of the capstone project process for the completion of the Master of Arts in Gerontology at Simon Fraser University.

#### **2.1. Step 1: Identifying the research question**

The research questions that guide the scoping review were identified, which include: 1) What are the most common pathways by which older adults and family caregivers experience transitions from home to LTC? This was

followed by two questions to gain in-depth understanding and add to the scoping review: 2) What are the most prevalent barriers and facilitators that are experienced by older adults and their family caregivers during these transitions? 3) What transitioning support (community and long-term care) is available for older adults and their caregivers moving into residential care to maximize integration and wellbeing? Throughout the scoping review, these research questions address the emotional journey of transferring to LTC and the potential barriers and facilitators for a well-ordered transition to establish a helpful knowledge base throughout practices and policies unique to each family, healthcare professionals and LTC homes.

## 2.2. Step 2: Identifying relevant studies

For this scoping review, the following databases were used to identify relevant studies, including: AgeLine, CINAHL, MEDLINE/PubMed and PsychInfo. Included in the search criteria were peer-reviewed articles dated from January 2010 to present date to include the most current findings. In addition, earlier resources were also included throughout the background review of literature to include concepts needed for further understanding the transition experience for both introduction and discussion. A search framework for the preliminary search was conducted to identify relevant key terms throughout the review including the Participants, Concepts, Context (PCC) approach designs by the Joanna Briggs institute (2015).

**Table 1. Participants, Concepts Context (PCC) concepts and keywords.**

<b>PCC</b>	<b>Inclusion Criteria</b>	<b>Alternative Keywords</b>
<b>Population</b>	Older adults 65 and over, family caregivers, next of kin.	Senior, elderly, 65+, aging.
<b>Concepts</b>	Transition experience to long-term care	Transitions, transitioning, move.
<b>Context</b>	Long-term care	Nursing homes, care homes, residential care, skilled nursing facilities.

Title, abstract and keyword fields were searched by using a combination of the following terms: An example of a search strategy for the



database is as follows: (“older adult\*” OR “senior\*” OR “elderly” OR “65+” OR “aging”) AND (“home”) AND (“long-term care” OR “nursing home\*” OR “care home\*” OR “residential care” OR “skilled nursing facilities”) AND (“family caregiver\*” OR “informal caregiver\*” OR “next of kin”) AND (“decision making” OR “decision making process”) AND (“transitions” OR “transitioning” OR “move”). This key search by words resulted in older adults (5 terms), home (1 term), long-term care (5 terms), family caregivers (3 terms), decision making (2 terms), and transition (3 terms). Boolean operators AND and OR were used for the search strategy, as well as parenthesis and truncation as needed (\*) to increase the number of studies throughout the search. For search to be consistent throughout the databases, the default search [All Fields] was used throughout the included databases to account for diverse possible fields that might discuss this topic.

### **2.3. Step 3: Study Selection**

The initial results from each of the databases used for this scoping review were saved through a Zotero extension included for google chrome, to then automatically import them as .csv files into Zotero for Mac. Zotero was used to organize the articles into different possible themes, sort out any duplicates that would arise from different databases, screen abstracts and screen full texts for inclusion. After this, data was charted by customizing the setting into a final PRISMA flow chart (Figure 1), highlighting the study selection process. To increase validity of the screened articles, an external reader (IR) took part in the abstract screening process, with abstracts being reviewed to be included or excluded based on the eligibility criteria described in the next section. Moreover, to meet the qualifications of this capstone project with the guidance of my supervisor (AW), I (HGV), screened full text articles for the final version of the inclusion criteria. In addition, after full text revision, screened texts were transferred from Zotero and uploaded to Microsoft Excel for final screening. All software used throughout this project was accessible or downloadable through an institutional licensing agreement from Simon Fraser University.

### 2.3.1. Eligibility Criteria

Inclusion and Exclusion criteria are highlighted in Table 2.

**Table 2. Inclusion and Exclusion Criteria**

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"><li>• Published in English language</li><li>• Address research on the transition experience of older adults and/or family caregivers from the home to LTC</li><li>• published between January 2010 to the beginning of the search of articles</li><li>• full-text and peer-reviewed articles</li></ul>	<ul style="list-style-type: none"><li>• no English full-text available</li><li>• published before January 2010</li><li>• systematic reviews, scoping reviews, book chapters</li><li>• research question/s specific to other residential care options (e.g., assisted living, home care, hospital, adult day centers)</li><li>• Older adults and family caregivers were not the primary participant group in the study.</li></ul>

### 2.4. Step 4: Charting the data

Data from the final selected studies were gathered and charted according to the finalized themes. Charting the data allowed for the reviewer to collect and sort the literature in an organized manner, sort findings according to the research questions guiding the research, the resulting themes and categories (Arksey & O'Malley, 2005), serving as visual representation of the literature. For charting articles, the independent reviewer (HGV) included the author, year and journal of publication, overall characteristics of older adults and family caregivers, geographic location of the study, study methods, barriers and facilitators throughout the transition experience, limitations and other key findings that may be important to account for.

## **2.5. Step 5: Collating, synthesizing, and reporting the results**

For this scoping review, the results are presented through narrative synthesis. Study demographics and participant characteristics were collated and presented in diverse graphics. Moreover, charts, diagrams and visualizations for different audiences are shown throughout the scoping review to convey additional findings of the selected articles in a visual representation. Strengths and limitations of the selected articles are included with their pertaining citations in the discussion section. Moreover, knowledge gaps and future research opportunities.

### **2.5.1. Narrative Synthesis**

Narrative synthesis was selected as the method to present findings due to the overall qualitative and mixed methods nature of the research found for this topic and selected for this scoping review. For this paper, Arksey and O'Malley's (2005) qualitative meta-synthesis will be followed for reference. Each of the articles that were selected for this scoping review were read in full to organize the answers to the review's three questions related to the transition experience from home to LTC as well as the barriers and facilitators that may hinder or expedite the move to LTC for older adults and family caregivers. To conduct a narrative synthesis, it was necessary to obtain descriptive statistics first such as age, geographical location, and research design of the selected studies in order to summarize findings and present them in visual tables. Moreover, a narrative synthesis, creating and organizing highlighted themes from the charted data is present in the results and discussion sections (Arksey & O'Malley, 2005).

### **2.5.2. Ethics Statement**

Institutional ethics approval was not required to complete this study, as scoping reviews, the study method used for this project uses preexisting data from published literature.

# Chapter 3.

## Results

### 3.1. Included Studies

Searching five social sciences databases using the aforementioned keywords for the topic of interest resulted in 21 articles. Duplicates were removed, leaving 179 for title and abstract screening. By conducting abstract screening, 128 articles were removed, resulting in 64 articles for full text screening. Finally, 21 articles met the inclusion criteria, and 43 studies were excluded (Figure 1).

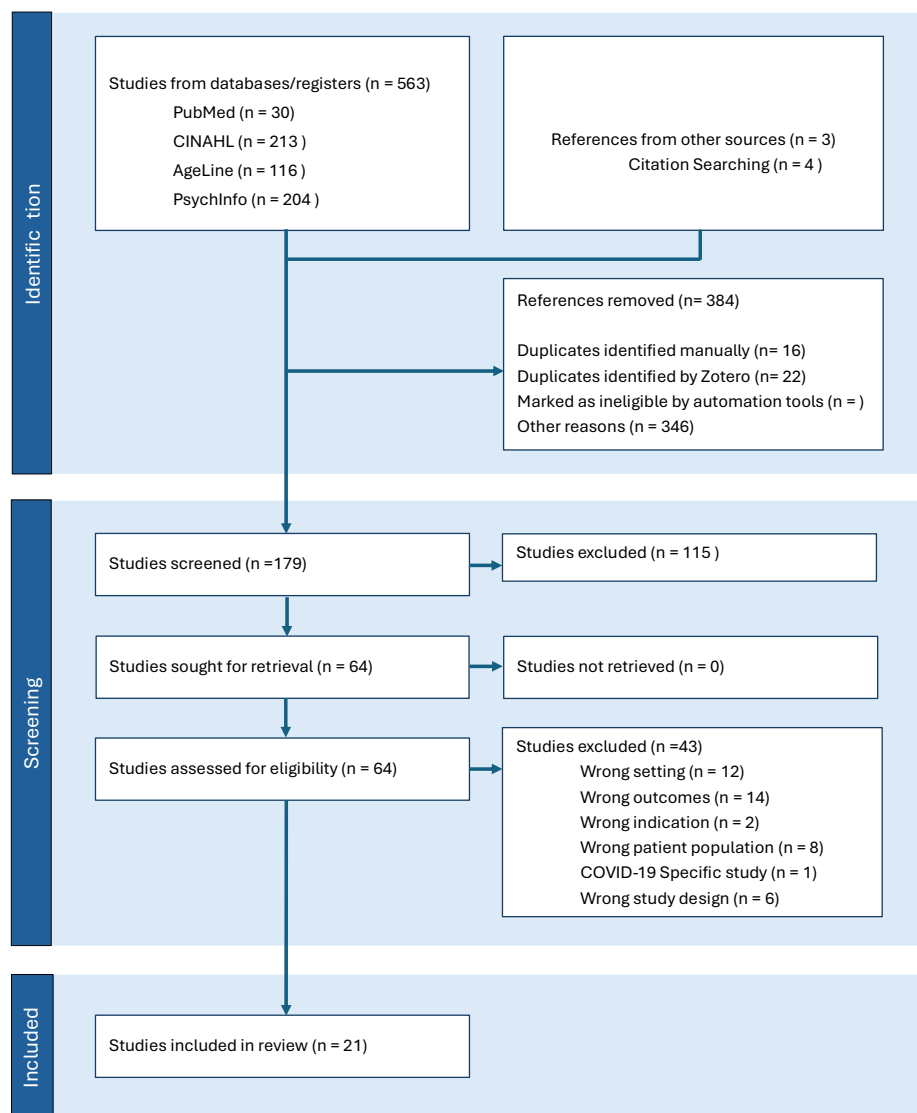


Figure 1. PRISMA flow chart: Screening process for study inclusion

### 3.2. Study Characteristics

A total of 21 articles were reviewed and included for this scoping review. All articles were published in English and available through the SFU Library Database. Most articles used qualitative (20), while one used a quantitative design (n=1), with no mixed methods studies. Most of the studies conducted qualitative interviews and included focus groups of older adults and/or family caregivers. The study nature of qualitative studies showed more in depth and descriptive results than those of quantitative style that have more structured results. The following subsections will include the characteristics of the chosen studies including geographic location, methods and concepts, and participant demographics.

The study characteristics for both qualitative and quantitative studies are shown in Table 3 (Appendix C). Overall articles explore the transition from home to LTC for both older adults (Groenvynck et al., 2022; O'Neill et al., 2019; O'Neill et al., 2020b;) and family caregivers accompanying older adults (Cottrell et al., 2020; Elka et al., 2013; Groenvynck et al., 2022; Hainstock et al., 2017; Konietzny et al., 2016; Koplrow et al., 2015; Ramanathan and Fisher, 2015; Robinson & Fisher, 2023; Ryan and McKenna, 2013; Scott and Funk, 2022; Sussman and Dupuis, 2012; Wu and Rong, 2020; Zamanzadeh et al., 2015). Some articles were focused on the phase prior to the move to LTC (Kiwi et al., 2017; Robinson and Fisher, 2023). Other articles aimed their focus into the early post-placement period and relocation impact on both family caregivers (Gaugler et al., 2010; Zizzo et al., 2020) and older adults (O'Neill et al., 2020a; Sun et al., 2021), which were helpful to gather information about the specifics over the last phase of the transition experience. Most articles had a qualitative thematic approach except for Gaugler et al., (2010), with a quantitative approach. Some articles such as the ones grounded theory, others used a gerontological approach, by encouraging researchers and others to consider the influences involved in older adults transitioning to LTC.

### **3.2.1. Keywords**

Keywords were gathered for all studies to gather the diverse ideas and research focus authors had for their studies. Together with the keywords that were displayed in the PCC table (Table 1), keywords throughout the studies include the central concepts of transition to long-term care, family caregiving, grief, relief, loss, the meaning of home, and changing roles. Even though dementia was not a term included in the overall scope of this scoping review, the prevalence of older adults with dementia moving into LTC due to overall health decline and other aspects was very present, creating a deeper understanding about the experience for both older adults and family caregivers of transitioning from the home to LTC.

### **3.2.2. Geographic Location**

There were no limitations placed for the country of origin where studies were conducted. Most publications originate from North America (Canada n=5, United States n=3). Followed by Canada, research ranges from 5 provinces from where literature was present (BC n=1, NWT=1, AB=1, MB=1 ON n=2). The United Kingdom (n=4), Netherlands (n=1), and Ireland (n=1) also provide some insight on the research interest of this topic throughout Europe. Norway (n=1) and Sweden (n=1) offer insight into the experiences of transitioning from home to LTC from a Scandinavian perspective, with Australia (n=2) for Oceania. Asian countries such as China (n=1), and Singapore (n=1) provide some insight from Asia, with Iran (n=1) for the Middle East with topics such as filial piety being highly present. The lack of studies from Africa (n=0), and South America (n=0) may be due to diverse models of care, contributing to the lack of research in this area.

### **3.2.3. Participant demographics**

Participant demographics have been recorded for table 1, which include the sample size, category (older adults/family members/LTC staff), time since the move to LTC, age range and/or average, gender, and race or ethnicity (if disclosed). It is important to note that not all articles included

characteristics such as race or ethnicity, with homogeneity mentioned as a limitation of their study if considered. Major themes that arose from available demographics and findings are presented below featuring pre-transition, during transition, post-transition and the diverse experiences throughout these stages for both older adults and family caregivers.

**Table 3. Participant demographics and characteristics**

Author (s) (Year) Country	Sample Size	Categories Older Adults/Family Caregivers/LTC Staff	Time Since the Move	Age Range	Race and Ethnicity	Gender
Cottrell et al., (2020) Canada	n=9	Self-identified family/friend of older (>65 years of age) frail persons with dementia, admitted to a 24-hour care home	Length of post-placement caregiving ranged from 5 to 55 months.	Mean age of participants was 67.57	Not disclosed	Predominantly female (89%), married (78%), not employed (78%), and caring for their spouse or life partner (89%).
Elka et al., (2013) Norway	n=18	10 next of kin to newly admitted 8 residents.	Older adults in LTC within 4 weeks of admission	Next of kin covered age categories from 30s to 80s. Older adults ranged from 70s-90s.	Not disclosed	3 sons, 4 daughters, 2 wives, 1 niece
Gaugler et al., (2010) United States	6-month post-placement cohort: 1,610 dementia caregivers. 12-month post-placement cohort: 1,116.	Baseline sample of MADDE included 5,831 caregivers and care recipients with dementia. MADDE collected data on 1,610 caregivers six months after NHA and 1,116 caregivers 12 months following NH entry.	6–12-month post-placement data	CR average age 71.47. CG average age 63.56.	CR is Caucasian (92%)	6-month post-placement cohort: Wife 33.4%, husband 17.8%, 26.6%, other 22.2%. 12-month post-placement cohort: wife 29%, husband 19.1%, daughter 29.1%, other 22.8%



<b>Author (s) (Year) Country</b>	<b>Sample Size</b>	<b>Categories Older Adults/Family Caregivers/LTC Staff</b>	<b>Time Since the Move</b>	<b>Age Range</b>	<b>Race and Ethnicity</b>	<b>Gender</b>
Groenvynck et al., (2022) The Netherlands	n=24	24 informal caregivers of PLWD moving to a LTC home	Length of stay at the nursing home: 0-6 months: 7 7-12 months: 2 1-2 years: 9 2-5 years: 6	Participants were on average 62 years old.	Not disclosed	Majority were women (n=17) and daughters. 7 men
Kiwi et al., (2017) Sweden	n=20	20 family caregivers.	N/A	30 to 63 years of age	Iranian family caregivers	11 female and 9 males; 9 daughters. 8 sons, 2 wives and 1 trustee
Konietzny et al., (2016) Canada	n=13	13 interviews with informal caregivers of older adults.	Within the past 6 months	Over 60% of participants (n=8) were aged 45-65 years, and the remaining participants were over age 65.	No data collected on demographic or cultural aspects.	9 female and 4 male. 4 Adult children, 3 spousal caregivers, 2 siblings, 2 other family, and 2/friend/neighbor.
Koplow et al., (2015) United States	n=10	A purposeful sample of 10 primary family caregivers.		Caregivers ranged in age from 52 to 86. with a mean of 70 years. Older adults ranged from 72-90 years, with a mean of 83 years.	All identified as non-Hispanic Caucasian	8 women, 2 men.

