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Goals of Family Caregivers of Persons with Dementia Across the Caregiving Career

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Abstract

Understanding goals of family caregivers of persons with dementia is critical to provide effective education and support. However, there is little understanding about family caregivers’ goals. This study investigated goals set by family caregivers prior to an education and training program and whether their goals varied across the caregiving career. Phases of the caregiving career were measured by relationship identity; the extent to which participants viewed their relationship in terms of familial and caregiver roles. Conventional content analysis on goals of 30 family caregivers yielded five categories which varied by relationship identity. Enhancing relationships reflected goals for the familial role primarily. Managing caregiver’s emotions, developing skills, and learning about dementia reflected goals for the caregiver role primarily. Supporting outlook of a relative with dementia reflected importance across the caregiving career. Findings advance a better understanding of family caregivers’ goals across the caregiving career to provide targeted education and support.

Keywords

Family caregivers, goals, dementia, caregiver identity theory, content analysis, caregiving career, education and support
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The best gifts I have received in my life are my roots and my wings.

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Chapter 1

1 Introduction: An Overview

Approximately 47.5 million people worldwide are diagnosed with dementia and 7.7 million new cases are diagnosed each year (World Health Organization [WHO], 2016). By 2038, it is anticipated that 1.13 million people in Canada will have dementia (WHO, 2016). Many want to stay at home for as long as possible (Steiner, Pierce & Salvador, 2015; Thompson & Roger, 2013). By 2038, 62% of people 65 years and older with dementia will be living in their homes, which substantially increases the need for community care services and support for persons with dementia and their family caregivers (Alzheimer Society Canada, 2010). It is estimated that family caregivers of persons with dementia, typically spouses or adult children, provided approximately 231 million hours of care in 2008 (Alzheimer Society Canada, 2010). By 2038, the total number of hours of informal family-led care will reach 756 million hours (Alzheimer Society Canada, 2015). Family members of all socioeconomic levels, in developed and developing countries, provide the majority of care to persons with dementia (Alzheimer Society Canada, 2015; Gitlin & Wolff, 2011; National Alliance of Caregiving, 2015). Family caregivers are faced with a dynamic set of challenges as the care tasks increase in intensity and frequency (Thompson & Roger, 2013). Competing responsibilities of family caregivers and the changing care needs of persons with dementia result in psychological, social, and physical distress for family caregivers (Austrom, Yueh-Feng, Perkins, Boustani, Callahan & Hendrie, 2014; Thompson & Roger, 2013).

Individuals attempt to seek balance in their lives by creating goals to resolve unmet needs (Burke, 1991). An unmet need is the recognition of a need that has not been satisfied by current supports and services (Bangerter, Griffin, Zarit, & Havyer, 2017). The goals and needs of family caregivers of persons with dementia are under acknowledged even though family caregivers provide most of the care for persons with dementia (Bangerter et al., 2017; Black, Johnston, Rabins, Morrison, Lyketsos & Samus, 2013; Ducharme, Beaudet, Legault, Kergoat, Levesque & Caron, 2009; Steiner et al.,
2015; Marziali, McCleary & Streiner, 2010). Needs assessments, surveys, and interviews are types of methods used to gain information on unmet needs. However, the methods used do typically focus on persons with dementia or the methods do not integrate the perspective of family caregivers (Bangerter et al., 2017; Gaugler, Anderson, Leach, Smith, Schmitt, & Mendiondo, 2004). Studies that do address the unmet needs include key priorities for family caregivers such as education and assistance with in-home care (Gaugler et al., 2004). There has yet to be a gold-standard developed to assess the needs and goals of family caregivers without researcher or clinician influences (Bangerter et al., 2017). Inadequate support to address unmet needs can result in the deteriorating health of family caregivers which, in turn, affects the care provided to relatives with dementia and can lead to early relocation to long-term care homes (Ducharme et al., 2009; Marziali et al., 2010).

