Understanding the Experience of Choice:
An Interpretive Description Exploring the Experiences of Family Caregivers

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Abstract

Over the last 20 years, policy has moved towards more patient-centered healthcare. Choice has been at the forefront of this agenda, including policy that outlines care for older persons. Currently, minimal research explores how choice is experienced by family caregivers helping older persons access supportive living services. The research question that guided this study was: How is choice understood by family caregivers of older persons awaiting placement in supportive living? Using Thorne's interpretive description approach, 12 family caregivers were interviewed and provided a rich description of their experience of choice while caring for an older relative awaiting placement in designated supportive living. Family caregivers reported that their experience of choice occurred in a context where they juggled multiple responsibilities alongside their caregiving roles, such as complex family relationships and employment, while facing relative uncertainty with finances and in the placement process for their older relative, who was experiencing significant declines in their health status, threatening their ability to remain safe in an independent setting. Four themes related to the caregiver's experience of choice were identified: (i) Making everyday choices, (ii) Seeing possibilities, (iii) Valuing the ability to choose, and (iv) Acknowledging the impacts and outcomes of choice. Participants described their personal experiences of choice as unique, shaped by their personality and outlook on life. They also described their experience of choice as everyday, where many choices were made on a daily basis including adjusting their personal schedules as well as sacrificing and balancing their own needs with those of their relative. Their experience of choice, and the choices that they made as caregivers, did not occur in a vacuum, but rather had significant impacts on their relationships with others. Despite the often uncertain context in which the participants provided care, they were able to see the possibilities in their individual circumstances and ultimately find choice. The findings from this study provide new insight into the experience of choice of family caregivers caring for their older relatives waiting for placement in designated supportive living. As the proportion of older persons within Canada continues to grow, family caregivers will play an increasingly crucial role. Both healthcare providers and policymakers should consider the complexities of caregiving to support the creation of policy and a tailored practice approach to improve the caregiver's experience of choice.

Preface

This thesis is an original work by Ashley Hyde. The research project, of which this thesis forms a part, received research ethics approval from the University of Alberta Research Ethics Board: “Exploring the Experience of Choice: An Interpretive Description Exploring the Experience of Older Persons Accessing Supportive Living in [a large, Western Canadian city],” NO. Pro000074476.

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Chapter 1 Introduction

Canada, similar to other developed nations, is facing an increasingly aging population. Recent statistics estimate Canada is home to 5.9 million older persons (individuals aged 65 years and older); by 2036 this number is expected to increase substantially to 10.4 million as Canada's largest birth cohort continues to age (Canadian Institute of Health Information, 2012; Statistics Canada, 2017). Not only will the sheer number of older persons present unique challenges for our healthcare infrastructure, but this forthcoming generation is facing more complex health needs given the prevalence of chronic conditions such as hypertension, arthritis, diabetes, and dementia (Canadian Institute of Health Information, 2012; Statistics Canada, 2016b). Many of these older persons will rely on the assistance of family caregivers to maintain their health and make decisions for facility care when they are no longer able to live safely in the community (Sinha, 2013; Turcotte, 2013).

Along with shifting demographics in Canada have come changes in the way that older persons and their family caregivers understand healthcare services that support aging. Increasingly, older persons and their family caregivers have vastly different expectations than previous generations as to where and how they will age (Kahana & Kahana, 2014; Pruchno, 2012). These expectations, paired with the pervasive influence of consumerism and movement towards patient-centered healthcare, have precipitated the inclusion of choice into contemporary health systems and policy, including documentation detailing continuing care services in Alberta (Alberta Health and Wellness, 2008; Markus & Schwartz, 2010; Nordgren, 2010).

In this chapter, I will (a) describe the patient-centered healthcare movement and its relationship to the concept of choice, (b) briefly discuss the Canadian and Albertan continuing care context, (c) describe the significance of the study and its contribution to knowledge in this area, (d) describe the purpose of the study, (e) state the research questions that guided the study, and (f) provide a definition of key terms used in the study.

Choice as a Feature of Patient-Centered Care

The notion that choice should play a central role in healthcare, particularly as related to older persons, is not entirely novel. Since the mid-1990s, choice has been a prominent feature of contemporary approaches to framing healthcare services as evident in the integration and emphasis of patient-centered care. On a fundamental level, patient-centered care is an approach to providing care in which the patient is the focal point of care. Ideally, this is reflected in all aspects of care, from interactions with healthcare providers to supporting patient choice and decision-making (Epstein, Fiscella, Lesser, & Stange, 2010; Pelzang, 2010). Elwyn et al. (2012) described choice as something that occurs within the context of decision-making. That is, decision-making can be understood as a process with three steps: (i) introducing choice, (ii) describing options, and (iii) helping patients explore preferences and make decisions (Elwyn et al., 2012). By extension, then, while distinct, choice and decision-making can be conceptualized as key components of patient-centered care. However, unlike decision-making, choice is the ability or power to make a selection between alternatives, that does not necessarily proceed to a final conclusion or resolution (Elwyn & Miron-Shatz, 2010).

This focus on patient-centered care and the concept of choice has also extended to our contemporary health policy including outlines of continuing care services in Canada. Many of these policies across Canada suggest that individuals accessing continuing care services will have choice regarding place of care or where they wish to receive care (Ontario Health, 2013).

Specifically, choice is discussed as a means of promoting the preferences of the individual older person and to maintain their independence and quality of life (Ontario Health, 2013).

The Canadian Continuing Care Context

Canada is renowned for its publicly funded healthcare system. The principles of Canada's health system were mandated by the Canada Health Act, a federal law passed in 1984 which stipulates that healthcare in Canada must be (i) publicly accessible, (ii) comprehensive, (iii) universal, (iv) accessible, and (v) portable (Government of Canada, 2019; Martin et al., 2018). Under this act, it is presumed that all Canadians, regardless of geographical location will have fair and equal access to all medically necessary services provided within the hospital setting (Government of Canada, 2019). While the Canada Health Act is federal legislation, the provinces and territories deliver most of Canada's health services in a manner consistent with the Act. Specifically, provincial and territorial governments are charged with planning and funding services provided within the healthcare system by physicians and other health professionals (including negotiation of fee schedules), planning of hospitals and other health facilities, and implementation of public health initiatives (Government of Canada, 2019; Marchildon, 2005).

Critical to note is that the Canada Health Act only mandates universal, accessible care for medical services provided within a hospital or public health unit, leaving coverage of continuing care services such as long-term care, supportive living and homecare at the discretion of individual provinces (Marchildon, 2005; Martin et al., 2018). These services, commonly referred to as secondary services, may be provided within the home or residential facilities and may or may not be publicly funded by provinces or territories. Typically, health and personal care services provided in homecare, supportive living and long-term care are publicly funded, with accommodation charges including rooms, meals, housekeeping and routine building maintenance in both supportive-living and long-term care being the financial responsibility of individual patients or their family members (Alberta Health, 2019; Government of Canada, 2019; Marchildon, 2005). Adding to the complexity of Canada's continuing care system is the mix of for-profit and not-for-profit operators in homecare, supportive living, and long-term care. While in homecare, long-term care and designated supportive living individual provinces may stipulate the maximum accommodation charges that operators may charge users of these services, supportive living operators who are typically for-profit may set their own accommodation charges (Alberta Health, 2019). These differences in funding paired with a mixture of for-profit and not-for profit operators and substantial differences in governance between provinces can making navigating the Canadian continuing care context somewhat challenging (S. Johnson, Bascu, McIntosh, Jeffery, & Novik, 2017). While there is much discussion of choice in provincial health policy outlining continuing care services (presented in Chapter 2), the concept of choice is virtually absent from federal policy. However, this is not entirely surprising given the power and responsibility of individual provinces to enact the Canada Health Act, at the patient (and family caregiver) level.

The Alberta Continuing Care Context

Though the majority of older persons (over 93%) can manage their health and live independently in the community, a small percentage require extensive health and personal supports and will, therefore, need to access continuing care services (Canadian Institute of Health Information, 2012). In Alberta, continuing care services include homecare, supportive living, and long-term care. Long-term care is typically reserved for individuals who have complex health needs, are frail or living with severe forms of dementia, and require access to 24-hour nursing care (Alberta Government, 2017). Homecare refers to scheduled health and personal support services that are provided in an individual's private residence and may be provided either on a short- or long-term basis (Alberta Health Services, 2017b). Supportive living, also called assisted living, "provides accommodation in a home-like setting, where persons can remain as independent as possible while they have access to accommodation and services that meet their changing needs" (Alberta Health, 2014, p. 1). In Alberta, supportive living (SL) is divided into four separate levels, with the division between levels based upon the amount of personal support or healthcare services an individual requires (Alberta Health Services, 2017a): (a) SL1 residential living, (b) SL2 lodge living, (c) SL3, and (d) SL4 and SL4D (Alberta Health Services, 2017a); see definition of terms at the end of this chapter.

Older persons and their family caregivers generally seek continuing care services such as supportive living for one of two reasons: (i) an increase in the health needs of the older person or (ii) a reduction in the ability of the family caregiver to cope with either the older person's or their own health needs (A. A. Ryan, McKenna, & Slevin, 2011). For some older persons, the decision to relocate and seek continuing care services is brought about by a fear of social isolation or the occurrence of a health crisis at home with no one to help, while others recognize that a deterioration in their health prevents them from remaining in their homes independently (Fraher & Coffey, 2011). Van Rensbergen and Nawrot (2010) found that older persons pursue admission to a facility most often as a result of a functional disability associated with a chronic condition such as a stroke, diabetes, or dementia, where these conditions interfere with their ability to mobilize and perform basic activities of daily living.

In some cases, it is not necessarily the health of the older person that precipitates the move to supportive living but rather the status of the family caregiver. For family caregivers, relocation of an older person from a private residence to a supportive living facility is often precipitated by a growing awareness of their inability to manage the older person's care, or a reduction in their own ability to cope in their caregiving role (Nolan & Dellasega, 2000; A. A. Ryan & Scullion, 2000). The caregiver's ability to continue caring for the older person is influenced by their own health status, which is shaped by both the aging process and the ongoing physical and emotional stresses associated with caregiving (Buhr, Kuchibhatla, & Clipp, 2006; Lundh, Sandberg, & Nolan, 2000; A. A. Ryan & Scullion, 2000). Caregivers can also experience exhaustion caused by the prolonged management of their caregiving role in conjunction with employment, family obligations, and other personal relationships (Lundh et al., 2000; A. A. Ryan & Scullion, 2000).

This decision to transition an individual from independent living to supportive living can be fraught with considerable stress for both the older person requiring care as well as their family caregivers (McAuley, Travis, & Safewright, 1997; Morgan, Reed, & Palmer, 1997). For family caregivers, this decision may be accompanied by feelings of guilt, failure, helplessness, powerlessness, and inadequacy (Lundh et al., 2000; Nolan & Dellasega, 2000; A. A. Ryan & Scullion, 2000). Furthermore, family caregivers often feel ill-prepared for the transition process and are confused as a result of a lack of familiarity with the unique care setting as well as the general lack of information regarding the care options available (McAuley et al., 1997; Nolan & Dellasega, 2000). Similarly, older persons may view this transition as a stressful experience made worse by poor communication with healthcare professionals involved in the transition process (Fraher & Coffey, 2011; R. A. Johnson & Bibbo, 2014; Somme, Thomas, de Stampa, Lahjibi-Paulet, & Saint-Jean, 2008). For both groups, these feelings are often exacerbated by their perceived lack of choice in accessing continuing care services.

Undoubtedly, even when desired, the relocation from a private residence to facility living (e.g., institutional setting) is often perceived as distressing for both older persons and family caregivers (Capezuti, Boltz, Renz, Hoffman, & Norman, 2006; Lee, Woo, & Mackenzie, 2002). However, recent inquiry has uncovered numerous factors that can positively impact the experience, including the degree of choice the individual has in relocation. Brownie, Horstmanshof, and Garbutt (2014) found that the degree to which older persons were able to participate in the relocation decision influenced their overall experience of relocation as well as their ability to feel at 'home'. Similarly, in a study of supportive living residents, Street and Burge (2012) found that having control over the relocation decision was positively associated with well-being. Specifically, when a move to a supportive-living facility was motivated by an acute need of the older person or when there was less choice for the older person due to their financial status, the older person's well-being was significantly impacted (Street & Burge, 2012). Moreover, active participation and choice in the decision to relocate has been found to influence both the individual's physical and psychological health and ultimately their ability to adapt to their new environment (Cooney, 2012; Le Grand, 2007). Like older persons, the family caregiver's experience was enhanced by the degree of choice or influence they had in the relocation or transition process (Merla et al., 2018; Strang, Koop, Dupuis-Blanchard, Nordstrom, & Thompson, 2006).

Significance

With Canada's aging population, an increasing demand for continuing care services for older persons unable to live independently within their homes is anticipated. Currently and going forward, family caregivers will play a crucial role in helping these older persons access continuing care services. Although the decision to transition to supportive living is often necessitated by increasing medical needs of the older person, it can nonetheless be a traumatic experience for both the family caregivers, marked by much uncertainty. This traumatic experience can be further compounded by the perceived lack of choice that often stands in direct contrast to Alberta's contemporary provincial continuing care policy that touts choice as a central feature of continuing care services.

Currently, the research literature has a gap related to explorations of family caregivers' experience of choice. In particular, studies exploring our unique Canadian context or Alberta context, the meaning or definition of choice from the perspectives of family caregivers, and the experience of choice within the context of current continuing care policy are lacking. Given the estimates of our aging population, an understanding of the experience of choice from the perspectives of individuals helping older persons access designated supportive living services could encourage dialogue on a macro policy level with policymakers, as well as with frontline healthcare providers who directly care for older persons and their family caregivers.

Purpose of the Study

In this study, I focused on the experiences of family caregivers of older persons accessing designated supportive living services. At the outset of this study, I had intended primarily to explore this experience from the perspective of the older persons, with supporting data from their family caregivers, as I saw the older persons as the heart of the experience of choice. They are the focus of Alberta's provincial health policy and are the ones experiencing a major (and often traumatic) transition. I saw this study as an opportunity to share their understandings in hopes of ultimately improving their experience of choice through policy or practice changes. However, upon commencing recruitment for this study and speaking with the community transition coordinators, I learned that most older persons seeking placement in designated supportive living do so because cognitive impairments preclude their ability to live safely in their own homes. Indeed, when I interviewed two older persons (who were described as having mild to moderate cognitive decline by their family caregivers), I found they had little awareness of their own transition to designated supportive living and were unable to articulate their understanding and experience of choice. Indeed, these older persons had relatively progressed dementia, with most in the middle stage which is characterized by "…a greater decline in the person's cognitive and functional abilities…with assistance with many daily tasks necessary" (Alzheimer Society of Canada, 2019). In these cases (and many others), it was the family caregivers that were driving the transition to supportive living and were the ones experiencing the choice that is outlined in provincial policy (Dellasega & Nolan, 1997).

While some studies have employed proxy respondents (who are often family caregivers), to enable participation of the older person with dementia, there are a number of concerns that can arise with this approach. For instance, proxy responses are often not a valid response particularly when they involve capturing experiences (Carpenter, Kissel, & Lee, 2007; Marosszeky & Sansoni, 2009). In fact, even in health-related quality of life (HRQoL), it has been noted that proxy respondents projected their own HRQoL onto the older person (Arons, Krabbe, Schölzel-Dorenbos, van der Wilt, & Rikkert, 2013), making results using proxies somewhat unreliable. As this study intended to explore the experience of choice, one that is inherently complex involving cognitive processes and personal experiences, it was inappropriate to use family caregivers as proxies for the older person accessing supportive living. Therefore, the purpose of this study shifted to explore the understanding of choice from the perspectives of family caregivers of community-dwelling older persons who are awaiting placement in a designated supportive living facility in a large Western Canadian city.

Research Questions

The primary question guiding this research was: How is choice understood by family caregivers of older persons awaiting placement in designated supportive living?

Secondary research questions included the following:

(i) What contextual factors influence this experience?

(ii) What is their experience of choice?

(iii) How can we help family caregivers experience choice?

Definition of Terms

The following is a list of definitions of key terms used in this study. Although some of the following terms may have different meanings in other contexts, definitions are provided as they apply to the Canadian context.

Family caregiver. A family caregiver is an individual (may or may not be a family member) who takes an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury, or a chronic life-limiting illness (Turcotte, 2013). This caring role may include responsibilities such as providing emotional support, helping with activities of daily living, and help managing appointments and medications (Alberta Health Services, 2018).

Older person. An older person is an individual aged 65 years or older. While different terms describe an individual over the age of 65 years, including ‘senior’ or ‘elderly’, the term most widely recognized and used in Canada is ‘older person’ (Schellenberg & Turcotte, 2007). Although a somewhat arbitrary classification, Chappell, McDonald, and Stones (2008) suggest this is the most commonly used criteria for older personhood and likely stems from the recognition that 65 years is typically the age of retirement and when individuals are able to receive full pension benefits in Canada (Schellenberg & Turcotte, 2007).

Continuing care. Continuing care is an umbrella term used to describe services that provide healthcare outside of the traditional acute care, hospital setting. In Alberta, ‘continuing care’ refers to services provided to individuals living in their own homes (homecare), in a supportive living, or long-term care facility (Alberta Heath Services, 2014). Typically, continuing care services provide care to individuals across the age span and for a variety of reasons including palliative or end-of-life care, restorative care, wound care, and pediatric services (Alberta Health, 2013). ‘Continuing care’ is a unique term not necessarily found in research and policy literature outside of Canada.

Long-term care. Long-term care is typically reserved for those individuals who have complex health needs, are frail or living with varying degrees of dementia, and require access to 24-hour nursing care (Alberta Government, 2017). Typically, the individual patient is responsible for the cost of long-term care, which includes accommodation, furnishings, meals, housekeeping, and recreation (Alberta Health Services, 2017c).

Homecare. Homecare refers to publicly-funded health and personal services that are provided to an individual residing in a private residence (Alberta Health Services, 2017b). Homecare aims to promote the individual’s independence with the goal of allowing them to remain safe in their homes for as long as possible. Typically, homecare clients receive a mix of professional health services (e.g., treatments and procedures, assistance with medication, rehabilitation, or end-of-life care) and personal care services such as bathing and grooming, dressing, toileting, and mobilization (Alberta Health Services, 2017b).

Supportive living. Supportive living provides individuals home-like accommodation while offering access to a range of services according to their health and personal needs, such as 24-hour monitoring, security, meals, housekeeping, and recreation (Alberta Government, 2014).

In the supportive living setting, the individual is responsible for paying their accommodation-related costs such as rooms, meals, and housekeeping, with personal care and healthcare services being publicly funded (Alberta Health Services, 2017a). Supportive living services in Alberta typically range from $800 to $2,650 per month (Strain, Maxwell, Wanless, & Gilbart, 2011), with the average accommodation fee for a private unit being $2,036 per month (Alberta Health, 2018). Alberta features four levels of supportive living: (a) SL1 residential living, (b) SL2 lodge living, (c) SL3, (d) SL4 and SL4D (Health Quality Council of Alberta, 2014). Supportive living Levels 3 and 4 are operated as a partnership between Alberta Health Services and the facility operator, and therefore Alberta Health Services has first access to the funded spaces on these levels. For this reason, these supportive living beds are often referred to as designated supportive living (DSL). Currently, Alberta has about 9,000 DSL3 and DSL4 spaces (Strain et al., 2011).

Designated Supportive Living 3 (DSL3). This type of supportive living is for individuals who are medically and physically stable but are living with physical disability, mild dementia or a mental health diagnosis, and may require a greater level of care than can be provided in a private residence (Alberta Health Services, 2017a). In the DSL3 setting, healthcare aides provide 24-hour personal care and medication assistance, with a registered nurse from homecare able to provide assessment and direction (Alberta Health Services, 2017a).

Designated Supportive Living 4 (DSL4). Similar to DSL3, individuals living in DSL4 live in a home-like setting with accommodation, meals, housekeeping, and recreation services provided (Alberta Health Services, 2017a). However, individuals living in DSL4 typically have more complex health needs and higher requirements for personal care and therefore have access to a higher level of personal care support and on-site healthcare services. In this setting, an on-site licensed practical nurse is available 24 hours per day, with a registered nurse from homecare available on call.

Designated Supportive Living 4 Dementia (DSL4D). DSL4D is supportive living for individuals with moderate to severe dementia who may be at a higher risk of wandering but are not a safety risk to themselves or others (Alberta Health Services, 2017a). As in the DSL3 and DSL4 settings, individuals living in DSL4D are provided with accommodation, meals, housekeeping, and recreation services as well as personal care supportive and healthcare services (Alberta Health Services, 2017a).

Chapter 2 Literature Review

The purpose of this chapter is to examine literature relevant to the experience of choice of family caregivers of older persons awaiting placement in a designated supportive living facility. In this chapter, I first discuss the concept of choice as it applies to everyday life and healthcare. This is followed by an exploration of the concept of choice in contemporary Canadian provincial continuing care policy. Subsequently, I examine the demographics of family caregivers of older persons in Canada and the current literature on family caregivers' experience of choice when helping older relatives access continuing care services, Finally, I summarize the literature in this area including the gaps in knowledge that my study was designed to address.

Choice as an Everyday Concept

The concept of choice is complex. The term is common, but the meaning can shift depending upon the context or circumstance in which it is used. According to the Merriam-Webster (2019) dictionary, choice is defined as "the act of choosing: the act of picking or deciding between two or more possibilities, the opportunity or power to make a decision." From this definition, we can see that people make many choices on a daily basis and are constrained by their potential options. For many, choice is so innate, engrained in everyday routines, that many choices are made almost as second nature. Choices are seen as a reflection of the chooser's values, beliefs, and intentions, with this ability to make a choice one of the purest expressions of free will (Feldman, Baumeister, & Wong, 2014). It is crucial to note, however, that choice is not necessarily experienced uniformly by all. That is, in certain circumstances, characteristics including age, gender, and socio-economic status may place some individuals at an advantage when faced with choice (Fotaki, 2010; Fotaki et al., 2005). For instance, those who are more articulate with a higher socio-economic status may indeed have more choice than those without access to education and wealth.