<b>Author (s) (Year) Country</b>	<b>Sample Size</b>	<b>Categories Older Adults/Family Caregivers/LTC Staff</b>	<b>Time Since the Move</b>	<b>Age Range</b>	<b>Race and Ethnicity</b>	<b>Gender</b>
Martz and Morse (2017) United States	n=17	14 family caregivers, one SNF social worker, one ALF nurse, and once hospice worker	Time since relative's death ranged from 6 months to 8 years	Ages ranged from 50 to 71 years, with the majority in the range of 56 to 60	Not disclosed	10 daughters, 4 daughters-in-law and one son.
O'Neill et al., (2020) United Kingdom (a)	n=17	17 older adults.	Over the course of 12 months at 4 points: prior to or within three days of admission, and at 3 points after the move (4-6 weeks, 4-5 months and 12 months).	Average age of 83.3 years (one participant is 60 years old).	Not disclosed	10 women, 7 men.
O'Neill et al., (2020) Ireland (b)	n=17	17 older adults from 8 care homes.	Between 5-12 months	Average age of 83.3 years (one participant is 60 years old).	Not disclosed	10 women, 7 men.
O'Neill et al., (2019) United Kingdom (c)	n=23	23 older adults	Focused on preplacement (7 days) and immediate post placement (within 3 days) period of the move to the care home	60 and over	Not disclosed	Older adults 14 women, 9 men.
Ramanathan and Fisher (2015) Singapore	n=12	12 family caregivers of the residents aged and above from a LTC home in Singapore were recruited	Length of stay ranges from 2 months to 5 years.	Family caregivers ranged from 38-70.	Not disclosed	4 sons, 7 daughters, 1 brother, 1 daughter-in-law. 5 males and 7 females

<b>Author (s) (Year) Country</b>	<b>Sample Size</b>	<b>Categories Older Adults/Family Caregivers/LTC Staff</b>	<b>Time Since the Move</b>	<b>Age Range</b>	<b>Race and Ethnicity</b>	<b>Gender</b>
Robinson and Fisher (2023) United Kingdom	n=13	13 family caregivers,	N/A	43-77 years old	Not disclosed	5 men and 8 women.
Ryan and McKenna (2013) United Kingdom	n=29	29 relatives of LTC home residents.			Not disclosed	Almost half were daughters (14), sons (6), wives (3), daughters-in- law (n = 2), nieces (n = 2) and nephews (n = 2)
Scott and Funk (2022) Canada	n=22	22 family members caring for an older adult.		Mean age of participants 55 (32- 74)	Not disclosed	20 female, 2 male. 17 sons/daughters, 2 spouse/partner 1 niece, 1 granddaughter, 1 friend
Sun et al., (2021) China	n=16	11 older adults. 5 staff members	Between 3-12 months	Older adults (≥65).	Not disclosed	Older adults: 6 men, 5 women Staff: 1 man, 4 women
Sussman and Dupuis (2012) Canada	n=20	20 family caregivers	Older adults had been in LTC from 8 days to 5 weeks, with an average of 20 days (three weeks).	Older adults admitted to LTC were 75 and over.	Not disclosed	17 women and 3 men. Three sons, three daughters-in-law, 10 daughters, three wives and one granddaughter.

<b>Author (s) (Year) Country</b>	<b>Sample Size</b>	<b>Categories Older Adults/Family Caregivers/LTC Staff</b>	<b>Time Since the Move</b>	<b>Age Range</b>	<b>Race and Ethnicity</b>	<b>Gender</b>
Tanya et al., (2019) Australia	n=38	12 residents, 14 family caregivers, 12 facility staff.	Between 2-6 months	Residents with dementia ( $\geq 65$ )	Not disclosed	Residents with dementia: 10 women, 2 men Family members of a resident with dementia: 9 women, 5 men RAC facility staff: 11 women, 1 man
Wu and Rong (2020) Taiwan	n=16	16 residents who had relocated to two LTC facilities	Lived in the facility up to 12 months	Older adults ( $\geq 65$ ) that had relocated to LTC	Taiwanese residents	Older adults: 11 women, 5 men
Zamanzadeh et al., (2015) Iran	n=23	20 residents and 3 formal caregivers	Average of 11 months (range 1-48 months)	Residents 62 and over.	Not disclosed	Older adults: 6 women, 11 men. Caregivers: 3 women
Zizzo et al., (2020) Australia	n=55	13 residents, 14 carer- relatives and 28 staff.			Not disclosed	Residents: 13 women, no men. Carer-relatives: 10 women, 4 men.

### **3.3. Overview of findings**

Key findings from each article related to the research questions regarding the most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC (RQ1); the challenges and facilitators throughout the transitioning experiences (RQ2); and transitioning support (community and long-term care) available for older adults and their caregivers (RQ3) were recorded in Table 5 and analyzed through narrative synthesis for further comprehension. From the extracted data, the included articles for this scoping review were then organized into 3 main themes for each of the two categories of family caregivers and older adults according to the qualitative meta-synthesis framework: 1) pre-move experiences, 2) move experiences, and 3) post-move experiences.

### **3.4. Older adult experiences**

The generated findings gathered from the studies used for this scoping review were used to aid in the development of thematic analyses, organized into three transitional stages for both older adults and family caregivers. For older adults, these include:

- Pre-move experiences
  - The Impact of Escalating Care Needs
  - The importance of Decision-making and Exercising Choice
- Move experiences
  - Limited Resources and Allocated Time for the Move to LTC
  - Loss of Identity When Leaving the Home
- Post-move experiences
  - Adaptation and Integration
  - Impact of the Move on the Psychosocial State of Older Adults
  - Maintenance of Self and Identity in LTC
  - The Loss of Familiar Roles and Independence

The different subsections highlight the distinct occurrences that have been recorded throughout the selected literature, from the beginning of the decision-making process, adapting into the new living conditions and maintaining familial relationships after the move into a LTC home, as well as taking into consideration the impact of the move and the resulting outcomes.

### **3.4.1. Pre-move experiences**

#### ***The Impact of Escalating Care Needs***

It is evident that the most predominant challenge as to whether to age at home or transition into a LTC home is dictated by the decline of physical and cognitive health, accompanied by escalating health and caregiving needs of the older person. O'Neill et al. (2020b; 2022) found that health decline increases care burden for family caregivers, who in many cases may not be capable to partake in the fulfillment of care demands that may be required, such as professional health care services to aid in ADLs. Specifically, changes in health, complex social circumstances limiting care availability, and increased health risks when living alone due to health conditions are reported to increase the need to move to a LTC home, often seen as last resort and at times seen as the only choice (O'Neill et al., 2020b).

Multiple articles showed that hospital visits due to health emergencies may leave older adults dependent on professional care and management of ADLs, with limited support if they were to return home, seconded by professionals that moving into LTC is the best and safest choice (O'Neill et al., 2022; Wu and Rong, 2020). Literature showed the high incidence of hospital admissions as part of the pre-move experiences to LTC, recorded to take place following an emerging or critical condition, resulting in consequent transfer to the first available LTC home, without account for individual preference and limiting choice for older adults (Hainstock et al., 2017; Scott and Funk, 2022). Hospital experiences are covered throughout the studies chosen for this scoping review to an extent, as moving from the hospital to a LTC home has been conveyed throughout literature as a liminal transit space that may result in LTC placement, accompanied by its own experiences and emotional responses.

### ***The Importance of Decision-Making and Exercising Choice***

Decision-making processes and exercising choice throughout the transition experience were shown to be incredibly relevant in multiple articles (Davison et al., 2019; O'Neill et al., 2022; Wu and Rong, 2020; Zamanzadeh et al., 2015), relating to both older adults and family caregivers. Multiple articles showed that the transition experience is affected by the ability to exercise choice on whether older adults were forced to move, not informed about the possibility of the move, or not involved in the decision-making process to move to LTC. Two articles highlighted how older adults may not have had the option to stay at home with increased home support services, which resulted in the transition to LTC to be a traumatic experience (O'Neill et al., 2020b; Zizzo et al., 2020). An article by Wu and Rong (2020) described the limited choice of older adults in their decision to relocate. Moreover, Wu and Rong (2020), also found that older adults experienced conflicting emotions between the desire to continue living in their own family homes and the need to avoid further disruption to the lives of their families whom they depended upon for ADLs. Multiple articles described how this experience was usually managed by family caregivers, hospital staff, case managers and other healthcare workers involved in the care of the older adult (Davison et al., 2019; O'Neill et al., 2022; Wu and Rong, 2020).

The increased need for LTC services has abruptly escalated waiting times for LTC admission, further restricting choice when considering appropriate and preferred home options (O'Neill et al., 2019). Two articles conducted by O'Neill et al., and Zamanzadeh et al. (2019; 2015), showed that older adults may not have an active role in negotiating changes to financial or care resources when beds become available in LTC due to the pressure placed in families to accept the next one available due to the high demand and year long waitlists. One article found that older adults involved in the decision to move to a LTC home adjusted better to the new environment and were more able to manage loss and grief (Zizzo et al., 2020). On the contrary, O'Neill et al. (2020b) found that not being involved in the decision-making process negatively impacts the feelings of "being at home" when moving into LTC. Moreover, Wu and Ruong (2020), stated that older adults experienced

psychological resistance while making the decision to move to LTC, fearing loss of autonomy and being able to perform selfcare. An article by Zamanzadeh et al. (2015) showed that, in some cases, older adults themselves initiated and/or willingly agreed to the move, since there was a noticeable personal loss in health, source of income, or death of a family member that was needed for the older adult to age in place, leading to the contemplation of LTC. A study conducted by Davison (2019) affirmed that the decision taken by older adults to move into LTC reinforced feelings of acceptance about the move, which reassured them as they knew that they would receive the required care at the LTC home. Another article by Zizzo et al., (2020) found that exercising choice by visiting diverse LTC homes and being presented with diverse residence options improved the overall transition experience, even when the preferred one was not available

### **3.4.2. Move experiences**

#### ***Limited Resources and Allocated Time for the Move to LTC***

Multiple articles have stated that informational resources are scarce and complex to navigate throughout transition and relocation into LTC (Groenvynck et al., 2022; Hainstock et al., 2017; Zizzo et al., 2020). Moreover, the aforementioned studies demonstrate that the limited or nonexistent support from staff and healthcare workers has impacted the overall knowledge that both older adults and family caregivers possess about what's needed for the move, procedures, and other aspects needed for a timely transition (Groenvynck et al., 2022; Hainstock et al., 2017; Zizzo et al., 2020;). Additionally, the time between receiving confirmation of bed availability and moving has shown to be incredibly short and anxiety invoking for the dyad, thereby limiting the time to process the move (O'Neill et al., 2019; Sussman and Dupuis, 2012). The move can often be a rushed process once a spot becomes available (O'Neill et al., 2019). Care managers/hospital staff were reported in the study by O'Neill et al., (2019) to make the decisions about the move, regardless of whether it's taking place from the hospital or one's home. In addition, four articles found that financial and funding resources for moving into preferred LTC homes limited aged care services,



exercise choice for placement, and increased the hardship throughout the transition (O'Neill et al., 2019; Robinson and Fisher, 2023; Zamanzadeh et al., 2016; Zizzo et al., 2020;). One author found that older adults entering LTC use different resources for the move, including: government pensions, charity organizations, and means of support from family, with its availability causing distress about having to use out of pocket expenses (Zamanzadeh et al., 2016).

### ***Loss of Identity When Leaving the Home***

Leaving one's home causes distress in older adults as they leave their community, friends and family behind, losing the identity that is tied to their home and related social and emotional aspects. O'Neill et al., (2020b) found that for some older adults, being able to say goodbye to their home was imperative, which included being able to sort out belongings and have someone that facilitated their house sale. A major challenge identified from a study conducted by Zamanzadeh et al. (2015) was the perceived loss of home life, which threatened identity, belonging and sense of self. O'Neill et al. (2020a) highlighted that individuals sometimes felt hopelessness and despair about their future in LTC. In addition, older adults in the aforementioned study were found to express feelings of sadness when moving to LTC yet were worried about expressing this anxiety about the move to others (O'Neill et al., 2020b). Feelings such as wishing for death upon admission were documented throughout a study by O'Neill et al. (2022), as a personal reflection of the psychological wellbeing of older adults at the time of the move. Death, anxiety, and isolation were shown throughout two studies to converge with feelings of grief about moving to LTC, creating a heightened awareness about death due to health decline and subsequent placement in LTC (O'Neill et al., 2020; Zamanzadeh et al., 2015).

### **3.4.3. Post-move experiences**

#### ***Adaptation and Integration***

Articles used for this theme showed that the move to a new home may enhance the need to find a sense of belonging and establish new

communication networks with other residents and staff. Research on the impact of the move showed both positive and negative emotions from older adults as some acknowledge that the move was necessary, trying to make the best out of the situation by aiming to create new relationships, yet understanding that LTC homes differ from the familiar and homelike environment of one's own home (Davison et al., 2019; O'Neill et al., 2020a; Sun et al., 2021). An article by O'Neill et al. (2019) found that after relocation, older adults feel out of place, with resident's levels of cognitive impairment as a fundamental obstacle to social engagement. Multiple articles found that reconstructing one's life and forging new relationships in the LTC is crucial to one's sense of identity and connectedness, which may enhance or reduce one's sense of self through the interaction with other residents by taking the steps to adjust, navigate their new environment, and get along with other residents and staff (O'Neill et al., 2019; O'Neill et al., 2020a; Sun et al., 2021). In addition, several articles demonstrated that creating new friendships within their new home significantly contributed to a sense of home, understanding each other's concerns, QoL and well-being (O'Neill et al., 2019; O'Neill et al., 2020b; Wu and Ruong, 2020). An article conducted by Wu and Rong (2020) described the experiences of viewing the relocation to LTC as a way of minimizing the burden of care for family caregivers to lessen the worry about caregiving. Sun et al. (2021) found that when moving in, older adults treated others as friendly as possible, attempted to make new friends, looked for companionship, gained encouragement, respect from others, and desired to be understood. Zamanzadeh et al. (2015) found that older adults that lost previous communication contacts with family, friends and neighbors attempted to establish new communication networks with other residents and staff, which helped in reducing the communicational gap and psychological impact on their life.

As part of living in a LTC home, staff may play a big part in the day-to-day interactions of residents. According to newly admitted residents from one study (O'Neill et al., 2020a), care home staff were primarily seen as providers of health care only and not as people with whom to develop relationships. Participants from this same study highlighted the negative emotional impact of

losing 'favorite' or 'good' staff when they moved on to other employment and the difficulty of developing relationships with staff due to high turnover (O'Neill et al., 2020a). In addition, older adults from multiple studies have highlighted the importance of having supportive and respectful staff that make residents feel at home from the outset of the move as well as on a day-to-day basis, enhancing relationships providing tailored care and emotional care, being valuable in their adaptation to the LTC home (O'Neill et al., 2020a; Sun et al., 2021; Wu and Ruong, 2020). However, two other research studies found that some older adults perceive some care staff to be authoritative and uncaring (O'Neill et al., 2020b; Zamanzadeh et al., 2015). Participants from the study conducted by Zamanzadeh et al. (2015) were greatly satisfied when communicating with formal caregivers. While there was a recognition of the inevitability and need "to get settled" in the care home on a gradual basis, participants from two studies also highlighted the importance of maintaining links with family and friends from outside the LTC home (O'Neill et al., 2020b; Wu and Ruong 2020).

Two articles found that the acceptance of being in a care home was accompanied by tears from older adults' post-relocation, as the reality dawned on them that they would not return home, voicing resignation, acceptance, and ultimately contentment (O'Neill et al., 2020a; O'Neill et al., 2020b). For other participants from a study conducted by O'Neill et al. (2020b), personal levels of resilience and positive thinking promoted positive adaptation and acceptance when living in the care home. When reflecting on positive elements of relocation, residents from three studies (O'Neill et al., 2020a; O'Neill et al., 2020b; Sun et al., 2021), identified opportunities to form new relationships, influencing their lives by gradually accustoming them to communal life in LTC, encouraging a sense of wellbeing, gain staff support regarding aspects of care, pursuing former hobbies and activities either individually or with other residents. In contrast, participants from two studies (Sun et al., 2021; Wu and Ruong, 2020), also found that the living conditions of sharing a bedroom made them feel like they were living with strangers and reported problems such as having difficulty sleeping due to roommates, finding it hard to adapt to the differences between the LTC home lifestyle and

their previous home. O'Neill et al. (2020b) found that getting to know other residents' families and friends when they come to visit was shown to enrich residents' lives.

### ***Impact of the Move on the Psychosocial State of Older Adults***

Findings shaping this theme include both positive and negative outcomes in relation to the impact of the move to LTC. An article stated that the move into LTC increasingly impacted previous communication with the community that older adults lived in, making it harder to access friends and family (Sun et al., 2021). O'Neill et al. and Zamanzadeh et al., (2020a, 2015) found that living in LTC increased communication isolation, generating overall negative responses to the move and integration into the new living environment, resulting in the desire from many participants to leave the home and return to their previous home situation, even after time passed. Multiple articles found that concerns about not having found a close friend in LTC may occur due to having little in common with other residents at the home, finding it difficult to find peers with similar interests, and/or other personality types (Davison, 2019; O'Neill et al., 2020b; Sun et al., 2021), or socioeconomic differences (Zamanzadeh et al., 2015). The level of intellectual incompatibility was found to impact relationships, causing some residents to avoid others with psychological and mental health issues, seeing this as an obstacle for social engagement (O'Neill et al., 2020a; Zamanzadeh et al., 2015). Two articles mentioned that instead of relationships, older adults may develop casual acquaintances which may lead to feeling lonely and isolated, especially for those with no family of their own outside of the LTC home (Davison, 2019; O'Neill et al., 2020b). Regarding conflict, one article found that it may arise from residents, especially among women (Sun et al., 2021), as coexisting with each other within the same environment, may create tension including expressions of annoyance at each other's behavior about other residents that may be at a severe stage of dementia (Davison, 2019). When strong relationships did emerge in LTC, O'Neill et al. (2020b) found that for older adults, the impact of losing 'care home family friends' after someone's relative in the care home passed away also impacted the emotional wellbeing of other residents, resulting in isolation and loneliness.

An article conducted by Davison (2019) found that organized group activities are part of the day-to-day living engagement of older adults in the LTC home, which were received by older adults to meet other residents, have fun and keep themselves busy, in addition to the maintenance of hobbies among residents. Even though organized group activities are meant for recreation and enjoyment, older adult residents from the same study reported having to “push themselves” to engage in these activities, even if they were enjoyable. In addition, two articles found that not all residents reported participating in activities that were personally meaningful, relevant, or interesting, creating frustration about the quality and diversity of activities, making it harder for residents to integrate into the collective life (Davison, 2019; Sun et al., 2021). A study conducted by Sun et al. (2021) recorded some positive responses of moving into LTC which included a sense of liberation, having more control of their life in LTC, getting rid of previous tasks and maintaining self-identity, and being content with the nursing home.