Education programs and support services target the needs of family caregivers and their relatives with dementia. Education programs target education about dementia, stress reduction, skill building and self-care activities (Feinberg, 2017) knowledge about dementia and the progression of the syndrome. Support services provide emotional support for family caregivers of persons with dementia (Feinberg, 2017). Education programs and support services that are flexible, offered in a timely manner, and specific to the needs of caregivers are more effective and person-centered compared to standardized programs (Ducharme et al., 2009; Gaugler et al., 2004; Vernooij-Dassen, Joling, van Hout, & Mittelman, 2010). Many health care services focus primarily on persons with dementia (Marziali et al., 2010) or use methods that focus primarily on the unmet needs of persons with dementia (Bangerter et al., 2017; Black et al., 2013; Gaugler & Teaster, 2006; Marziali et al., 2010). The needs of family caregivers of persons with dementia are often overlooked (Reinhard, Fox-Grage & Feinberg, 2016). However, goals and unmet needs of family caregivers of persons with dementia and the varying nature of their needs are not always limited to their relative with dementia (Austrom et al., 2014; Bangerter et al., 2017). A better understanding of goals and unmet needs of family caregivers of persons with dementia is essential when developing
education programs and support services because family caregivers are the cornerstone of the health care system. Ineffective support and coping skills among caregivers can lead to an increased cost to the health care system (Ducharme et al., 2009) because of more frequent doctors’ visits, more outpatient tests, and higher use of medications (Alzheimer’s Association, 2016). Effective coping by family caregivers results in lowered health care expenditures because they are physically and mentally healthier and can take better care of themselves and their relatives with dementia (Aminzadeh, Byszewski, Dalziel, Wilson & Papahariss-Wright, 2005; Black et al., 2013; Ducharme et al., 2009; Marziali et al., 2010).

1.1 Dementia

Dementia is a syndrome that impairs cognitive functioning, social behaviour, emotional awareness, and the ability to complete everyday activities (Mendez & Cummings, 2003; WHO, 2016). Deterioration in these functions is not part of what is observed in normal aging. Dementia is categorized as a major neurocognitive disorder (NCD) in the Diagnostic and Statistical Manual of Mental Disorders (DSM), however, the term dementia is accepted widely (Diagnostic Statistic Manual [DSM-V], 2013). Complex attention, executive function, learning and memory, language, perceptual-motor function, and social cognition are domains compromised with dementia (DSM-V, 2013). The word dementia encompasses a range of subtypes including Alzheimer’s disease, vascular diseases (i.e., commonly known as vascular cognitive impairment), dementia with Lewy Bodies, mixed dementia, and frontotemporal dementia, among others. Types of dementia also can be caused by a variety of diseases or injuries including Parkinson’s disease dementia, Creutzfeldt-Jakob disease, normal pressure hydrocephalus, Huntington’s disease, and Wernicke-Korsakoff syndrome, among others (Alzheimer’s Association, 2016; WHO, 2016). Dementia is one of the major causes of disability and dependency among older adults and as a result negatively impacts their family caregivers, the universal health care system, and society (Mendez & Cummings, 2003; WHO, 2016).
1.2 Caring for Persons with Dementia

Increasing care responsibilities for family caregivers of persons with dementia is the result of the rising percentage of the population with dementia who live at home, many of whom have multiple co-existing complex medical conditions (Gitlin & Wolff, 2011). Family members provide care for relatives with dementia for an average of eight to ten years after diagnosis, thus creating what is referred to as a “caregiving career” (Aneshensel, Byszewski, Dalziel, Wilson, & Papahariss-Wright, 1995; Farran, Loukissa, Perraud, & Paun, 2002; Keady & Nolan, 2003). The caregiving career begins when family caregivers notice changes in their relative with dementia (Keady & Nolan, 2003), although they very rarely view themselves as “caregivers” until later in the caregiving career (Montgomery & Kosloski, 2003). The caregiving career ends when family caregivers relinquish caregiving duties or bereavement (Gaugler & Teaster, 2006).

Family caregivers provide care in a variety of settings including the family home, assisted living, and long-term care homes (WHO, 2012). Family caregivers help their relatives with activities of daily living, monitor changes of functioning, and provide emotional support, among other tasks (Feinberg, 2017; Montgomery & Kosloski, 2013; Reinhard et al., 2016). Caring for a person with dementia can be overwhelming for family caregivers because it includes physical and emotional demands; these pressures lead to increased caregiver needs for support from health, social, financial, and legal systems (Thompson & Roger, 2013; WHO, 2016).