Choice has been used interchangeably with other overlapping concepts (Fotaki, 2006; Iyengar, 2011), such as decision and the active process of decision-making. Whereas choice is the ability or power to make a selection between alternatives, decision relates more to a process in which a conclusion or resolution is made after consideration of options (Elwyn & Miron-Shatz, 2010). Decision-making cannot occur without the presence of choice, whether it be the power to decide or deciding between options (Dietrich, 2010; Harris, 1998). Conversely, as the essence of choice is the power or ability to make a selection, choice can occur outside of the context of decision-making. The terms choice, decision, and decision-making are commonly used, with some understanding them as interchangeable. It should be noted, however, that there is distinctness between these concepts, with choice being much more value-laden than the process of decision-making, in which choice plays a smaller role with the end goal being a conclusion or resolution.

As an everyday endeavor, choice can be considered a societal value, which may be explained by the powerful psychological effects of choice. Iyengar and DeVoe (2003) described this value of choice using self-determination theory (R. Ryan & Deci, 2000), a metatheory of human motivation and personality that combines six micro theories: cognitive evaluation theory, organismic integration theory, causality orientations theory, basic psychological need theory, goal content theory, and relationship motivation theory. Proposed by R. Ryan and Deci (2000), self-determination theory suggests that behavior is motivated by the individual’s need for autonomy, competence, and relatedness, and fulfilling these needs ultimately results in an individual having both intrinsic and self-determined extrinsic motivation (Legault, 2017). In considering the relationship between self-determination theory and the concept of choice, Botti and Iyengar (2006) acknowledged the cognitive rewards of choice, whereby having choice enhances perceived feelings of both autonomy (feeling self-directed or independent) and competence (feeling effective), ultimately enhancing the perception of both self-determination and intrinsic motivation with individuals feeling they are in control of their own fate or destiny. This perception of control is associated with greater satisfaction and feelings of positivity for the individual making a choice (Iyengar & DeVoe, 2003). In essence, being able to make a choice feels good and is “what enables each person to pursue precisely those objects and activities that best satisfy his or her own preferences with the limits of his or her resources” (Markus & Schwartz, 2010, p. 344).

The value of choice may also be seen as a culmination of cultural, political, economic, and societal factors. From an early age, we are taught that choice and freedom are strongly associated, with these values woven into both our government policies and constitutions. In this view, choice is socially constructed and foundational to our existence as beings in a free society. However, in the Western literature, choice is most commonly associated with economics. As such, choice is conceptualized as closely tied to the political and economic ideologies underpinning Western society, including democracy and a free-market economy that encourages the freedom and choice of the individual (Markus & Schwartz, 2010; Nordgren, 2010). This ideology, which regards the individual consumer as the ultimate purveyor of choice, arose from a neo-liberalism movement during the 1970s (Fotaki, 2010; Kekewich, 2014; Nordgren, 2010). In this view, “individuals are conceptualized as active consumers of public services, able to exercise enhanced choice over how their needs should be met, and thus, experience greater control over their own lives” (Arksey & Glendinning, 2007, p. 166). Believing in the largely positive impacts of choice can be traced to classic economic models such as rational choice theory. This theory assumes that "consumers" will be better off with more available options, with more choices meaning fewer constraints, and that they have the ability to make choices rationally according to which option benefits them the most (Botti & Iyengar, 2006; March, 1978). While this theory offers some value in terms of explaining the desire for an abundance of choice, it does not adequately account for the complexity of certain choices (such as those made in healthcare) or the feelings that may stem from confronting emotionally laden options (Botti & Iyengar, 2006; Fotaki, 2006).

Choice in the Context of Healthcare

With the proliferation of choice and, ultimately, control in our everyday lives, choice also plays a significant role in the context of healthcare, particularly within the clinical context where patients are free to make informed choices regarding their own individual care. Ideally, patients are provided with high-quality information by healthcare practitioners, are given room to deliberate, and make choices based upon personal preferences (Elwyn et al., 2012). However, this conceptualization extends beyond the patient to the healthcare practitioner, who is expected to respect and support their patient's right to make choices. Choice in this context is embodied within the codes of ethics and professional practice standards. For instance, registered nurses in Canada are guided by the Canadian Nurses' Association's Code of Ethics, which is comprised of seven primary values; one of these encourages nurses to respect their patient's ability to make informed decisions regarding their own health and treatment options (Canadian Nurses Association, 2017). While this code does not explicitly mention choice in its mandate, it is indirectly referring to the registered nurse's responsibility to act in a manner that promotes patient autonomy. Autonomy has been described as "the capacity to think, decide, and act on the basis of such thought and decision freely and independently and without hindrance" (Gillon, 1995, p. 324). In this case, the term autonomy strictly relates to patient autonomy at the clinical level and the rights of the patient to be engaged in choice regarding their own health and treatments. Sandman and Munthe (2010) stated that "patient choice implies that the patient somehow remains in authority over the decision as to what should be done. Hence, in the end, regardless of how the actual process leading up to the decision looks like, the patient makes the final choice among existing alternatives" (p. 67). It is in this context that the nurse has an ethical responsibility to ensure the patient can act autonomously and engage in choice. Thus choice is a focus of clinical nursing practice and understanding choice is very important to nurses.

Choice is also a central element of shared decision-making which is a process whereby patients (and caregivers) work together to make healthcare decisions after consideration of clinical evidence as well as patient preferences and values (Haesebaert, Adekpedjou, Croteau, Robitaille, & Légaré, 2019). Elwyn et al. (2012) define shared decision-making as a crucial model for clinical practice having three steps: (1) Choice talk (making patients aware that reasonable options that exist), (2) Option talk (providing detailed information about options), and (3) Decision talk (the work of considering preferences and ultimately making a decision). Within this model, the importance of choice is acknowledged with attention given to the individual patient's preferences. This consideration, though not the primary focus of the model, is crucial to truly achieving choice as it provides the patient a degree of power and control in a situation that may be somewhat uncertain.

Indeed, the current emphasis on shared decision-making is pronounced as much energy has been devoted to the development of interventions to enhance shared decision-making in many different practice (Légaré et al., 2018). Within the context of providing care to older persons with dementia, there has also been a focus on shared decision-making. However, the application of this process is somewhat contentious with differing opinions on what shared decision-making means within this context. For instance, a systematic review conducted by Daly, Bunn, and Goodman (2018) suggests that there is no common understanding of what shared decision-making means within the context of caring for those with cognitive impairment. Miller, Whitlatch, and Lyons (2016) similarly found that there was a variation in what constituted shared decision-making within the context of dementia, with involvement in shared decision-making influenced by a number of characteristics including education, age, gender, and the relationship to the older person. There is, however, agreement that shared decision-making does have notable benefits to both older persons and their family caregivers including improved patient outcomes, as well as increased feelings of autonomy and self-determination (Bunn et al., 2018). Perhaps what is less clear in this body of literature is the specific role that choice plays in the process beyond the assumption that choice is always present within the context of shared decision-making. Certainly it is important that choice is present, but it is also worth acknowledging how the participants feel about choice, specifically the choices at hand.

Another perspective that sees choice as a key value embedded in the policies framing contemporary healthcare services through the integration and emphasis of patient-centered care. On a basic level, patient-centered care can be conceptualized as a way of providing care in which the patient is the focal point of care and is ideally reflected in all aspects of care, from interactions with healthcare providers to supporting patient choice and decision making (Epstein et al., 2010; Pelzang, 2010). This patient-centeredness implies that patient choice and preferences are at the heart of all interactions between the healthcare practitioner and patient, and the healthcare practitioner must support all patient choices, even when they may perceive them as wrong (Barry & Edgman-Levitan, 2012). Specifically, healthcare practitioners must operate under the assumption that patients “are qualified to decide their own needs and expectations, and that they are able to make decisions and choices about what they need and want” (Pelzang, 2010, p. 912), which may be challenging or downright uncomfortable in the context of opposing practitioner knowledge, values, and preferences (Barry & Edgman-Levitan, 2012).

McCormack and McCance (2006) have worked to expand the concept of patient-centered care away from a medically-dominated rhetoric to acknowledge the humanness of the individual at the heart of the care through their work on person-centeredness and The Person-Centered Nursing (PCN) Framework. This framework is comprised of five main person-centered processes including working with the patient’s values and beliefs, providing holistic care, having sympathetic presence, engagement, and shared decision-making, with person-centered outcomes (including satisfaction and involvement with care, feeling of well-being and creating a therapeutic culture) only achievable through the provision of care considerate of these constructs (McCance, McCormack, & Dewing, 2011). While choice is not explicitly discussed within this framework, we can see elements of choice within the processes of shared decision-making and in a consideration of the patient’s values and beliefs, indicating that choice is a key element to the provision of person-centered nursing care.

Choice in the Context of Canadian Continuing Care

Contemporary Canadian continuing care policy often references the concept of choice. Four policy documents that include the term choice were found from online searches for Canadian provincial health policies published from 2000 to 2018. These policies—representing the provinces of Alberta, Saskatchewan, Ontario, and New Brunswick and published from 2003 to 2013—have several commonalities in terms of the way choice is discussed. Choice is a means of promoting patient preference and maintaining independence, and the focus of these policies is primarily the older person. Only three of these documents (Alberta, Saskatchewan and Ontario) speak to the integral role of family caregivers in the older person's access to continuing care services, with not all addressing instances where, due to the cognitive impairment of the older person, the family caregiver serves as a proxy decision-maker for the older person. In these instances, it is ultimately the family caregiver who is experiencing (or not experiencing) choice.

Choice as a means of promoting patient preference. Provincial policy documents frequently discuss promoting choice as means of ensuring the preferences of older persons are respected. Specifically, choice is a mode for enabling older persons to maintain their independence and quality of life (Alberta Health, 2010; Province of New Brunswick, 2012; Saskatchewan Provincial Advisory Committee of Older Persons, 2003). For example, Alberta's continuing care policy states that older persons "prefer choices that permit them to preserve their independence, quality of life and personal dignity [in the context of aging]" (Alberta Health, 2010, p. 4). In this instance, one's ability to choose directly correlates with their independence and quality of life. That is, if one is unable to make their preferences clear through choice, then quality of life and independence will suffer. This is problematic as the concept of quality of life is subject to variability and is dependent on personal and structural factors. Likewise, in policy from Saskatchewan, choice is framed as a means of ensuring older persons maintain their independence or self-determination (Saskatchewan Provincial Advisory Committee of Older Persons, 2003). This policy situates choice as a foundational principle in developing provincial continuing care policy and describes it as "being in control of one's life, being able to do as much for oneself as possible" (Saskatchewan Provincial Advisory Committee of Older Persons, 2003, p. 4). At the broad, provincial policy level, choice in this instance is an antecedent or fundamental principle to creating sound continuing care policy for the older person.

Choice as a means of maintaining independence. The other manner in which choice is discussed in Canadian continuing care policy is with respect to independence. Here, choice is presented as a means of ensuring that the older person can age in an independent manner that is relatively free of government interference. There is a wide spectrum of older persons in our society; some are physically and mentally able to engage in well-informed choice and maintain their independence while others have more restricted capacity. In examining the constructed relationship between choice and independence in health policy, choice is assumed to be a necessary precursor to independence. More specifically, independence is understood as nonexistent without choice. This is illustrated in a document released by Alberta Health (2010, p. 12) that describes choice and independence (together) as one of five key values to ensure healthy aging and seniors' wellness: "Being in control of one's life, and being able to do as much as possible. Making choices and knowing help is available when needed." A policy document from New Brunswick, entitled Living Healthy Aging Well (Province of New Brunswick, 2012), describes independence and choice in a similar manner, including improving the independence of older persons by allowing them to age in the residence of their choice.

The conundrum of choice in healthcare. While the inclusion of choice in healthcare is promising—representing policymakers' responsiveness to the wishes of the general public who perceive choice as favorable—multiple issues stem from this inclusion of choice. Victoor, Delnoij, Friele, and Rademakers (2016) describe incorporating such language into health policy as a policy instrument or mechanism founded on the government's assumption that citizens think critically enough about certain characteristics of healthcare to make rational, informed choices.

The success of choice in this context, therefore, rests on the assumption that individuals have both the capacity and information available to make rational choices (Victoor et al., 2016). According to Dowding and John (2009), such assumptions are problematic as having choice in public policy has significant associated costs, including information costs (providing enough detail for individuals to rationally choose between alternatives) and psychological costs (when individuals regret choices). Furthermore, choice in an economic context is much different than choice in a healthcare context, which can be complex, unpredictable, and involve highly emotional conflicts (Botti & Iyengar, 2006). With the uncertainty in healthcare, people can be challenged to make rational choices that involve weighing the advantages and disadvantages of one uncertain future against another (Mol, 2008).

Furthermore, in the healthcare context, where choice is featured prominently in contemporary continuing care policy, who this policy may favor should be considered. As choice generally requires rational individuals with access to the appropriate information, such policy may only benefit those older persons (or family caregivers) who can access said information through the social support of family members or communication with their healthcare providers and who live in a geographical location where alternatives do exist. Therefore, in examining the experience of choice of family caregivers accessing supportive living services, the choice should not be considered in isolation of factors such as income, race, geographic location, social support, and ethnic background, as experiences of choice may differ according to personal context.

Family Caregivers of Older Persons in Canada

Family caregivers play an integral role in supporting the health and well-being of older persons in Canada. Approximately 3.8 million family caregivers in Canada currently provide care to an older person, and this figure is expected to grow with an aging population (Turner & Findlay, 2012). Hollander, Liu, and Chappell (2009) estimate that caregivers contribute $25 billion to the Canadian healthcare system in unpaid labor. Additionally, Tal and Mendes (2017) estimate that each Canadian caregiver (to an older relative) spends $3,300 in out-of-pocket expenses directly related to caregiving, representing $6 billion annually to the Canadian economy. For community-dwelling older persons, approximately 70-80% of care is provided by family caregivers (Health Council of Canada, 2012), including (but not limited to) providing meals, transportation, personal care, and medications as well as liaising with healthcare professionals on behalf of the older person (Health Council of Canada, 2012; Sinha, 2013; Turcotte, 2013).

Most Canadian family caregivers provide care to an older relative, with 56% providing care to a parent and 11% providing care to a spouse (Sinha, 2013; Turcotte, 2013; Turner & Findlay, 2012). Often, these caregivers are women (56%) who are balancing their own lives, including child rearing and employment, with the needs of the older person (Turner & Findlay, 2012). Sinha (2013) estimates that 44% of caregivers are aged 45-64 years and 60% of these caregivers maintain full-time employment outside of their caregiving duties. Outside of caregiving, a substantial proportion of caregivers have children (or grandchildren), with 28% of caregivers reporting that they had a child under 18 years of age at home (Sinha, 2013). On average, family caregivers provide 6-11 hours of care per week, with most describing care as a daily occurrence (Turner & Findlay, 2012).

Providing care to an older person can be an all-consuming endeavor with consequences to the family caregiver's health and well-being. Turner and Findlay (2012) found that 56% of family caregivers experience difficulties and challenges with their caregiving role, including stress, fatigue, emotional demands, and less personal time. Family caregivers can also experience declines in physical health related to the chronic stress that may be associated with the caregiving role (Health Council of Canada, 2012; Turcotte, 2013). This may be especially pronounced in approximately 33% of caregivers who are managing chronic health conditions of their own (Sinha, 2013). Moreover, family caregivers are at higher risk for declines in emotional well-being, including depression, anxiety, irritability, and isolation (Sinha, 2013; Turcotte, 2013; Turner & Findlay, 2012). Furthermore, family caregivers can face significant financial strain: 43% reported that caregiving impacts their paid employment, including causing work disruptions such as arriving at work late (or needing to leave early) and missing work to accompany the care recipient to appointments (Sinha, 2013). Compounding disruptions to employment, caregivers can also incur out of pocket expenses including modifications to the older person's dwelling, specialized transportation, respite services, specialized equipment, and prescription drugs (Turcotte, 2013).

Though family caregivers can experience significant disruption to their everyday lives to accommodate their caregiving roles, 95% reported positive aspects of caregiving (Turner & Findlay, 2012). Some family caregivers saw positivity in their ability to engage in reciprocity, where they were able return the care they had received from the older person in the past (Funk, 2011; Peacock et al., 2009; Silverstein, Conroy, Wang, Giarrusso, & Bengtson, 2002). For others, positive aspects were seen in a sense of personal growth, mastery, and fulfillment in the caregiver role (Cohen, Colantonio, & Vernich, 2002; Peacock et al., 2009; Sanders, 2005; Turner & Findlay, 2012).

Family Caregivers' Experience of Accessing Continuing Care Services

While there is a substantial body of literature on the family caregiver's experience of providing care to an older relative, little is known about the caregiver's experience of helping an older person who is accessing continuing care services. Even less is known about the caregiver's experience in helping an older relative access supportive living services. For many older persons, the transition from a private residence to supportive living is difficult, even traumatic, and marks a loss of independence and, for some, the acute realization of a declining health status (Lundh et al., 2000; Nolan & Dellasega, 2000; Nolan et al., 1996; A. A. Ryan & Scullion, 2000). As such, family caregivers of these older persons may also experience trauma in relation to this process. The focus of this inquiry was the family caregiver so the forthcoming review of the existing literature will focus on their perspectives.

Search Strategy

In consultation with a research librarian, I developed a search strategy using concepts from the review question: What is known in existing literature about the experience of choice in place of care for older adults and/or family caregivers accessing continuing care services. The search strategy included a combination of subject headings and keywords tailored for each database, including the following terms: choice, patient admission, relocation, placement, nursing homes, residential facilities, long-term care, assisted living facility, homecare, family caregiver, older adult, and senior. I searched a total of five electronic databases in May 2019, including CINAHL, MEDLINE, EMBASE, PsycInfo, and Web of Science. Grey literature searches were conducted of relevant websites (government websites, continuing care association sites), Google Scholar, and ProQuest Dissertation and Theses. I also hand-searched the reference lists of studies included in the review in order to ensure we included all studies that met our inclusion criteria. I limited the search strategy to English language articles published after the year 2000. The time span was chosen for the review in recognition of the recent focus on choice within continuing care policy and our interest in exploring the contemporary experiences of choice of older adults and family caregivers accessing continuing care services.

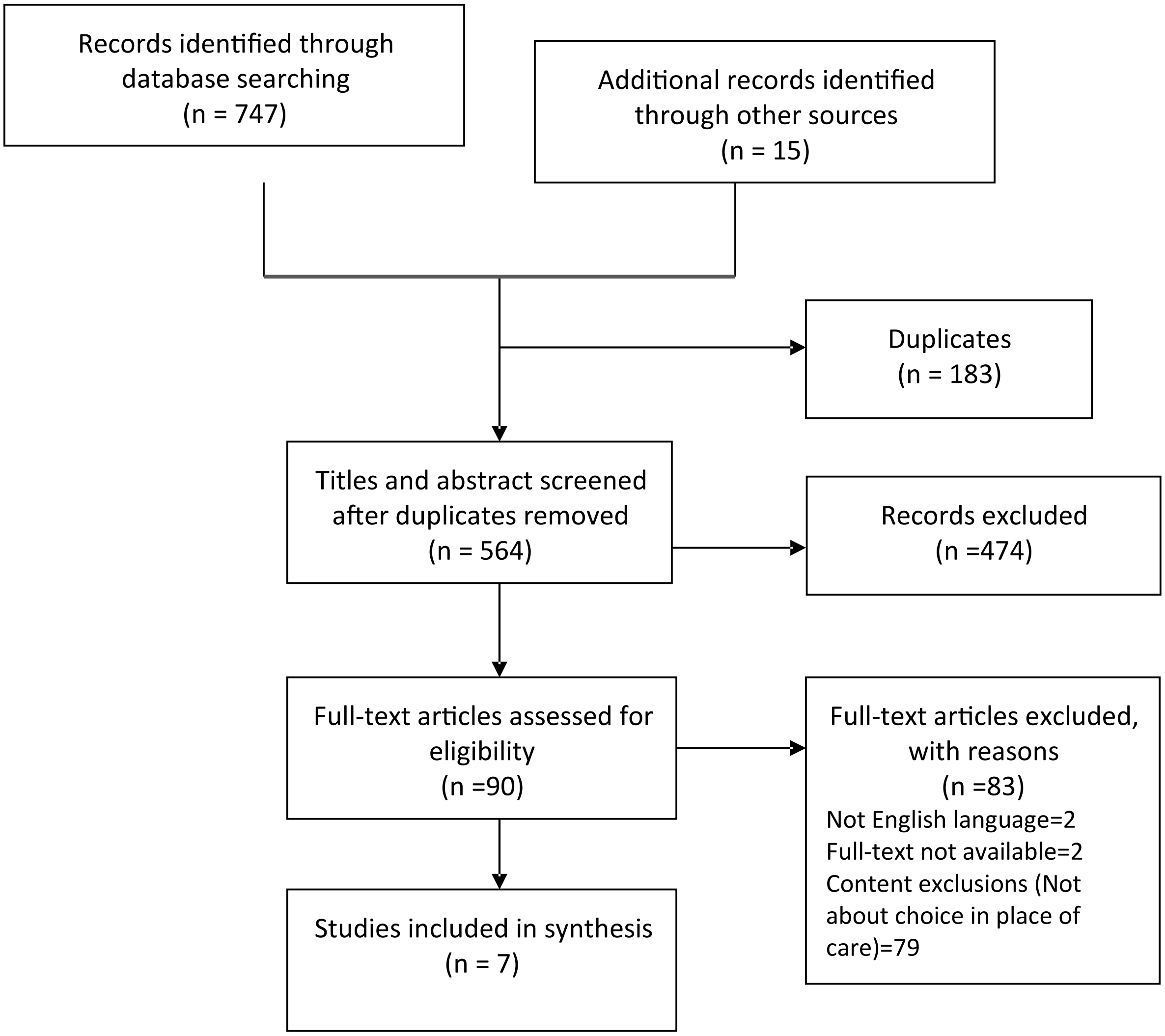

Figure 1: PRISMA Flow Diagram

Perspectives of family caregivers on choice in continuing care. At the time of this study, no published studies were found that had examined the experience or understanding of choice of family caregivers of an older person awaiting placement in supportive living. Therefore, in this section I draw on the literature on the general experiences of both family caregivers and older persons accessing continuing care services.