A study conducted by Zamanzadeh et al. (2015) also reported a profound impact on the older person’s maintenance of previous communication networks such as friends and family, with reported cases of family members reducing visits to the LTC home after transition, creating feelings of loneliness. Zamanzadeh et al. (2015) stated that transitioning to LTC also caused ill-being and depression, with experiences of emotional crisis ultimately giving rise to emotional turmoil accompanied by feelings of frustration, desperation, sorrow, confusion, homesickness, depression, impatience, feeling of emptiness, being forgotten, being confined and feeling imposed upon. In addition, the transition to LTC and the loss of autonomy caused most of the residents from this study to gradually lose meaning in their life, creating dissatisfaction with communal aged care living (Zamanzadeh et al., 2015). Access to finances and other resources were also found to enhance emotional disturbance in older adults from the aforementioned study, with those that have sufficient financial resources when living in the community experiencing more severe emotional disturbances compared to participants who had limited to no financial resources prior to the transition (Zamanzadeh et al., 2015).

### ***Maintenance of Self and Identity in LTC***

Findings throughout this theme show the efforts of older adults towards the maintenance of self and identity in their new environment. An article found that as older adults move into LTC homes, the desire to maintain contact and previous connections with family members and friends is present, as the perceived loss of the individual's home life may threaten identity, belonging and sense of self (O'Neill et al., 2019). Zamanzadeh et al. (2015) stated the importance of maintaining continuity between past, present roles, and relationships, with family connections seen as vital for future adaptation to life within the new LTC environment. Maintaining pre-established connections were found to encourage the individual's self-esteem and personal identity (O'Neill et al., 2019; O'Neill et al., 2020a). Residents from LTC homes in two studies were found to appreciate regular visits from family members (Davison et al., 2019; O'Neill et al., 2020b). Another study found that residents welcomed when families arranged outings and opportunities to leave the facility such as for traditional holidays (Sun et al., 2021). In addition, leaving the residence was found to break the routine of daily care home life for older adults, as they have been reported to be dependent upon care home staff and family to go outdoors (O'Neill et al., 2019; O'Neill et al., 2020b). Even though the aforementioned studies have informed about the significance of outings, Davison et al., (2019) noted the importance of highlighting the balance of providing both familiarity and support, as well as allowing the resident to be apart from the family for longer periods of time to get used to living in the LTC home. Multiple studies (O'Neill et al., 2019; O'Neill et al., 2020a; Wu and Ruong 2020), identified that being able to move to a care home close to their community is important in maintaining family and friendship relationships for a sense of well-being and to avoid alienating themselves from those who they were emotionally close to, as well as being surrounded in a more familiar neighborhood. One article mentioned that bringing in possessions and photographs symbolized identity and enhanced identification of previous relationships to sustain identity in the LTC home (O'Neill et al., 2020a).

### ***The Loss of Familiar Roles and Independence***

Three articles have stated that for residents, having to fit within the LTC home's schedules and rules resulted in them losing much of their independence in daily life activities, finding their self-determination at risk by experiencing feelings of powerlessness (Zamanzadeh et al., 2015; O'Neill et al., 2020a; Zizzo et al., 2020). Moreover, not being able to have control over when they can leave the home, and over their personal daily schedules (e.g., bathing, eating, resting, or waiting for care services), are among some of the most important experiences that have been found to seriously threaten independence, inducing a sense of dependency on family caregivers by limiting the progress they would have liked to have in adapting to the LTC home (O'Neill et al., 2020a; Zamanzadeh et al., 2015; Zizzo et al., 2020). O'Neill et al., (2019; 2020a) stated that residents experienced a dependence on both staff and family to get out or come into the care home to "see family", "see my home", "go to chapel", "go shopping" or just "being in the garden". In addition, residents from the aforementioned study expressed frustration that care home staff were preventing them from engaging in activities they were willing to participate in, or doing things for them that they were able to manage themselves (Sun et al., 2021). Many participants with physical and mental health issues from a study conducted by Wu and Ruong (2020) were concerned about their overall safety from injuries and accidents when first arriving at the LTC facility yet as they accommodated to their new home.

Part of facing the challenges of the new LTC environment for some individuals involved resisting dependency (O'Neill et al., 2020a). Sun et al. (2021) reported the grief experienced by residents over loss of control, lack of privacy, and no freedom, which made residents feel as if they were trapped in prison. O'Neill et al., (2020a), highlighted that some residents were happy and noticed their health improving following physiotherapy and self-governed exercise routines, while others were frustrated about losing progress made while they were in the hospital, which made them more dependent on staff.

### **3.5. Family Caregiver Experiences**

As with the previous section, the three stages of pre-move experiences, during the move and post move resulted in multiple unique subsections.

- Pre-move Experiences
  - The Role of the Caregiver
  - Decision-making Processes & Exercising Choice
  - Preparation for the Move
  - System Navigation
- Move Experiences
  - Geographic and Socio-economic Issues
  - The Absence or Presence of Support
- Post-move Experiences
  - Adapting to the Relinquishment of Care
  - Impact on Caregiver Well-being
  - Changing Roles

These diverse subsections highlight the unique experiences, challenges and facilitators recorded throughout the selected literature chosen for this scoping review, from the continuous change of caregiving needs to the need for considering LTC transition, leading to subsequent transition and the adaptation of the relinquishment of care of their loved ones and the resulting emotions that arise throughout this process.

#### **3.5.1. Pre-move experiences**

##### ***Role of the Caregiver***

Caregiving roles become more pronounced as the need for care increases due to risk for critical conditions and accidents, resulting in the ultimate decision of moving the older adult into LTC. An article by Koplow (2015) stated that family members may transition from the role of being same



kin to becoming a family caregiver with a set of responsibilities and expectations to fulfill as the health conditions for older adults worsen. Several of the reviewed articles covered the range to which families aim to manage the caregiving situation by either taking responsibility themselves to maintain them at home (Konietzny et al., 2018), hire professional in-home care services (Robinson & Fisher, 2023; Scott & Funk et al., 2023), or other additional services (i.e., Meals on Wheels) (Konietzny et al., 2018). Two studies found that family caregivers see home care as a stepping stone before transitioning to residential care due to the adamant and reluctant behavior of older adults and family caregivers that residential care may not be appropriate for them (Eika et al., 2013; Robinson & Fisher, 2023). A study conducted by Robinson & Fisher (2023), found that the increase in comorbidities and care demands may result in the realization that alternative options to LTC are no longer viable to provide provisional care due to the older adult struggling with personal hygiene, nutritional or medical care, requiring intense care. Another study showed that the physical care that some older adults require (e.g. bathing, toileting, and transfers) may be physically overwhelming, particularly for older caregivers (Konietzny et al., 2018). Kiwi et al. (2017) further established that when family caregivers cannot cope with the demands (i.e., rapid cognitive decline) the problem of the provision of care remains unsolved until further action is taken.

Kiwi et al. (2017) found that when next of kin become caregivers, there is a shift in the familial relationship with less capacity to live as a family and not being able to address one's own needs when care responsibilities increase. The transition to LTC can still be considered as an unwanted option to be avoided at all costs until caregiving becomes unmanageable (Robinson & Fisher 2023; Scott & Funk, et al., 2023). Other articles found that the transition to LTC was considered as last resort and only after making significant personal sacrifices to keep the older adult at home for as long as possible (Kiwi et al., 2018; Konietzny et al., 2018; Ramanathan et al., 2015;). Family caregivers from a study conducted by Scott & Funk (2023) expressed feelings of disempowerment over the degree of nature over their involvement in family care that had an impact on their lives, often as a result of their

perceived lack of control of official service arrangement conditions during the pre-placement period. Moreover, staying at a parent's home or taking a cut in income for freelance work to help provide care were among some of the sacrifices reported by non-spousal caregivers found to avoid formal services and delay transition to LTC (Scott & Funk, 2023).

Another sub-theme that arises in the reviewed studies entails differences between spousal and non-spousal caregiver contexts, with the former seen as a natural progression in the course of their partnership, and the latter as an obligation (Koplow et al., 2015). One study stated that the immersion of caregivers in their caregiving role resulted in ultimately losing their identity in the process of caregiving, with the relationship changing from being one's child or spouse to becoming their "parent", complicating the way to which one can extricate from the caregiving role (Cottrell et al., 2018).

Koplow et al. (2015) found that the reception over the transition to LTC due to the absence of alternatives was perceived by family caregivers as a forced necessity, for medical purposes and as a safety solution. In addition, Robinson & Fisher (2023) stated that participants saw the transition to LTC as an improvement in QoL due to the availability of professional healthcare. Three studies highlighted the impact interpersonal conflict and relationship dissatisfaction due to opposing views about the move to LTC may have within families (Eika et al., 2013; Kiwi et al., 2017; Robinson & Fisher, 2023; Zizzo et al., 2020;).

Four studies observed that the stress of finding alternative living options for older adults and the worry that may arise throughout the care home transition, which may lead to mental health problems for many older adults and next of kin (Groenvynck et al., 2022; Koplow et al., 2015; Robinson & Fisher, 2023; Zizzo et al., 2020). Another article by Eika et al. (2013) found that mediating between one's home dwelling parents and the matters at stake in the attempt to balance attention between them may increase conflict resolution and distance the damaged relationship between their parents. In comparison, a study conducted by Groenvynck et al. (2022) reported positive emotions from family caregivers about the decision to move their loved one

into LTC, with the relinquishment of care to a more suitable environment met with relief and acceptance that the older adult will receive appropriate care and QoL, recognizing their limitations when care became too burdensome. The aforementioned study also reported positive results from the positive experience of family caregivers in relation to the practical and emotional support offered by healthcare professionals (Groenvynck et al., 2022).

### ***Decision Making Processes & Exercising Choice***

An article conducted by Kiwi et al. (2017) found that the maintenance of personal roles, together with caregiving roles come into conflict throughout the caregiver experience. Another article by Groenvynck et al. (2022) highlighted the guilt that family caregivers feel when excluding older adults from the decision-making process and the need to relinquish care due to increased care demands, which made some participants feel like they were imprisoning them. Two articles found that the complex living situations of family caregivers' impact both personal freedom and the social atmosphere within the family (Kiwi et al., 2017; Zizzo et al., 2020). This impact was present within marriages that care for an older adult with mental health conditions (i.e., dementia), increasing the difficulty of care and responsibilities that lead to prioritizing the role of the caregiving for their parent rather than one's own marriage (Kiwi et al., 2017).

Three studies found that excluding older adults from the decision-making process serves as a marker that influences the quality of the transition experience for family caregivers, and especially when excluding older adults with dementia (Eika et al., 2013; Kiwi et al., 2017; Ramanathan et al., 2015). Other articles found to health care workers to additionally exclude older adults from decision making processes in conjunction with family caregivers, including hospital staff (Scott & Funk et al., 2023), social workers (SW) (Sussman and Dupuis, 2012), and others (Groenvynck et al., 2022). In addition, Scott and Funk (2023) found that family caregivers feel disempowered of not pushing back enough regarding the nature of their involvement in the choice of care for the older adult. Furthermore, the aforementioned study highlighted that occasionally, and with the appropriate

assistance put in place, older adults may have been able to remain in their community or find a more suitable housing option that would meet their needs instead of having to rely on urgent decisions without taking into account their loved one's preferences (Scott & Funk et al., 2023).

Two articles highlighted the struggle family caregivers experience finding the best approach to explain to the older adult about the complexities of shared decision making, which had to be made on their behalf, imposing adverse effects on residents' transition experiences and grief responses (Ramanathan et al., 2015; Zizzo et al., 2020). In addition, Zizzo et al. (2020) found that triggering events (i.e., accidents, falls, changes in care needs), make the engagement of older adults in decision making more difficult by escalating the need to expedite the transition and find a suitable LTC home. One study found that having a sense of duty towards providing care for one's parents as the main motivating factor in keeping older adults at home by highlighting the notion of patriarchy, whereby having no permission of placing the older adult in LTC made family caregiver feel as if going by against an authority figure (Eika et al., 2013). Moreover, participants from a study conducted by Eika et al. (2013) highlighted that gaining the care recipient's agreement to the decision was crucial for a sense of relief in care duties and for the release of guilt, even though for some this may not be viable, as mentioned in aforementioned studies.

The impact of culture was also present throughout the findings that shaped this subtheme. A study by Ramanathan et al., (2015), highlighted the impact of culture in transitioning experiences, where for some cultures keeping the older adult at home until it becomes unmanageable is seen as "giving back", showing the importance that filial piety has in the fulfillment of familial roles and society's expectations. Another study conducted by Scott & Funk (2023), found that in addition to familial ideals, aspects such as emotional and financial costs, socioeconomic security, system constraints and gatekeeping may delay institutionalization to avoid formal services. Furthermore, Zizzo et al., (2020) found family caregivers to do the move in stages by easing the transition over several months or years, slowing down

the process by first downsizing their home into smaller units, living in independent units, or arranging respite stays to get used to living in a residential environment.

### ***Preparation for the Move***

Articles gathered for this theme highlight the preparation for the move and the emotional and physical responses towards the upcoming life transition. Two articles have mentioned family caregiver guilt, which may result from the unfulfilled internalized ethical standard to continue looking after the older parent no matter what by keeping them in their own home, sadness due to the need to transfer the older adult to an environment where they had never anticipated to be in (Konietzny et al., 2018; Robinson & Fisher, 2023). In addition, Groenvynck et al. (2022) found feelings of guilt to be present in family caregivers after being advised by healthcare professionals to prepare older adults' transition process behind their backs. A study by Kiwi et al. (2017) found that some family caregivers may not feel guilty for the decision to move the older adult to LTC, as they acknowledge that they did all they could for the person's wellbeing. Additionally, multiple articles report shared feelings of relief and acceptance (Groenvynck et al., 2022; Kiwi et al., 2017; Ramanathan et al., 2015; Zizzo et al., 2020), as family caregivers put tremendous effort into managing care at home leading to extreme pressure, resulting in the relinquishment of care. In addition, Zizzo et al. (2020) found that due to the time consuming effort of taking care of their loved ones, family caregivers experienced feelings of isolation, exclusion and loneliness both before and after transition to LTC as well as anticipatory grief. Eika et al. (2013) stated that when preparing for the move, family caregivers expressed profound feelings of insecurity, as they feared they would handle a crisis incorrectly, feeling on their own by having little support from community nurses and uncertain about corresponding responsibilities.

Family caregiver experiences recounted throughout two studies (Groenvynck et al., 2022; Scott & Funk, 2023), how unusual timely transitions to LTC homes are, with families postponing the consideration of moving for as long as possible by avoiding traditional care until the home situation becomes

unsustainable and dangerous, resulting in a hastened transition. In addition, family caregivers from the study by (Groenvynck et al., 2022), reported feeling overloaded with tasks/information, having no time to process the upcoming move (Groenvynck et al., 2022). Family caregivers from the aforementioned article reported that, in retrospect, they would have preferred a timely transition plan with sufficient time to prepare for the transition process, discuss with older adults and visit LTC homes for careful consideration (Groenvynck et al., 2022).

A study conducted by Hainstock et al. (2017) described the limited availability of LTC homes, with seniors being placed on a waiting list. In addition, LTC homes with shorter waitlists were found to be less desirable (e.g., typically older, larger facilities, shared rooms), with longer waitlists especially for “first choice” placements. Furthermore, two studies found that when home care situations become unmanageable, the pressure to move made family members change their “first choice” to a less desired option with a shorter waitlist to expedite the process (Konietzny et al., 2018; Scott and Funk, 2023).

Two studies (Scott and Funk, 2023; Sussman and Dupuis, 2012), found that the speed at which family caregivers were asked to make key decisions about the move to LTC from the hospital compound their perceived lack of control, especially when such choices were undesirable and are expected to make quick decisions about LTC placement within 24-48 hours, to make sure the system flows. In addition, as waitlists are kept confidential, family caregivers are left in the dark, without being able to do predatory packing to be ready for the move when the time comes to start thinking about what to take, and what to leave behind. Studies by Hainstock et al. (2017) and Konietzny et al. (2018) found that some family caregivers felt forced to accept a bed in their least preferred home or decline the offer and face the consequences of being removed from all waiting lists for three months, creating stress for older adults to clear up the room for incoming admitted individuals. Furthermore, the study conducted by Scott and Funk (2023), found that turning down an offer is not usually viable, since it may result in

penalties, being removed from the waitlist, accrued service charges, as well as impacting further experiences with the system. In another study conducted by Sussman and Dupuis (2012), families stated that this quick time frame does not allow them to sit and process the move with their relative, to facilitate a pre-placement visit, or even see the rooms in which older adults would be living in (Sussman and Dupuis, 2012).

Disappointment and discouragement were experienced by family caregivers throughout the study conducted by Scott and Funk (2023) due to negative interactions with the health care system throughout the transition process, who disregarded concerns about appropriate moves and LTC homes to move older adults to. Sussman and Dupuis (2012), found that those families that were given longer projected wait times became frustrated when they were offered a space within months and only given a day to accept a bed to move. However, participants from a study conducted by Eika et al. (2013) found that some next of kin knew of waiting lists for placement into LTC homes and were grateful that their family members were chosen.