Negative health outcomes of caregiving include stress, poorer physical and mental health, and even cognitive decline for the family caregiver (Brodaty & Donkin, 2009; Sorensen & Conwell, 2011; Vitaliano, Zhang, Young, Caswell, Scanlan, & Echeverria, 2008; Whitlatch et al., 2001). Family caregivers experience higher levels of depression, anger, and anxiety compared to non-caregivers (Whitlatch et al., 2001). Spousal caregivers of relatives with dementia are almost five times more likely to experience psychiatric morbidity compared to non-caregiving spouses (Liu & Gallagher-Thompson, 2009; Schinkothe, Altmann & Wilz, 2014; Sorensen, Duberstein, Gill & Pinquart 2006; Whitlatch et al., 2001). Higher levels of stress hormones for family
caregivers may lead to the deterioration of health and reduced immune function (Alzheimer’s Association, 2016). Additionally, they are more likely to have cardiovascular disease and have poorer self-rated health compared to non-caregiving counterparts (Merrilees, 2016). Family caregivers of persons with dementia are twice as likely to encounter financial, emotional, and physical struggles compared to non-caregivers (Alzheimer’s Association, 2016).

Family caregivers who experience unmet needs as a result of providing care to persons with dementia are more likely to experience negative caregiving outcomes such as depressive symptoms (Black et al., 2013). Unmet needs are the needs of family caregivers that have not been satisfied. Approximately 30% of family caregivers of persons with dementia meet the diagnostic criteria for a depressive disorder compared to 5-7% of non-caregivers (Alzheimer’s Association, 2016; Covinsky et al., 2003; Cuijpers, 2005). Predictors of depression among family caregivers of persons with dementia include aggression, egocentrism, and addictive behaviours exhibited by relatives with dementia (Diehl-Schmid et al., 2013). Furthermore, caregiver depression can be more severe when witnessing a decline in health status or anticipating the death of a relative with dementia (Glozman, 2004). Family caregivers who experience higher levels of depression are more likely to experience caregiver burden (Merrilees, 2016).

Family caregivers of persons with dementia are a vulnerable group who experience higher levels of burden when compared to family caregivers of other chronic illnesses (Black et al., 2013; WHO, 2012). High levels of burden are associated with caring for persons with dementia who have complex, ever-changing needs (Adelman et al., 2014; Alzheimer’s Association, 2016; Bailes, Kelly, & Parker, 2016; Sutcliffe, Giebel, Jolley & Challis, 2015; Svendsboe et al., 2016). Those who are at risk of caregiver burden tend to be younger in age, are women, and reside with their relatives with dementia (Adelman et al., 2014; Diehl-Schmid et al., 2013; Montgomery & Kosloski, 2013; van der Lee et al., 2017). Moreover, lower levels of education also contribute to greater levels of burden (Adelman et al., 2014) because those who have higher levels of education can access resources that help enhance their coping skills and knowledge about accessing
appropriate programs and services (van der Lee et al., 2017). Common predictors of caregiver burden include the cognitive decline, dependency with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and responsive behaviours exhibited by persons with dementia, and the nature of the relationship with their relative with dementia (Pinquart & Sorensen, 2011; Black & Almeida, 2004).

Negative caregiver health outcomes are often associated with family caregiving because of long care hours, mentally and physically draining care tasks, and the responsibility to balance careers and family with caregiving (Brodaty & Arasaratnam, 2012). However, many family caregivers choose to provide care to persons with dementia at home even when there are negative health implications for them (Pearlin, Mullan, Semple & Skaff, 1990). Some family caregivers choose to provide care to persons with dementia because of factors such as feelings of love and reciprocity, spiritual fulfillment, sense of duty, guilt, or social pressures (Brodaty & Donkin, 2009). These positive aspects of caregiving act as a buffer to decrease negative outcomes of caregiving (Tarlow, Wisniewski, Belle, Rubert, Ory & Gallagher-Thompson, 2004).

Though family caregiving can be rewarding and enriching (Reinhard et al., 2016), family caregivers often feel ill-prepared to complete caregiving tasks for relatives with dementia because they may be untrained and unsure of ways to provide the most appropriate care or they may feel what they are doing exceeds their expectations for their relationship (Adelman et al., 2014; Bailes, Kelly & Parker, 2016; Savundranayagam & Montgomery, 2010). The caregiving context is the environment in which family caregivers manage care needs of persons with dementia (Montgomery & Kosloski, 2013). The caregiving context involves the type of needs required to provide care, the resources available, and other responsibilities or obligations of the family caregiver (Montgomery & Kosloski, 2013) and can contribute to negative health outcomes of family caregivers (Sorensen & Conwell, 2011). Family caregivers have their own negative health outcomes as a result of providing care to persons with dementia. Therefore, it is crucial to look at family caregivers in terms of clients instead of solely looking at them as resources (Bangerter et al., 2017).
The Stress Process Model (Pearlin et al., 1990) provides a basis for understanding the effects of caregiving on the relationship between a family caregiver and their relative with dementia and the negative health implications for family caregivers (Pearlin et al., 1990). As the person with dementia becomes more dependent, the relationship with their family caregiver can become more challenging (Pearlin et al., 1990). Primary and secondary stressors lead to negative caregiving outcomes experienced by family caregivers of persons with dementia (Pearlin et al., 1990; Whitlatch, Schur, Noelker, Ejaz & Looman, 2001).