Overall, four studies were identified that examined the family caregiver's experience of accessing continuing care services. Another three studies examined the older person's perspective. Most were published within the last 15 years (n=5), which suggests that choice may be an increasingly important concept, and were from Europe (n=5) or the United States (n=2). The studies predominantly used qualitative methods (n=5), including grounded theory (n=3) and phenomenology (n=3); one used quantitative methods and one used mixed methods. Sample size in the qualitative studies with family caregivers ranged from 10 to 54, with these caregivers ranging in age from 41 to 90 years. The qualitative studies (n=2) with older persons had eight participants, ranging in age from 68 to 97 years. The quantitative study had 3,583 older person participants that ranged in age from 80 to 90 years. Generally, study quality was high, with an adequate description of the methods, data collection, and analysis approaches, as well as being trustworthy.

For many family caregivers, the experience of helping an older relative access continuing care services, including supportive living, can be incredibly stressful (Dellasega & Nolan, 1997; Strang et al., 2006). Along with acknowledging their loved one's declining health, the 102 family caregivers in the mixed-methods study described how they decided which continuing care facility was most suitable for their older relative, using only a list of facility names and locations and without prior knowledge about the facilities (Dellasega & Nolan, 1997). Often, this period is marked by feelings of guilt, helplessness, sorrow, self-doubt, and a sense of failure as the family caregiver is no longer able to care for their older relative without institutional care (Afram, Verbeek, Bleijlevens, & Hamers, 2014; Dellasega & Nolan, 1997; Strang et al., 2006).

Most caregivers, across studies, described a largely negative experience with little choice in helping their older relative transition to continuing care. In a grounded theory study examining the experiences of 14 Swedish spouses who had to place a partner in long-term care, Lundh et al. (2000) found that the caregiver's experience of choice was almost invariably negative, with a lack of choice leading to feelings of severe emotional upset and powerlessness. Similarly, A. A. Ryan and Scullion (2000) found that most of the 10 caregivers in their study described the choice to place their older relative in a specific long-term care facility as being made by medical staff; when the selection was framed as a choice, no reasonable alternatives were available in terms of long-term care facilities. In several studies (n=4), the negative feelings of caregivers could not solely be attributed to the perceived lack of choice or "expert-driven" nature of the decision (Lundh et al., 2000; Nolan & Dellasega, 2000; A. A. Ryan & Scullion, 2000; Strang et al., 2006). Caregivers in two studies also felt negatively about the lack of information to make an informed decision about the facility most suited to the needs of their older relative (Afram et al., 2014; Nolan & Dellasega, 2000). Overall, these studies suggest that caregivers perceived their experience negatively with little or no choice.

Perspectives of family caregivers on the nurses' role in choice in continuing care. Family caregiver experiences of choice are heavily influenced by healthcare professionals, including nurses, who are often the primary healthcare provider assisting with accessing continuing care services. For example, in four qualitative studies with family caregivers, healthcare professionals played a major part in the decision-making process in regards to the transition to different continuing care contexts, though this was not always perceived as positive (Lundh et al., 2000; Nolan & Dellasega, 2000; A. A. Ryan et al., 2011; A. A. Ryan & Scullion, 2000). Not only was there no clear acknowledgment of the choice(s) facing the caregivers in these studies, but there also did not seem to be a consideration of the caregiver's preferences or values, which is a key element of both choice and the decision-making process (Haesebaert et al., 2019). In their mixed-methods study, some of the 102 family caregivers felt the choice to place their older relative in a continuing care facility was very much "expert driven" (Nolan & Dellasega, 2000), with little or no consideration of their preferences or the older adult's preferences. In these studies, most caregivers felt they had little choice or role in the decision-making process and that they needed to display an assertive and persistent approach to influence the decision-making process in terms of choosing long-term care or another option, such as homecare or supportive living (Lundh et al., 2000; Nolan & Dellasega, 2000; A. A. Ryan et al., 2011; A. A. Ryan & Scullion, 2000).

In most situations, the presence of nurses was not discussed positively as family caregivers felt they had no choice, as the decisions were made without their input. For example, according to Lundh et al. (2000), family caregivers reported that "in many instances the decision [to relocate] was primarily, if not exclusively, 'expert' driven [referring to nurses and physicians]" (p. 1182). Similar experiences were found by Nolan and Dellasega (2000), who comment on the healthcare provider's major influence on the decision to relocate, with little choice for the older person or their family caregiver. Certainly, in some situations the older person saw the heavy involvement and influence of the nurse as a relief (Fraher & Coffey, 2011); however, most often this involvement was perceived as negative and detracted from the experience of choice (Lundh et al., 2000; Nolan & Dellasega, 2000; A. A. Ryan & Scullion, 2000). This involvement of healthcare professionals (including nurses) largely contributed to feelings of no choice, powerlessness, further compounded by a lack of information to guide the decision and a perceived lack of control over the decision-making process (Lundh et al., 2000; Nolan & Dellasega, 2000; A. A. Ryan & Scullion, 2000).

A Critique of the Literature

The lack of evidence on the family caregivers experiences of choice when helping older persons relocating from a private residence to supportive living is striking. Of note, no published studies specifically concerning the caregiver's experience of choice while helping an older relative access continuing care services or supportive living services were found. This may be, in part, due to the traditional trajectory of transition of the older person (from private residence to long-term care) and the relative newness of supportive living as a reasonable option for older persons no longer able to live independently in their private residences. Furthermore, the paucity of literature in this area may be related to a fundamental lack of understanding of the importance of choice to family caregivers.

Although no studies were located that explored the experiences of choice, a small number of studies aimed to understand the experience of family caregivers helping older persons access continuing care services. While the studies almost universally identified implications for clinical practice, none used a practice-based qualitative approach, such as interpretive description, that specifically aims to generate clinically relevant knowledge. Rather, they employed methodologies such as phenomenology and grounded theory, which are aimed at understanding the lived experience or process involved with helping an older relative access continuing care services.

From the limited research evidence available, the experiences of family caregivers helping older relatives relocating to supportive living are clearly far from ideal. This prompts the question: How can nurses improve the experience of choice for family caregivers? Indeed, nursing is a practice-based discipline with a social mandate to promote all aspects of a patients' health and well-being, with nurses acting as stewards of the complex healthcare system (McCurry, Revell, & Roy, 2010; Risjord, 2010). This concept of stewardship is embodied in the Canadian Nurses' Association Code of Ethics (2017), which sees the notion of advocacy as central to nursing practice and paramount to the provision of quality healthcare. Key to this advocacy is the nurse's ability to support or recommend a choice based on the needs and preferences of a patient or their family caregiver (Canadian Nurses Association, 2017; Negarandeh, Oskouie, Ahmadi, Nikravesh, & Hallberg, 2006).

Relative to this context, when practicing as a community transition coordinator and tasked with helping in the relocation to supportive living, nurses would act as a steward or navigator of the system. They would wholly consider the expectations of both the older person and family caregiver, including the degree to which they desire to be involved, as well as the information required to make an informed choice. While the primary intent of this inquiry is not to examine the practice of the nurse as a community transition coordinator, this study also aimed to uncover how nurses may improve the experience of choice for family caregivers.

Summary

With an aging Canadian population, demands for supportive living services for older persons unable to live independently in their homes will increase, with many of these older persons requiring assistance to access services from their family caregivers. Though the decision to transition to supportive living is often necessitated by increasing medical needs, it can be further compounded by the perceived lack of choice in place of care. This may stand in direct contrast to Alberta's contemporary provincial continuing care policy, which touts choice as a central feature of continuing care services.

Currently, a gap in the research literature exists with respect to exploring the experiences of family caregivers. In particular, studies exploring the unique Canadian context and the meaning or definition of choice from the perspectives of family caregivers and healthcare professionals are lacking. Furthermore, the majority of the studies exploring the experience of family caregivers have focused on those helping older relatives transition to long-term care, thus necessitating an examination of the experience in the supportive living context. Specifically, the following questions remain: (1) What is the understanding of choice from the perspectives of family caregivers of older persons awaiting placement in designated supportive living? (2) What contextual factors influence family caregiver's experience of choice? and (3) How can we help family caregivers experience choice in the transition from community to designated supportive living? As this study represents the first inquiry into this subject area that I am aware of, an exploratory approach is considered to be appropriate. Specifically, one that is designed to explore the experience and meaning of this concept, that aims to capture the perspectives of family caregivers and the clinical experts in this context, community transition coordinators. Therefore, the focus of this study using a qualitative, interpretive description approach was to explore the experience of choice of family caregivers of older persons awaiting placement in a designated supportive living facility.

Chapter 3 Methods

Exploring the experience and understanding of choice from the perspectives of family caregivers of older persons accessing supportive living services is a topic amenable to study through the use of qualitative methods. Furthermore, as my research questions were exploratory, prompted by observation of a real-word clinical problem, a method such as interpretive description that is clinically oriented with aims to directly impact practice was appropriate. The purpose of this chapter is to present an overview of the interpretive description approach that I used to explore my research topic, including my study's setting, sampling and recruitment strategies, data collection and analysis procedures, and ethical considerations as well as the strategies I employed to enhance rigor.

Situating the Self: Understanding my Epistemological and Ontological Perspectives

As a discipline, nursing recognizes the uniqueness of the human experience, meaning it recognizes the diversity in human health and illness situations (Meleis, 2012). As a practicing nurse and novice nurse researcher, I have witnessed the richness in the individual patient's or participant's experience and endeavored to comprehend how one's past experiences and present understanding shapes their attitudes and actions toward a particular situation. This appreciation for the subjective nature of truth and multiple, unique realities has influenced the selection of a qualitative paradigm to explore my research area of interest, as well as the particular qualitative approach, interpretive description. Aligned with my choice of qualitative approach, knowledge (including nursing knowledge) is socially constructed, with this construction being highly influenced by context and the people who are creating this knowledge. Consistent with my view that knowledge is socially constructed and highly contextual, I acknowledge that there are multiple realities within a single experience and the subjective nature of truth. My epistemological and ontological beliefs are directly congruent with those Thorne has outlined in interpretive description. Though I have selected a qualitative approach to explore the research questions guiding this inquiry, I do acknowledge that for other studies alternative methods (including quantitative) may be more suitable.

An Introduction to Interpretive Description

Interpretive description was first described in detail in 1997 by Thorne, Kirkham, and MacDonald-Emes and was developed in recognition of the fact that some qualitative inquiry being conducted was not necessarily congruent with more traditional approaches but was nonetheless useful. It also developed from a disciplinary recognition that nursing research needed a methodology that was "…grounded in our own epistemological foundations, [would] adhere to the systematic reasoning of our discipline and yield legitimate knowledge for our practice" (Thorne, Kirkham, & MacDonald-Emes, 1997, p. 172). While interpretive description is a unique approach to qualitative inquiry, its components are not entirely novel. Elements of 'methodological borrowing' can be seen in the way interpretive description encourages constant comparative analysis (grounded theory); appreciation of multiple ways of data collection, including participant observation (ethnography); and the acknowledgement of multiple realities contributing to the subjective human experience (phenomenology) (Hunt, 2009; Mayan, 2009; Thorne, 2016).

Philosophically, interpretive description is aligned with the tenets of naturalistic inquiry as proposed by Lincoln and Guba (1985). These tenets can be seen as influencing the approach's epistemological and ontological underpinnings, and thus are reflected in its means of data collection and analysis (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). These influencing tenets include the following:

> 1) Multiple constructed realities that can be studied only holistically. Thus, reality is complex, contextual, constructed, and ultimately subjective.
>
> 2) The inquirer and the object of inquiry interact to influence one another; indeed, the knower and the known are inseparable (Thorne et al., 2004, p. 5).

Furthermore, Thorne's approach relies on the following assumptions: (i) applied research in the health sciences, particularly using interpretive description is founded on the recognition of clinically-relevant knowledge gaps (research "within the health disciplines draws its lifeblood directly from the world of clinical realities" (p.27), (ii) unlike other social science research traditions like grounded theory, the objective of interpretive description is not theory generation, and (iii) to facilitate a truly inductive research process, theory should be used not prior to inquiry, but after to facilitate understanding of an experience or phenomenon (Thorne, 2016). As such, it is incorporated during data analysis, where it enhances interpretation of the findings.

Interpretive description privileges itself as a research approach directly aligned with nursing's mandate and epistemological foundation which appreciates clinical, conceptual and empirical knowledge (Schultz & Meleis, 1988; Thorne et al., 1997). Though not explicitly stated, one could argue that this nursing mandate appreciates multiple realities giving rise to multiple forms of knowledge (Thorne, 2016). Interpretive description recognizes the development of knowledge as a co-construction that occurs through a transactional relationship between researcher and participant in which research findings are created during inquiry (Guba & Lincoln, 2000; Thorne, 2016; Thorne et al., 2004). This co-construction of knowledge or constructivist epistemology lends itself to a perspective that acknowledges the subjective nature of truth and appreciates that participant realities are often socially constructed and highly contextual (Guba & Lincoln, 2000; Hansen-Ketchum & Myrick, 2008). This orientation towards constructivism and appreciation of subjectivity can be seen in the manner in which interpretive description recognizes findings emerging from the analysis as "tentative truth claims" (Thorne et al., 2004, p. 6) relatable to a particular context rather than generalizable absolutes (Hunt, 2009). Further evidence of this appreciation of the subjective nature of truth can be seen in the way interpretive description encourages multiple means of data collection, including interviews, focus groups, participant observation, and documentary sources (Thorne, 2016).

On the surface, interpretive description appears to be a relatively generic approach to qualitative inquiry that is primarily concerned with the production of knowledge that is useful in clinical applications (Thorne et al., 1997). It is not overtly critical in nature, nor does it readily address issues of power and inequality. It does not aim to be completely prescriptive but rather functions to serve as a framework for practical, clinically relevant research. Therefore, interpretive description allows the researcher the flexibility to explore clinically relevant topics, with the ideology dependent on the research question and the nature of the subject matter under investigation. While a study of the experience of choice was amenable to exploration through different qualitative approaches, interpretive description offered the flexibility to explore the experiences of participants—free from a predetermined theoretical mandate to examine choice from a specific worldview—and ensure the construction of data that is ultimately relevant to clinical practice and patient care (Hunt, 2009; Thorne, 2016).

Setting

The setting for this study was a large Western Canadian city in Alberta. Alberta has a significant proportion of older persons, with approximately 12.3% of the population being over the age of 65 (Statistics Canada, 2016a). This proportion is similar to the city in which the study was conducted, where approximately 12.1% of individuals are over the age of 65 (Statistics

Canada, 2016a). As of 2016, the Province of Alberta had about 9,000 designated supportive living beds, with the majority being occupied by older persons (Alberta Government, 2017). In the healthcare zone where the study was conducted, about 49 facilities offer some type of designated supportive living services representing about 3,240 beds in total (E. Risling, personal communication, April 10, 2017; Alberta Health, 2016). Typically, when an older person is assessed as requiring designated supportive living services, they (often in conjunction with their family caregiver), will identify the top three facilities they would like to live in.

Currently, the demand for designated supportive living beds outweighs the supply within the city where the study was conducted and there is therefore an extensive waitlist to access these services. At present, approximately 407 individuals are on the waitlist for placement in a designated supportive living facility, with the vast majority (278) currently residing within private residences in the community (E. Risling, personal communication, April 10, 2017). On average, an individual residing within the community waits for a designated supportive living bed for about 111 days, though at some points the waiting period can extend for 12 to 18 months. (E. Risling, personal communication, April 10, 2017). This waitlist and the speed in which older persons receive placement in a designated supportive living facility is determined by a number of factors including their health status and ability to safely remain in their current dwelling, and the supportive living facilities they (or their family caregivers) have selected as their preferences, with some facilities in higher demand than others.

Participants

This study featured two groups of participants: (i) family caregivers and (ii) community transition coordinators. While understanding the experiences of family caregivers was the primary focus of this inquiry, Thorne (2016) suggests that “multiple angles of vision” (p. 87) may be necessary to comprehend a complex clinical problem and recommends interviewing 'experts' in the form of practicing clinicians. Therefore, to more wholly understand the experience of the family caregiver as well as to generate clinically relevant findings, it was also necessary to explore this experience from the perspectives of community transition coordinators. It is important to acknowledge that while the community transition coordinators were not the primary focus of this inquiry, the data collected from the interviews provided an important understanding of the process of accessing designated supportive living, the context in which family caregivers experienced choice and methodological guidance in recruitment and data collection from family caregivers.

Family caregivers

The first group of participants for this study was family caregivers. The family caregivers in my study provided care to an older person who was awaiting placement in a designated supportive living facility. To be eligible to participate in my study, the family caregivers had to be English speaking and able to provide consent for the study.

Community transition coordinators

The second group of participants for this study were community transition coordinators. Transition coordinators are registered nurses employed by a provincial health services organization that, upon referral from homecare case managers, assess individuals residing in community settings to determine if they are able to remain in their current setting, such as a private residence, or if they require transition to designated supportive living or a long-term care facility. Approximately 40 transition coordinators are employed within the large Western Canadian city. To have been eligible for participation in my study, these individuals had to be employed as a transition coordinator at the time of the interview.

Sampling

Two sampling approaches were used to select participants for my study. Initially, I used a purposive sampling approach where I selected participants according to their experiences (as a family caregiver or community transition coordinator), characteristics (age, sex, length of time on the waitlist, relationship to their older relative: spouse vs. adult child) and their ability to provide insight into their experience of choice when accessing designated supportive living services (Mayan, 2009; Thorne, 2016). This purposive sampling strategy was based on existing literature acknowledging the differences in caregivers and conversations with clinical experts prior to commencing recruitment. As my study progressed, and after I had completed some preliminary data analysis, I then employed principles of theoretical sampling, including maximal variation sampling, which helped to (i) ensure I spoke with family caregivers that had diverse experiences (Patton, 2015; Thorne, 2016) and (ii) collected data that enabled me to refine developing categories and themes (Charmaz, 2014). For instance, I applied principles of theoretical sampling when I refined my interview guide (Appendix G) after interviewing and analyzing several family caregiver interviews in order to explore emerging themes from the data in greater detail (Coyne, 1997). Specifically, in my first interview guide I asked family caregivers more broad questions on the meaning of choice and the degree of choice they felt they had in helping their relative access supportive living. Then, in response to my preliminary analysis and developing themes around the emotions associated with choice, the everyday choices caregivers make, and the relational impacts of choice, I refined my interview guide to probe more deeply into these areas. According to Thorne (2016), however, "interpretive description studies do not require the full scale of analytic depth that theoretical sampling contributes in grounded theory methodology" (p.101) as the intent of this approach is not theorizing but rather the generation of knowledge relevant to clinical practice.

Prior to commencing my study, my proposed sample size was four to six family caregivers and three to five community transition coordinators. However, after starting data collection, I recognized that this sample size would need to be adjusted based on developing findings, quality of the data, and the amount of useful information given by participants (Morse & Field, 1995). Thorne (2016) advises not to use the principle of data saturation as a guide for smaller studies using an interpretive description approach, but rather suggests that the researcher acknowledge "…that there would always be more to study" (p. 108). Therefore, the sample size for this inquiry was guided by an iterative consideration of the knowledge needed (in this case, knowledge about the experience of choice in accessing supportive living services), the ways this knowledge may be gathered, and the ethical conduct of the study (Thorne, 2016).

Recruitment

Recruitment occurred from November 2017 to April 2018. Following ethics approval from the Health Research Ethics Board at the University of Alberta and operational approval from the provincial health services organization, I gave an overview of my study to the individual in charge of transition services for the city where the study was conducted and provided copies of my information sheets (see Appendices A and B) and recruitment brochure and poster (see Appendices C and D). Because I wished to recruit family caregivers as well as community transition coordinators, the director sent a message to her staff providing details of the study and my contact information. Interested transition coordinators contacted me via e-mail or telephone to arrange a mutually agreeable interview time. Transition coordinators were asked by their director to identify and contact potentially suitable family caregivers. If a family caregiver was interested in hearing more about the study and willing to be contacted, the community transition coordinator would obtain their written or verbal consent for me to contact them and explain the study in greater detail.

In January 2018, I was invited to attend a meeting of all community transition coordinators by the Director of Transition Services. I attended this meeting to explain the study in greater detail in hopes that the transition coordinators would continue to identify potentially suitable participants for my study. In the end, about eight transition coordinators helped me recruit 12 family caregivers to participate in my study. This spoke to the importance of support from key staff to the success of recruitment (Grafton, Reid, & Coyne, 2016; Namageyo-Funa et al., 2014; Newington & Metcalfe, 2014).

Data Collection

Data collection commenced in November 2017. Family caregivers were invited to participate in the study after their older relative had been assessed by the transition coordinators as requiring designated supportive living services and were on the waiting list. After receiving the 'consent to contact' from the transition coordinators, I followed up via telephone with potential participants to provide more detail about the study and schedule an interview. All of my interviews, with the exception of one (due to participant illness), were conducted face-to-face at a location of the participant's choosing. Thorne (2016) recommends that "…interpretive description studies [be] conducted in as naturalistic a context as possible in a manner that is respectful of the comfort and ethical rights of all participants" (p. 82).

At the outset of each interview, I collected demographic data from the family caregivers including age, sex, relationship to older person, length of time providing care, caregiver chronic illnesses, and older person illnesses (see Appendix E). For my community transition coordinator participants, I collected demographic information including sex, current place of employment, and length of time in current job (see Appendix F). The collection of demographic data allows for a rich description of study participants and the contextualization of research findings including the experience of choice (Connelly, 2013).