### ***System Navigation***

This theme highlights the complexities that family caregivers experience when navigating the healthcare system, as well as the challenges encountered when seeking information and resources to aid in the transition of older adults to LTC. Three articles highlighted the experiences of family caregiver experiences relying on the healthcare system when preparing for transition to LTC (Groenvynck et al., 2022; Hainstock et al., 2017; Zizzo et al., 2020). The aforementioned studies stated that when starting the transition on time, family caregivers found to be impeded by an inefficient healthcare system that was incredibly complicated to navigate, impacting the transition experience, making them feel naïve, lost and unfamiliar within the system its rules and regulations (Groenvynck et al., 2022; Hainstock et al., 2017; Zizzo et al., 2020;). Some family caregivers from the study by Scott and Funk et al. (2023) found it impossible to initiate the care transition process themselves, which was followed by the unrelenting need to complete endless paperwork, service eligibility needs assessments, and gatekeeping; in addition to the

complexities of navigating a time consuming administrative and bureaucratic system that has been confusing for many family caregivers from diverse studies (Groenvynck et al., 2022; Zizzo et al., 2020; Hainstock et al., 2017; Scott and Funk et al., 2023). Family caregivers from multiple studies have noted that the system is composed of care providers lacking empathy, effort, support and compassion (Hainstock et al., 2017; Eika et al., 2013; Konietzny et al., 2018). In addition, family caregivers from these studies felt like they were not taken seriously about their caregiving circumstances (e.g., unsafe environments, no other proximate family members to take care of them) when addressing the need for transition once the responsible healthcare professionals were contacted (Groenvynck et al., 2022; Hainstock et al., 2017), creating feelings of apprehension and fear about moving their relative into LTC (Robinson & Fisher, 2023).

According to a study conducted by Hainstock et al. (2017) most caregivers found themselves assuming an advocacy role while preparing to relocate their family caregiver to LTC. articles recounted that due to the complex circumstances throughout the transition and placement process, caregivers described themselves as becoming more forceful and belligerent in their advocacy roles, as well as issuing formal complaints and writing letters while others have shown to threaten to take their concerns publicly due to receiving misleading information about the time frame of relocation (Hainstock et al., 2017; Konietzny et al., 2018). Konietzny et al., (2018), found that some family caregivers have been found to push back delaying application or acceptance of a LTC bed, as they believed that accepting a bed to be an act of settling, with these locations perceived to be providing less than good care and being located outside of the preferred distance for regular visitation.

In their research, Kiwi et al. (2017) found that many family caregivers to be proactive in acquiring knowledge after a critical point was reached. Many family caregivers from the study conducted by Robinson & Fisher (2023), shared their lack of preparedness, and perceived little guidance and support from outside agencies regarding the logistics of the move by contributing to an already present anxiety. Three articles found that for many family caregivers,



the transition to LTC is the first transition of its kind, with increased reliance on both formal (e.g. SW, case managers, doctors) and informal sources (e.g., local radio broadcasts, friends and family) which impacted the choice of an appropriate LTC home, being unsure on how to judge the quality of care when there was little to no direction (Hainstock et al., 2017; Kiwi et al., 2017; Robinson & Fisher, 2023).

Family caregivers from one study shared that having practical information and advice would be the most useful way to support the transition, as well as having an advocate or someone to assist with major decisions (Zizzo et al., 2020). In addition, two articles recounted that families that had brokers to locate beds, and advisors to assist with finances describe feeling more able to manage bureaucratic requirements associated with entering LTC than those that did not have resources to aid in the transition (Hainstock et al., 2017; Zizzo et al., 2020). Still, Zizzo et al. (2020) that availability and access to these services were limited due to the cost to employ these services and having adequate financial resources. Hainstock et al. (2017) found that communication between health care professionals across different settings (e.g., family doctor, and doctor on call at the time of hospitalization) were noted as problematic, complicating information flow related to caregiving efforts, as well as from other informal networks. In addition, family caregivers from the previously mentioned study reported that the ongoing staff changes (with case workers, case managers, SW, nurse practitioners, and doctors) promoted a lack of continuity in the care communication received throughout, adding another layer of complexity to overall system navigation (Hainstock et al., 2017). Carers who resided in the local community, as the vast majority of respondents did in a study conducted by Ryan and McKenna (2013), were familiar with local health and social care practitioners and sought support from such. In addition, such support took the form of validating the placement decision and acting as an advocate for the carer during the transition process (Ryan and McKenna, 2013). In most instances, the familiarity felt by carers in this study was not limited to familiarity with the home, the staff or the residents but rather, a combination of some or all these factors (Ryan and McKenna, 2013).

### **3.5.2. Move experiences**

#### ***Geographic and Socio-economic Issues***

This theme highlights the importance and impact of LTC geographical locations and socio-economic issues faced by family caregivers. Even though research showed that exercising choice for placement is limited or restricted due to various reasons, two articles found that if given the opportunity, family caregivers focused on location, proximity to family (e.g., a familiar neighborhood for the older person) and the context of the LTC home (e.g. easy access to the outdoors) (Groenvynck et al., 2022; Hainstock et al., 2017). An article by Kiwi et al. (2017) stated that among many of the issues family caregivers had to deal with when their family member moves to a LTC home is the geographical distance between them and the LTC home, as well as diverse rules within certain municipalities/district boundaries to deal with respected municipality rules. The aforementioned study (2017), found that when having the option to choose the LTC and move to a specific district, older adults and family caregivers had to meet with various responsible authorities to receive permission to move into their chosen LTC home, resulting in the transition process taking longer than anticipated. Another study highlighted the challenges related to transportation throughout moving day, which include hiring community transportation services or asking other family members to help (Hainstock et al., 2017). Additionally, family caregivers from two studies (Hainstock et al., 2017; Scott and Funk, 2023), spoke about the emotional challenges of moving day, which include the decision over which belongings to take and which to leave behind. In addition, both articles reported this experience to be particularly difficult for both family caregivers and older adults, as room and space availability for customization were limited. One article found the presence of anticipatory anxiety in family caregivers, ongoing foreboding and worrying during the move and following placement (Hainstock et al., 2017).

#### ***The absence or presence of support***

This theme highlights the absence or presence of support throughout the move to LTC, and how this impacts the experience and future interactions

with the LTC home. Two articles throughout the scoping of existing literature presented findings over the impact in the absence or presence of support during the move. Multiple articles have highlighted that when the move comes both older adults and family caregivers have less than 48 hours not only to confirm a placement offer, but to move the older adult to the LTC home regardless of circumstances (e.g., needing to book time off work, travel into town, book moving services etc.) (Scott and Funk et al., 2023; Sussman and Dupuis, 2012). Evidence noted moving day to be a long process for family caregivers requiring the combination of administrative responsibilities (e.g., completing financial and medical paperwork), and emotional work (e.g., reassuring the resident) (Hainstock et al., 2017; Sussman and Dupuis et al., 2012). Sussman and Dupuis (2012), found that having support from family caregivers facilitated the moving experience, such as family members accompanying the older adult during moving day. In addition, Sussman and Dupuis (2012) showed that being unaware of the administrative requirements expected of family caregivers (e.g., review documents and sign contacts) created a pull between expectations on moving day of LTC homes and having to meet the needs of older adults to provide emotional support and reassurance throughout the move. In addition, both articles found that even though families supporting transitions may be well informed during the pre-move phase, it was not the case related to the admission information required on moving day (Sussman and Dupuis et al., 2012; Scott and Funk, 2023). The aforementioned studies found that having prior-contact with someone at the LTC home who was familiar with admission practices for a particular home to be the most common reason for receiving proactive information about moving-day policies and practices (Scott and Funk, 2023; Sussman and Dupuis et al., 2012). Still such information was rarely available for families in a formal format (Scott and Funk, 2023; Sussman and Dupuis et al., 2012).

Sussman and Dupuis (2012) found diverse aspects that supported a positive experience by inciting confidence and creating comfort in family caregivers when leaving the older adult including existing prior information on the admission process, items required, move-in date flexibility and presence of other family members throughout the move. In addition, Sussman & Dupuis

(2012) highlighted that having the presence of other family members during the move-in day allowed carers to balance administrative demands, immediate support and direction upon arrival (Sussman and Dupuis et al., 2012). Sussman and Dupuis (2012) found positive experiences reported by family caregivers during the move in day, where families were greeted by staff, feeling immediately welcome, describing the admission to be supportive and compassionate. Other participants from the same study recounted negative experiences where older adults and family caregivers had to find their own way to the resident's room and wait for a staff or person to initiate the admission process, feeling lost and unsupported (Sussman and Dupuis et al., 2012).

### **3.5.3. Post-move experiences**

#### ***Adapting to the relinquishment of care***

Four articles have noted that family caregivers are still committed to provide care for family members once they relocate to a LTC home (Hainstock et al., 2017; Koplow et al., 2015; Ramanathan et al., 2015), and feel responsible for the care they receive (Eika et al., 2013). Sussman and Dupuis (2012), found that families' adjustment processes were intimately tied to those of their relatives, with improvement in their relative's QoL (e.g., being more at ease, being mobile and using the washroom, more enthusiastic and engaged, less confused), which was instrumental for facilitating their own adjustment post-move, reinforcing that the placement decision was important. Eika et al. (2013) found next of kin to do some of the same caregiving roles they did when the older adult still lived at their home (e.g., combing hair, bringing in the newspaper). In addition, two articles found that visiting regularly contributed keeping up connections to their former lives, preserve the relationship, keep an eye on their living conditions, support circumstances that may threaten dignity, maintain personhood, standards of care and QoL (Eika et al., 2013; Ramanathan et al., 2015).

Two articles found that good communication with staff, including during the first few weeks about residents' unique characteristics and asking

information about their parent to be important for family members, reassuring them that they are considered partners in the care process (Cottrell et al., 2018; Sussman and Dupuis, 2012), as well as increasing familiarity with staff (Ramanathan et al., 2015). Sussman and Dupuis (2012), highlighted positive experiences of family caregivers, recounting that respectful nature of staff in LTC homes (e.g., knocking on the door before entering, greeting family members by name, speaking in a friendly reassuring calming tone, proactively volunteering specific information about relatives) made families feel that staff members were connecting with their relative as a person. Two articles have also shared negative experiences in which family members experienced lack of communication from staff, having to push for information (e.g., medical test results), which made families question the extent to which staff members cared about their relative's wellbeing (Cottrell et al., 2018; Sussman and Dupuis, 2012). In addition, two articles reported the presence of power dynamics, such as feelings of disempowerment from a perceived lack of reciprocity in information with feedback not welcomed by staff (Ramanathan et al., 2015), as well as considering family caregivers as non-experts about the care for their parents which dismissed caregivers' voices (Kiwi et al., 2017). The article by Kiwi et al. (2017) also recounted that to manage being dismissed by staff, family relatives had to build an arsenal of knowledge and become difficult when being shut out or not consulted for older adults to achieve personalized care.

Family caregivers from a study by Cottrell et al. (2018) highlighted that experiences from family caregivers call for training that focuses on relationship building, partnering and working together as well as for family caregivers to receive orientation and advocacy skills training to advocate for older adults in LTC homes living with dementia. Additionally, family caregivers from two studies pointed out that staff turnover led to frustration, concern about the placement decision, inadequate staffing, poor quality of care and safety risks (Ramanathan et al., 2015; Scott and Funk et al., 2023).

Sussman & Dupuis (2012) found that family caregivers that had positive pre-move experiences also appeared to allow caregivers to cope

better when faced with post-move challenges such as imperfect communication, the occasional unfriendly staff member, or residents that were not adjusting. Additionally, this study highlighted that having the support needed throughout the pre-move to emotionally accept the placement appeared to cope better to manage post-move complications, especially when placing relatives supported by family, friends and/or professionals (Sussman & Dupuis, 2012). In comparison, negative pre-move experiences of participants from the same study complicated the adjustment process, making it more difficult for family members to adapt to the change (Sussman and Dupuis, 2012).

An article by Koplow et al. (2015) found notable differences in priorities influencing caregiving responsibilities between spouses and non-spousal caregivers, with spousal caregivers maintaining care out of respect and love for their partners whereas non-spousal caregivers see care management as a family responsibility. In addition, Koplow et al. (2015) found that when providing care, some spouses noted that the goal with placement was to move from identifying themselves as their caregiver back to being their spouse. One study found that all caregivers maintained a visible presence at the facility, with visits per week ranging from three to seven, with caregivers caring for a spouse reported to visiting more frequently than those caring for their parents (Hainstock et al., 2017). In addition, family caregivers from the aforementioned study noted a change in the relationship with family members after transition, with those caring for a parent or sibling improving, while those caregivers caring for a spouse focused on the change in how “close” they felt to their partners after the transition (Hainstock et al., 2017). The relinquishment of care has shown to be incredibly complex for family caregivers, resulting in both negative and positive emotions that the research highlighted throughout.

### ***Impact on caregiver well-being***

The research gathered for this scoping review has highlighted the impact that the post-move of older adults can have in the wellbeing of family caregivers. Zizzo et al. (2020) found that guilt commonly extended to the post-

move experience by having feelings of betraying their loved ones, that they could have done more to care for them at home, taking away their independence, moving them against their will, personal failure, or seen as an inability to fulfill obligations for the relative who had moved into LTC. In addition, the aforementioned study highlighted that some care relatives felt that their loved one's lack of adjustment was indicative of a reduction in their QoL or were receiving inappropriate care, exacerbating their guilt in the placement decision (Zizzo et al., 2020). In contrast, female spouses from the same study rejected feelings of guilt for placing their partners with dementia in LTC (Zizzo et al., 2020). LTC staff members from the study by Zizzo et al. (2020) also highlighted that the move to LTC may also improve the relationships between families and residents, as once they are not angry about the move, families can take them out, enabling them to accept the situation and helping negative emotions to dissipate. In contrast, staff from this study also reported that family members who visit daily seem to be those that struggle the most with guilt, using frequent visits as a coping strategy, feeling a sense of obligation, needing to reaffirm a sense of purpose in the context of role loss (Zizzo et al., 2020).

Five articles have highlighted the presence of feelings of relief from family caregivers post-transition, where LTC seen as proxy for the care they were unable to provide themselves at home with the focus returning to the familial relationship (Hainstock et al., 2017; Kiwi et al., 2017; Koplów et al. 2015; Ramanathan et al., 2015; Zizzo et al., 2020), acknowledging that the move was the right thing to do (Robinson and Fisher, 2023). Studies also found the comfort and relief felt by family caregivers for knowing that their relative was cared for and adjusting well to their new home helping them see the value of the move on their QoL (Konietzny et al., 2018; Koplów et al., 2015; Robinson and Fisher, 2023). Five articles found that relief was present due to previous effort from caregivers of managing care, associated to a pressure that became extreme, influencing their own health and wellbeing (Hainstock et al., 2017; Kiwi et al., 2017; Konietzny et al., 2018; Zizzo et al., 2020;), with the move decreasing anxiety and worry by removing care burden, no longer being the port of call for medical emergencies (Robinson and

Fisher, 2023). Kiwi et al. (2017) stated that after LTC placement, the once stressful life vanishes, with family caregivers having the opportunity to focus on their family and other social interests. Participants from this same study found the experience joyful, and remarkable, being able to sleep at night without worry, since the LTC home was reliable, secure, safe, and enjoying the company of others with the same cultural background (Kiwi et al., 2017).

Zizzo et al. (2020) reported feelings of isolation from family caregivers of PLWD post-transition, described as feeling additional burden by a sense of obligation to manage the emotions of other family members alone, particularly adult children that find dementia distressing and are reluctant to visit their loved ones in LTC (Zizzo et al., 2020). An article by Cottrell et al. (2018) found that families experienced an overwhelming and pervasive sense of loneliness due to multiple losses, including: loss of their previous role, loss of their familiar self, and loss of control as the health care system assumed care for their family member (Cottrell et al., 2018).

A study conducted by Gaugler et al. (2010) accounted for a considerable amount of variance in persistent depression in the 6-month and 12-month post-placement period, with husbands 4.87 times and 5.89 times more likely to indicate persistent depression than other caregivers in the 6- and 12-month post-placement period respectively (Gaugler et al., 2010).

Zizzo et al. (2020) found that family caregivers appreciate the support from friends and other family members post-move but were often not available due to their loss of connections throughout the course of the dementia journey. In addition, Zizzo et al. (2020) stated that the relinquishment of care of the older adult to LTC prompts the realization about next steps in the caregiving journey, and anticipatory grief. Koplow et al. (2015) also found that the relinquishment also led to further realization about mortality and the inevitability of their family members' eventual death (Koplow et al., 2015). In addition, Robinson and Fisher (2023) stated that for family caregivers, the transition to LTC means the ending of life as an independent individual and the last place their parent would live.



## ***Changing roles***

Research has shown that after the move, family caregivers may cease to provide care, maintain care or experience a change in roles as the care is transferred to LTC staff. Cottrell et al. (2018) found that for family caregivers, letting go of older adults created feelings of loss, yet was considered an active process by marking the end of one type of caregiving and the beginning of new caregiving roles. Gradually, participants from the aforementioned study stated that post transitions consisted in balancing caregiving with recreating a new self, with caregiving roles and associated tasks being different (Cottrell et al., 2018). Four articles found that the post-placement involved “different care” roles for most family caregivers, noticing that they were not necessarily providing less care, but that the kind of care they provided had changed including more emotional support and assistance with activities that were outside of the care provided by the LTC home (Cottrell et al., 2018; Hainstock et al., 2017; Ramanathan et al., 2015; Scott and Funk et al., 2023). In addition, most caregivers from a study conducted by Hainstock et al. (2017) also engaged in care management activities such as Instrumental activities of daily living (IADL), including the management of finances (e.g., completing income tax returns), paying bills and scheduling appointments (i.e., doctor, optometrist, and specialists). Other family caregivers from this same study engaged in personal care tasks (e.g., cleaning dentures, helping with dressing, painting nails, maintaining wardrobes and overseeing related care duties (Hainstock et al., 2017).