**Primary Stressors.** Primary stressors include the needs or demands of the person with dementia and the shifting of the relationship (Pearlin et al., 1990). Activities and time commitments directly related to providing assistance to persons with dementia contribute to primary stressors (Pearlin & Aneshensel, 1994). Time spent managing responsive behaviours, cognitive functioning, dependency of ADLs and IADLs, psychological symptoms, and lack of reciprocity in the relationship are primary stressors of family caregivers (Pearlin et al., 1990; Schulz & Martire, 2004; Sorensen & Conwell, 2011; WHO, 2012). Responsive behaviours include agitation, wandering, sexual behaviors, repetitive questions, or aggression exhibited by persons with dementia (Black & Almeida, 2004). Primary stressors are likely to increase over the course of the caregiving career because they are related to the demands and needs required to assist with dementia-related impairments (Pearlin et al, 1990).

Over 90% of persons with dementia exhibit behavioural and psychological symptoms, which can be distressing for family caregivers (Feast, Moniz-Cook, Stoner, Charlesworth & Orrell, 2016). Stress in family caregivers is more likely to develop when persons with dementia are resistive to care (Pearlin et al., 1990). Family caregivers are more likely to experience depression and caregiver burden when relatives with dementia engage in responsive behaviours or exhibit greater cognitive impairments (Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Whitlatch et al., 2001). Moreover, assisting with ADLs and IADLs can be indicators of primary stressors. On average, family caregivers of relatives with dementia assist with three or more ADLs and five IADLs, such
as grooming, toileting, or feeding (Alzheimer’s Association, 2016). Fifty-three percent of persons with dementia receive help from family caregivers with ADLs or household tasks compared to 11% of older adults without dementia (Alzheimer’s Association, 2016). Dementia impairs normal functioning which leads to an increase in dependency. The progressive nature of dementia can challenge the reciprocity within family relationships and lead to a decrease in supportive activities in the caregiving dyad (Pearlin et al., 1990).

Secondary stressors. Secondary stressors are the result of stressors outside of the direct caregiving tasks (Pearlin & Aneshensel, 1994; Schulz & Martire, 2004). Secondary stressors include conflicts within the family and conflicts between work and caregiving duties (Austrom et al., 2014). Secondary stressors can negatively impact family caregivers, yet are rarely addressed or reported in the literature (Austrom et al., 2014). Secondary stressors can include financial problems caused by reduced household income or increase in expenses due to costs related to caregiving for persons with dementia (Gies, Pierce, Steiner, van der Bijl & Salvador, 2013; Pearlin et al., 1990). Family caregivers miss or leave work when caregiving-related duties are intensified in quantity and quality. By 2038, Canadian family caregivers of persons with dementia will add 56 billion dollars to the health care expenditure because of lost time at work (Alzheimer Society Canada, 2010). Work life and social activities can be compromised due to added responsibilities of family caregiving (Blom, Zarit, Zwaan, Cuijpers & Pot, 2015; Gallagher et al., 2011; Glozman, 2004; Schinkothe et al., 2015). Family caregivers of persons with dementia are at risk of social isolation (Tanner et al., 2015; Zarit & Femia, 2008) because they may be less engaged in their social networks as caregiving responsibilities increase or as the dementia-related impairments worsen with syndrome progression (Pearlin & Aneshensel, 1994).