Interviews with both family caregivers and community transition coordinators were semi-structured and guided by an interview guide comprised of open-ended questions (see Appendices G and H). According to Morse and Field (1995), "the semi-structured interview is used when the researcher knows most of the questions to ask but cannot predict the answers" (p. 94) and is useful "…because this technique ensures that the researcher will obtain all information required…while at the same time, gives the participant freedom to respond…" (p. 94). Interviews lasted from 30 to 75 minutes, with most taking around 45 minutes. Community transition coordinators were interviewed once, while most family caregivers were interviewed twice. Multiple interviews with family caregivers allowed for the development of a trusting relationship between the participant and interviewer (me) and enabled me to seek clarification on points arising from previous interviews. All interviews were digitally recorded and transcribed to ensure an accurate record of the interaction was kept (Opdenakker, 2006).

I also used journaling to capture reflections on the data collection process, including my personal interpretations or impressions of emerging findings as well as thoughts about particular interviews and areas of future questioning (Kitchenham, 2010). While I did not analyze this reflexive journal in the same manner as the interviews, it helped to contextualize the data and situate the interpretation of participant experiences as a reflection of my personal influences (Thorne, 2016).

Thorne presents several options for data collection when using interpretive description which include interviewing, focus groups, participant observation, arts-based methodologies and electronic message boards (Thorne, 2016). Similar to face-to-face interviews, focus groups are useful in eliciting "experiential knowledge about a phenomenon" (Thorne, 2016, p. 142) while leveraging the interactions amongst participants to enhance data quality (Patton, 2015). However, they are not appropriate in all instances and must be employed after consideration of their weaknesses (Mayan, 2009; Thorne, 2016). For instance, focus groups are not considered ideal in situations where the research topic is considered highly personal or sensitive (Patton, 2015). Furthermore, focus groups can privilege participants that are more social and feel more comfortable expressing their opinions in group settings (Thorne, 2016). As well, focus groups tend to occur at a location and time chosen by the researcher, removing participants from their natural settings where they may be most comfortable (Madriz, 2000). I chose not to employ focus groups as a means for data collection for this study for several reasons. Firstly, I recognized that though this study was about the caregiver's experience of choice, interview questions about caregiving in general, health status of the older person and family relationships are inherently sensitive, not necessarily best explored in a group setting. Indeed, several of the family caregivers that participated became emotional during the interview, which may have been uncomfortable in a group setting. Additionally, because of the sensitive subject matter of the interview and potential for emotional release, I also recognized that participants would feel most comfortable in a location of their choosing, which would not have been possible with a focus group. Lastly, focus groups produce much data beyond the participants' words. They also create group interaction data which is the interactions that occur between participants which may undoubtedly serve to influence the conversation and nature of the data (Duggleby, 2005). As I was focused on the individual caregiver's experience of choice, these group interactions would not have necessarily enhanced my data.

Data Analysis

In interpretive description, data collection and analysis typically occur in a concurrent and iterative manner to allow for refinement of interview questions and reflection on the research process (Thorne et al., 2004). (see Figure 2 below)

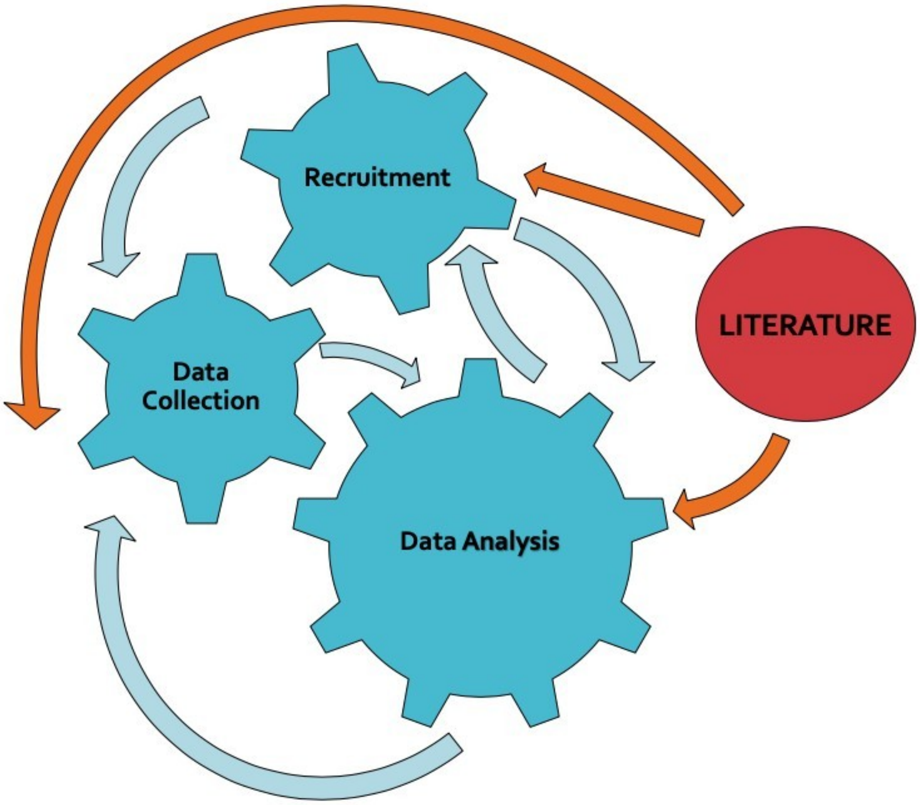

Figure 2 is a diagrammatic representation of the concurrent, iterative processes of recruitment, data collection, and data analysis that occur in interpretive description. Also conveyed is the role of literature (empirical and theoretical) in the data analysis process with this literature aiding in comprehension of a phenomenon.

Additionally, this approach to analysis "…forms a mutual interaction between what is known and what one needs to know" (Morse, Barrett, Mayan, Olson, & Spiers, 2002), thus identifying areas warranting further exploration through subsequent participant interviews. I commenced the process of data analysis following my first interview and continued this process up until writing my findings chapter. For me, the data analysis process was immersive, where I was deeply engaged with the interview transcripts, reading and re-reading the transcripts to ensure I had an understanding of my participant's experiences and perspectives.

Data analysis in interpretive description involves a process of finding a pattern among the pieces of data and interpreting data in a manner that is considerate of both the research question and disciplinary standpoint (Thorne, 2016). It follows an inductive approach, whereby "variables, concepts, constructs, and hypotheses are derived from relationships observed during the process of coding the data" (Morse & Field, 1995, p. 242). Thorne (2016) identifies three phases of the data analysis process: (i) sorting and organizing, (ii) making sense of pattern, and (iii) transforming pattern into findings.

I engaged in the sorting and organizing phase of analysis by coding transcripts individually using an open coding process whereby I broke raw data down into interpretable segments that were later more easily grouped into patterns, then larger findings (Benaquisto, 2008; Thorne, 2016). I did not engage in an excessively detailed coding process, as Thorne, Reimer Kirkham and O'Flynn-Magee (2004) note that this type of coding can "…detract from the mind's inherent capacity to see patterns, follow intuitions, and retrace a line of logical reasoning among and between pieces of data" (p. 14). Rather, I identified words and phrases that I believed in some way represented the family caregiver's experience of choice.

Following the sorting and organizing phase, I moved to the making sense of pattern phase. In this phase, Thorne suggests the researcher sort codes into areas of commonality or patterns that allow for the consideration of relationships amongst patterns themselves, as well as in relation to the larger research question. She also suggests this phase be guided by techniques of constant comparative analysis in which every piece of data (from the larger interview to the minutiae of individual codes) is compared to understand similarities and differences as well as theorize relations amongst the data (Thorne, 2016). I looked across my data and grouped common thoughts and experiences, while questioning the relationships and contextual factors influencing these experiences.

The last phase of the analysis process, transforming pattern into findings, involves reflecting on credible patterns, considering what these patterns mean individually and as a whole, and discovering how these patterns contribute to knowledge that was not possible prior to the study (Thorne, 2016). Initially, I analyzed data according to participant group (family caregivers and community transition coordinators) and sought to identify areas of both commonality and difference. I then considered the findings of each group as a whole and looked at how the words of each participant collectively spoke about the experience of choice.

The primary intent of my study was to understand the experience of choice from the perspective of family caregivers, and therefore the voice of the family caregiver is predominant in my findings. However, the data I collected from my community transition coordinator participants served the important role of enhancing my understanding of the context in which the family caregivers' experience occurs.

In the final phase of data analysis, I examined my findings in relation to my original research questions and overarching aim of my study. Thorne (2016) suggests this is a way to make sense of the findings and place them within the larger research context in a meaningful way. I also considered my findings in relation to existing literature and theory to determine areas of commonality and differences. This served as the foundation for my discussion, which can be found in later chapters of this dissertation. Table one (below) is an example of how selected data excerpts from my study were initially organized, analyzed and combined to constitute a theme. In the example, only a few exemplar quotes were used, and this does not represent all the data that were coded, rather the purpose was to demonstrate how some of the analytic decision-making occurred.

Table 1

Example of Analytic Process

Data Excerpts	Codes	Categories	Theme
“Trying to even set up her room, do we get new furniture or do we not? I didn’t have to make these decisions on my own. My sister from Holland, she was so grateful to have input, but **it helped me**”	Collaboration Support		
“So the choice is now that…she’s being cared for now. **I can enjoy it more. Visit and enjoy it**….there’s freedom”	Independence Enjoyment	Positive Impact	
			Acknowledging the impacts and outcomes of choice
“I used to go to the gym, but if I go to the gym, **I feel bad, because that’s an hour I could spending with my dad**”	Guilt	Negative Impact	
“I have siblings, and there’s a lot of **different opinions** about how things should go….even though I have two brothers here, **they’re in and out of the picture**”	Disagreement, Inconsistent Support		

Data Management

I used Quirkos to manage data and support the analysis process (Morse & Field, 1995). Quirkos is a qualitative software program that helps researchers analyze textual data such as interview transcripts, surveys, and articles. It allows the researcher the opportunity to understand and analyze data on a visual platform. While Quirkos was certainly crucial to my data analysis process, it was merely a data management tool and did not serve as a substitution for my immersion in the data analysis process (Morison & Moir, 1998; St. John & Johnson, 2000).

I stored data electronically on a password-protected computer. Any audio recordings and transcripts were kept in password-protected files that only my supervisors and I could access (Flick, 2014). I used a pseudonym naming system to protect the confidentiality of my participants, which consisted of a combination of participant initials and the date of data collection (e.g., ST 03202016). I maintained a spreadsheet linking this naming system with original participant details in a separate password-protected folder. Data will be stored for a minimum of 5 years.

Rigor and Reflexivity

Paramount to conducting credible qualitative research is careful consideration of strategies to ensure a study is rigorous. As this study employed an interpretive description approach, it used the means to enhance credibility and quality proposed by Thorne (2016): (i) epistemological integrity, (ii) representative credibility, (iii) analytic logic, and (iv) interpretive authority.

Epistemological integrity involves the demonstration of a defensible line of logic and methodological coherence from the research question, data collection, and analysis strategies, to the eventual interpretations and knowledge claims of the study (Thorne, 2016). Throughout my study, I reflected on my past experience as a nurse and family caregiver and considered how these factors may be influencing interpretations of my data.

Representative credibility involves whether the knowledge claims arising from a study can be substantiated based upon the sample of participants studied. In this study, I addressed representative credibility through prolonged engagement with my participants. I conducted multiple interviews with the majority of my participants so I could more fully understand their experience of choice and how their personal context influenced this experience (Lundy, 2008).

Analytic logic involves the demonstration of the researcher's decision-making processes throughout the study. Throughout the recruitment, data collection, and analysis phases of my study, I maintained an audit trail that detailed my methodological decisions and early interpretations (Morse & Field, 1995). I referred to the notes in my audit trail throughout data analysis, with some of these notes influencing my eventual findings.

Lastly, interpretive authority relates to the need for assurance that the findings from a study can be taken as accurate and reflective of participant experiences rather than influenced by personal biases held by the researcher. I had frequent meetings with my supervisors in which I shared my interpretations of the data and we discussed whether the themes I had generated were well supported with participant quotes (Mayan, 2009).

Ethical Considerations

This study was submitted to and received approval from both the University of Alberta Health Research Ethics Board (HREB) and the health ethics board at the provincial health services organization. The primary ethical considerations for this study included: (i) ensuring understanding of informed consent and study participation, (ii) the potential for misrepresentation, and (iii) the potential for identification of participants in published papers. Prior to commencing each interview, I provided a letter of information to each participant that explained the aspects of the study, including: (i) research purpose, (ii) research procedures, (iii) description of benefits and risks to participating, (iv) assurance of confidentiality and anonymity, and (v) an option to withdraw (Byrne, 2001).

The potential for misrepresentation involves the influence of the researcher's preconceived philosophical standpoint, personal experiences, and characteristics on qualitative data (Richards & Schwartz, 2002). To mitigate the risk of misrepresentation, I had frequent meetings with my supervisors in which we discussed my analytic decisions and ensured themes were reflective of participant experiences.

I ensured the privacy and confidentiality of my participants in several ways. I concealed the identities of my participants with pseudonyms and secured raw data (audio recordings of interviews, researcher journals) through the maintenance of a password-protected computer and electronic filing system. Additionally, I secured any written materials such as participant consent forms in a locked filing cabinet at a secure location.

Summary

Interpretive description is a qualitative approach that aims to explore a human experience or phenomenon with the ultimate goal of generating clinically relevant findings. It aims to go beyond description of the phenomenon towards an understanding of the relationships and patterns within the phenomenon to generate knowledge that may be applied to the practice context (Thorne, 2016). In this chapter, I described how I used interpretive description to explore the understanding of choice from the perspectives of family caregivers and community transition coordinators. While my overarching research question may have been answerable through the use of other qualitative methods, interpretive description allowed me the opportunity to gain a deep understanding of this experience in a manner continually considerate of potential clinical implications.

Chapter 4: Findings

In this chapter, I present the findings of my study. By reflecting on their experience of choice and the encompassing context, family caregivers provided a window into a deeply personal and intense period of their lives. Each caregiver had a unique story that shared common threads with other participants. Complementing these family caregiver experiences were the insights into accessing designated supportive living shared by the community transition coordinators. The following research questions guided my study:

- What contextual factors influence the family caregiver's experience of choice?
- What is the family caregivers' experience of choice?
- How can nurses help family caregivers experience choice?

Collectively, these questions helped to answer the overarching research question: How is choice understood by family caregivers of older persons awaiting placement in designated supportive living?

This chapter is organized into five sections. Section 1 presents the demographic characteristics of family caregivers and community transition coordinators. Section 2 describes the contextual factors that influence the family caregivers' experience of choice. Section 3 describes the findings of the family caregivers' experience of choice, and Section 4 presents the findings about how nurses can help family caregivers experience choice. Finally, Section 5 provides answers to the overarching research question: How is choice understood by family caregivers of older persons awaiting placement in designated supportive living?

Section 1: Demographic Characteristics of Study Participants

The sample was comprised of two different groups of participants: family caregivers and community transition coordinators. I interviewed 12 family caregivers in total. Five family caregivers were interviewed twice following refinement of the interview guide, with the remaining seven caregivers interviewed once, for a total of 17 interviews. Eleven family caregivers were adult children providing care to a parent and one caregiver was providing care to their spouse. Ten family caregivers were providing care to their mother, one family caregiver was providing care to her father, and one family caregiver was providing care to his wife. Eleven family caregivers were providing care to older persons experiencing dementia. One family caregiver was providing care to her mother who had multiple sclerosis and right-sided weakness. Nine family caregivers were female. Family caregivers ranged in age from 50 to 81 years (M = 61.3 years, SD = 8.8 years). The mean time on the waiting list at the time of the caregiver interviews for designated supportive living services was 7.9 months (SD = 2.8 months), with a range of 2 weeks to 12 months. Eight family caregivers reported having their own health concerns, including bilateral hip replacements, vertigo, knee replacements, diabetes, vascular necrosis, fibromyalgia, blindness, osteoarthritis, hypertension, and chronic bronchitis.

I also interviewed five community transition coordinators one time each, all of whom were registered nurses (RN). These transition coordinators could be considered experienced, having been in the role from 7 to 23 years (M = 13.4 years, SD = 5.3 years). All of the transition coordinators worked in a large Western Canadian city.

Section 2: Understanding the Context of Caregiving

Contextual factors are those that can influence or intensify an experience (Patton, 2015). They are the circumstances in the background of life that may have significant implications in certain situations. In this study, the experience of choice was one that occurred within the context of the caregiver’s everyday life. Context of the caregiver experience was crucial for understanding the family caregivers’ experience of choice. Five themes described the context in which the family caregivers provided care and experienced choice: (1) juggling multiple responsibilities, (2) complex family relationships (3) relative uncertainty, (4) declining health, and (5) precarious finances.

Juggling multiple responsibilities. Family caregivers caring for a parent needed to balance their caregiving role with caring for children or grandchildren, employment, and other personal relationships. Beyond impacts on their ability to maintain a relatively normal daily schedule, caregiving also impacted special personal activities such as family vacations or spending time with children or grandchildren. Some family caregivers were challenged to balance their personal daily routines with the (typically) unscheduled needs of the older person. One family caregiver said the following regarding her employment: "There is some travel involved with my job and I had to push back a little bit and reorganize things. I need to have the flexibility to be available at the drop of a hat." Another daughter, Victoria, who was trying to maintain her employment whilst caregiving, said:

> For instance, today. I know my mom's going to phone. I know the school phoned and said I have to work today. I can't go to bed and say, "I'm gonna do this, this, this, and this" because that phone can ring. And I need to be able to go there and help her. It [working] all depends on the phone call from my mom.

Anne, a daughter who acted as the primary caregiver for her mother, spoke of juggling her everyday life to ensure she was available for her mother:

> I am very aware that she may need to get a hold of me. I'm the first person they call-like if she has a fall. I try to visit her twice a week at least, so I plan my other activities around that.

Some caregivers had to juggle their caregiving roles with employment. This juggling involved choices related to anticipating when they may need to provide care, accessing the support of family members, and scheduling work around their older relative's needs.

For some family caregivers, this juggling of roles extended to their role as parents or grandparents. One daughter, Patricia, who was caring for her father who had dementia, described missing family vacations with her teenage children to ensure her father was cared for:

> I'm what they call the sandwich generation, between elderly parents and teenaged kids. Last year my husband had to take the kids to Machu Pichu. I couldn't go with them because I had stay with my parents.

Charlotte, a daughter who had moved from a town four hours away to live with and care for her mother with dementia, described how caregiving impacted her role as a grandparent: "I became a great grandmother and I've only seen the baby once. I feel like I'm missing out on a very, very special part of my life." Similarly, another family caregiver, Mary, actively involved in caring for her grandchild described juggling her multiple roles:

> Sometimes I get either mentally or physically tired just because it's very busy. The grandkids I look after are 9 and 11. I look after them two evenings, and have a number of different [work] meetings, so by Friday, I'm ready for an early sleep.

Others spoke of having less time with their spouses. For instance, one family caregiver, Susan, stated,

> Every weekend is a sacrifice because I work all week. My husband works all week. His mom is a senior as well. So, we devote one day to both of them. We're giving up one of our weekend days, when we only have two.

Beatrice, a family caregiver who cared for her mother added, "my husband and I went on a vacation-this past year and this was the first time in 5 years." For this caregiver (and others), the choice to juggle their role as a spouse or parent impacted their experience of choice.

Transition coordinators confirmed that many family caregivers are juggling multiple roles and responsibilities. This constant juggling over an extended period can lead to caregiver burnout or a decline in the caregiver's health. As one transition coordinator stated:

> Sometimes the caregiver will be a daughter or son who's coming in and coming out, and they also work full time, and we're looking at that generation of people and their children work full time, have families, and can't manage that person full time.

Family caregivers, almost universally, described the need to juggle their caregiving roles with other aspects of their lives, including their employment and the needs of their immediate family and grandchildren. This ongoing need to juggle these multiple responsibilities undoubtedly influenced the context in which they experienced choice.

Complex family relationships. For many family caregivers, the experience of choice occurred in the context of complex family relationships. That is, their experience was influenced by both past and present relationships with their older relative (care recipient) and their spouse or other family members. While some reflected on these relationships with fondness or nostalgia, others described them as more strained or fractured. Several family caregivers recounted particularly difficult relationships with their parent(s) for whom they were currently providing care. Victoria, a daughter, spoke of the ongoing strained relationship she had with her mother:

> My mom takes a lot of stress. She's a very angry, angry lady. I was the youngest, I was daddy's little girl, so she's always resented me for that. We've never had a good relationship even though I do a lot for her.

Despite this strained relationship with her mother, this caregiver made a conscious, deliberate decision to "let go of all those resentments" and chose to care for her mother, honouring what she felt to be her role as a daughter.

For other family caregivers with a stable and loving bond prior to caregiving, the relationship impacted their experience of choice in a different manner. They viewed the caregiving role as an opportunity to express gratitude, and a means of reciprocating the care they had received at the hands of their older relative in the past. One daughter, Beatrice, spoke of this reciprocity:

> I'm exhausted, but I know that it's not going to be like this forever. So, until the day comes, I'm here to serve my mother. She did it for me, when I was little, so it's payback time, good or bad.

Despite the challenges she encountered in providing care for her mother while she awaited placement in designated supportive living, her desire for reciprocity enabled her to persevere, find choice in her experience, and think of her role as "not actually much of a burden."

While their past relationship with the older person was crucial to influencing many family caregivers' current experiences of choice, other family members and siblings were equally important. Victoria who described herself as "the baby sister," recalled her experience of choice as shaped by the collaboration with her siblings:

> Anything to do with mom, the three of us siblings are pretty good. I will not make a big decision without talking to the two of them. We do many conference calls because my brother lives out of town. However, I'm the little baby sister, so sometimes what I do, they don't agree with just because we're a huge generation gap. So, they may not agree with me, and I may not agree with them but for the most part, we're pretty good at making choices for Mom.