Participants from a study conducted by Koplou et al. (2015) noted that even though some family caregivers expressed difficulty in relinquishing management of caregiving activities to the LTC staff, there was a recognition of doing so and spending quality time re-establishing the familial relationship that previously existed. An article by Scott and Funk (2022) found that staff hold assumptions that when family caregivers visit, they would provide personal care for their relatives (e.g., grooming, feeding). In addition, the aforementioned study found that the care family caregivers give to older adults when visiting may also extend to other residents (e.g., sitting at the

same table for lunch), providing unpaid care as a result of staffing and service constraints (Scott and Funk 2022).

## Chapter 4.

### Discussion

By reviewing the experiences from older adults and family caregivers throughout the transition experience from the home to LTC, this scoping review demonstrates the complexities and intricate processes that occur at a psychosocial emotional level for the dyad, and the delay of considering transition to LTC as the next step of the care journey, complicating the move. Older adult's health journey may decline as comorbidities increase (O'Neill et al., 2020b; O'Neill et al., 2022; Robinson & Fisher, 2023), increasing the need for health care provision from informal caregivers. Consistent with findings from this scoping review, once the level of care needed overcompensates the availability and ability of family caregivers to perform and provide appropriate care tasks, care burden increases and home care becomes unmanageable (Robinson & Fisher 2023; Scott & Funk, et al., 2023), increasing the need for 24-hour care services. The disinclination from both family caregivers and older adults of moving into LTC was present throughout the research and resulted in increased burden that led to accidents and visits to the hospital (O'Neill et al., 2022; Wu and Rong, 2020). These visits left older adults dependent on professional care, with limited support if they were to return home, seconded by professionals who managed care processes of moving the older adult to LTC (Davison et al., 2019; O'Neill et al., 2019; O'Neill et al., 2022; Wu and Rong, 2020;).

Research has established that the move itself happens rather quickly, with both positive and negative experiences recorded throughout this stage. As the delay for LTC placement led in some cases to hospital admission, the pathway for LTC home transition becomes rushed once a bed is available, with a 24–48-hour timeline to accept the room and move into the new home (Sussman & Dupuis, 2012). This experience is present with families that apply to LTC home placement in advance, with waitlists ranging from months to years (Scott and Funk, 2023; Sussman & Dupuis, 2012), to which some families cannot manage and may choose a LTC home that was not within

their preferred choices (Konietzny et al., 2018; Scott and Funk, 2023). Having extra support to help during the move showed to ameliorate the moving process (Hainstock et al., 2017; Sussman and Dupuis et al., 2012), with family caregivers being able to fill forms, aid with the move and navigate other matters when arriving at the LTC home. As older adults come to terms with the move, emotional aspects such as losing one's home and community (O'Neill et al., 2020b; Zamanzadeh et al., 2015), integrating into life at LTC (Davison, 2019; Sun et al., 2021), and establishing new connections become prime concerns (Davison, 2019; O'Neill et al., 2020b). For family caregivers, post-transition and the relinquishment of care has proven to be an important flexing point in the caregiver journey, with emerging feelings of guilt (Robinson & Fisher, 2023; Zizzo et al., 2020), relief and acceptance (Groenvynck et al., 2022; Kiwi et al., 2017; Ramanathan et al., 2015; Zizzo et al., 2020), and anticipatory grief (Koplow et al., 2015; Robinson & Fisher, 2023; Zizzo et al., 2020).

Key findings from pertinent literature have confirmed that the transition to LTC, specifically from older adults, still lacks the presence of transition programs. In addition, findings highlight the need for support from LTC homes and healthcare workers for the dyad to enhance transitions in a timely and effective manner that currently relies on the proactive doings of family caregivers. From the included studies, transition programs or how diverse services ameliorated the move were often not explicit throughout the findings. Challenges and facilitators related to the transitioning experiences to LTC were mostly presented from the post-move experiences of older adults, pre- and post-experiences for family caregivers, with little information *during* the move. This absence of experiences throughout the transition reinforces the need for the implementation of transition support and programs that are created by both LTC homes and regional health authorities as resources to be used when the move to LTC is close and/or imminent. Nevertheless, emerging key findings have suggested increased knowledge provision and information administration to be provided to family caregivers and older adults.

From the results presented in table 5, key findings emerged from all included studies to thoroughly describe the overarching information of what family caregivers and older adults are experiencing through the transitioning process (RQ1). The studies chosen for this scoping review confirm and strengthen the importance of expanding on the transitioning experience and the necessary resources to support both families and older adults experiencing this transition, supporting the importance of the relationship and emotional support between healthcare providers, families and older adults are in providing a smooth and positive experience and comfort with navigating the necessary resources for LTC admission. Even though the findings to the first research question showed a linear description of the overall transitioning experience, both second and third questions were more intricate to locate and define. The findings shown in Table 5 demonstrate the limited engagement of health care staff in showing understanding and aiding in the decision-making process to move to LTC other than it being efficient and fast to release spots for other incoming patients by allowing short times to relocate to LTC when a bed becomes available. Moreover, this table shows the need for proper system navigation tools for family caregivers and older adults for necessary support throughout. Challenges and facilitators to the transition experience (RQ2) are included and explored further in the discussion section.

In addition to the findings of this scoping review was the similarity of key findings and future steps from the TRANSCIT theoretical model developed by Groenvynck et al. (2021). Other results relate to the discourse of the under-representation of diverse cultural groups of family caregivers and older adults transitioning to LTC throughout findings as potential areas for future research related to the impact of culture in transitioning experiences. This section ends with reflections on the role of funding for transition programs into LTC homes and a global positioning to improve QoL in LTC for older adults to be able to age with dignity in their home away from home, impacting the perception of senior residential care and care provision in LTC settings.

## **4.1. Connection of findings to research questions**

The present findings highlight the work that researchers and advocates are bringing to the voices and experiences of older adults and family caregivers in their transitioning experience to LTC. Findings have shown that overall, since 2010 (start date of search for this review), Canadian researchers have been interested in qualitative methods to increase the recorded number of experiences and knowledge of the dyad about access to informational resources that may be supportive for the moving experience. This is noticeable throughout international literature including American, European, Asian and Scandinavian countries that have published articles narrating diverse transitioning experiences. Regarding the three research questions that have guided this review and have been discussed throughout Table 5, RQ1 is descriptive and helpful in presenting the overall results, overlapping with RQ2 in some ways, with RQ3 being more complex to detail from the articles used for this scoping review. All sections are summarized and discussed at a more in-depth level in the next 3 sections.

### **4.1.1. What are the most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC?**

Converging experiences due to similar occurrences and patterns throughout the transition delineated an array of *pathways* characterized by the individual exposure of the older adult and family caregiver within each of the transition stages. Approaches to common pathways to the transition from home to LTC were recorded from all 21 studies used for this scoping review. Health decline, hospital stays, decision making processes regarding the home situation and fragmentation in the healthcare system have been informed by the TRANSCIT model (Groenvynck et al., 2021). Consistent with the model and included throughout the findings of this scoping review is the lack of information, communication, support and time. For the pre-transition phase, both older adults and family caregivers are met with the acknowledgement of having to move the older adult to LTC yet unaware of the process, support, sources of information and ports of communication needed to start the moving

process (Davison et al., 2019; Kiwi et al., 2017; Robinson and Fisher, 2023). The absence of knowledge and resources, may then lead to a delayed transition as well as pushing for alternate care options such as home care and numerous sacrifices, resulting in rushed and unmanaged transitions to LTC (Ramanathan et al., 2015; Scott and Funk, 2022). Next is mid-transition or move experiences, with emotional responses to leaving the home, as older adults leave their community of family and friends (O'Neill et al., 2019; O'Neill et al., 2020a; Zamanzadeh et al., 2015). At the same time, family caregivers experience the oncoming relinquishment of care of their loved one to health care professionals in addition to hands-on encounters with a healthcare system characterized by waitlists, uncertainty about the move, and unfamiliarity of move-in procedures (Groenvynck et al., 2022; Hainstock et al., 2017; Sussman and Dupuis, 2012; Zizzo et al., 2020;). Lastly, post-transition identifies the adaptation course into LTC home living for the dyad, the impact of the move both physically and mentally, as well as communication strategies and interactions with their surroundings including staff, other residents and the overall healthcare system (Cottrell et al., 2018; Davison et al., 2019; Eika et al., 2017; Koplow et al., 2015; O'Neill et al., 2020a).

#### **4.1.2. What are the most prevalent barriers and facilitators experienced by older adults and their family caregivers during these transitions?**

From the review of literature, it is apparent that most challenges for the transition from home to LTC homes were related to the absence of support during the move (Eika et al., 2013; Kiwi et al., 2017; Robinson and Fisher, 2023; Sussman and Dupuis, 2012;), and the complexity of seeking information in a fragmented healthcare system (Cottrell et al., 2018). Overall, older adults found the transition experience to be distressing (Kiwi et al., 2017; Konietzny et al., 2018; Scott and Funk 2022). During the *pre-move* stage, being excluded from the decision-making process related to the move to LTC or other related aspects impacted the overall transition to LTC (Kiwi et al., 2017; O'Neill et al., 2019; O'Neill et al., 2020; Zizzo et al., 2020). During the move, the loss of one's home threatened identity, belonging, and sense of self (O'Neill et al., 2020). Post-move experiences were experienced

throughout one's engagement with their surroundings, understanding new living conditions, and adapting to the LTC community by familiarizing with one another (Davison, et al., 2019; O'Neill et al., 2020). From the point of view of family caregivers, the transition itself enhanced the coping mechanisms on the emotional challenge of moving their loved one into LTC, experiencing feelings of guilt, distress and depression among others (Gaugler et al., 2010; Hainstock et al., 2017; Zizzo et al., 2020). Policies and procedures were highly valued as inaccessible and ill-suited, with waiting lists ranging from months to years to then be notified suddenly, having to accept the vacant home within 24-48 hours, including the move-in (Scott and Funk, 2023; Sussman & Dupuis, 2012). Insufficient resources, including the time to move, assistance when moving, and information about the move-in process were found throughout the moving stage to be a universal challenge in the transitioning experience and perception about the initiatives taken by the LTC home to facilitate the move (Hainstock et al., 2017; Zamanzadeh et al., 2015; Zizzo et al., 2020). Post-move, family caregivers found the change of roles and interaction with the provision of care from LTC home staff incredibly complex, in addition to the changing roles of caregiving after home care relinquishment and new beginnings (Cottrell et al., 2018; Hainstock et al., 2017; Ramanathan et al., 2015; Scott and Funk et al., 2023).

#### **4.1.3. What transitioning support (community and long-term care) is available for older adults and their caregivers moving into residential care to maximize integration and wellbeing?**

Several articles mentioned that having support throughout the move-in day, finding staff helpful by guiding family caregivers and older adults throughout the home into their own room was found to increase the familiarity with the home and the environment by improving the initial integration into the home (Kiwi et al., 2017). Other forms of support were seen through the reassurance and professionalism of staff at LTC the home, which for families this created comfort knowing that their family member was integrating into the home and receiving quality of care. Moreover, related to post-transition, the presence of activities and programs at the LTC home fostered a sense in older adults to seek participation and integration into the home by attempting

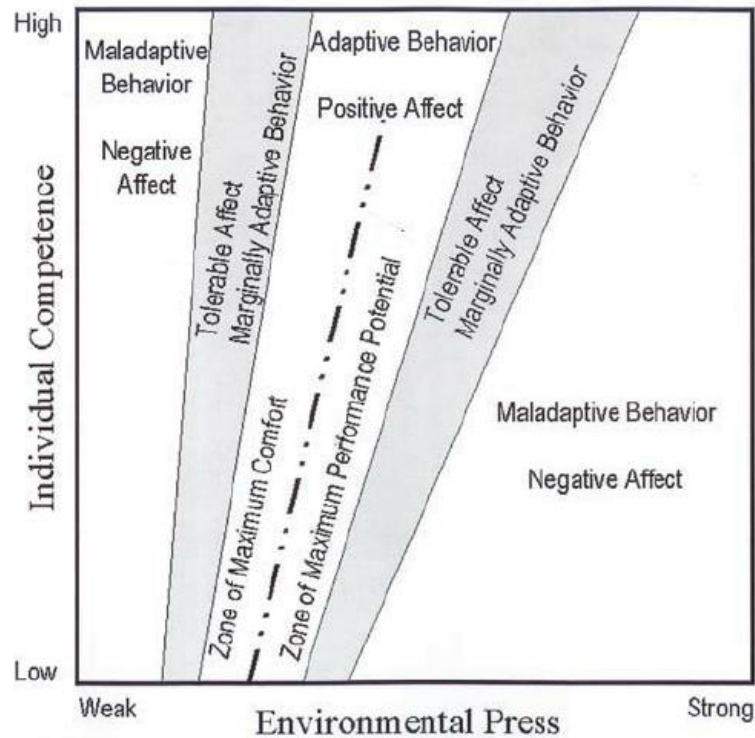


to connect with staff and other older adults through participation in such (Zizzo et al., 2020). Research findings did not specifically provide the presence of support services that family caregivers and/or older adults used throughout the research, limiting the extent of findings in response to this research question. One common observation throughout the research was the little guidance and/or support from outside agencies regarding the logistics of the actual move to the LTC home creating negative repercussions for participants and contributing to the anxiety of an already stressful time (Kiwi et al., 2017; Robinson and Fisher, 2023), as well as the absence of support from healthcare professionals throughout the overall transition (Groenvynck et al., 2022). Aside from this, community support services were mentioned for those that aided throughout the care of older adults at home to enhance home care and delay the move to LTC such as with Meals on Wheels or veteran affairs, which enhanced wellbeing for a period of time before these could no longer meet their demands (Konietzny et al., 2018). Other services included in supporting the transition that were available included employing a brokerage service. Still, this was limited as this support may only be available to those families with adequate financial resources, and even these were difficult to access, as some individuals mention finding such services through “word of mouth” (Zizzo et al., 2020)

## **4.2. Linkage of findings to concepts and theories**

In conjunction to this scoping review, the ecological model (Lawton and Nahemow, 1983) and the TRANSCIT model (Groenvynck et al., 2021) may be used in relation to pertinent research to conceptualize the complex nature of diverse home environments regarding older adults and family caregivers throughout later stages in life. The ecological model orients its attention to the mutually influential transaction by conceptualizing aging in place as a “dynamic person-environment process” (Greenfield et al., 2011). According to the ecological model of aging, a person’s functioning is the result of their biological, psychological, social resources; together with environmental characteristics and the fit between ever-changing individuals and their ever-changing environment (Greenfield et al., 2011). Within this model, when the

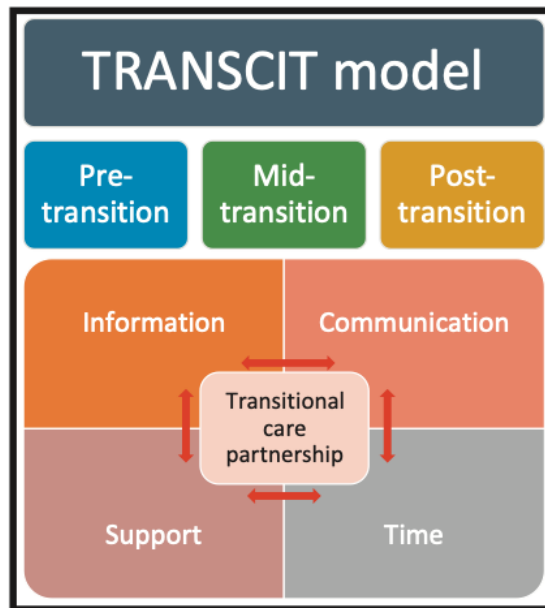
demands of social and physical environments overwhelm one's resources - due to changes within the individual's environment - the individual is less likely to age in place (Lawton, Weisman, Sloane, & Calkins, 1977). Together with transitioning experiences for this scoping review, when the demand of physical, cognitive and living environment conditions are not being met, considering LTC placement may become the next step for older adults to live in an environment capable - both built environment and LTC staff - to meet care demands throughout the care journey of family caregivers. The ecological model can also be adapted to the conditions of family caregivers throughout the transition experience, especially prior to the move. When caring for an older adult with complex comorbidities and increased health care demands becomes unmanageable (e.g., time, knowledge in the provision of care, money restraints etc.), the ability for the older adult to remain safely and comfortably cared for in the home by the family caregiver may be limited, resulting in necessary changes for the provision of care, including LTC placement. Nonetheless, transferring the older adult to a supportive environment with resources that provide proper care and respite for the family caregiver would be suitable. In the context of transitions to LTC homes, this model ultimately highlights the interaction between environmental press and individuals' competence that may allow for older adults to remain home or express the need to move to a LTC home.



**Figure 2. Ecological Model of Aging (“Competence Press Model”)**  
 Source: adapted from Lawton & Nahemow, 1973

The findings of this scoping review have highlighted the need for the defragmentation of the healthcare system regarding transitional care partnership, flow of information, communication, the absence of support, and the need for time to deal with affairs prior to transition to LTC for both family caregivers and older adults. The TRANSCIT model developed by Groenvynck and colleagues (2021), further discusses the levels in which the healthcare system should optimize transitional care and avoid fragmentation by addressing the needs of both older adults and informal caregivers throughout transition. This model focuses on the three identifiable stages of transitions, which include: 1) pre-transition; 2) Mid-transition; 3) Post-transition. This theory-based model identified 4 components throughout the transition trajectory (ie, pre-, mid-, and post-transition), which include: (1) **support**, (2) **communication**, (3) **information**, and (4) **time**. These 4 components were identified to be interrelated and interdependent. Throughout transition, effective communication is important in order to be able to offer helpful information and provide support. Both effective communication and helpful information require an appropriate amount of time. This model identifies and

addresses the needs of the dyad throughout the transition stages that have been highlighted throughout the scoping review for an effective, positive and timely transition, optimizing the care continuum and flow of information.