1.3 Caregiver Burden

Caregiver burden includes the negative psychosocial, economic, or physical effects of providing care to a family member with dementia (Gaugler, Mittelman, Hepburn, & Newcomer, 2010). Caregiver burden is multi-dimensional including
elements called objective burden, stress burden, and relationship burden (Montgomery, Borgatta & Borgatta, 2000; Savundranayagam, Montgomery, Kosloski & Little, 2011). Objective burden refers to the extent to which a person feels that his/her caregiving responsibilities infringe on his/her life, especially in terms of time (Savundranayagam & Montgomery, 2010). Common contributors to objective burden include care tasks that infringe on caregivers’ time including driving to appointments or preparing meals. These tasks contribute to greater levels of burden because the care tasks exert a large impact, physically or mentally, on the caregivers’ personal lives (Bailes, Kelly, & Parker, 2016). Additional care tasks, outside of the traditional familial role, result in family caregivers having less time for themselves or for other aspects of their lives (Savundranayagam et al., 2011). Family caregivers can feel trapped in the caregiving role due to care responsibilities that interfere with their privacy or other aspects of their lives (Savundranayagam et al., 2011). Family caregivers still feel the pressures of caregiving even with more respite care or hired professional care (Bailes, Kelly & Parker, 2016) because burden is multidimensional. Caregivers who receive respite care, which can address objective burden by freeing up the caregivers’ time, can also experience other forms of burden. For example, stress burden encompasses the emotional impact related to family caregiving, such as worry, anxiety, depression, and feelings of hopelessness (Bailes et al., 2016; Savundranayagam & Montgomery, 2010). Responsive behaviours (e.g., aggression) exhibited by the persons with dementia can contribute to stress burden and is linked to spousal caregivers’ self-rated health status (Savundranayagam et al., 2011). Family caregivers also may experience relationship burden. Relationship burden involves a strain in the relationship between family caregivers and their relatives with dementia (Montgomery, Borgatta & Borgatta, 2000). Relationship burden is the extent to which family caregivers perceive their relative to be demanding, manipulative, or making unreasonable requests (Bailes et al., 2016; Savundranayagam et al., 2011). Higher levels of relationship burden were linked with intention to relocate relatives to more formal care by both adult-child and spousal caregivers (Savundranayagam et al., 2011).
Family caregivers can experience one type of burden or combinations of all three types (Savundranayagam, Montgomery & Kosloski, 2010). Often, the lack of awareness and understanding of dementia by the general public can contribute to the stigmatization of the syndrome and can create barriers for accessing support (Alzheimer Society Canada, 2015; WHO, 2016). Support services provided to family caregivers of persons with dementia may be underutilized because of a lack of perceived need of the family caregiver, a mismatch between services and caregivers’ needs, or barriers created by providers (i.e., not providing culturally competent services; Montgomery & Kosloski, 2013). It is important to gather information on the types of unmet needs of family caregivers because it may influence the type(s) of burden family caregivers experience. Better understanding of predictors of burden can lead to targeted education programs and support services to address the discrepancy between the perceptions of the caregiving activities and the norms of the relationship or the change in how the family caregiver views the relationship (Montgomery & Kosloski, 2013).

1.4 Theoretical Framework: The Caregiving Career as Reflected in the Caregiver Identity Theory

Caregiving for persons with dementia is often described as a career because it is rarely a one-time event and can last approximately eight to ten years (Keady & Nolan, 2003; Aneshensel et al., 1995). Persons with dementia typically live eight to ten years (Alzheimer Society Canada, 2015). The caregiving career can include a variety of transitions such as entry to the role, changes within the relationships, or planning for long-term care (Ducharme et al., 2009; Gaugler & Teaster, 2006). Transitions can also occur at different time points in the caregiving career, further displaying the dynamic nature of the caregiving career (Gaugler & Teaster, 2006; Montgomery & Kosloski, 2013). The caregiving career for family members varies based on the level of cognitive impairment of the person with dementia, the amount of support from family and friends, the financial situation, and the availability of and access to services (Aneshensel et al., 1995; Pearlin & Aneshensel, 1994). Taking on the caregiving role is not always a
natural transition (Savundranayagam & Montgomery, 2010), nor are the caregiving experiences universal (Montgomery & Kosloski, 2013). Family members do not always remember when they initially viewed themselves as caregivers; however, they do remember when assistance with care tasks began (Aneshensel et al., 1995; Pearlin & Aneshensel, 1994). The length of time a relative with dementia remains at home depends largely on how the family caregiver manages their distress throughout the caregiving career (Ducharme, Lévesque, Lachance, Kergoat, & Coulombe, 2011). Different roles and responsibilities take place during the caregiving career which, in turn, contributes to predictors of stress (Aneshensel et al., 1995; Savundranayagam & Montgomery, 2010).