Similarly, Charlotte, another family caregiver recalled her supportive relationship with immediate and extended family in coming together to care for her mother. She spoke of having "family meetings on a monthly basis," with care provided 24 hours a day by family members from both in and out of town. She acknowledged the relief that this intensive family support provided to her in her role as primary caregiver: "It makes a difference…I'm not alone in this game."

Some family caregivers also discussed the complex and strained sibling relationships and how this served to color their experience of choice. As Amelia, a daughter who was caring for her mother said:

> I have a sister in the city. I have a brother in the city too, but we never see him. He never comes around. If I phone and ask him to do something, you don't hear the end of it. They were here for Christmas day and haven't been back since.

Spouses played the vital role of support person for several family caregivers, especially those who were parenting younger children. Spouses often shouldered the responsibilities of childcare so that the family caregiver could be there for the older person. Patricia described her supportive relationship with her husband:

> My husband's very supportive. We've been married for 28 years. But I'm lucky. I mean, you know, some other guys wouldn't understand. Because it-for sure, you know it takes up time [caregiving].

For this and other caregivers, these complex, sometimes strained relationships served to color their experiences of choice. Whether the relationships with their older relatives and families were supportive or complex, family caregivers recognized their influence. For those with more supportive relationships, their experience of choice tended to be more positive as they found comfort in these relationships, which made everyday choices easier. Conversely, those participants with more complex relationships faced additional barriers and a more complicated context in which they experienced choice.

Relative uncertainty. Family caregivers spoke of the extended waiting period they experienced while helping their older person transition to the supportive living facility of their choice. During this period, the family caregivers faced varying degrees of uncertainty and precariousness as the health status of the older person continued to decline and whether they could remain safely in their current dwelling came into question. For many family caregivers, this decline threatened their ability to select their supportive living facility and increased the potential of transition to an undesired facility on an urgent or crisis basis. One daughter, Anne, spoke of this decline and its associated uncertainty:

> She's been on the waitlist for just over a year, but her situation has changed somewhat. Her symptoms have sort of increased. The confusion and memory issues are definitely

> progressing. We've managed some of the issues with medication changes but she's starting to wander more. So we need to get her into a place where she's more secure.

This uncertainty also extended to include concerns with the general transition process. Some family caregivers expressed confusion and frustration with the waiting list and how this was compounded by a lack of information from transition coordinators. Susan, a daughter, stated:

> I was told, there's nothing we can do, she's on the list. All you can do is change the place that you want her to go, and maybe your chances will be better. It took a long time for her [the transition coordinator] to even give me where she was on the waitlist.

Transition coordinators confirmed this finding, often witnessing family caregivers struggle with the uncertainty of this period. As one stated, "the challenge is the wait. The wait is the big thing, but also they're in crisis [with the older person's declining health]." At times, this ongoing uncertainty had implications for the physical and mental health of the family caregiver and impacted their ability to continue their caregiving role. Within this period of waiting and accompanying uncertainty, family caregivers experienced choice.

Declining health. All but one family caregiver provided care to an older person with dementia. A dementia diagnosis increased day-to-day involvement in caregiving activities, and family caregivers reported that their older relatives experienced unpredictable declines in health that impacted their ability to remain in their current dwelling safely. Three family caregivers who lived with the older relative were involved in almost every aspect of daily care, which then impacted their own health and well-being. One family caregiver, Charlotte, described remaining at home to ensure her mother, who had dementia, did not wander from the home:

> I have to make sure there's somebody here at all times to look after her. I went grocery shopping one day and was only gone maybe half an hour, and she'd gone to the neighbors three times in that short little period. After that, I never left her.

Other caregivers described how the mental capacity of the older person precluded their involvement in the decision-making process to transition to designated supportive living. One daughter, Anne, reflected on her mother's declining abilities and health: "Her memory is so poor. Her judgment is so poor. Her perception is so terrible. You can't really involve someone who has no judgement, and doesn't remember that she fell, or that she's unsafe." One transition coordinator echoed the observations of family caregivers:

> I've seen a lot [of older persons] where their cognition is just so poor that it's hard for them to…even answer simple questions, let alone decide where they want to go and what they want. They don't even know why they have to move.

A further challenge was when relatives experienced declining cognition and ability during the waiting period for supportive living. Victoria described her mother's worsening dementia: "Since she was diagnosed last fall…she's suddenly gone whacky. She's having delusions, but she thinks it's real. How do you deal with that?" The changes in cognition and ability to safely remain in their current dwelling during the prolonged waiting period played an important role in the family caregivers' experience of choice.

Precarious finances. Most family caregivers discussed the role that financial resources played in their experience of choice. Several family caregivers reported hiring additional personal support services to assist the older person they were caring for while they were waiting for placement in supportive living. These services were generally paid for from their own finances or the older person's finances. One son, Arthur, who had chosen to move his mother into his home while she awaited placement in their selected supportive living facility, spoke about hiring private respite workers, which allowed him to the freedom to leave the house for work meetings or engagements with his children. He reflected on his choice to hire private caregivers as follows:

> We also have some help come in, they are people that I know personally that work in this area and I hire them to look after her. It gives me time to do stuff that I need to get done without having her with me. Usually I have to take her wherever I go, I can't leave her alone.

For other family caregivers, the availability of financial resources was much more precarious, which made the lengthy waiting period more stressful. Anne, a daughter, described this experience:

> We had to hire a private caregiver to pick up the pace because the on-site care wasn't doing it. We have a woman who comes three times a week and just makes sure my mom's up and dressed. We had to hire out of pocket, to the tune of a thousand dollars additional a month, and our funds are dwindling.

In these instances, family caregivers sought privately paid support as a means of ensuring their older person remained safe and adequately cared for while they waited for the supportive living facility of their choosing. For other family caregivers, for whom financial supplementation was not possible, there loomed the undesirable possibility of their older person being placed on a crisis basis without a choice in the facility.

Section 3: Understanding the Experience of Choice

Within the aforementioned context, family caregivers lived a multifaceted experience of choice. Four themes describe this experience of choice for family caregivers helping older persons to access supportive living services: (1) making everyday choices, (2) seeing possibilities, (3) valuing the ability to choose, and (4) acknowledging the impacts and outcomes of choice.

Making everyday choices. Within the context of caring for their older relative while they awaited placement in a designated supportive living facility, family caregivers made choices daily or even multiple times a day. For example, choices included adjusting their schedules to accommodate their caregiving roles, making personal sacrifices, advocating for the needs of their older relative during the waiting period, and balancing their own needs with the needs of their older relative through self-care.

All family caregivers described leading full lives outside of their caregiving roles. Therefore, they made the daily choice to adjust their schedule to provide care. The degree of this adjustment varied according to the individual caregiver, with situations differing based on multiple factors including where the older person was residing during the waiting period for supportive living. For example, if the older person was living in a private lodge setting (with meals and some degree of personal support services), less adjustment seemed to be necessary for family caregivers. One family caregiver, Amelia, described the support her mother received in her current facility: "her lunch and supper are provided…they have activities daily, and the staff is good at redirecting her because she gets confused and wanders." For this family caregiver, though she chose to "visit and take her out two to three times a week," the degree to which she adjusted her daily schedule was not necessarily comparable to those caregivers with an older relative living in a private residence or even their own home. For instance, Arthur, who cared for his mother with dementia, spoke about how he made the choice to move his mother into his home during her transition period. Though a significant adjustment to his schedule, he recognized how this benefited his mother:

> She's happy. She's comfortable here, relaxed, not agitated because with dementia patients, you know change is very tough on them. I've just accepted the fact that she's living here, and were dealing with it and we're okay with it.

He later went on to explain how this choice affected his daily life and work:

> It's been tough; it's been an adjustment. Like anything else, your life is upside down, it's an adjustment. I do a lot of traveling with work, my wife and I. We just got back from Atlanta last weekend and my sister had to fly in from Vancouver to look after her.

Similarly, Charlotte, a daughter who was living with her mother in a private residence described her choice to adapt her sleep schedule on a nightly basis to ensure her mother remained safe overnight:

> Oh, sometimes when I get up, I'm more tired than when I went to bed. Sometimes she gets up three, maybe four times in the night, and I listen for her. What if she fell or something like that? It's either adapt to it…or we're gonna have to put her in a home.

Many family caregivers spoke about their choice to advocate for the needs of their older relative. They advocated by choosing to remain in close contact with the community transition coordinators. Susan, a daughter, chose spoke of "bugging the transition coordinator every once in a while" so that she could learn about where her mother was on the waitlist and provide updates on her mother's health status. Another family caregiver, Anne, described the need to take a slightly more aggressive approach in advocating for her older person, noting that it "seem[ed] like all I ever did was yell at them [the transition coordinators]." Though these actions are different in their approaches, they both represent an active choice on the part of the family caregiver to advocate for the needs of their older person. Other family caregivers chose to advocate by remaining informed about which supportive living facility would be best suited to the needs of their older person. For one daughter, Rose, this involved visiting and "phoning places" to learn which one might be appropriate for her mother.

For some family caregivers, making everyday choices enabled them to maintain balance between their own busy lives and the ongoing (and sometimes increasing) needs of their older relative. For example, Henry described his choice to hire private caregivers at his own expense to allow him a reprieve from caregiving, allowing him to work and maintain his family business. He described this choice:

> I just accepted the fact that she's living here [in his home], and I made that decision. Sometimes I need more flexibility, to do what I have to do, workwise. So, I have some people that I know work in this area come in, when I have stuff to do in the office. It gives me time to get stuff done without her, because I can't leave her alone, right…

For Henry, the choice to hire a private caregiver enabled him to juggle caring for his mother with his employment, with this choice made possible by the availability of personal financial resources. Another family caregiver, Mary, recalled choosing to work closely with her siblings and adult children to ensure her mother had round-the-clock care:

> Currently, my daughter and her husband live in my mom's basement, so they take care of night shift. And my son in unemployed, so he's taken over the day shifts. And I've got a sister who comes in one weekend a month, just to give everyone a break. So we've got 24 hours a day pretty much covered with family and friends.

This choice or decision to delegate care between family members enabled the older person to remain at home safely while awaiting placement in the desired supportive living facility. However, because of the complexity of family relationships, not all caregivers were able to receive assistance from their family members. Henry, another family caregiver, who cared for his mother, spoke about his strained relationship with his brother and how he solely shouldered the caregiving responsibilities:

> There are some people whose family comes every day [to visit their relative]. My brother, well he doesn't see her often. He just saw her for the first time since she's moved. He really didn't believe me for the longest time that there was anything wrong with her, because they don't see her. We've had family fights over it.

Many of the family caregivers reported having their own significant health conditions, such as diabetes, arthritis, and blindness. With the emotional toll of caregiving, these health conditions necessitated the daily choice to find balance with self-care activities. Charlotte, a caregiver, who lived with her mother, described her daily choice to find balance between her own needs as an individual and her mother's needs via a weekly crib outing. For her, the outing was a reprieve from "the loneliness" and an opportunity to regain the social life she felt she had lost. Others were less specific about the activities they used to find balance, but recognized that they needed a "mental break."

Though many spoke of the choices taken to find balance in their roles as caregivers with other roles, such as mother, father, or spouse, some family caregivers reflected on the guilt they encountered when they made the choice to engage in self-care activities:

> My biggest issue is stress, so I go to the gym three days a week and try to get enough sleep to manage that. But that's time away [from caregiving] …

For some, this experience of choice prompted caregivers to make the choice to find balance between their own emotional needs as an individual and their responsibilities as a caregiver. As one family caregiver with a strained and stressful relationship with her mother said, "I'm learning to how to meditate, I pray." For Victoria, choosing to engage in meditation allowed a reprieve from the "stress" involved with her experience of choice and caring for her mother. This appreciation or ability to see the smaller, almost daily choices within the larger choice of facility for their older relative was crucial to the caregiver's overall experience of choice.

Seeing possibilities. For many family caregivers, their experience of choice occurred within a period of uncertainty where they had to balance the needs of their older person with their own full lives. They had very little control over how long their relative would wait for placement in supportive living and whether their health would be stable enough to remain in their current dwelling. However, rather than succumbing to the stresses of their caregiving roles and the uncertainty associated with the process, they chose to see the possibilities in their individual circumstances. Seeing possibilities also involved acknowledging some choices that were not always positive. Beatrice reflected on this:

> We don't necessarily like the choices in life, right? We can find private care---there are spots available in a much shorter time frame. So, there's always choices. Just not necessarily good things to choose from.

Participants also described how their outlook allowed them to see (and be open to) the choices surrounding them in their experience. For example, several family caregivers acknowledged that their experience of choice and the ability to see possibilities were heavily influenced by who they were as people. That is, they saw their personalities or outlooks as being a key component influencing their experience of choice. Rose saw the experience of choice as influenced by personality, with different personality types (such as pessimists and optimists) having different experiences. She spoke of this relationship between choice and personality in the following manner:

> Choice is something that I think relates to personality, because some people see the world with optimism for everything, so there's always a choice. And then, there's others that are more of Debbie Downers, more negative seers, so there isn't much of a choice. I think that really is perspective. I think that we all have lots of choice, even in how we approach an elderly parent. And yet, I can feel sometimes that I don't have any choice. I have to do this. So, I think it really depends a lot on our outlook, the choice.

Similarly, Charles recognized the influence of his outlook on his experience of choice. For him, his outlook shaped not only his experience of choice, but his larger life.

> Life is never perfectly what one dreams. I'm more of a glass-is-half full kind of guy, I tend to offer encouragements….to keep going, to do what needs to be done. That's my disposition. I've never despaired. This too shall pass. The sun will come out tomorrow, I guess that's…. the way I live.

To Charles and several family caregivers, the experience of choice was predominantly internal, with outside context having less of an impact. For example, Beatrice, who described herself as a "Pollyanna," spoke of what she termed as her "gratitude attitude":

> I've made a bridge, created a bridge that people can cross if they want, and there's love here. We're not going to stay in resentment. We're here to appreciate our parents and their love. If I hadn't had let go of all those resentments, I'd be pretty miserable [in my caregiving role].

It was this internalization that enabled her to enjoy her caregiving experience despite the stresses of other aspects of her life, such as employment and the relationship with her spouse. Caregivers recognized that although a situation may be inadvertently difficult, the ability to be open to possibilities and ultimately have choice resided within them as individuals.

This recognition of the internal nature of the experience of choice enabled caregivers to see how an alternate outlook might influence their experience. For instance, Rose recognized how a more pessimistic mindset may impact the overall caregiving experience and its associated stresses: “If you were of the mind, I suppose, that it’s [caregiving] such a terrible thing, I think it would just bother you more.” For some, recognizing a less than ideal outlook prompted them to take steps to shift their mindset. For example, some caregivers who were self-professed pessimists who “complain too much” described their experience as one in which they were learning to adopt a more positive mindset. In part, this process involved accepting the inevitable decline in the older person’s health status, knowing “it’s not going to get better” and taking it “day by day.” For some, it was this shift in outlook that enabled them to see the possibilities that ultimately influenced their individual circumstances.

For others, shifting their mindset also involved identifying personal deficiencies and employing tools to help them have a more positive attitude, which ultimately helped them see possibilities and find choice. Personal faith provided family caregivers a means to reflect upon their role as caregivers, enabling them to see the possibilities within their experience of choice. In this view, family caregivers recognized the possibility that challenges encountered throughout their experience could be attributed to “God’s timing for us,” and comfort was found in the belief that “He is doing for us, what we see as needful and what we also see is appropriate.” Some acknowledged that, without this support in the form of personal faith, they “would have more trouble” coping with their caregiving roles.

For others, seeing possibilities enabled them to develop new skills and tools, find the choice in their personal experience, and undergo personal growth. For example, some developed a self-awareness that was not present prior. Beatrice described reaching within to find forgiveness for her mother for whom she was providing care:

> There's been forgiveness that's happened. There's been all kinds of really good things happen because I'm in this role. And…you know…I had to go through… "I can't be blaming you anymore." And I've had to accept myself and my responsibilities.

For this family caregiver, her ability to find forgiveness for transgressions of the past represented a powerful personal choice—one that was solely in her control and important to her perception of choice. Other family caregivers reflected on the uncertainty of the experience and the unpredictable nature of the older person's disease progression. They spoke about recognizing characteristics of their own personalities that did not necessarily serve them well in finding the possibilities within this experience. For instance, Victoria, who cared for her mother reflected on her desire for control and organization in life. Through this experience, she realized that her desire for control would not serve her well in a situation where she had relatively little control of external factors such as the supporting living waitlist and her mother's health. She said:

> I've learned I can't be in control anymore. In order to survive and to be sane… um… whatever happens, happens. I can't-I can't worry about… "It's not going my way." I can't be in control.

Though this ability to see the possibilities within their individual experiences of choice was slightly different for each caregiver, it collectively, manifested as a shift in outlook and involved an acknowledgment of the positive aspects of caregiving. Seeing the possibilities allowed caregivers to recognize their intrinsic strength, appreciate the development of deep self-awareness, and experience personal growth.

Valuing the ability to choose. Participants' ability to see possibilities influenced their perceptions about choice and, specifically, having the ability to choose. For some, this ability to choose was linked to a desire for acknowledgement or consideration of their wishes and needs.

However, for others the ability to choose was more closely tied to perceptions of power, control, free will, and independence.

Participants described how consideration of their own wishes and desires as caregivers was important. To them, an acknowledgement of these preferences allowed them to feel that they had a central role in the choices at hand. Victoria described this ability to choose as follows:

> Having choice means that your wishes, desires, and needs are taken into account… that you end up having the final say, if it is a real choice.

For this family caregiver and others, the ability to choose was also tied to feelings of control and power, where having choice and ultimately, control, was perceived as “something that makes me happy…makes me feel fulfilled.” Similarly, another family caregiver recognized the ability to choose as an individual’s expression of control. She said, “Choice means being able to decide what you want to do and doing it.” One caregiver, Anne, reflected on the origin of this desire for control in her experience of choice. She felt that it potentially stemmed from the unpredictable nature of her mother’s dementia: “you really don’t have any control [over her decline], and she doesn’t have control.”

While family caregivers recognized the ability to choose as an opportunity to express their desires, they also saw making a choice as an expression of their free will and independence. One family caregiver, Susan, stressed the importance of feeling as if she was making independent choices that were “free from hassle and red tape.” She said:

> I see my choice as my choice. If I choose to ask the questions, then you have to give me the answers.

For this family caregiver and others, recognizing this drive for ownership over choices enabled them to understand how this influenced interactions with others within their experience of choice. She described how her desire for free will impacted the way she interacted with the community transition coordinators:

> Whereas a lot of people would just be like butterflies on the wall and just do what they [the transition coordinators] want, I've never lived my life that way.

Similarly, another family caregiver, Victoria, a daughter caring for her mother who had dementia, said, "[choice is] something that…is about me and that I don't have to consider others…It's something that I do on my own." For both of these family caregivers, not only was having the ability to choose crucial but they also wished for independent choice, unimpeded or uninfluenced by outside parties. Though they desired communication and information from the community transition coordinators to guide their experience of choice, they wished to largely retain control over the daily choices they made, as well as the choice of supportive living facility for their older relative.

Family caregivers valued having the ability to choose in their personal contexts, which influenced their experiences of choice. For some, this ability to choose was tied to an acknowledgement of their personal values and needs, while for others it was related to a desire for control, power, and independence in their individual experiences. Regardless of their values or perspectives on choice, the ability to exercise choice was an important aspect of their overall experience of choice as it enabled caregivers to feel some sense of control despite the unpredictable nature of the context around them.

Acknowledging the impacts and outcomes of choice. Family caregivers described a key aspect of their experience of choice as acknowledging both the impacts and outcomes of choice. They recognized that their daily choices did not occur in a vacuum and not only affected themselves but also those around them, including family members. They also acknowledged the outcomes or feelings associated with these choices and how this influenced their overall experience of choice.

Several family caregivers acknowledged that their choices as a caregiver impacted their relationships with their children, spouse, or family members. For some, the impacts were positive and served to strengthen family bonds; for others, however, the impacts were more negative, further straining relationships. One son, Henry, who was caring for his mother who had dementia, chose to move his mother into his home while she awaited placement in a designated supportive living facility. This choice was not well received by his siblings who felt that their mother should be waiting for placement in another facility. Ultimately, this choice negatively impacted his relationship with his siblings. He spoke about the impacts of his choice:

> I have siblings, and there's a lot of different opinions about how things should go. They didn't like my decision to have my mom here [in his home] and even though there I have two brothers here [in the city], they're in and out of the picture. The wanted her in a facility immediately.

Another family caregiver, Arthur, described his caregiving choices having a similar impact on his relationships with his sibling. He described a situation in which his sibling did not believe his assertion that their mother's health was declining so rapidly and his choice to place his mother on the waitlist for supportive living. Not only did his brother disagree with his choices, but these choices sparked a deep rift between these siblings, with the caregiver mentioning that "they didn't talk to us for several months afterwards."

While some family caregivers spoke of the negative impact their choices had on relationships with their siblings, others spoke of more positive impacts. Sometimes positive impacts stemmed from the caregiver's choice to consciously and deliberately involve those around them in their caregiving choices. One daughter, Rose, who was the sole caregiver to her mother as a by-product of geographical separation, spoke about her choice to involve siblings who were overseas in caregiving choices. She spoke of the mutually beneficial collaboration with one of her siblings:

> Trying to even set up her room-you know, do we get new furniture or do we not? I didn't have to make these decisions on my own. My sister from Holland, she was so grateful to have input, but it helped me. I would not have found it easy being a single child, it would have been more of a burden then.

This caregiver acknowledged that this choice had an impact on both the relationship with her sibling as well as her overall experience of choice. The choice to involve her overseas sibling, though an additional effort, also "helped" her in feeling that she had a support system throughout her experience.