**Figure 3. TRANSCIT Model**  
Source: Groenvynck et al., 2021.  
<https://doi.org/10.1016/j.jamda.2020.09.041>  
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In addition to previous mentioned models, the theoretical model of residential normalcy by Golant (2011), builds upon the understanding of constructing principles that delineate where to grow old successfully, as well as the conditions under which residential environments correspond or are compatible with older adults' needs and goals. Within this model, diverse zones identify the experiential state in which the older adult is in congruency with their environment. When older adults experience hassle free, memorable feelings and overall joy they are theorized as being in their residential comfort zone; and in their residential mastery zone when they feel competent and in control of where they live (Golant, 2011). When older adults are outside of either or both zones, they may initiate accommodative and/or assimilative ways of coping to reach *residential normalcy* (Golant, 2011). This theoretical model, together with the transition stages that have been covered throughout the scoping review, incorporates the temporal and life course components

that are present (e.g., health comorbidities, socioeconomic status, family status, presence/absence of caregiver support etc.) and result in the diverse transition experiences to LTC. As older adults may become in need of diverse healthcare needs and goals that the current environment they reside in may not meet, the aforementioned coping strategies come into place. When transitioning to LTC takes place, coping strategies may differ depending on whether they are in their residential comfort zone or mastery zone.

### **4.3. Relevance of findings to policy and practice**

LTC waiting lists have been an issue for many years. Waiting lists, such as those presented by Interior BC for preferred LTC homes have shown to vary from 3 months to 12 months, and over a year in some exceptional cases (Interior Health, n.d.). With the increase in comorbidities of older adults and care demands from family caregivers, the length of such waitlists become unsustainable for families to keep older adults' home, needing other living and caring arrangements for the QoL of older adults. Alternatives of care such as adult day care centers (ADCs) have been found to provide respite for family caregivers, accommodating a variety of programs and services run by different types of providers and operate in diverse areas around cities with the aim to reach a wide range of clients (Orellana et al., 2020). These programs have an overall goal of helping older adults remain active in the community, provide social care, socialization, rehabilitation, assessment, and treatment (Kelly, 2016; Liu et al., 2015; National Adult Day Services Association, 2015). Even though day centers may be used as a steppingstone during the wait for LTC, the remaining time throughout the day that the older adult spends at home may also require attention. I am a believer that the funding of ADCs remains of high priority throughout communities for the improvement of health and respite, with diverse levels of care to address the needs found throughout different communities (e.g., rural/ urban, Cantonese speaking/English speaking).

In terms of findings related to QoL community wise, there is no place like living at home. Still, the care burden of family caregivers to be able to

provide this care is unsustainable compared to the quality of care provided in LTC. Nevertheless, the population of older adults has been experiencing a shift away from institutionalized care and towards home care (Statistics Canada – The Daily, 2017). There are an estimated two million users of publicly funded home care services in Canada, with 70% aged 65 and over (Gonzalez, 2018). Even though data is generalized to the overall population, the following findings can be used proportionally to the older adult population. According to Statistics Canada, about 1 in 14 households received home care services in the past 12 months, with about 8 in 10 reporting that these services were helpful and allowed recipients to stay at home (Statistics Canada, CCHS, 2022). The average of home care services that helped recipients stay at home in Canada was 83.2%, with 78% for BC, falling under the average. On average, half of the Canadian population wait 4 days from the date that the initial referral was received, to the date when the first home care service was received, while 1 in 10 people wait for about a month (CIHI, 2022). Moreover, about 1 in 10 newly admitted LTC residents could have potentially been cared for at home, with those living in rural areas and living alone being more likely, compared to other new residents (CIHI, 2022). These statistics show the need for enhancing the provision and allocation of home care services to potentially extend their stay at home, and hopefully remain at home.

#### **4.4. Limitations and gaps**

Due to the nature of scoping reviews, this method has various limitations that must be discussed. First, the reason for using a scoping review and not another research method was due to the limited number of articles available after the initial search was conducted for this topic. The results found were conditioned by a small number of articles, having to include the ones available that followed the eligibility criteria, focusing more on what was available rather than choosing from a pool of articles. Second, this scoping review and the findings from research articles could have been reinforced by having additional reviewers throughout data extraction, as it was solely done by myself (HG), and my supervisor (AW) for edits and corrections. For the

purpose of this graduate research project, the project proposal served as a protocol outlining the search strategy and scoping review steps which did not change from the proposed methods until completion of the manuscript in May 2024. Third, due to the referral to LTC and the diverse terminology that may have been used internationally, other relevant studies could have been included if more variants of the terms were made explicit in the search history throughout the beginning of the search. Moreover, the use of English only articles may have limited the use of pertinent global literature about other insightful research of transitioning experiences that could have been helpful for this review. The eligibility criteria was mostly limited to next of kin informal caregivers and cases of older adults caring for their partners. Still, informal caregivers encompass the wider scope of individuals that provide unpaid caregiving to a family member, increasing the pool of potential articles related to the transition experiences to LTC from other family members.

Overall, the cultural aspects of transition experiences have not been addressed throughout the research, except for the ones by Kiwi et al., (2017); Sun et al., (2021); Zamanzadeh et al., (2016); Zizzo et al., (2020); and Wu and Ruong (2020), which discuss the familial aspect of filial piety as an impacting factor in the beliefs of transitions to aged care. Other cultural factors discussed include traditional family structures, expectations of care from next of kin as well as negative perspectives over the admission into LTC which resulted in delayed entry, and hospitalization among others. Researchers that cover various fields and possess valuable knowledge from different cultural backgrounds may be helpful for a deeper understanding on the impact of culture within transition experiences.

Several limitations arose from the existing studies included in this scoping review. First, most of the studies, specifically all the qualitative studies, had very small sample data of family caregivers and/or older adults (Cottrell et al., 2018; Wu and Rong et al., 2020). Convenience and purposive sampling were common limitations throughout qualitative research, indicating that most of the participants interviewed were from similar socio-economic groups, limiting the representation of other areas that may have found the

move to LTC different (Kiwi et al., 2017; Konietzny et al., 2018; Robinson and Fisher, 2023;). In addition, some articles presented participants experiences from the same organization such as with the Alzheimer society recruited from the study by Cottrell et al., (2018), which may limit the representation from participants that do not seek and/or receive this kind of support by providing additional insights.

Some articles were conducted online due to the Covid-19 pandemic rather than face to face, limiting the assessment of body language, with interviews feeling formal and impersonal, as well as possible connectivity issues resulting in occasional disrupted communication (Robinson and Fisher, 2023). Some of the interviews conducted throughout the articles chosen for this scoping review were done in retrospective by participants to reflect on the previous transition experience, which may create the possibility of having recall bias (Ramanathan et al., 2015; Robinson and Fisher, 2023). Subject bias - when participants from a study know the expected outcome and act in a specific manner to achieve such outcome (Duignan, 2016) - was found to be a common issue throughout caregiver research (Ramanathan et al., 2015). Some studies such as the one by Davison et al., (2019), did not interview specific subgroups of residents such as those with cognitive impairment (i.e., moderate-severe dementia), which may have caused findings to be non-generalizable (Davison et al., 2019; O'Neill et al., 2022; Zamanzadeh et al., 2015).

From this research, I expected to come across the presence of support services in place throughout different communities where the research took place that family caregivers and older adults made use of throughout the move. Still, findings did not disclose the presence of such throughout the research chosen much in-depth, but the absence of such, creating a visible gap in the presence of support services for aid and guidance for the dyad throughout the transition to LTC. Moreover, this gap in literature was addressed as a practical implication, citing that the results from the experiences have the potential to inform future practice surrounding support



provided to individuals who engage in the process of deciding to move an older parent or relative into LTC (Robinson and Fisher et al., 2023).

#### **4.5. Ethical considerations**

Multiple aspects to consider throughout the studies for this scoping review include the recruitment of participants, workplace politics in the study design, interpretation and dissemination of findings among others. Research that is conducted with participants that are non-native speakers of English may create additional considerations to account for, such as cultural boundaries, translation issues or perceptions of power and authority. Some of these articles were conducted and interpreted by English speakers, yet some of them were conducted in countries of participants with English as a second language (ESL), English as a foreign language (EFL) or English as an additional language (EAL) (Athannasoulis & Wilson, 2009). Informed consent is a fundamental aspect of conducting ethical research, which can be given verbally or in written form (Athannasoulis & Wilson, 2009). Because this research was conducted with older adults, informed consent and the procedure of research presents an ethical dilemma as some of them had dementia and cognitive impairment. Most studies have taken the steps that relate to the protection of vulnerable adults, participants' information, consent, autonomy, and confidentiality such as with the article by O'Neill et al., (2022). Having peer-support groups throughout the studies when focusing on a specific issue may bring their problem known to other peers, other family caregivers from known family members, and other participants, exposing their struggles whereas someone might not have potentially disclosed these in another situation (Windsor 2015). Most of the studies used for this scoping review had a qualitative design with small sample size. Although no authors disclosed potential conflicts of interest, many of the researchers involved in the studies had some connection with the LTC sites. Throughout the Canadian literature included many of the researchers received funding by regional grants, provincial health authorities or initiatives brought forward by the national government as an initiative to promote research and implementation in the area, which will be detailed throughout Appendix C.

## 4.6. Implications for future research

Several implications were identified throughout the synthesis of the literature for future research and practice. First and foremost, findings inform future research, which has shown that caregivers require adequate support at key stages in order to ameliorate the rapid escalation of needs, increase support and guidance by providing training to address possible issues of feeling under resources when performing ADLs, and lessen feelings of disempowerment (Konietzny et al., 2018; Ramanathan, 2015). Therefore, as studies state, future emphasis may be beneficial in identifying the right time to make placement decisions or determining what type of support is optimal to reduce burden and depression among caregivers and care recipients rather than the emphasis on preventing institutionalization overall (Gaugler et al., 2010). As residential care will be necessary in the years to come until other services become more accessible, LTC home research should be advocated as a key transition faced throughout the course of some older adults, instead of a life clinical endpoint (Gaugler et al., 2010). In addition, removing older adults from waitlists when bed offers are declined currently result in penalties. Research has highlighted the re-evaluation of policies of this sort to facilitate care transitions while maintaining the well-being of the dyad (Konietzny et al., 2018).

Directions for future research from the experiences included in each study could potentially uncover the areas that need to be further explored and produce accessible documentation for families to use to prepare for transition. Some distinguished directions for future research include the development of guidelines and recommendations for staff to facilitate the move and adjustment into LTC, and the dissemination of such informational tools for LTC transition to be as smooth as possible, as well as discussing the LTC options with family members at an early stage to help prompt discussions and aid individuals in feeling more prepared (Groenvynck et al., 2022; Robinson and Fisher, 2023). Moreover, recommendations by Sussman and Dupuis (2014) on the transition experience include the development of a clear care home induction process pre-move by including visits to possible care homes,

moving day plans, welcome orientation, meetings with residents and staff, information on facilities and more. Therefore, involving advocacy services that may facilitate the transition to a LTC home would maximize QoL and well-being of individuals (Sussman and Dupuis, 2014). Future research should focus in further understanding the transition experience to identify strategies and create interventions that meet the unique needs of such groups by mitigating the implications of stress and impact in mental health (Cottrell et al., 2018), such as the development of screening processes to identify families at-risk for burden or depression immediately prior and after institutionalization to ameliorate the impact (Gaugler et al., 2010).

According to the CIHI, 87% of older adults in LTC homes had some form of cognitive impairment (including dementia and other conditions such as stroke or trauma) (CIHI, n.a.). Research has shown that due to retained cognitive abilities such as dementia, families may exclude older adults living with dementia to try and ameliorate decision-making processes before their relative is ready to relinquish the autonomy of decision-making (Canadian Centre for Elder Law, 2019). Health care systems such as LTC homes have also shown to create barriers for older adults to be involved in decision-making processes within the move to LTC due to organizational culture and time constraints, as PLWD may need extra time to process and manage the move (Canadian Centre for Elder Law, 2019). As a result, complications in management due to time constraints lead to anxiety. For this reason, it becomes easier for family caregivers and other care partners to take over such matters (Canadian Centre for Elder Law, 2019). Future research should focus on conducting research that reports the perspectives and experiences of both family caregivers and PLWD by interviewing them together. This could provide a deeper understanding of how the relationship between the PLWD and family caregiver influences the decision-making process and transition experience to LTC.

To delineate the decision-making process when incapacity is present, Canadian provinces and territories develop their own policy and legislation (Inclusion Canada, 2022). The Representation Agreement Act of British

Columbia has been considered as a pioneer in legislation as one of the first decision-making legal regimes in the world (Representation Agreement Act, 1996). Overall, when an older adult lacks the level of decision-making needed to make important decisions about their health, a substitute decision-maker (SDM) is designated to authorize such decisions on their behalf (King et al., 2024). Such important legislative measures have shown incredible progress throughout the care continuum across Canada, as SDMs can receive support from the directives provided within one's advance care plan, statements done in the past and other healthcare aspects that may have been previously registered by the PLWD (Healthwise staff, 2023). More recently, Supported Decision Making has been incorporated into BC legislation as an alternative to substitute decision making. Rather than transferring the decision-making rights from one person to another, supported decision making enhances self-determination by allowing one or more to participate in decisions that impact one's live circumstances (Canadian Centre for Elder Law, 2019). As policies change, future research should focus on providing people with dementia the tools to participate in exercising decision-making choices throughout the transition process in conjunction with the appointed family caregiver that has been entrusted by the PLWD throughout this process.

As most of the articles were found to be of a homogeneous sample, future research should be made in transcultural settings, taking into account cultural differences helpful in understanding a wide variety of transition experiences (Sun et al., 2021). Representation of cultural and geographical groups with a homogeneous sample limited the exploration of cross-cultural insights or other relevant information from marginalized groups (Davison et al., 2019; Kiwi et al., 2017; Konietzny et al., 2018; Koplow et al., 2015; O'Neill et al., 2019; Sun et al., 2021; Zamanzadeh et al., 2015; Zizzo et al., 2020). Some studies used focus group interviews, which may limit individual in-depth understanding of the transition experiences (Cottrell et al., 2018). Therefore, due to the limiting factor of a small homogeneous sample of articles from the search of global literature, the results pertaining to different geographic locations disclose the need for future research of analyzing findings from

different regions to gain a deeper understanding due to the lack of representation from South American, Asian and African countries.

Person-centered care has become more popular in gerontological research, especially within research related to the provision of care, meeting individual needs, and improving QoL in LTC homes. In addition, taking a family-centered care approach to service delivery would be beneficial when accounting for cultural differences, considering families as a package when the transition to LTC home takes place, and addressing psychological needs both individually and as part of a family. Counseling services to address psychological aspects that might arise from the transition experience should be further explored for the benefit of family caregivers and older adults during and following transition to a LTC home (Zamanzadeh et al., 2015). Surprisingly, most of the recent studies conducted during or after the COVID-19 pandemic did not discuss in detail the implications of their research on the subsequent transition experiences to LTC in the future.

#### **4.6.1. Sources of funding**

The results presented in Chapter 3 and during the process of analysis and synthesis, highlighted aspects of funding for the articles included in this scoping review. Even though the interest for this scoping review was to analyze the data available regarding the transitioning experience to LTC, it was important to analyze the sources of funding from the different articles, as these are shown to reflect risk of bias or conflict of interest when assessing an article for its usability, as well as to highlight government and societal priorities (Windsor, 2015). All resources of funding were recorded throughout the data charting process. Information such as research country of origin, funding source, full title of the supported publication and authors were included in Table 6 in the Appendix to include funding sources for future research.

Over the past decade, research articles, health agencies and organizations have brought into attention the scarcity of research conducted in the implications of moving into LTC for older adults and family caregivers, consequently seeing a steady increase in such research. Even though most of

the studies gathered from this scoping review had small sample sizes and homogeneous participants from the same geographical area with lack of generalizability, most of them received some sort of financial support. The present funding and continuous involvement in the understanding of transition experiences brings expectations to the interest in this topic for future research and practical applications from transitional projects such as with the TRANSCIT model by Groenvynck et al., (2021). In addition, the support provided by funding this area of research shows an interest in improving the transition experience itself. The transition to LTC is a complex process that may include health care professionals from diverse backgrounds, researchers, and educators that are in contact with their communities to uncover the cultural beliefs of LTC homes. Studies included for this scoping review present diverse approaches to improve the transition to LTC to promote evidence-based programs and interventions for the improvement of such experiences, resulting in improved living conditions.

## **Chapter 5.**

### **Conclusion**

This scoping review contributes to the discussion of the sometimes overwhelming experiences that moving can create for older adults when leaving their home and moving to LTC, by amplifying the experiences and the emotional complexity of it requiring support from professionals with diverse roles that aid in the move, interaction with the system and resulting transition. Involving health care workers needed in the transition and dealing with the practicalities of the move from the home/hospital may generate its own complications, as research has shown that the move itself happens rather quickly, leaving no time for rigorous planning and consideration. Family caregivers have shown that the care they provide for older adults is the result of intricate processes that pertain to interactions within the present familial relationship, cultural expectations, beliefs, and emotional states that result in worry and feelings of responsibility from family caregivers to provide the appropriate care that their loved ones may require for an improved QoL. The results of this scoping review show that most family caregivers are willing to be engaged in the continuance of care post-transition. Environments that enhance the communication between LTC staff and family caregivers was desired throughout many studies from this scoping review, yet this is not the sole solution to the overall workload of healthcare workers when providing care for older adults in an already saturated system. To improve collaboration for improved care, organizational support throughout all transition stages is needed. This support is then essential for the ever-changing needs of older adults.