**Changing role identities across the caregiving career.** Caregiver identity theory is grounded in Burke and colleagues’ (1999) Identity Theory which explains the internal need for an individual to seek balance between the role of how he/she views him/herself in the relationship (i.e., child, spouse, etc.) and the behaviours in which he/she engages to fit the role. Individuals respond according to a reference point that is expected based on societal, cultural, and family norms. The reference point guides and shapes individuals’ expectations and behaviours, and forms a relationship identity. The relationship identity is a role a person plays in accordance with the expectations of him/herself due to the societal, cultural, and family structures. The caregiver role can merge with the family role identities (Montgomery & Kosloski, 2013).

According to Montgomery and Kosloski (2013), caregivers shift through five phases of caregiving throughout the caregiving career. In the initial phase (i.e., Phase I) of the caregiving career, family caregivers assist with tasks in which they may not have helped with in the past. For example, a daughter may begin to help her father organize his finances or may drive her father to appointments. Family caregivers enter Phase II when they acknowledge tasks are outside the initial familial relationship. Family caregivers still identify with the initial familial role; however, they begin to recognize the shift in responsibilities. During Phase III, the level of care tasks begins to increase and the care responsibilities go beyond what is expected in the initial familial role. Distress
may occur when family caregivers struggle to accept the new care responsibilities that are incongruent with the initial familial role (Montgomery & Kosloski, 2013). For example, a daughter may begin to help her father with grooming tasks which is outside of the traditional relationship identity involved in the father-daughter relationship. Family caregivers enter Phase IV when care responsibilities increase in intensity and quantity. The initial thoughts of alternative living arrangements may take place before Phase V when the family caregivers are no longer responsible for primary care tasks for the person with dementia. This may be the result of moving the person with dementia to a long-term care home or to another family member’s home. Moving a person with dementia out of the family home to a long-term care home does not equate with an end of caregiving career. In phase V, caregiving tasks are significantly reduced and the caregiver identity theory states that the caregiver reclaims more of the initial familial role (Montgomery & Kosloski, 2000). The phases of the caregiving career do not always occur in a unidirectional manner. A caregiver can shift back and forth between phases due to the variation in trajectories of caregiving careers. Caregiver burden emerges when there is a discrepancy between the perceptions in care activities provided to persons with dementia and to the norms of their traditional familial role (Montgomery & Kosloski, 2013).

Caregiver identity theory accounts for differences within and across the caregiving career (Savundranayagam & Montgomery, 2013) and offers insights into the role of unmet needs of caregivers. Caregiver identity theory has three components based on existing research findings. Firstly, the caregiver role is acquired by social norms as discussed below. Secondly, family caregiving is a dynamic process that changes as the syndrome progresses. The dynamic nature of caregiving is characterized by the meanings that caregivers attach to their caregiving responsibilities or tasks (Montgomery & Kosloski, 2013; Staff & Pearlin, 1992). The meanings a person attaches to caregiving are dependent on an array of factors such as personal histories or normative pressures to assume such roles (Montgomery & Kosloski, 2013). For example, an adult-child may feel responsibility to care for his/her aging parent, or a wife may feel
the need to care for her husband. Thirdly, individuals have a strong desire to seek balance in their behaviours and in their relationship identity. Burden is minimized when balance between behaviours and relationship identity (and the associated norms and expectations for that relationship identity) is achieved and maintained (Savundranayagam & Montgomery, 2010). Behaviours exhibited by family caregivers fluctuate to maintain the health of the family unit and to satisfy the caregiving needs (Montgomery & Kosloski, 2013). As dementia-related symptoms become more pronounced, family caregivers take on more care tasks that may be incongruent with the initial familial role, resulting in an identity shift from family member to caregiver (Savundranayagam & Montgomery, 2010). The incongruence between the relationship identity and the attached meaning of the care responsibilities contributes to caregiver burden (Savundranayagam & Montgomery, 2010).