Family caregivers also acknowledged the outcomes or feelings they experienced from making choices. Family caregivers generally equated having choice with feelings of happiness, fulfillment, and independence. However, participants also experienced feelings of being uncomfortable and guilty. For example, Charlotte, who was caring for her mother with dementia, despite her growing awareness that her mother's health was declining, stated that she "just [felt] guilty that we're going to put her into a home." She recognized that although she felt "uncomfortable" and "guilty" about making the choice to move her mother to a supportive living facility, it was necessary as she could not "keep struggling along."

Feelings of guilt were not isolated to the choice to seek placement in a supportive living facility. Other family caregivers described guilt as a result of other choices they made, such as engaging in self-care activities. Patricia described guilt associated with her choice to go to the gym. She said, "I used to go to the gym, but if I go to the gym, I feel bad, because that's an hour that I could be spending with my dad." Guilt was not limited to choices about providing care to their older relative. The same caregiver reported guilt about spending less time with her teenaged children and husband as a result of her choice to act as primary caregiver to her father. She acknowledged the “high cost” of caregiving and feeling as though she was “missing out on special time with them” as a result of her choices.

Family caregivers also experienced strong feelings when the choice (or choices) they faced or made were not perceived as ideal. Though they recognized choices were available, they did not see any of the options as favorable, which resulted in feelings of frustration, helplessness, and anger. Susan, a daughter caring for her mother, felt both frustration and helplessness when she was faced with the prospect of moving her mother to a particular supportive living facility. She acknowledged that she did have choices (either move her mother or have her remain in her current dwelling), but the choice she ended up making was not ideal:

> I have a choice. I can take one place [supportive living facility] in all of [city] or she can stay where she is. But that’s all I can do. It’s really out of my hands. It’s really frustrating.

The outcomes or feelings associated with a particular choice (or choices) were an important piece of family caregiver’s experiences of choice. Many of the choices they made throughout their experience were not made in isolation and not only affected their relationships with other family members but also had a significant impact on their well-being as caregivers. Sometimes, the choices they made even resulted in feelings of guilt, anger, helplessness, and frustration. While some of these outcomes and impacts of choice were perceived as negative, others were positive; specifically, family caregivers acknowledged how the choices they made had a positive impact on the relationships with those around them.

Section 4: Understanding How We (Nurses) Can Help

Though the primary focus of this inquiry was to explore how choice is understood by family caregivers of older persons awaiting placement in designated supportive living, it was also necessary to explore how we (nurses) can improve their experience of choice for several reasons. First, this study employed an interpretive description approach, a clinically grounded method that ultimately aims to improve the healthcare experiences of patients and families (Thorne, 2016). As a nurse, and given the predominant role that nurses play in the transition to supportive living and overall experience of choice, I also felt it was crucial to understand what steps nurses can take to potentially help family caregivers that are helping their older relatives transition to supportive living. Through the analysis of data from both family caregiver and transition coordinator interviews, two predominant themes emerged that were related to this research question: (1) access to credible information about supportive living services and (2) communication and transparency.

Access to credible information about supportive living services. Family caregivers described their experience of choice as multidimensional. That is, it was influenced by the everyday choices they made as caregivers, their personality and outlook on life, the outcomes of their choices, and the ability to choose. Despite the largely internal nature of their experience of choice, family caregivers felt that access to credible information about supportive living experiences was key to their ability to function as caregivers. Before their current experience, most family caregivers had little or no prior exposure to or knowledge of designated supportive living services. Mostly, their existing knowledge was gathered from friends or "previous family or people we know that have been in this." It tended to focus on the aesthetics of certain facilities or the subjective experience of one's relative. For instance, one family caregiver, Charlotte, noted the following: "I met a lady at crib on Friday. And she was saying that she knows people that have been there [supportive living facility]. And she says it's an excellent facility. They have people that come and play music." Similarly, Henry who cared for his mother remarked:

> I've had people, friends of mine and acquaintances who've had relatives in there, and they're the ones that recommended those [facilities] to me. We just heard some great

> things about them, you know we just know some people in there. So we have that personal connection.

While this shared information could have been reassuring, it did not necessarily provide the knowledge that some family caregivers desired. For instance, one daughter, Victoria, recalled a conversation with a close friend whose mother also had dementia and required placement in a supportive living facility. She recalled, “My mom and her mom were very similar…Her mom is living in [name of supportive living facility], and they’ve had a lot of problems, but my mom’s not quite there yet.” Though the experience shared by her friend provided comfort, it did not provide this family caregiver the details she needed to guide the choices she faced while her mother was awaiting placement in a supportive living facility. Furthermore, this information, at times, could be incorrect. One community transition coordinator recalled:

> Some families will say, ‘we want them at exactly this facility’ and I know that’s not even an option. They’ve been told by friends or that kind of thing, the wrong information, then you kind of have to steer them back to the most appropriate options.

Several family caregivers spoke of their attempts to gather information through internet research. They explained, however, that this research was virtually fruitless: “Online there is some [information]. A little bit, but it doesn’t really explain it [the facilities]. It tells you how many beds, but it’s still vague.” This was echoed by several transition coordinators who spoke of the information shared online and its tendency to only reflect overly negative experiences:

> Online. It’s good and bad. I find a lot of people who are happy with where their parents are, but there’s no need to go online and rant about that. But if you’re unhappy, that’s where you go. And you…give a bad review. So, the patients or families go online and see all the bad reviews and that’s often a barrier. Sometimes they’ll call and say, “Oh I don’t want on the list for that facility, ‘cause I went online and there were horrible reviews”.

Not only was misinformation found online, it was also found in newspaper, radio, and television advertisements. Designated supportive living services within this large Canadian Western city are provided through a mix of publicly and privately funded beds; however, family caregivers' knowledge about these services was often heavily influenced by the portrayals of private supportive living facilities in advertisements. As one community transition coordinator reflected:

> Often, some of the education for supportive living that's out there is…for the private supportive living, which is a huge misconception. Families hear the advertisements on the radio. They see them in the newspaper, and what the private supportive living is offering is totally not what funded supportive living beds are like…The pictures the families see, the suites are never the smaller suites. It's always the huge, beautiful…whatever.

Even with more credible sources of information such as the local published directory of seniors' services, family caregivers struggled to understand designated supportive living and the facilities available or felt "overwhelmed" at the sheer volume of information. One transition coordinator reflected on this:

> Families can look at the [local directory of seniors' services] which is a difficult resource to use. It doesn't really make any sense. It's hard to follow. It's a huge to book to wade through. If you're in a crisis, you'll need somebody to help you interpret it. And that's the difficult part.

Family caregivers saw information as crucial to making informed choices during this period of waiting, for example about what designated supportive living facility was most suitable for their older person. However, their information needs went beyond that of anecdotes gathered from family and friends. When asked if she felt that she had enough information to decide about supportive living services, one family caregiver answered, "Yes and no. We have information of people's opinions… but we need more information from our transition coordinator." Another family caregiver shared a similar desire for the expertise of the community transition coordinators, something that was not experienced in her situation:

> The transition person ideally would spend more time getting to know the sites, so that they could give advice. I don't think [transition coordinator] was able to give me the understanding that I needed. She didn't have a clue. She didn't tell me anything… she was ultimately quite useless.

Unfortunately, this experience was not unique and several other family caregivers described similar experiences in which their transition coordinator was unable to provide them with the information or resources they desired. Arthur, a family caregiver who was looking after his mother while she awaited placement in a supportive living facility recalled that, “In every other part of healthcare, whenever there’s been some sort of transition worker, they’ve always had…a plethora of information. This is the first time that that didn’t happen.” He went on to say that “the person [was] awesome. And very nice, and very caring,” but they “just didn’t have all of the information we needed.”

Communication and transparency. Throughout the interviews, family caregivers stressed the importance of open and frequent communication with their transition coordinators. They saw this communication and transparency as crucial to understanding the process of accessing supportive living services and their ability to make daily choices as caregivers. As the typical waiting period for an older person to be placed in a designated supportive living facility was significant, some family caregivers saw communication with their transition coordinator as a means of keeping updated on their older person’s place on the waitlist and reporting any difficulties they may be encountering. Victoria who was caring for her mother with dementia reflected on the communication with her transition coordinator positively: “she’s been very helpful. She keeps me updated. I usually get an e-mail once a month to tell us where she [her mother] is within the waitlist.” For others, this communication was less frequent or perhaps less helpful. Another family caregiver, Susan, recalled an exchange with her transition coordinator that left her with more questions than answers:

> The last time I talked to the transition coordinator, about 2 months ago, she told me that my mom was fifth on the list. And then, when I phoned her about 2 weeks ago, just so I could see what was going on, she told me that she was seventh on the list. So I asked why

> did the number change? And she said because if somebody that's on the list prior to your mom decides she wants her location, she gets to jump the list. It's just…really frustrating.

Transition coordinators were aware of the challenges family caregivers experienced in understanding the process of waiting for placement in designated supportive living. One transition coordinator reflected on this complexity, describing the system as "a giant crossword puzzle every day." She went on to acknowledge the difficulty that even she had in comprehending the waitlist and bed-matching process:

> If you look at our waitlists and you look at how our bed matching happens, it's totally confusing. A bed will come up, and then it will populate all the people that match to that bed. And then that coordinator has to make a decision. It's not the person on the top of the list, probably. It's madness.

In addition to challenges in understanding the waitlists they would experience, family caregivers were almost universally completely new to the process of accessing designated supportive living and often felt "overwhelmed because we knew what we wanted [for our mother], but we didn't know the process of this whole thing." While they appreciated the complexity and enormity of the designated supportive living system, family caregivers also desired transparent communication with their transition coordinator during the prolonged waiting period. As one daughter reflected, "I can understand there's a waitlist. I have no issue with the waitlist. I…one hundred percent appreciate that people are living longer. There is just no way to predict how long [the wait is]." Recognizing that transparency in the waiting period would be beneficial to family caregivers was also echoed by several transition coordinators. As one transition coordinator said:

> You know, I guess it could be more…publicly told about the…length of wait. I have no idea if it's told to the public beforehand. It would be nice, if they knew.

However, other transition coordinators recognized that a general education about the process was not the best course of action to suit all family caregivers:

> You know, it's like everything else. People don't listen to it unless it's pertinent to them. They could hear it-we could try and educate, but unless it's something that's in your own life, you're not really paying as much attention.

Several, but not all, transition coordinators spoke about the individualized approach to communication they used that considered previous life experiences or knowledge of the family caregiver. They described needing to "read the person [family caregiver] I'm talking to a bit" to determine the level of detail about the process they could give. As one transition coordinator recalled:

> Some people [family caregivers] will push, and I'll explain it to them. So, I'll try to give them the Coles notes version of how this is going to go down, without too much detail- they can't always understand the big picture.

This abridged version of the process would certainly be useful to some family caregivers who perhaps have limited knowledge of the healthcare system and the process to access supportive living services; however, some family caregivers perceived this as a barrier to making an informed decision about their older person's care. For instance, one daughter, Mary, reflecting on the lack of communication around selection of facilities for her mother and their respective waitlists said:

> …the biggest thing though would be to have an understanding of the process. There's no information about the waitlists [for specific facilities] and I found that very…confusing. If I knew that one [facility] has a really short waitlist, I might have wanted to request that, but that information was not available. Or they refused to give it.

Family caregivers valued information, communication, and transparency from their transition coordinators. Caregivers had varied experiences regarding the frequency and quality of communication with their transition coordinators, though nearly all expressed their desire for more credible information and advice. Though caregivers described their experience of choice as heavily influenced by their own personalities, their relationships with family, and their daily choices, the interactions with their transition coordinators likely (at least to some extent) shaped their experience of choice.

Section 5: Answering the Overarching Research Question & Developing a Conceptual Understanding of Choice

The focus of the present study was to explore the understanding of choice from the perspectives of family caregivers of older persons awaiting placement in designated supportive living. The intent of this inquiry that used an interpretive description approach was not to generate theory. Rather, it was to generate an understanding of the family caregiver's experience of choice in the context of helping their older relatives access designated supportive living services. Though my intent was not to theorize, I believe I have instead developed a unique conceptualization of choice that, at this point, is specific to the context in which I conducted my study. Therefore, the conceptual definition of choice arising from this study is: **Choice is a deeply personal, relational, daily experience in seeing possibilities within a context of uncertainty.** A diagrammatic conceptualization of choice arising from the exploration of the experiences of family caregivers helping their older relatives awaiting placement in designated supportive living is presented in Figure 3. . In this conceptualization, the core elements of choice (daily, relational, personal experience in seeing possibilities) are interrelated and influenced by conceptual elements which include juggling multiple responsibilities, precarious finances, complex family relationships, declining health, and relative uncertainty.

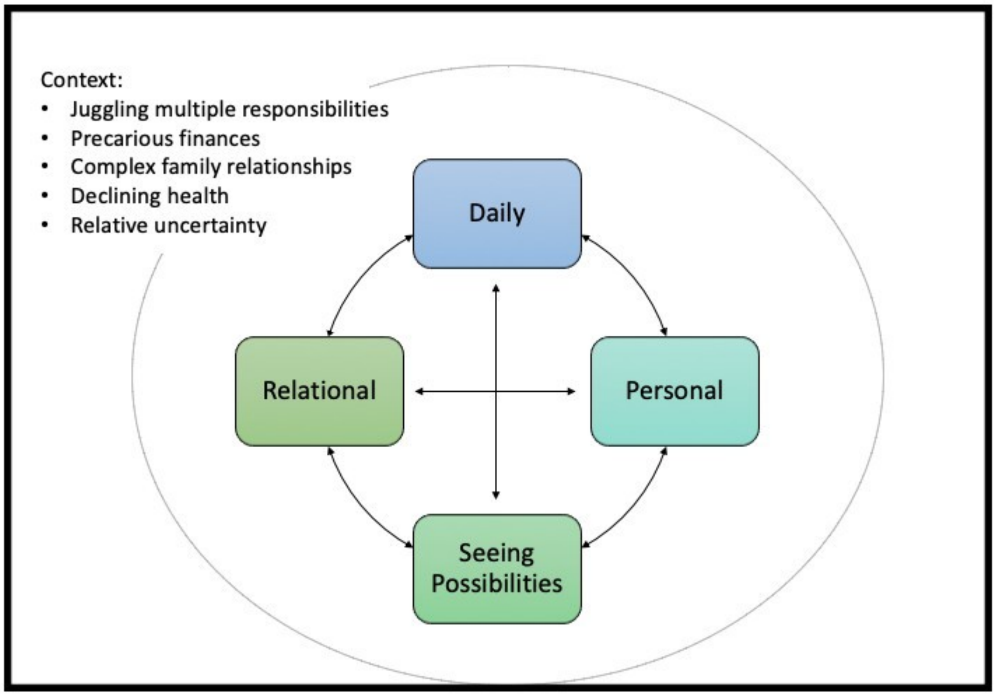

Figure 3. Family caregivers' experience of choice

This understanding is shaped by both the caregivers' external context as well as their personal experiences. Family caregivers' experience of choice occurs within a context of uncertainty associated with accessing designated supportive living services, precarious finances impacting their ability to access additional support services, the progressive decline in the older person's health, the constant juggling of their multiple responsibilities including family, employment, and personal health, and complex family dynamics. For the family caregivers, choice was more than an isolated event such as the choice of supportive living facility; they described the multiple choices they made daily, such as accepting their role as caregiver, engaging in self-care activities, and advocating for the needs of their older relative. Family caregivers did not understand choice as merely deciding between two alternatives. Rather, they understood choice as something that was omnipresent, even when the choices presented were not favorable. They understood their experience or personal perceptions of choice as being largely internal, where their personality or outlook played a significant role in whether or not they could find choice. They recognized that their drive and ability to choose was rooted in a desire for power and control and that truly having a choice meant a consideration of their personal values and needs. Lastly, they acknowledged that their choices had widespread outcomes and impacts, not only on themselves but also on the relationships with those around them. In summary, as a concept or an experience, choice is complex. An understanding of choice in any given situation should look beyond a more simplistic conceptualization (such as the absence or presence of choice) to consider the context in which it is occurring and the person (or persons) at the heart of the choice. It should be noted that although this conceptual understanding is framed within the caregivers' experience in helping their older relatives access supportive living; however, it is amenable to further exploration and potential theoretical explication in other care contexts.

Chapter 5: Discussion

In this chapter, I discuss my research findings about the understanding of choice of family caregivers of community-dwelling older relatives awaiting placement in designated supportive living. The discussion first focuses on the conceptualization of choice that was developed from the findings and its relationship to other concepts tangentially related to the context including waiting, transition and decision-making. The discussion then focuses on the main themes of the study that describe the experience of choice of family caregivers, including making everyday choices, seeing possibilities, valuing the ability to choose, and acknowledging the impacts and outcomes of choice. The findings are discussed in the context of existing literature and within the limitations of this study.

As described in the previous chapter, the findings of this study led to the development of a conceptualization of choice unique to the context of caregivers helping their older relatives awaiting placement in designated supportive living: **Choice is a deeply personal, relational, daily experience in seeing possibilities within a context of uncertainty**. There are similarities between the experience of choice and the experience of caregiving, particularly for a relative with dementia. For instance, caregivers in my study described their experience of choice as occurring within a context where they had to juggle their caregiving role with their personal and professional pursuits. Indeed, this juggling or balancing of caregiving with other aspects of life is seen throughout the caregiving literature (Brodaty & Donkin, 2009; Gaugler et al., 2018; Guberman & Maheu, 1999; Sinha, 2013). As well, there is some overlap between my study and those exploring the experience of providing care to an older relative with dementia in the uncertainty caregivers face in the progressive decline of the older person's health (Edwards, 2015; Hwang et al., 2017; World Health Organization, 2012). Though aspects of caregiving and caregiving with dementia provide an important picture of the context in which the family caregivers in my study experienced choice, they were not the central focus of this inquiry. The findings of my study also assist in clarifying the concept of choice and its differences to other concepts found within the caregiving context such as waiting, transition, and decision-making.

The Experience of Choice and the Experience of Waiting

In this study, the caregivers described their experience of choice as occurring within a context of relative uncertainty, with this uncertainty in part related to the waiting period associated with accessing supportive living services. Indeed, waiting for healthcare services is a commonly experienced problem, and has been the subject of research including several concept analyses. Fogarty and Cronin (2008) defined waiting for healthcare as "an unspecified yet measurable period of time between identification of a healthcare problem and its diagnosis and treatment, when clients experience uncertainty and powerlessness whilst anticipating a disease outcome" (p. 467). Similarly, Irvin (2001) found that waiting is "a stationary, dynamic, yet unspecified time-frame phenomenon in which manifestations of uncertainty regarding personal outcomes remain in suspension for a limited time, but for the definite purpose of something expected" (p. 133). The family caregivers in my study did discuss feeling degrees of uncertainty related to the process of accessing supportive living (including the length of waiting), personal finances, and the declining health of their older person. However, unlike these conceptualizations of waiting, they did not define their experience of choice by these uncertainties, rather key to their experience was their ability to see the possibilities within their personal circumstances. Furthermore, unlike with the concept of waiting, caregivers did not focus on the temporal aspects of choice. They did acknowledge, however, that some of their choices, particularly in situations where family relationships were complex, would have long-term effects on them and those around them. Furthermore, they acknowledged that though the types of choices they faced might shift with changes in context, their overall experience of choice would likely remain the same.

The Experience of Choice and the Experience of Transition

The transition from home to facility-based living is one of the most significant transitions older persons face over the course of their life (Vrkljan, Montpetit, Naglie, Rapoport, & Mazer, 2019). Not only does this transition mark a major physical change in environment, it also often signifies a loss in ability or change in health status which necessitates an increased level of support (Cheek et al., 2006). Family caregivers in my study were caring for older relatives that because of a decline in health status and ability, most often related to the progression of dementia, required relocation from home to designated supportive living. Merla et al. (2018) conducted a scoping review of 37 articles on the family caregiver perspective on transition of older persons from home to alternative levels of care. They found that the transition period was one of crisis for family caregivers, that had significant impacts on the caregiver's personal and professional life, relationships with other family members, as well as feelings of powerlessness, and uncertainty. While there is overlap in the caregiver's experience of choice and experience of transition, particularly in its impacts on the caregiver's life and relationships, these similarities may be present as they are related to the nature of caregiving, in general. I would also argue that a congruence between these experiences is to be expected as the caregivers in my study were, in fact, also in a period of transition even though this transition was not an explicit focus of the study.

The Experience of Choice and Decision-Making

In Chapter 2, I delineated the concepts of choice, decision and decision-making. I also discussed the current emphasis on decision-making in healthcare, known as shared-decision-making, and the relationship between this concept and choice. The findings of this study have further emphasized that there is an important distinction between choice and decision-making. That is, decision-making is a process with a definite conclusion whereas choice is an ongoing experience that is personal and involves seeing the possibilities (or potential for choice) despite uncertain circumstances (Elwyn et al., 2012; Elwyn & Miron-Shatz, 2010). Though an exploration of shared decision-making in the context of family caregivers helping their older relatives awaiting placement in designated supportive living would be interesting and could potentially enhance the shared decision-making literature, it was not the focus of this inquiry and, in fact, would have resulted in very different findings. For instance, as decision-making is a well-defined process, an exploration focusing on this process likely would have employed an alternative qualitative approach like grounded theory. With the selection of a grounded-theory methodology, there would be changes in the questions guiding the study, data collection and analysis methods, potentially leading to significantly different research findings.

This study sought to go beyond knowing whether family caregivers experienced a presence or absence of choice in helping their older relative access supportive living, to achieve an understanding of their experience of choice, including the complex contextual factors that influenced this experience. The participants in this study recognized ever-present choice in their individual experiences and daily choices exercised as caregivers. Their experience of choice did not occur in isolation; rather, ongoing choices both positively and negatively influenced relationships around them. They acknowledged the importance of having choice or choices and the effect this had on their overall experience, with choice serving to strengthen their perception of having control or power in a relatively uncertain situation. Further, they described the internal nature of the experience of choice that involved deep introspection and shifting their mindset to see choices around them.