Caring for an older parent is part of the aging process within families, with different levels of engagement that may stem from cultural beliefs, availability and familial attachment. Continuing to acknowledge the complexity of the transition process, identifying challenges and facilitators, as well as improving practices may then support the approaches from healthcare workers to guide family caregivers and older adults for wellness and QoL.

This scoping review presents areas that are potentially promising for future research. Future research is necessary in this area in order to develop and implement practices such as the one from Groenvynck et al., (2021), to support aspects within transitions that are in need of improved informational resources for family caregivers, as well as to implement cultural, policy and practice changes as the demand for LTC homes continues to increase. To care for older adults moving to LTC is a meaningful experience. Findings suggest that ongoing education, self-care, strengthening, affirming interpersonal and community connections through gate breaking are complementary strategies to foster a smoother transition, improve mental health and wellness of those involved.



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## Appendix A.

### PRISMA-ScR Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	
Limitations	20	Discuss the limitations of the scoping review process.	
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., Lewin, S., ... Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of internal medicine*, 169(7), 467–473. <https://doi.org/10.7326/M18-0850>

## Appendix B.

### Study Characteristics

Author(s) (Year) Country	Key Words	Study Design	Objective(s) or Research Question(s)
Cottrell et al., (2020) Canada	Caregiver; dementia; nursing home placement; qualitative thematic analysis; focus groups.	Qualitative Thematic and conversational analysis. Focus groups. (n=9)	To explore the transitions experienced by caregivers of persons with dementia after their relatives relocated to a 24-hour care home.
Elka et al., (2013) Norway	Care home, family caregivers, family members, long-term care, relative, transition	Constructivist hermeneutical design. Participant observation. (n=10)	To describe and explore experiences of next of kin during the older persons' transition into long-term care
Gaugler et al., (2010) United States	N/A	Longitudinal analysis of dementia caregivers. Burden measured with a modified version of the Zarit Burden Inventory. Depression symptoms assessed with the Geriatric Depression Scale	To determine whether clinically significant changes in symptoms of burden and depression occur among caregivers within 12 months of LTC admission of their relatives with dementia, and to identify key predictors of persistent burden and depression in the first year after the move.
Groenvynck et al., (2022) The Netherlands	Transitional care, nursing homes, older persons with dementia and informal caregivers, older people, qualitative	Secondary data analysis using interpretative phenomenological design. (n=24)	To capture the experiences of older persons and informal caregivers throughout all phases of the transition into LTC.
	Transition, home care, residential care, family caregivers, long-term care.	Qualitative interview data, thematic analysis. (n=16)	To explore the roles and responsibilities of family caregivers for family members making the care transition from home care to residential care.

<b>Author(s) (Year) Country</b>	<b>Key Words</b>	<b>Study Design</b>	<b>Objective(s) or Research Question(s)</b>
Hainstock et al., (2017) Canada			
Kiwi et al., (2017) Sweden	Caregiver, dementia diseases, Iranian immigrants, care at home, care at residential nursing home, transition	Semi-structured interviews, content analysis by Elo and Kyngäs (2008). (n=20)	To show how the decision to ease caregiving at home is taken, and what underlying factors form the basis of such a decision.
Konietzny et al., (2016) Canada	Aging, care transitions, informal caregivers, family caregivers, long-term care	Qualitative description. Sandlowski's (2000) approach to qualitative description to answer research questions (n=13)	To explore informal caregivers' experiences of transitioning an older adult into long-term care (LTC)
Koplow et al., (2015) United States	Family caregivers, nursing home placement, qualitative research, Family Management Style Framework	Qualitative description. Family management style framework (n=10)	To examine the experiences of caregivers involved in the management of care and placement of an older family member
O'Neill et al., (2020) United Kingdom (a)	Older people, adaptation, care home, transitions, grounded theory	Semi-structured interviews (n=17)	To explore older adults' experiences of living in a care home, during the four-to-six-week period following the move.
O'Neill et al., (2020) Ireland (b)	Adaptation, care home, grounded theory, older people, quality of life, transitions.	Purposive sampling, grounded theory methodology, theoretical sampling, semi-structured interviews. (n=17)	To explore how older adults' experience the transition from living at home to a care home with focus on the latter part of the first year of the move
O'Neill et al., (2019) United Kingdom (c)	Aging, care homes, care of older people, decision-making, long-term care, older people, transition	Grounded theory method used to conduct semi-structured interviews. (n=23)	To explore the experiences of older adults moving into a care home, focused on the preplacement (7 days) and immediate post placement (within 3 days) period of the move to the care home
Ramanathan and Fisher (2015) Singapore	Caregivers, long-term care, caregiver stress, stress, older adults, placement, interventions.	Qualitative design. (n=12)	To understand caregiver experiences during the process of providing care, particularly at times of transition when moving into LTC.

<b>Author(s) (Year) Country</b>	<b>Key Words</b>	<b>Study Design</b>	<b>Objective(s) or Research Question(s)</b>
Robinson and Fisher (2023) United Kingdom	Ageing, care home, life transitions, qualitative method, older parents	Retrospective narrative (n=13)	To explore the personal experiences of individuals making the decision to move an older parent into a residential care facility and gain understanding of how individuals experienced transition, emotions felt at specific moment throughout transition and the perceived effect it had on their psychological well being
Ryan and McKenna (2013) United kingdom	Family carers, nursing homes, older people, rural health care	Qualitative study, semi structured interviews, grounded theory principles and procedures (n=29)	To explore rural family carers' experience of the nursing home placement of an older relative.
Scott and Funk (2022) Canada	Long-term residential care, care transitions, family caregiving, older adults	Secondary qualitative analysis. Critical gerontological perspective (n=22)	Through a critical gerontological lens, to analyze families' experiences across a broad continuum of older adults' moves into LTRC. To explore the causes and consequences of the structural burden of carers' experiences navigating systems.
Sun et al., (2021) China	Nursing home placement, adaptation, transition, filial piety, person-centered care	Qualitative study. Purposeful sampling with semi structured interviews. Content analysis (n=16)	To explore the adaptation of older adults' transition to nursing homes in mainland China
Sussman and Dupuis (2012) Canada	Aging, long-term care, family carers, relocation, nursing home	Grounded theory study (n=20)	To explore family members' experiences supporting a relative's move into a LTC home throughout each stage of the transition process
Tanya et al., (2019) Australia	Adjustment, dementia care, family carers/caregivers, long-term care, nursing homes, residential aged care, skilled nursing facility	Parallel interview schedules. Thematic analysis. Study adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines (n=38)	To determine factors that facilitate or impede adjustment to residential aged care (RAC) from the perspectives of residents with dementia, families of residents with dementia and facility staff.

<b>Author(s) (Year) Country</b>	<b>Key Words</b>	<b>Study Design</b>	<b>Objective(s) or Research Question(s)</b>
Wu and Rong, (2020) Taiwan	Elderly wellbeing, relocation stress, long-term care facility	Qualitative study based on grounded theory.	To explore the relocation experiences of the elderly to a LTC facility to inform policy and practice to address their needs effectively
Zamanzadeh et al., (2015) Iran	Caregiver, older adult, long term care, culture, filial piety, transition	Thematic analysis of interview data. (n=23)	To understand caregiver experiences of the process of providing care, particularly at times of transition, such as when the care recipient moves into a nursing home.
Zizzo et al., (2020) Australia	Aged care policy, aging, loss and grief support, non-death-related loss, residential aged care	Qualitative study. Thematic analysis. Loss and grief theoretical lenses. Triangulation (n=55)	To report findings of the experiences of people living in RAC, carer-relatives of people living in RAC and RAC staff, identifying features of the transition to RAC and the types of support mitigate features of the transition associated with unresolved loss and maladaptation to changed circumstances



## Appendix C.

### Key findings on transition experiences from the home to LTC.

Author	(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC	(RQ2) Challenges and facilitators	(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers
Cottrell et al., (2018)	<p>(p.228) Experiencing overwhelming feeling of loneliness due to loss (Loss of previous role, familiar self, loss of control due to having to relinquish care, loss of friends and support networks)</p> <p>(p. 230) Necessity to build relationships with staff during the early post-placement period.</p> <p>(p.230) Assuming multiple roles when balancing caregiving and recreating a new-self post placement</p>	<p>Facilitators:</p> <p>Challenges: (p.229) The relationship between caregivers, the health care system, and sense of control is complex.</p>	<p>(p. 231) Alzheimer's society from which participants were recruited, an organization that provides support for family caregivers</p> <p>(p.230) Support groups provided camaraderie, where participants offered suggestions and advice to one another about the experience, seeing as a good start.</p>
Davison et al., (2019)	<p>(p. 3904) Separation from community, family, friends, home due to losses related to physical health and independence, declining cognitive function leading to relocation.</p> <p>(p.3904) Distress and confusion from older adults following relocation due to unfamiliar environment. Also, having relief and security in case anything happens.</p> <p>Family caregivers relieved that relatives receive a higher level of care in LTC</p> <p>(p.3905) Feelings of resignation about placement. Trying to stay positive and make the best of it.</p>	<p>Facilitators: Importance of a homelike environment when moving into LTC. Customizing residents' rooms with favored items. Family support, arranging outings to leave the facility, providing a sense of continuity. Building relationships with other residents, mealtimes and group activities.</p> <p>Challenges: Not finding meaningful relationships in LTC. Having to push themselves for activities. LTC homes provide suboptimal activities.</p>	<p>(p.3911) The provision of support for the adjustment of older adults into LTC, yet no formal programmes in place to help families and older adults.</p> <p>(p.3905) Staff trying to address families' concerns by providing education and support to help understand, cope with the transition, and see benefits of the new environment for the resident.</p>

Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
Eika et al., (2013)	<p>(p.2189) Next of kin had little formal information about the nursing home before admission. Expressing feelings of insecurity in periods when older family member's health declined.</p> <p>(p.2190) Next of kin knew of waiting lists for LTC placement and were grateful that their older family members were chosen.</p> <p>(p.2190) Having one parent at home and one experiencing transition appeared to create preference of care towards the one transitioning, contributing to distance between parents.</p> <p>(p.2191) As transition took place, next of kin had to face the older adult's critical conditions, triggering reflections and memories of their previous life together.</p>	<p>Facilitators:</p> <p>(p.2190) Positive remarks of the care and attention provided when older adults are admitted into LTC homes.</p> <p>Challenges:</p> <p>(p.2190) Next of kin having little communication with staff and feeling like disturbing staff routines at night.</p> <p>(p.2190) Feeling responsible for the older adult after they had moved to LTC, challenging relationships with families.</p>	(p.2192) Support from staff varied for spouses throughout transition, this being inconsistent, arbitrary and confusing to next of kin.
Gaugler et al., (2010)	(p.6) Caregivers who reported clinically significant burden decreased from pre-placement to six-month post-placement follow-up. Similar happens to clinically significant depression following institutionalization eventhough less pronounced.	<p>Challenges:</p> <p>Facilitators:</p>	N/A

Author	(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC	(RQ2) Challenges and facilitators	(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers
Groenvynck et al., (2022)	<p>(p.3) Informal caregivers experience the older person's transition to LTC as a complex care process characterized by paradoxes with "ostensibly, contradicting emotions."</p> <p>(p.4) Having negative feelings associated with LTC home at the beginning but having feelings of relief and acceptance afterward.</p> <p>(p.5) Understanding that the move was necessary after realizing that the dangerous home situation was unsustainable and worrisome.</p>	<p>Facilitators:</p> <p>(p.5) Coping with the emotional challenge of transition by focusing on re-establishing routine and homeliness for the older person. Having a place that looks like home (e.g., furniture), with similar routines and habits.</p> <p>Challenges:</p> <p>(p.5) The absence of emotional support from healthcare professionals throughout the transition.</p> <p>(p.6) Encountering an inefficient healthcare system when seeking information about transition that influences experience by not being taken seriously, being a lengthy process when contacting health care professionals about requirements.</p>	N/A
Hainstock et al., (2017)	<p>(p.34) Older adults being hospitalized prior to relocation into residential care, making the hospital a pivotal setting within the caregiving journey.</p> <p>(p.34) Family caregivers feeling naive and unfamiliar with policies and protocols of LTC upon entering the system. Relying on multiple sources of information to help make decisions about the transition.</p> <p>(p.35) Family caregivers found themselves assuming an advocacy role when preparing to relocate their family member to ensure, support and maintain their family member's well-being and QoL when making decisions related to care preferences</p>	<p>Facilitators:</p> <p>Challenges:</p> <p>(p.34) Older adults wanting to return home right after relocating, increasing stress and burnout in family caregivers).</p> <p>(p.35) The nature and timing of service eligibility and needs assessments, unexpected short stay user fees charged for staying in hospital while waiting for transfer.</p> <p>(p.36) Transportation challenges when move was imminent.</p>	N/A

Author	(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC	(RQ2) Challenges and facilitators	(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers
Kiwi et al., (2017)	<p>(p.27) Demand of professional care becoming clear to all informal caregivers as symptoms of dementia become more manifested in everyday life, affecting the family.</p> <p>(p.31) Feeling that there is no option but LTC and not discussing the decision with the PLWD.</p> <p>(p.36) Feeling liberated and relieved after placement, an opportunity to delegate time towards other areas of life.</p>	<p>Facilitators:</p> <p>(p.31) Having a positive attitude towards LTC home and caregiving made it easier to make the decision of moving family members into LTC.</p> <p>(p.34) Families being interested and willing to be involved with the care given at the LTC home.</p> <p>Challenges:</p> <p>(p.27) Stress arising within the family as they had more difficulty in taking care of loved ones with dementia.</p> <p>(p.29) Not having the physical and mental strength to take care of someone with dementia at home.</p> <p>(p.32) As the need for a nursing home approached, information seeking was harder to obtain.</p> <p>(p.35) Geographical distance between them and the rules within the geographical area they live in.</p>	<p>(p.31-32) Information and access to family support differs with individuals. Some turned to their circle of friends, others to shops nearby, local radio broadcasts and others to social services.</p> <p>(p.24) Temporary support such as home health care, meal services, safety alarms, home adaptation, transportation services and others to manage home care until it becomes unmanageable.</p>
Konietzny et al., (2016)	<p>(p.467) Expanding scope and enlisting additional services through Local Health Integration Network (LIHN) and other resources such as Meals on Wheels, and Veteran affairs to supplement caregiving necessities.</p>	<p>Facilitators:</p> <p>Challenges:</p> <p>(p.468) Physical care that older adults required at home was physically overwhelming, especially for older caregivers.</p> <p>(p.469) Encountering a healthcare system that was rigid and compassionless when family caregivers tried to find the right home for their loved one.</p>	N/A
Koplow et al., (2015)	<p>(p.482) Noted difference in the priorities that influenced caregiving responsibilities between spouses and non-spousal caregivers.</p> <p>(p.484) LTC home placement eased some of the burden of the direct hand-on-care so the focus could return to the familial relationship.</p>	Facilitators:	N/A

Author	(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC	(RQ2) Challenges and facilitators	(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers
		<p>(p.481) LTC staff effectively handle their family member's condition, reducing caregiver burden. Having direct contact with staff and being able to communicate concerns.</p> <p>Challenges:  (p.481) Health condition deteriorating, preventing home care and leaving them alone due to safety reasons.</p>	

Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
O'Neill et al., (2020) (a)	<p>(p.358) Main reason for relocation was deterioration of health, recent bereavement, and no-one to take care of them/changing family circumstances.</p> <p>(p.362) When moving to LTC, residents feel out of place. Being able to form new relationships was crucial for one's sense of identity and connectedness to people within their new home.</p> <p>(p.363) Maintaining one's identity and autonomy is considered as a significant factor when moving into a care home.</p> <p>(p.365) Residents were found to have restrictions in routines and practices at the LTC home, impacting independence and autonomy.</p> <p>(p.366) Experiencing feelings of hopelessness and despair on admission about the future, seeing no purpose when physical, mental and social abilities diminished.</p>	<p>Challenges:</p> <p>Cognitive impairment and frailty as obstacles to social engagement in LTC. staff seen as care providers and not as people with whom to develop relationships. Feeling restricted due to routines and practices, feelings of powerlessness. Care home restrictions, standardized routines and "risk-averse practices" threaten independence and autonomy, generate frustration and passivity.</p> <p>(p.364) Becoming dependent on staff for assistance due to health decline.</p> <p>(p.367) Experiencing dependency on both family and staff to get out or come into the care home.</p> <p>Facilitators:</p> <p>(p.367) Maintaining links with family when in LTC and spending time outside together. Support from staff, providing information and sharing practicality of the move. Bringing in possessions to symbolize and sustain identity. Reflecting on positive elements of relocation.</p> <p>(p.364) Positive perception over the decision to move to a care home. Aspiring to maintain independent physical function.</p>	<p>(p.369) Most individuals identified that adapting to life in LTC was an ongoing process where they were mostly trying to navigate themselves with little support from care home staff or others.</p>

Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
O'Neill et al., (2020) (b)	<p>(p.483) Being excluded from the decision process and having an overall negative first impression permeated the experience of the move over the first year. Resigning to the fact that there was no other option for them but to be living in the care home. (p.485) Important to be able to say goodbye to the home.</p>	<p>Challenges: (p.483) Being excluded from the decision making process. (p.486) Care staff being authoritative and uncaring. Negative impact of losing favorite or good staff when they moved to another employment. High staff turnover. (p.489) Experiencing loneliness for those that had no family of their own, or individuals who had no shared interests with other residents.</p> <p>Facilitators: (p.483) Being involved in the decision making process improved the feelings of being at home. Resilience and positive thinking promote positive adaptation and acceptance. (p.485) Getting on with residents and care home staff. Being able to leave LTC and break the routine of daily care home life. Continuance of relationships with family and friends.</p>	<p>(p.489) Some participants identified how they were positively supported by SW and care home staff to control how and when they said goodbye to their house when they were letting go of the home and how this enabled a successful adaptation to their new home. (p.486) Recognizing the significance of supportive and respectful staff that made them feel at home from the outset of the move and on a day-to-day basis.</p>