Family caregivers may experience different unmet needs over the course of the caregiving career because the needs of the dyad are changing (Ducharme et al., 2009). Family caregivers experience a great amount of distress when the caregiving tasks do not fall within the boundaries of their relationship identity and when the caregiving context does not support the family caregiver (Montgomery & Kosloski, 2013). In the early phases, family caregivers may express needs based on education, diagnosis process, or progression of the syndrome. Whereas in later phases of the caregiving career, family caregivers may focus on their personal needs due to increase in burden, may need more support or hired help with care tasks, or may need information on long-term care options. The focus on personal needs further stresses the importance of understanding the unmet needs of family caregivers at the different phases of the caregiving career. A better understanding of the goals or unmet needs of family caregivers across the caregiving career may increase effectiveness of support services (Ducharme et al., 2009), and thus, decrease caregiver burden and distress. In addition, the goals and unmet needs across the caregiving career may be better understood, and therefore, education programs and support services could be provided in a specific and timely manner (Bangerter et al., 2017; Ducharme et al., 2009).
1.5 Rationale of the Study

Negative health outcomes of family caregiving, such as caregiver burden, often are targeted objectives of education programs and support services. Yet, these services yield a mild to moderate positive impact on the health and well-being of family caregivers of persons with dementia (Bass et al., 2013; Brodaty & Arasaratnam, 2012; Bourgeois, Schulz & Burgios, 1996; Mittelman et al., 2006; Pinquart & Sorensen, 2006; Schulz et al. 2002; Sorensen et al., 2002; WHO, 2012; Zarit & Femia, 2008). Education programs and support services aim to address care needs of persons with dementia (Gaugler & Teaster, 2006), but have been created with limited understanding of caregivers’ needs across the caregiving career from the perspective of family caregivers (Bangerter et al., 2017; Black et al., 2013; Steiner et al., 2016). One in three caregivers has reported doctors, nurses, or social workers have asked family caregivers what their needs are to provide support for a relative with dementia. Of the one in three, half as many family caregivers have been asked what their needs are for themselves (Reinhard et al., 2016). Nonetheless, researchers have underscored the importance of better awareness of the role of family caregiving and the need to develop more targeted and effective education programs and support services (Ducharme et al., 2009; Keady & Nolan, 2003; Montgomery & Kosloski, 2013; Pinquart & Sorensen, 2011). The complex needs of family caregivers vary based on the type of dementia and severity of cognitive abilities and psychological history of persons with dementia, among other factors (Black et al., 2013). Due to the progressive nature of dementia and to the changing needs of those who suffer from it, family caregivers require different supports across the caregiving career (Keady & Nolan, 2003; Montgomery & Kosloski, 2013). Education programs that teach information on dementia might not be specific enough to meet the needs across the caregiving career (Ducharme et al., 2009). Fundamental principles to providing education programs and support services should consider the goals and unmet needs of family caregivers of persons with dementia in order to provide family-centered care (Reinhard et al., 2016).
Researchers often assume the needs of family caregivers and base education programs and support services around these needs (Ducharme et al., 2009; Zarit & Femia, 2008). Assuming the needs of family caregivers can result in a mismatch between caregivers’ goals and the program objectives (Ducharme et al., 2009; Zarit & Femia, 2008). The needs of family caregivers are under acknowledged which, in turn, impacts the caregiving experience (Bangerter et al., 2017; Keady & Nolan, 2003; Marziali et al., 2010). Family caregivers play a key role in providing care for persons with dementia and in saving the health care system significant money (Steiner et al., 2016). Unmet needs of family caregivers have detrimental consequences for their relatives with dementia, to the family unit, and to the health care system. Better knowledge and understanding of goals and unmet needs of family caregivers may help dementia care and service providers to reduce the negative health outcomes of family caregivers, decrease the number of hospital visits, and delay relocation to long-term care homes for persons with dementia (Black et al., 2013). It is vital to monitor the health of family caregivers, to create more opportunities for education and training that align with family caregivers needs, and to provide support to family caregivers of persons with dementia (Alzheimer Society Canada, 2010; Bangerter et al., 2017; Ducharme et al., 2009; WHO 2012).

It is not a new phenomenon that flexible support to family caregivers with dementia is needed; however, how this would be achieved is a long-standing question (Gaugler & Teaster, 2006). This study seeks to understand better the goals of family caregivers of persons with dementia and to answer when education programs and support programs are most suitable across the caregiving career. Better awareness of family caregivers’ goals across the caregiving career may target negative health outcomes of family caregivers more effectively. In turn, it could result in better care for persons with dementia, result in delayed relocation to more formal care, and result in lowered costs to the health care system (Steiner et al., 2016). Personalized goal setting for family caregivers may facilitate better outcomes for education program and support services and may decrease caregiver burden (Toto, Skidmore, Terhorst, Rosen & Weiner, 2015). Accordingly, the aims of the current study are to examine the goals of family...
caregivers of community-dwelling persons with dementia prior to an education and training program and to investigate how their goals may vary across the caregiving career.