Understanding the Experience of Choice

Making Everyday Choices

One of the most surprising findings of this study was the family caregivers' ability to identify numerous everyday choices. They described making the choice to adjust their schedules to accommodate their caregiving roles, choosing to sacrifice time with family or friends to care give, advocating for the needs of their older relative by choosing to remain in contact with the community transition coordinator, as well as making the choice to engage in self-care. Though the choice of a supportive living facility for their older relative was important, the recognition of the daily choices (sometimes multiple choices in a day) was equally important. This finding stands in great contrast to the literature in which choice is conceptualized in a binary manner, i.e., the presence or absence of a choice (Lundh et al., 2000; Nolan et al., 1996; A. A. Ryan et al., 2011; A. A. Ryan & Scullion, 2000). For example, choice has been largely described as a single decision external to the family caregiver: the continuing care facility (Lundh et al., 2000; Nolan & Dellasega, 2000). In these studies, family caregivers saw choice in a simplistic manner, in that they felt they had little choice. This resulted in a negative perception of their experience of accessing continuing care services. Family caregivers in my study recognized choices were available to them on a daily basis. Though they did not always like the choices presented to them, they acknowledged that they nonetheless had choice.

Seeing Possibilities

One key finding was that, within their experiences of choice, family caregivers chose to see possibilities even in difficult circumstances. For some, this involved reflecting on how their personalities and outlook on life served to color their ability to see possibilities. Other caregivers, who tended towards a more pessimistic outlook and perhaps struggled to find choice, employed tools such as faith and self-awareness to enable them to see the possibilities within their own experience. Caregiving sometimes occurred in chaotic personal contexts where they had to juggle their employment, relationships with children and family members, the uncertainty of the waiting period to access supportive living, and the progressive decline of their older relative's health. Some had tenuous relationships with siblings, further strained by the choices they made as caregivers. However, some family caregivers deliberately chose to have a "gratitude attitude" and find the positive aspects of their roles.

The concept of cognitive reframing from the psychology literature is a process whereby an individual deliberately changes the way they see things and tries to find alternative ways of perceiving ideas, events, or situations (Throop, 2013). Most often, this involves shifting thoughts to see a more positive meaning (Jonas, 2005). Family caregivers described how they shifted their attitudes to be more positive, to see possibilities and subsequently find choice. Despite their challenging circumstances, they managed to find "freedom" in their caregiving experience and see the omnipresent choices that surrounded them. This deliberate choice or act of cognitive reframing could help explain the family caregivers' ability to positively view their experience of choice.

Some family caregivers in my study also reported recognizing characteristics of their personalities that did not necessarily serve them well in seeing the possibilities within their experience of choice. They described learning and experiencing personal growth throughout their experiences of choice. Personal growth is defined as "a component of psychological well-being that involves feelings of continued development, seeing oneself as growing and expanding, being open to new experiences, seeing improvement in self and behavior over time, and being able to change in ways that reflect more self-knowledge and effectiveness" (Leipold, Schacke, & Zank, 2008, p. 203). Other studies also report caregivers experiencing personal growth. In a study of family caregivers of persons with dementia in Singapore, Netto, Jenny, and Phillip (2009) describe caregivers becoming more patient, self-aware, and resilient through their experiences; these are important aspects of personal growth and satisfaction. Caregivers gained more insight into their strengths and weaknesses, which enabled them to better cope with their roles. Similarly, family caregivers in my study spoke about developing a greater self-awareness and ultimately undergoing personal growth, which allowed them to see possibilities. What is unique from other caregiving literature, however, were the seemingly deliberate actions of family caregivers to see possibilities; this allowed them to find choice in their experience of helping their older relative who was awaiting placement in supportive living.

Valuing the Ability to Choose

Another unique finding of this study was the value that family caregivers ascribed to having the ability to choose. They spoke about the importance of having the transition coordinators acknowledge or consider their personal wishes and needs, and feeling as if they were in control and had power in their caregiving roles. This was especially important for caregivers who recognized that their experience of choice did indeed occur in a relatively uncertain context with many factors well beyond their control. For instance, many family caregivers described how their experience occurred during unpredictable declines in their older relative's health; they had little control or power to prevent the progression of their relative's dementia. This control was further challenged by the uncertain nature of the wait for supportive living services, with it difficult for even healthcare staff to predict when the older person might receive a placement. Therefore, having a sense of control of power, no matter how large or small, was crucial to some family caregivers' experiences of choice.

The concepts of control and power as well as having the ability to choose are seldom discussed in the caregiving literature. In their study of caregivers of older persons with dementia, Szabo and Strang (1999) describe how caregivers who felt they had little control seemed unable to cope with the stresses associated with caregiving and felt burdened. While my study did not explicitly explore the concept of caregiver burden, it was remarkable to note that nearly all caregivers spoke positively about their experience of choice and providing care. This sense of power and control perhaps mitigated feelings of negativity and burden. Despite the concept of choice being linked with satisfaction and control (Iyengar & DeVoe, 2003), the caregivers in this study did not explicitly discuss feeling satisfied. This may, in part, be related to the choices that the caregivers faced and their acknowledgment that both the choices and the outcomes of these choices were not always desirable.

In previous research specifically examining choice, the concept has been conceptualized as a reflection of the chooser's values, beliefs, and intentions (Feldman et al., 2014). This is congruent with my findings, in that family caregivers viewed their choices as a reflection of their desires and needs. Even though they were making choices on behalf of their older relative, transition coordinators providing choice, or acknowledging caregivers' personal desires, made them feel "happy" and "fulfilled." Feelings of contentment with having a choice can also be traced to the psychological literature and self-determination theory, which postulates that having choice enhances feelings of autonomy, competence, and the perception of control (Botti & Iyengar, 2006; R. Ryan & Deci, 2000). Given the positive psychological implications of choice and the essential human desire to control one's own fate, it is not surprising that the family caregivers in this study emphasized and valued their experience of choice. For many, their roles as a caregiver occurred during a period of great unpredictability, and having choice, or even the perception of choice, may have lessened feelings of powerlessness.

The results of this study, specifically in relation to feelings of power and control may also be considered in the context of caregiving theories such as Modernization Theory. This theory postulates that the rise of an industrialized and modernized society has had significant impact on the value of older persons in society as the increased use of technology, urbanization, and creation of new types of employment has lowered the social value of these older persons (Aboderin, 2004; Heinz, Cone, Da Rosa, Bishop, & Finchum, 2017; Little, 2013). As the role and value of the older person has shifted with this modernization, so too has the role of the family caregiver. Aboderin (2004) suggests that changing professional and socioeconomic realities have led to significant changes in the ways that family caregivers are able to care for their older relatives, with caregivers often juggling multiple responsibilities including employment and parenting, thus often decreasing their abilities to care give. Certainly, there have been many benefits to this modernization including increased levels of education and income, improved health and quality of life (Durant & Christian, 2006). However, these benefits must be considered alongside the drawbacks of modernization as well as our societal value of power, control and choice. The caregivers in my study experienced the professional, personal and socioeconomic constraints outlined by Modernization Theory, which, as my findings have demonstrated, impacted their experience of choice. Caregivers described their desire for control and power in their experience, while acknowledging the role of their individual circumstances in attaining this control and power. Interestingly, despite the uncertainties they faced (which, in part, may be explained by Modernization Theory), they did endeavor to find these feelings of power and control and ultimately experience choice. Therefore, Modernization Theory may be helpful in understanding caregiving context, but less useful in understanding the nuances of the caregiving experience including the experience of choice.

Acknowledging the Impacts and Outcomes of Choice

The family caregivers in this study acknowledged that their choices impacted both themselves and those around them, and feelings about these impacts often colored their overall experience of choice. Some experienced negative ramifications in terms of relationships with siblings who disagreed with certain choices. In these instances, choices ultimately served to weaken already fragile family bonds. However, for others, caregiving choices served to foster feelings of cooperation and collaboration with siblings who banded together over shared interests concerning their older relative. The results of these choices were more positive, with caregivers feeling supported.

Several caregiving studies describe changes in family relationships that resulted from caregiving, but did not explore the impact of choices on relationships. Netto et al. (2009) spoke of tightening family bonds as family members shared in caring for the older relative. Peacock et al. (2009) also described a similar negotiation of family relationships, where the common interest of the older person's well-being was a unifying factor between family members that ultimately served to provide support. This tightening of family bonds is also confirmed by Edwards (2015), who describes how the family caregivers in her study found a support network within the immediate family and used this support to confer on choices relating to the older person. Similarly, several family caregivers in my study reported experiencing a tightening of bonds and accessing immediate family for support. For some caregivers, this tightening was related to the deliberate involvement of family members in choices that needed to be made about their older relative’s care. Even having family members involved in relatively minor choices, such as choice in furniture, was helpful and seen as a relief from the “burden” of solely shouldering the choices.

The negative outcomes associated with caregiving choices are less frequently described in the literature. Hwang et al. (2017) described the experience of adult children caring for a parent with dementia and found that, for some families, care decisions served to create tension between siblings, which eventually decreased social support and estrangement. This tension generally arose when expectations around the level of involvement of siblings in care or understanding of legal or financial requirements differed. This is similar to some family caregivers in my study, several of whom described that their choice to seek supportive living for their relative resulted in a serious breakdown in communication and a resulting withdrawal of support from family members. This breakdown in sibling or family relationships was most pronounced in instances where one sibling perhaps did not acknowledge the ongoing decline in their older relative’s health and did not believe that they required placement in a supportive living facility.

Limitations

I took multiple steps to ensure trustworthy data throughout the conceptualization and conduct of my study. My supervisors provided constant mentorship throughout data collection and analyses to ensure that my interpretations were meaningful and indeed reflective of participant experiences. I maintained an audit trail to document decisions made throughout the research process. I also provided rich descriptions of the context and a diverse range of participant quotes to demonstrate rationale for my final themes. However, the findings need to be cautiously interpreted given several key limitations.

First, despite efforts to recruit a diversity of caregivers, the sample was primarily composed of Caucasian females, around 60 years of age, who cared for a parent, and had financial resources to access support services outside the public realm. The financial means and privilege of the family caregivers in this study are likely not representative of the general caregiver population. Williams, Forbes, Mitchell, Essar, and Corbett (2003) report significant differences in the experiences of low income (income less than $25,000 per year) vs. other Canadian caregivers. Specifically, they found that low income caregivers spent significantly more time providing care, and reported feeling powerless, lonely, isolated, and more challenged than their higher income counterparts. Considering these findings in conjunction with those of my study, the experience of choice for low income caregivers might look much different. For instance, their likely inability to afford private caregiving services may impact their ability to make some of the everyday choices noted in my study, such as finding balance in their roles and engaging in self-care activities.

Though females represent the majority (54%) of caregivers (Sinha, 2013), as was reflected in my sample, the experience of choice of a sample of predominantly male caregivers may have resulted in different findings. The differences in caregiving hours, stresses experienced, and caregiver well-being are significant between males and females (Pinquart & Sörensen, 2006; Sharma, Chakrabarti, & Grover, 2016). In a meta-analysis of 229 studies, Pinquart and Sörensen (2006) found that females had higher levels of burden and depression, had a lower subjective well-being, provided more caregiving hours, and had lower levels of physical health than male caregivers. These gender differences in the experiences of caregivers noted in the literature suggest that the findings of my study may have differed if my sample had contained a larger number of male caregivers.

Notable differences are also evident in the experiences of caregivers caring for a spouse vs. a parent. Eleven of the caregivers in my study provided care to a parent, with only one caregiver providing care to a spouse. Oldenkamp et al. (2016) found significant differences in the burden experienced by caregivers as well as the time invested in caregiving activities between spousal caregivers and caregivers caring for a parent. Spousal caregivers experienced more burden related to their caregiving roles, and reported having more mental and physical health problems. As such, my findings around both the context and experience of choice may have differed if my study had a greater proportion of spousal caregivers.

The experience of choice may also differ for those of different ethnicities. Pinquart and Sörensen (2005) conducted a meta-analysis of 116 studies and found that ethnic minority caregivers (Asian, African, Indian) had stronger filial obligation beliefs, lower socioeconomic status, and less support than Caucasian caregivers. Not only may non-Caucasian caregivers experience greater burden than their Caucasian counterparts, they may also experience greater caregiving challenges related to language barriers and discrimination (Vickrey et al., 2007). Therefore, the experience of choice may look different for non-Caucasian caregivers as they may have less access to resources, such as private caregivers, and may be less able to easily access information in their native language to guide the decision-making process around choosing a supportive living facility for their older relative.

Considering the health status of the older relative is also important. With the exception of one family caregiver, all cared for an older person with dementia. Certainly, the caregiving experience and level of involvement in day-to-day activities would differ between caregivers caring for older persons with dementia vs. those without such cognitive impairment. The demands on caregivers of persons with dementia are clearly documented to exceed that of other caregivers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; World Health Organization, 2012). Caregivers of persons with dementia, on average, spend more time providing care, experience more distress, and are at higher risk for developing depression and exacerbating pre-existing illness (Canadian Institute of Health Information, 2012). Though the majority of family caregivers in this study described an experience of choice marked by positivity, self-reflection, and relationships, findings could differ for caregivers of older persons with other health conditions.

Summary

Although the concept of choice is ubiquitous in contemporary health policy, the study of the experience of choice is relatively absent in the scholarly literature beyond conceptual explorations. This study is the first to specifically explore the experience and understanding of choice from the perspectives of family caregivers as well as community transition coordinators (nurses) working in this area. Research to date has focused on the general experience of helping an older relative transition to continuing care, with a smaller commentary on the presence or absence of choice in this process (Lundh et al., 2000; Nolan et al., 1996; A. A. Ryan et al., 2011; A. A. Ryan & Scullion, 2000). None of these studies explored this experience in the Canadian context, nor examined the supportive living aspect of continuing care. This study is also the first to employ a practice-based qualitative approach—interpretive description—with the intent to develop clinically relevant findings that are directly applicable to nurses practicing as community transition coordinators.

This study provided insight into the experience of choice of family caregivers of older relatives awaiting placement in supportive living. Family caregivers viewed having choice as key to feeling that their needs and wishes were acknowledged, ultimately resulting in the perception of power and control. Their experience of choice was nuanced and went beyond merely the presence or absence of choice. Family caregivers saw choice as omnipresent and as a reflection of their personal mindset or outlook on life. They recognized that the choices they made did not occur in isolation, but rather often had significant impacts on the relationships with those around them.

Chapter 6: Conclusion

The focus of the present study was to explore the experience of choice from the perspectives of family caregivers of older persons awaiting placement in designated supportive living. In this chapter, I discuss potential contributions of the findings to understanding family caregiving, modernization theory in caregiving and relationship centered care for family caregivers. I also explore the implications for policy, practice, and research and provide both a personal reflection on the research process and concluding remarks.

Implications for Practice

Nurses have a central role in family caregivers' experience of choice. They are often the only healthcare provider in constant contact with family caregivers while awaiting placement of the older adult in designated supportive living. Caregivers described frequently reaching out, on sometimes a daily basis, to transition coordinators for information and advocating for the needs of their relative. As the key contact throughout this transition, nurses are uniquely positioned to positively impact family caregivers' experience of choice. At the end of Chapter 4, I presented the findings from my third research question: how can we help family caregivers experience choice? Family caregivers described their experience of choice as occurring in a context of uncertainty, with multiple factors contributing to this uncertainty. First was the family caregivers' general lack of knowledge about supportive living and its associated transition process, including the extensive waitlist. They were also largely unaware of how to gain credible knowledge about selecting an appropriate facility for their older relative, beyond anecdotes provided by family and friends who had already been through the experience, as well as how the waitlist for supportive living functioned. In reality, this waitlist was complex and influenced by the geographic location of available supportive living beds, capacity of local hospitals, and caregivers of older persons requiring urgent placement, amongst other factors.

Though transition coordinators are not necessarily in the position to directly influence the waitlist's complexity or the process to access supportive living services, they can mitigate this complexity through their interactions with family caregivers in a number of ways. First, transition coordinators can communicate with family caregivers on an ongoing basis. During these communications, it is important that they not only inquire about the health status of the older person but also the physical and emotional well-being of the caregiver. Transition coordinators should also be transparent about the process of accessing supportive living and the complexity associated with the waitlist. Though not all family caregivers may understand (or even wish to understand) this complexity, transparent communication can foster a trusting relationship between the caregiver and transition coordinator, which may be seen as a source of support by the caregiver in more difficult periods. Finally, transition coordinators should support family caregivers by providing information not only to guide the selection of a supportive living facility but also to support choice in the period when they are awaiting placement of their older relative. Transition coordinators in my study did identify gaps in publicly available information about supportive living. While this publicly available information is helpful, they should also recognize that some caregivers found their professional expertise or guidance equally as valuable.

The findings of this study suggest that choice should be seen as much more than an isolated event or selection between two or more alternatives. Rather, choice should be seen as a deeply personal, relational, daily experience in seeing possibilities despite uncertainty. Related to the concept of choice is the process of decision-making, which cannot occur without the presence of choice (Dietrich, 2010; Harris, 1998). Where choice is the feeling or experience, decision-making is a more discrete process that commences with introducing choice, followed by describing options and exploring alternatives (Elwyn et al., 2012).

Within healthcare, the discussion of choice can be mentioned alongside shared decision-making. Shared decision-making is a partnership between healthcare providers (including nurses) and patients or caregivers whereby there is bi-directional information sharing, a discussion of options, and final arrival at a decision (Truglio-Londrigan & Slyer, 2018). Extensive evidence in the healthcare literature exists regarding the benefits of shared decision-making for patients and caregivers, including increased satisfaction (Mandelblatt, Kreling, Figeuriedo, & Feng, 2006; Shabason, Mao, Frankel, & Vapiwala, 2014), empowerment (Hain & Sandy, 2013; Sacchi et al., 2015), and self-determination (Christine & Kaldjian, 2013; Landmark, Gulbrandsen, & Svennevig, 2015). The benefits of shared decision-making overlap with many elements of self-determination theory, which explains the motivation or desire for choice including perceived feelings of autonomy, competence, and self-determination (R. Ryan & Deci, 2000).

The core elements of shared decision-making are also reflected within the principles of relationship-centered care, a conceptualization that acknowledges the importance of relationships in healthcare and the role they play in the provision of quality care. In this conceptualization, relationship-centered care is founded on four principles which include: (i) an acknowledgement of the unique experiences and perspectives of clinicians and patients, (ii) a recognition of the importance of affect and emotions in healthcare relationships, (iii) understanding that health and related actions do not occur in isolation, and (iv) the maintenance of relationships between clinicians and patients has moral value (Beach & Inui, 2006). Specific to the context of caring for older persons with dementia, The Senses Framework builds upon relationship-centered care to acknowledge the six senses that must be experienced by patients, family caregivers and clinicians in order to have ‘good relationships’ which ultimately results in ‘good care’. These senses include: (i) security, (ii) continuity, (iii) belonging, (iv) purpose, (v) achievement, and (vi) significance (Nolan, Davies, Brown, Keady, & Nolan, 2004; Nolan, Grant, & Keady, 2003). While this framework provides and outline for achievement of the ‘senses’ for older persons, clinicians, and family caregivers, most relevant to this study are family caregivers. In this framework, ‘good care’ can be achieved by caregivers when they feel confident in the knowledge they possess and their abilities as a caregiver, are able to confide in trusted individuals, and are able to feel valued in their caregiving roles. My findings demonstrate that the experience of choice is unique to the individual caregiver and dependent on their personality, value of choice, and context. Despite the uniqueness of each caregiver’s circumstances, transition coordinators working in this area could employ both principles of shared decision-making and relationship-centered care by more overtly acknowledging this uniqueness (including personal circumstances, perspectives, and values), employing a strategy for communication, and building a trusting relationship to ultimately enhance feelings and the experience of choice (Truglio-Londrigan & Slyer, 2018). According to Beach and Inui (2006), employing such an approach would lead to benefits to the patient (or caregiver in this situation) including increased satisfaction, lower anxiety, greater engagement, while also having benefits for the clinician including protection against professional burnout and personal gratification.

Above all, transition coordinators should consider the experience of choice from the perspective of the family caregiver. They should recognize that the family caregiver’s experience of choice extends beyond choosing a supportive living facility for their older relative. It occurs daily and is influenced by the family caregiver's individual context, including their family relationships and commitments (employment, caring for children or grandchildren), as well as the uncertainty and declining health of their older relative. It involves acknowledging their unique wishes, preferences, and needs and that each choice impacts not only the caregiver but those around them. Therefore, a tailored approach to interactions with the family caregiver is necessary, one that is mindful of their circumstances and attitudes, information needs, and preferences for the frequency of communication.

Implications for Policy

The demand for continuing care services, including supportive living, is unlikely to diminish in the coming years, nor is the concept of choice in health policy likely to fall away. While I am not advocating for eliminating the concept of choice from policy, I caution its use without further explication. To truly support choice in any health service requires a policy that supports the individual patient's and caregiver's experience. Family caregivers in my study had to wait for an extended period before their older relative was placed in a supportive living facility. They were challenged to balance the demands of their own lives, including employment and family, while witnessing the progressive decline in their relative's health. One means of supporting caregivers in similar situations (and perhaps enhancing their experience of choice) is by mitigating the impacts of their stressful contexts through further implementation of national or provincial policies to increase the availability of publicly funded respite or homemaking services. Though some caregivers, including several in my study, have the financial resources to hire private support services, an increase in publicly funded services would protect vulnerable caregivers who are prone to distress and burnout. Furthermore, an increase in respite support may allow caregivers greater choice in their everyday lives, including if they wish to maintain employment, spend time with family and friends, and even vacation.

Other important considerations are policy implications for the health system or site that may positively impact the experience of choice of family caregivers. Both family caregivers and transition coordinators identified deficiencies in information available to guide the selection of a supportive living facility. This information plays a crucial role in empowering caregivers and enhancing feelings of self-determination, which can ultimately enhance their experience of choice (Hain & Sandy, 2013; Landmark et al., 2015). Resources that are currently available to the public are difficult to navigate or somewhat misleading because they are provided by private facility operators. Implementing a policy to create an information package for caregivers or a database of supportive living facilities could help to correct these deficiencies. Lastly, creating clinical practice guidelines for transition coordinators that outline a communication strategy (timelines, frequency) may improve caregivers' experience of choice.