Author	(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC	(RQ2) Challenges and facilitators	(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers
O'Neill et al., (2019)	<p>(p.6) Changes in health, social circumstances such as a carer becoming unwell or dying and an increased vulnerability to living alone were predictors of the move to a care home, with the move seen as inevitable as needs increase in tandem with decreasing health and physical capabilities.</p> <p>(p.7) Having previous hospital visits, deterioration in health, with little or no family support led to seeing the care home as the only choice.</p> <p>(p.6) The move to the care home is a rushed and hasty affair regardless if it was from the hospital or their own. Care managers/hospital staff are the key people making the decisions about moving to the care home.</p> <p>(p.9) When arriving at the care home, individuals seen as if they were wrongly placed, that the home does not meet their needs, looking for other options.</p> <p>(p.9) Becoming dependent upon care home staff to go outdoors and maintain continuity with home and the community.</p>	<p>Facilitators:</p> <p>(p.8) Positive contribution of family visits and old friendships facilitate the maintenance of a sense of connectedness between past life and current life at the care home.</p> <p>(p.9) Getting a care home close to home to maintain a sense of well-being, enhancing the continuance of previous relationships.</p> <p>Challenges:</p> <p>(p.8) Having a small window of opportunity to obtain a care home bed, long waitlists, further restricting choice. "Having to take the next one available."</p> <p>(p.8) Age influences the choice of care home, finding care homes that accommodate residents under the age of 65.</p> <p>(p.8) The perceived loss of the individual's home life, therefore threatening identity, belonging and sense of self.</p>	N/A



Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
Ramanathan and Fisher (2015)	<p>(p.10) Cultural aspects such as filial piety impact the way family caregivers draw meaning and made decisions about the placement process</p> <p>(p.12) Mixed feelings about placement decisions, feeling uncomfortable about LTC and holding ideals of providing care at home.</p> <p>(p.13) Opting for institutionalization only after making significant personal sacrifices to keep the care recipient at home.</p> <p>(p.16) Increase level of communication with staff to improve individualized care for their relative at the LTC home.</p>	<p>Facilitators:</p> <p>(p.15) Families' encouragement of maintaining the relationship with the older adult to enhance the transition experience</p> <p>Challenges:</p> <p>(p.10) Feeling the burden of having to fulfill their obligations as next of kin due to cultural norms and reciprocity of care.</p> <p>(p.12) Gaining the care recipient's agreement to the decision to move into LTC.</p>	<p>(p.14) Next of kin providing financial and emotional support to parent whose partner moved into LTC by taking care of their parent at home, making sacrifices</p>
Robinson and Fisher (2023)	<p>(p.6) The prospect of transition creating stress and conflict among family caregivers, making the transition more complex and emotionally fraught.</p> <p>(p.7) Having no alternative options on relocation created a perceived forced necessity, for medical purposes, safety or QoL.</p> <p>(p.7) Family caregivers experiencing guilt due to the transition, sadness in seeing older adults in an unknown environment, fear of moving their relative into a care home, grief, and relief after the transition leading to less anxiety and worry knowing their loved one would be cared for.</p> <p>(p.8) After the move, family caregivers slowly prepare for their relative's death, with the transition symbolizing the end of life.</p>	<p>Facilitators:</p> <p>(p.8) Perceiving the transition into LTC as "the right thing to do" and feeling comfort about how the care provided was sufficient to the relative's needs.</p> <p>Challenges:</p> <p>(p.6) Struggling with relatives and older adults about the prospect of transition.</p>	<p>Many discussions centered on lack of preparedness, with some sharing how they received little guidance or support from outside agencies regarding logistics of the move.</p>

Author	(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC	(RQ2) Challenges and facilitators	(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers
Ryan and McKenna (2013)	(p.3) Living in a rural area and moving into LTC influenced by the carers' familiarity with the LTC home history, staff, residents and local community.	<p>Facilitators:</p> <p>(p.4) The familiarity of having known the home-owners for several years. Knowing the staff in the nursing home long before their relative was admitted created a source of great comfort to them and the older relative.</p> <p>(p.5) The comfort of knowing that their relative would have something in common with other residents due to being locals in the same community.</p> <p>Challenges:</p> <p>(p.4) Residing outside of the community did not provide familiarity with the system and the LTC home.</p>	N/A
Scott and Funk (2022)	<p>(p.440) Caregivers experience feelings of disempowerment over the degree of involvement in family care as a result of perceived lack of control of service arrangement.</p> <p>(p.441-442) Staying overnight at parents house to provide overnight care due to increased demands of care, unable to hire care and worry. Opting for freelance work to help support care.</p> <p>(p.444) Lack of control and involvement throughout the paneling process, feeling compelled to advocate for their family members preferences and needs.</p>	<p>Facilitators:</p> <p>Challenges:</p> <p>(p.440) Having little power over how much formal services they can access to support the possibility of maintaining older adults at home (policy and practice).</p> <p>(p.444) Due to waitlists, families change their first choice facility for a less desired option with a shorter waitlist if things become unmanageable at home.</p> <p>(p.445) Having no available staff to provide information during the move further disempowered families.</p>	(pg.441) The use of supportive housing to receive support and supervision in personal care to delay LTRC

Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
Sun et al., (2021)	<p>(p.320) Cultural elements impact the transitioning experience of older adults moving into LTC homes. Showing maladaptation to the LTC home due to aspects about familialism and hoping to have been cared of at home.</p> <p>(p.321) After transition, family members often visited older adults weekly and took them home on holidays. Months later, residents aimed to reconstruct new life, building new relationships, and companionship.</p>	<p>Facilitators: (p.321) Having helpful staff encourage, guide and facilitate the building of new relationships.</p> <p>Challenges: (p.321) Having poor quality and food services at the home. Having difficulty communicating with friends, family and with other older people at the residence. (p.321) Experiencing loneliness at the LTC home made seniors not adapt into their new environment. Grieving loss of control, lack of privacy, no freedom.</p>	N/A

Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
Sussman and Dupuis (2012)	<p>(p.400) Initial awareness that LTC placement may need to be considered can come months or years before intensive reflection and contemplation.</p> <p>(p.400) Family members accessing LTC placement are found to happen under a crisis status, either from the home or hospital.</p> <p>(p.403) Having a positive pre-move experience determined by where they moved from appeared to cope better when faced with post-move challenges. Negative pre-move experiences often complicated the adjustment process, making it more difficult for family members to adapt.</p>	<p>Facilitators:</p> <p>(p.401) Take part in assessment to determine if LTC home placement was needed, helping them accept LTC as a viable option during the pre-move process.</p> <p>(p.402) Having the flexibility to reserve a space to delay move, supporting relocation, allowing to make important decisions about the move.</p> <p>(p.403) Being greeted at the LTC home immediately made them feel welcomed and supported. Having prior information about the admission process, items required.</p> <p>(p.403) Caring and respectful nature of staff towards family caregivers and residents.</p> <p>(p.404) Having the opportunity and support throughout the pre-move phase to emotionally accept LTC home placement.</p> <p>Challenges:</p> <p>(p.402) Families from all starting points expected to accept a bed offer within 24 hours and move a family member into LTC a day or two later, giving no time to organize moving arrangements.</p> <p>(p.403) Having to push on information about medical test results questioned the care of a relative's wellbeing.</p>	<p>(p.405) Some participants were invited to one meeting at the retirement residence to discuss placement and contemplate options of care.</p> <p>(p.406) Staff in retirement homes seemed less prepared to support families in preparation for making the transition to a LTC home.</p> <p>(p.406) Providing families some flexibility regarding the date and time of the move allowed families to visit the facility once more, move furniture in and rally additional familial support for the day of the move.</p>

Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
Wu and Rong (2020)	<p>(Pg.4) Experiencing conflicting emotions between desire to continue living in their family home and the need to avoid disrupting the lives of their families who they depended upon for the activities of their daily living.</p> <p>(Pg.4) Desire to keep the connection with family members and friends to avoid alienation from those they were emotionally close to. Choosing LTC homes near friends and family.</p> <p>(Pg.6) Reasons for relocation include lack of family support and inability to perform self-care. Psychological resistance on the decision to leave home and move to the facility.</p> <p>(Pg.6) Unfamiliar or uncomfortable environment of the LTC facility was a shock for some participants in the initial months of the stay in the LTC home.</p> <p>(Pg.7) Accept the stay in LTC and to adapt themselves to the new environment due to the needs for constant care.</p>	<p>Facilitators:</p> <p>(Pg.8) Having the desire to keep the connection with friends and family members and avoid alienating themselves from those who they were emotionally close to.</p> <p>(Pg.6) Provision of tailored care and emotional care from staff in the LTC home as valuable in adapting to the new environment and home. Appreciation for staff that showed concern and intimacy.</p> <p>Challenges:</p> <p>(Pg.6) Dislike or lack of trust in the care provider and facility inadequately meeting the care needs.</p> <p>(Pg.6) Fear of being neglected and being concerned about the overall safety from injuries and accidents, especially when first arriving at the LTC home. Missing home and family and a persistent desire to return home.</p>	N/A

Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
Zamanzadeh et al., (2015)	<p>(p.5) Experiencing personal loss of previous social and communication networks, inability to replace these with new ones of the same type at LTC.</p> <p>(p.5) Family connections seen as vital for participants with poor responses to the LTC home.</p> <p>(p.5) Attempts to make new communication helped reduce the communicational gap and psychological impact of the transition</p> <p>(p.6) The move being as involuntary for older adults, playing no active role in negotiating changes due to experiencing significant loss such as health, death of a family carer and loss of other sources of income.</p> <p>(p.6) The way being required to live in the LTC to fit in with schedules and rules resulted in them losing autonomy, independence in daily life activities, losing meaning in life.</p>	<p>Facilitators:</p> <p>(p.5) Satisfied on different levels when communicating with formal caregivers.</p> <p>Challenges:</p> <p>(p.5) Family members reducing or stopping visits after transition to LTC, causing feelings of rejection and severe loneliness.</p> <p>(p.5) Attempts to establish communication with other residents failed or was avoided due to socio-economic differences, intellectual incompatibility or others.</p> <p>(p.6) Receiving pension far less than the living costs on entry to the LTC, causing distress about expenses.</p> <p>(p.6) Neglect of resident's individual needs resulting in negative emotions, feeling undervalued by caregivers.</p>	<p>(Pg.6) Having access to financial resources supported by government subsidies.</p>

Author	<b>(RQ1) Most common pathways by which older adults, family caregivers, and as dyads experience transitions from home to LTC</b>	<b>(RQ2) Challenges and facilitators</b>	<b>(RQ3) Transitioning support (community and long-term care) available for older adults and their caregivers</b>
Zizzo et al., (2020)	<p>(p.481) Family caregivers struggle with the best approach to explain that a decision had to be made on their behalf as it was no longer possible to meet care needs at home.</p> <p>(p.482) Family caregivers have negative experiences when navigating the system due to endless paperwork, forms and complexities of a confusing and difficult to navigate.</p> <p>(p.483) Guilt commonly expressed among carer-relatives, associated with feelings of personal failure and inability to fulfill obligations.</p> <p>(p.484) Feelings of relief with the decision to move, creating reassurance due to intensive care provided in LTC compared to care at home.</p>	<p>Facilitators:</p> <p>(p.481) Engaging in decision making with their families were more likely to report positive outcomes, ability to manage loss and grief than those older adults that did not.</p> <p>(p.482) Having practical information and advice would be the most useful way to support the transition to LTC.</p> <p>(p.483) Using brokers made families more able to manage bureaucratic requirements related to entering the LTC facility.</p> <p>Challenges:</p> <p>(p.481) Triggering events (e.g., accidents, falls or sudden changes in care needs) meant that decision making was often difficult due to pressure to find a suitable LTC home.</p> <p>(p.482) The need to complete forms and to navigate time-consuming administrative and bureaucratic processes drained their emotional and mental resources.</p>	<p>(Pg.486) Peer support and friendship developed in LTC was an important element of adaptation and managing loss and grief. Develop friendships and support networks.</p> <p>(Pg.483) Families using brokers to locate beds and advisors to assist with finances described feeling more able to manage the transition. Limitations due to access to financial resources.</p>

## Appendix D.

### Sources of Funding

Country	Funding Source	Study Title	(Author(s), Year of Publication)
Australia	Dementia Centre for Research Collaboration.	Adjusting to life in a residential aged care facility: Perspectives of people with dementia, family members and facility care staff	(Tanya et al., 2019)
Australia	AnglicareSA funding	Loss and grief: The experience of transition to residential aged care	(Zizzo et al., 2020)
Canada	Canadian Frailty Network [grant number CAT2015-04].	Using focus groups to explore caregiver transitions and needs after placement of family members living with dementia in 24-hour care homes	(Cottrell et al., 2020)
Canada		Supporting a Relative's Move into Long-term Care: Starting Point Shapes Family Members' Experiences	(Sussman and Dupuis, 2012)
Canada	Canadian Institutes for Health Research (CIHR): Partnerships in Health System Improvement (PHSI) Grant Program, and the Michael Smith Foundation for Health Research (MSFHR) to Penning and Cloutier et al., 2012-2016 (CIHR #122184). In addition, this project was supported by a University of Victoria Internal Research Grant/Creative Projects Grant Program.	From home to 'home': Mapping the caregiver journey in the transition from home care into residential care	(Hainstock et al., 2017)
Canada	Supported by the Manitoba Health Research Council	Cumulative Disempowerment: How Families Experience Older Adults' Transitions into Long- Term Residential Care	(Scott and Funk, 2022)



Country	Funding Source	Study Title	(Author(s), Year of Publication)
Canada	Saskatchewan Health Research Foundation Team Grant, Canadian Frailty Network (formerly Technology Evaluation in the Elderly Network), which is supported by the Government of Canada through the Networks of Centres of Excellence program.	Muscled by the System: Informal Caregivers' Experiences of Transitioning an Older Adult into Long-term Care	(Konietzny et al., 2016)
China	Postgraduate Research & Practice Innovation Program of Jiangsu Province (KYCX18_1444), Superiority Discipline Construction Project of Jiangsu Province: Nursing [2018] (87), and The Key Project of Jiangsu Vocational Institute of Commerce JSJM19012.	The Adaptation of Older Adults' Transition to Nursing Homes in Mainland China: A Qualitative Study	(Sun et al., 2021)
Iran	the research deputy of Tabriz University of Medical Sciences (Grant number 5.55.6388)	Psychosocial changes following transition to an aged care home: qualitative findings from Iran	(Zamanzadeh et al., 2015)
Ireland	Martha McMenemy Scholarship for assistance with this research study.	'The Primacy of 'Home': An exploration of how older adults' transition to life in a care home towards the end of the first year	(O'Neill et al., 2020) (b)
Netherlands	TRANS-SENIOR Project; European Union's Horizon 2020 Research and Innovation Program under the Marie Skłodowska-Curie grant agreement No. 812656.	The paradoxes experienced by informal caregivers of people with dementia during the transition from home to a nursing home	(Groenvynck et al., 2022)
Norway	Centre for Caring Research- Southern Norway, Telemark University College.	Experiences faced by next of kin during their older family members' transition into long-term care in a Norwegian nursing home	(Elka et al., 2013)

<b>Country</b>	<b>Funding Source</b>	<b>Study Title</b>	<b>(Author(s), Year of Publication)</b>
Singapore	No external funds were received for the conduct of this project.	Singaporean caregivers' experiences of placing a relative into long term care.	(Ramanathan and Fisher, 2015)
Sweden		Deciding upon Transition to Residential Care for Persons Living with Dementia: why Do Iranian Family Caregivers Living in Sweden Cease Caregiving at Home?	(Kiwi et al., 2017)
Taiwan	No specific funding was received for this study	Relocation experiences of the elderly to a long-term care facility in Taiwan: a qualitative study	(Wu and Rong, 2020)
United Kingdom		'Waiting and Wanting': older peoples' initial experiences of adapting to life in a care home: a grounded theory study	(O'Neill et al., 2020)
United Kingdom	The first author (M O Neill) received a Martha McMenemy Scholarship for assistance with this research study.	"You're at their mercy": Older peoples' experiences of moving from home to a care home: A grounded theory study	(O'Neill et al., 2020)
United Kingdom		Experiences of moving an older parent into a care home or nursing home in the UK: a qualitative study	(Robinson and Fisher, 2023)
United Kingdom		'Familiarity' as a key factor influencing rural family carers' experience of the nursing home placement of an older relative: a qualitative study	(Ryan and McKenna, 2013)
United States	This research was supported by grant R21 AG025625 from the National Institute on Aging/National Institutes of Health.	Clinically significant changes in burden and depression among dementia caregivers following nursing home admission	(Gaugler et al., 2010)

Country	Funding Source	Study Title	(Author(s), Year of Publication)
United States	funding from the University of Illinois at Chicago Chancellor's Education Award Fund; Illinois Area Health Education Centers Network, Health Professions Student/Fellowship Grant; Midwest Nursing Research Society Dissertation Research Grant; Sigma Theta Tau International, Alpha Lambda Chapter Research Award; and the University of Illinois at Chicago College of Nursing Seth and Denise Rosen Research Award.	Family Caregivers Define and Manage the Nursing Home Placement Process	(Koplow et al., 2015)
United States	The author(s) received no financial support for the research, authorship, and/or publication of this article.	The Changing Nature of Guilt in Family Caregivers: Living Through Care Transitions of Parents at the End of Life.	(Martz and Morse, 2017)