Implications for Nursing Education

The findings of this study suggest that choice is an inherently complex concept, especially in the context of caregivers helping their older relatives access designated supportive living services. For the participants in this study, their experience of choice was deeply personal and unique to their personal contexts. Currently, from early in their undergraduate education, nurses are instructed to apply an ethical lens to their practice. As I discussed in Chapter 2, this is focus is often centered around the Canadian Nurses' Association's Code of Ethics, which touts patient autonomy as one of its core principles (Canadian Nurses Association, 2017). While it is certainly important for nurses to be informed of their role in respecting and enhancing patient autonomy through the promotion of informed decision-making, nurses should be educated to appreciate the complexities of the choices their patients may face. Specifically, nurses should be instructed to look beyond choice as an isolated event or mere choice between alternatives, but instead consider the factors that may influence this choice including personal disposition or worldview, relationships with others, and contextual factors. An appreciation or acknowledgement of these complexities may do nothing more than reassure the patient or caregiver or it may serve to enhance their therapeutic relationship.

As mentioned above, family caregivers in my study highlighted the importance of having access to credible information and frequent, transparent communication with the community transition coordinators in their experience of choice. In many undergraduate nursing curricula, the importance of effective communication is emphasized, with this effective communication being directly linked with increased patient (and caregiver) satisfaction and better patient outcomes (Boschma et al., 2010; Furnes, Kvaal, & Høye, 2018; Kennedy Sheldon, Barrett, & Ellington, 2006; McGilton, Robinson, Boscart, & Spanjevic, 2006). Caregivers in my study saw frequent and transparent communication as critical to their overall experience of choice, with this communication serving to ease their anxieties during an often prolonged waiting period. Kennedy Sheldon et al. (2006) conducted a study exploring difficult communication between nurses and patients from nurses' perspectives. They found that nurses reported feeling challenged by communication with patients and family who were experiencing stress related to illness, which commonly manifested as frustration and anger towards the nurse. Nurses acknowledged that these types of communication required advanced skills beyond what is typically offered at the undergraduate level.

Most caregivers in my study described feeling stress associated with the declining health of their older relative, their family relationships, and their juggling of multiple responsibilities.

While most did not find communicating with their community transition coordinator difficult, others reporting feeling angry and frustrated with this communication. The nurses in my study did acknowledge the challenges they felt in communicating with some family caregivers as they recognized the decline in health their older relative was experiencing and the lack of concrete information they had about the older person's progress on the waitlist. As Kennedy Sheldon et al. (2006) found, nurses reported finding communication difficult with patients or families where there was uncertainty or where they felt helplessness when patients experienced disease progression.

In considering the challenges that may face nurses working within this setting, there is a need to educate both students and experienced nurses on techniques to enhance difficult communications with patients and families. Not only can these enhanced communication skills impact the quality of patient care, but they can also improve nurse's self-efficacy (Kennedy Sheldon et al., 2006; McGilton et al., 2006). Furthermore, enhanced communication skills and an expanded knowledge of dealing with difficult conversations could serve to enhance patient and caregiver's experiences of choice.

Future Research

In Chapter 2, I discussed the dearth of literature on the family caregiver's experience of choice, particularly in the area of supportive living services. To my knowledge, this is the first Canadian (and global) study to examine the understanding of choice from the perspectives of family caregivers of an older person awaiting placement in supportive living. While this study is a first step towards understanding the experience of accessing supportive living services, more research is needed to further explore the experience from diverse perspectives.

One such perspective is that of the older person. At the outset of this inquiry, my intention was to explore the perspectives of older persons; however, I experienced challenges in recruiting older persons who were able to articulate their experience of choice due to advanced dementia. Given the health status of older persons that typically access supportive living services, it may be necessary to explore their understanding of and perspectives on choice in advance of them needing these services.

Future research should also aim to explore the experience of choice for different types of caregivers. For instance, the experience of choice may be drastically different for caregivers of a lower socioeconomic status (i.e., unable to access private support services) or from diverse cultural or spiritual backgrounds (i.e., with different traditional approaches to caregiving). Similarly, the experience may differ for caregivers of older relatives with multiple chronic conditions or who are not suffering from cognitive impairments such as dementia.

Furthermore, exploring the differences between choice and decision-making and how these terms are understood by consumers of health services would also be worthwhile. While the two terms are markedly different in the conceptual literature, participants in my study often used the terms choice, decision, and decision-making interchangeably. Not only does this present challenge for identifying potential solutions in nursing practice, it also creates confusion in the interpretation and creation of health policy. Conceptual clarification would enable a more uniform application across policy and practice, and perhaps help patients experience choice.

The concept of choice is present in many other health policies besides continuing care policy. How choice is experienced in different contexts, such as with caregivers of children, caregivers of persons with disabilities, and within acute care settings, would also be worth exploring. A comparison of these experiences may yield interesting insights into how we might best support caregivers in diverse contexts.

Personal Reflection on the Research Process

My interest in the concept of choice arose early in my doctoral program. As part of my coursework, I spent 150 hours at the Continuing Care Branch of Alberta Health. During my time at Alberta Health, staff were working to update the provincial continuing care strategy, a document that heavily featured the concept of choice. Over the course of this experience I wondered how the choice written into the policy manifested in reality for older persons and their family caregivers who were accessing continuing care services.

Later in 2016, I found myself in the position of family caregiver helping an older relative access these same services. In my case, the older relative was my 94-year-old grandfather, Dr. Owen Cornish, a proud and fiercely independent man, former healthcare provider, and a heroic World War II pilot. I recall this period in my life with both fondness and sorrow. It was a sort of changing of the guard, one where the younger generation assumed the role of guide and protector. Though I felt well qualified and proud to assist with the transition, I also wrestled with realizing that this was one step closer to the end for my grandfather.

Before my involvement in my grandfather’s transition in 2016, I had little to no knowledge of his health status and ability (or inability) to cope with activities of daily living. He was cognitively sharp, a voracious reader and consumer of knowledge. He still enjoyed his daily happy hours complete with a signature drink of gin and tonic. By all accounts, he seemed to be coping well; however, I came to learn that he was increasingly frail and unable to bathe or toilet without assistance. After involving a community transition coordinator, we determined that my grandfather’s needs exceeded what was possible within his home and he required a transition to a facility. I (along with other family members) was faced with the task of choosing the facilities we felt would best suit his needs. It was then that I realized I was in the midst of the choice discussed in the continuing care strategy that I had worked on the year before at Alberta Health.

My grandfather ended up in a lovely facility, one of our top choices. Though happy about this facility, it did not discount the emotions we felt during the transition: helplessness, uncertainty, and anxiety. Though my training as a nurse as a nurse provided some insight into the innerworkings of the healthcare system, I found it challenging to comprehend the options and the waitlists associated with accessing designated supportive living services. These emotions continued through to my grandfather's death on November 11, 2016, a mere 2 months after his arrival at the facility. It was my own experiences as a family caregiver to my grandfather that solidified my desire to explore the experiences of other family caregiver helping an older person transition from home to facility living. Particularly, I wanted to understand how choice factored into this experience.

Upon commencing data collection in November 2017, I reflected on both my experiences at Alberta Health as well as my role as a family caregiver. I wondered if it was possible to explore the experiences of others in a way that was mindful of how my own experiences might be imparted on those of my participants. While qualitative researchers recognize the impossibility of removing all personal biases from the research process, it was nonetheless important to consider how these past experiences could impact my study. I recognized that my experiences did color aspects of my study, including the interview questions and my interpretation of their experiences. Through the research process, I learned that acknowledging one's past personal experiences and their potential influences is crucial. This reflexive thinking is an approach that I will employ in future qualitative research.

From my past experiences, I anticipated the findings would take on a certain tone. That is, I thought family caregivers would describe a largely negative experience of choice, one that might mirror my own and that was focused on the singular choice in facility and the feelings they experienced. Furthermore, through my exploration of literature and theory prior to commencing data collection I expected that family caregivers would feel under-involved in decisions surrounding placement of their relative and describe their experience as being driven by the healthcare professionals. Though family caregivers certainly described challenges, they overwhelmingly spoke of how they saw choice in their everyday lives and that through this experience they chose to see the possibilities in their individual circumstances. They recognized that their choices impacted others, with some choices serving to either strengthen or weaken relationships. Though my past experience as a caregiver no doubt influenced my decision to pursue this topic, I was relieved to learn that I could keep an open mind and let my study be guided by the experiences of my caregivers.

I started this study with a rather simplistic definition of choice, but through this inquiry my conceptualization of choice has shifted. That is, I see that choice is never really as simple as deciding between alternatives. To think of choice in this manner would discount the monumental influence of the individual experiencing choice, their context, and the complexity of the system in which the choice is occurring. My new conceptualization of choice is one where choice is an everyday experience in seeing possibilities despite uncertain and relatively precarious situations. I learned that there are shades of choice in each caregiver’s experience, influenced by individual circumstances such as personal health, level of education, and financial resources. These circumstances, however, preclude choice from being experienced uniformly, with certain circumstances such as financial resources placing some caregivers at an advantage over others.

As a consumer of health services myself, the inclusion of the concept of choice is appealing; however, I am now acutely aware of how unique and vastly different these experiences may be.

Concluding Remarks

The purpose of this study was to gain an understanding of the experience of choice of family caregivers of older persons awaiting placement in designated supportive living. Through the qualitative analysis of the experiences and perspectives of my participants, this study generated important insights into their experience of choice. Specifically, this study served to illuminate the complexity of caregiver experiences and the uniqueness of their experience of choice. As the proportion of older persons within Canada continues to grow, family caregivers will increasingly play a crucial role, including that of advocates or decision-makers in the transition to facility living. Healthcare professionals, namely nurses, working with these family caregivers should, therefore, consider this complexity to create a tailored care approach that aims to help caregivers experience choice.

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APPENDIX A: FAMILY CAREGIVER INFORMATION & CONSENT

Family Caregiver Information & Consent

INFORMATION LETTER and CONSENT FORM

Study Title: Exploring the Experience of Choice: An Interpretive Description Examining the Experience of Older persons Accessing Supportive Living.

Research Investigator:	**Supervisors:**	
Ashley Hyde	Dr. Diane Kunyk	Dr. Wendy Duggleby
ECHA 5-380c	ECHA 5-319	ECHA 4-017A
University of Alberta	University of Alberta	University of Alberta
Edmonton, AB	Edmonton, AB	Edmonton, AB
Ashley.hyde@ualberta.ca	diane.kunyk@ualberta.ca	Wendy.duggleby@ualberta.ca
780-884-8505	780-492-9264	780-492-8660

Background
- The move from a private residence to a supportive living facility can be stressful for both older persons and their family caregivers. This move may be even more stressful if there is a lack of choice.
- You are being asked to be in this study because you are a family to an older persons (over the age of 65) who are in the process of moving to a supportive living facility.
- The results of this study will be used in support of my PhD thesis.

Purpose
- The purpose of this study is to gain an understanding of the experience of choice of older persons who are planning to move to a supportive living facility

Study Procedures
- Participating in this study will involve one interview which will take approximately 45 minutes to 1 hour of your time. This interview will take place at a location chosen by you.
- The purpose of the taped interview will be to learn about your experience caring for an older person accessing supportive-living services.

Benefits
- You are not expected to get any benefit from being in this research study
- We hope that the information we get from doing this study will help us better understand how to support people that need to move to supportive living.
- There are no costs associated with being involved in this research study.
- You will receive no compensation for being involved in this research study.

Risk
- Some people may experience distress while speaking about their experiences accessing supportive living. Should you experience distress, you can stop the interview and audio recording at any time. With your permission, I may notify the Community Transition Coordinator of your distress.

Voluntary Participation

- Participation in this study is completely voluntary.
- You are not obliged to answer any specific questions even if you are participating in the study.
- Even if you agree to be in the study you can change your mind and withdraw at any time
- If you withdraw, we will continue to use the data we have collected for analysis for up to three weeks after the interview has taken place, unless you request otherwise.

Confidentiality & Anonymity

- The research data that I collect will be confidential and only be reviewed by me and my doctoral supervisors.
- The data will be kept confidential at all times, except when professional codes of ethics or legislation require reporting
- The results of this research will be used to support my doctoral thesis and may be published in academic journals or presented at conferences.
- Your name or any identifying details will not be included in these publications or presentations.
- The data I collect will be kept in a secure place for a minimum of 5 years following completion of this research project. Any electronic data will be password protected.
- We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board.

Further Information

- If you have any further questions about this study, please do not hesitate to contact Ashley Hyde at 780-884-8505, Dr. Diane Kunyk at 780-492-9264 or Dr. Wendy Duggleby at 780-492-8660
- The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

CONSENT

Title of Study: Exploring the Experience of Choice: An Interpretive Description Examining the Experience of Older persons Accessing Supportive Living.

Principal Investigator:
Ashley Hyde, BScN, RN
Doctoral Candidate
Faculty of Nursing
University of Alberta

Phone Number(s): 780-884-8505

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without penalty?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records?	☐	☐

Who explained this study to you? ____

I agree to take part in this study:

Signature of Research Participant ____

(Printed Name) ____

Date:______________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ______________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Version: August 12, 2017

APPENDIX B: COMMUNITY TRANSITION COORDINATOR INFORMATION & CONSENT

INFORMATION LETTER and CONSENT FORM

Study Title: Exploring the Experience of Choice: An Interpretive Description Examining the Experience of Older persons Accessing Supportive Living.

Research Investigator:	**Supervisors:**	
Ashley Hyde	Dr. Diane Kunyk	Dr. Wendy Duggleby
ECHA 5-380c	ECHA 5-319	ECHA 4-017A
University of Alberta	University of Alberta	University of Alberta
Edmonton, AB	Edmonton, AB	Edmonton, AB
Ashley.hyde@ualberta.ca	diane.kunyk@ualberta.ca	Wendy.duggleby@ualberta.ca
780-884-8505	780-492-9264	780-492-8660

Background

- The move from a private residence to a supportive living facility can be stressful for both older persons and their family caregivers. This move may be even more stressful if there is a perceived lack of choice in the process.
- Currently, there is little research on the experience of moving to a supportive living facility.
- You are being asked to be in this study because you provide care to older persons (over the age of 65) who are in the process of moving to a supportive living facility.
- You are being given this information letter because your manager has identified you as someone who may be able to provide information about the experience of older persons accessing supportive living services.
- The results of this study will be used in support of my PhD thesis.

Purpose

- The purpose of this study is to gain an understanding of the experience of choice of older persons who are planning to move to a supportive living facility

Study Procedures

- Participating in this study will involve one interview which will take approximately 30 to 45 minutes of your time. This interview will take place at a location chosen by you.
- The purpose of the taped interview will be to learn about your experience caring for individuals accessing supportive living services.

Benefits

- You are not expected to get any benefit from being in this research study
- We hope that the information we get from doing this study will help us better understand how to support people that need to move to supportive living.
- There are no costs associated with being involved in this research study.
- You will receive no compensation for being involved in this research study

Risk

- There are no risks associated with being a part of this research study.

Voluntary Participation

- Participation in this study is completely voluntary.
- You are not obliged to answer any specific questions even if you are participating in the study.
- Even if you agree to be in the study you can change your mind and withdraw at any time
- If you withdraw, we will continue to use the data we have collected for analysis for up to three weeks after the interview has taken place, unless you request otherwise.

Confidentiality & Anonymity

- The research data that I collect will be confidential and only be reviewed by me and my doctoral supervisors.
- The data will be kept confidential at all times, except when professional codes of ethics or legislation require reporting
- The results of this research will be used to support my doctoral thesis and may be published in academic journals or presented at conferences.
- Your name or any identifying details will not be included in these publications or presentations.
- The data I collect will be kept in a secure place for a minimum of 5 years following completion of this research project. Any electronic data will be password protected.
- We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board.

Further Information

- If you have any further questions about this study, please do not hesitate to contact Ashley Hyde at 780-884-8505, Dr. Diane Kunyk at 780-492-9264 or Dr. Wendy Duggleby at 780-492-8660
- The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

____ ________________

Participant's Name (printed) and Signature Date

____ ________________

Name (printed) and Signature of Person Obtaining Consent Date

APPENDIX C: RECRUITMENT POSTER FOR COMMUNITY TRANSITION COORDINATORS

PARTICIPANTS NEEDED FOR RESEARCH IN SUPPORTIVE LIVING

We are looking for volunteers to take part in a study of
the experiences of older persons accessing supportive living services

You would be asked to speak about your job as a community transition coordinator and your role in helping older persons transition to supportive living.

Your participation would involve one or two interviews that would be 30 to 45 minutes long.

For more information about this study, or to volunteer for this study,
please contact:
Ashley Hyde, PhD Student, RN
Faculty of Nursing, University of Alberta
780-884-8505
Email: ac20@ualberta.ca

Call Ashley Hyde
780-884-8505
Or
Email:
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APPENDIX D: RECRUITMENT BROCHURE FOR FAMILY CAREGIVERS

This study has been reviewed and approved by the University of Alberta Research Ethics Board.

If you have concerns or questions about your rights as a participant or about how the research is conducted, please contact the University of Alberta Research Ethics Office by phone at: 780-492-2615

My faculty supervisors can be reached at:

- Dr. Diane Kunyk 780-492-9264
- Dr. Wendy Duggleby 780-492-8660

Whose choice is it anyway?

An interpretive description examining the experience of older adults accessing supportive living.

Research Investigator:
Ashley Hyde
Doctoral Student
Faculty of Nursing
University of Alberta

About this project

The move from home to a supportive living facility can be stressful for both older adults and their family caregivers. This move may be even more stressful if there is a lack of choice. I hope to explore the experience of older adults and family caregivers in accessing supportive living services in order to understand the move and how to make it better. Though we know a lot about other experiences, like moving to long-term care, little research has been done on supportive living.

About the researcher

I have been a registered nurse since 2008 and have worked in long-term care, the neonatal intensive care unit and in pediatrics at the Stollery Children's Hospital. Since I started my graduate studies I have been involved in research about older adults with chronic conditions (including diabetes), as well as research about family caregivers. My interest in the experience of older adults and family caregivers accessing supportive living developed after I helped my grandfather move to supportive living.

Participant's Role

I am inviting older adults and family caregivers to tell me about their experience of moving from home to a supportive living facility. I am interested in hearing about how much choice you have or have not had in moving to supportive living and what the ideal experience of accessing supportive living would look like for you.

I will conduct individual interviews. Interviews will follow a general guideline, but will be open-ended so that you may share your thoughts during the interview. Interviews will last 30-45 minutes in length, and I may ask you to do 2 or 3 interviews depending on your availability.

Our interview will take place in a mutually agreed upon quiet and comfortable location. With the permission of participants, I will use a small digital voice recorder to tape the interview.

Confidentiality

- All records of my tapes of individual interviews and conversations will be kept private and will only be available to my supervisors and supervisory committee.
- Records and basic demographic information of participants will be used only for research purposes and will be kept in secure storage.
- I will use pseudonyms in all publications, and no one will be identified by name in this study.
- If there are any questions that participants feel uncomfortable answering or that they would prefer not to answer they may skip over that section or stop the interview.
- Participation in this research is completely voluntary and participants can decide to withdraw from this study at any time.

Ashley Hyde,
PhD Student, RN

University of Alberta, Faculty of Nursing
ECHA
11405 87 Avenue
Edmonton, AB, T6G 1C9

780-884-8505
ac20@ualberta.ca

APPENDIX E: FAMILY CAREGIVER DEMOGRAPHIC FORM

Participant Name: ___________________________

Participant Alias: ___________________________

Date of Birth: _________________

Sex: _______

Marital Status: ___________

Health Diagnoses: ____

____

Highest level of education attained: _____________________

Are you a part of any community or religious organizations Y N

If yes, please specify ___________________________

How long has the older person you are caring for been on the waitlist for supportive living services? _________________

APPENDIX F: COMMUNITY TRANSITION COORDINATOR DEMOGRAPHIC FORM

Participant Name: ___________________________

Participant Alias: ____________________________

Current place of employment: ____________________

Job title: _________________________

Amount of time in current job: ____________________

APPENDIX G: INTERVIEW GUIDING QUESTIONS-FAMILY CAREGIVERS

1. Speaking broadly, what does choice mean to you? How do you define choice?

2. In your situation as a caregiver, what are the everyday choices that you make?

3. What kinds of adjustments or changes have you made to your life in order to care for your older relative?

4. What kinds of sacrifices have you made?

5. Can you tell me why the older person you care for is accessing supportive living services?

6. Tell me what the ideal experience of accessing supportive living would look like for you.

7. How much of a choice do you think you have in selecting a supportive living facility?

8. Tell me about what your experience in accessing supportive living has been thus far.

9. How have you and your older relative experienced or not experienced choice in accessing supportive living?

10. Are you comfortable with the decisions that you've made as a caregiver? Why or why not?

11. How does making these choices make you feel?

12. What choices have you made to get to this point?

13. What factors influence your feelings of choice?

14. How does this choice compare to other choices that you’ve made? What’s different about it? What makes this choice so big?

15. What would make your experience better? Or worse?

16. Have healthcare providers played a part in your selection of a facility? Have they supported your choices? How were the various options presented to you?

17. What would the ideal role for healthcare providers to help those accessing supportive living services?

18. Is there anything else you’d like to share about your experience of choice?

APPENDIX H: INTERVIEW GUIDING QUESTIONS-COMMUNITY TRANSITION COORDINATORS

1. Tell me about your current job role and your role in helping individuals transition to supportive living.

2. In your view, how does choice factor in to this transition? Can you describe the points at which individuals are able to express their choices?

3. In the ideal world, what would this transition look like?

4. What is the role that family members typically play in this transition?

5. What do you believe are common misconceptions about the transition to supportive living?

6. What challenges have you encountered in helping individuals transition to supportive living?