1.6 Organization of Thesis Chapters

Chapter 2 includes a literature review of the goals and unmet needs of family caregivers of community-dwelling relatives with dementia. The chapter addresses how goals vary by the way in which they are elicited and when they are elicited. Chapter 2 includes evidence of the importance of education programs and support services to align family caregivers’ goals and unmet needs to program objectives. Chapter 3 describes the method used for collecting goal data from family caregivers of persons with dementia and the process of analyzing the data. Chapter 4 follows with a description of the participants and a report of study results. Chapter 5 includes a discussion of the results, significance and implications for education programs and support services, the limitations and strengths of the current study, and recommendations for future research.
Chapter 2

2 Literature Review Introduction

The growing number of people with dementia and the well-documented health consequences on their family caregivers should be of grave concern to policy-makers world-wide (WHO, 2012). Family caregivers are needed to provide a safe and supportive environment that promotes the quality of life for persons with dementia (Black et al., 2013). However, caregiving is linked with negative health outcomes including depression, frequent use of psychotropic medication, and physical illnesses (Blom et al., 2015; Gallagher et al., 2011; Reinhard et al., 2016; Schinkothe et al., 2015). Moreover, the demographic of family caregivers is changing (WHO, 2012); spousal caregivers are becoming, on average, older, and less able to provide care. Further, younger family members are less available to provide care due to competing work/family demands, daughters are in the workforce, and families are living farther apart (Alzheimer Society Canada, 2010). Research has substantiated the importance of family caregivers of persons with dementia (Black et al., 2013; Blom et al., 2015; Gallagher et al., 2011; Schinkothe et al., 2015). However, there is a dearth of research addressing the goals and unmet needs of family caregivers prior to enrolling in education programs and support services (Feinberg 2017). The purpose of the following literature review is to present critically the goals and the unmet needs of family caregivers of community-dwelling persons with dementia prior to and after attending education programs and support services. The review will examine when the goals and unmet needs are elicited and describe how these goals and unmet needs vary by the way in which they were elicited. In addition, the literature review will provide evidence of the importance of education programs and support services that align with goals and unmet needs of family caregivers.
2.1 Goals and Unmet Needs of Family Caregivers of Persons with Dementia

It is necessary to shift the focus solely from persons with dementia to include the value of family caregivers through caregiver education and training and other programs that support the role of family caregivers (Alzheimer Society Canada, 2010; Reinhard et al., 2016). Family caregivers are an important aspect of our health care system and should be considered a valuable source of information (Reinhard et al., 2016) based on, typically, multiple decades of a relationship with their relative with dementia. Family caregivers often are required to take on more care tasks and may need added assistance in providing care for persons with dementia as the dementia-related symptoms increase in concert with the inexorable progression of the syndrome. Researchers have explored the unmet needs and challenges faced by family caregivers for persons with dementia, however, there is little consensus on the prevailing needs (Bangerter et al., 2017; Boots, Wolfs, Verhey, Kempen & de vught, 2015; Hinton, Chambers, Velasquez, Gonzalez & Haan, 2006; Samia, Hepburn & Nichols, 2012). The goals and unmet needs of family caregivers can vary based on the methods used to gain information and the timing of when goals and unmet needs are assessed, among other reasons (Keady & Nolan, 2003).

The literature review outlines the types of caregiver goals and the differences between goals and unmet needs of family caregivers prior to versus after attending education programs and support services. The need to conduct an assessment of family caregivers’ goals and of their unmet needs prior to attending education programs and support services is starting to receive some recognition (Ducharme et al., 2009). However, goals and unmet needs are documented in the literature more often after attending education programs and support services (Boots et al., 2015; Hinton et al., 2006; Samia et al., 2012).

Two methods are used often to elicit goals and unmet needs of family caregivers: restrictive methods and unrestrictive methods. Restrictive methods, such as needs assessment surveys, require family caregivers to answer in accordance with specific questions. Responses of the family caregivers must fit within the parameters of
the tool. Restrictive methods can limit the response of family caregivers or tend to focus on the person with the diagnosis (Gaugler et al., 2004). Methods that restrict the response about the goals or unmet needs rarely focus on the family caregiver but rather focus on the symptoms or behaviours exhibited by persons with dementia (Steiner et al., 2016). In contrast, unrestrictive methods, such as open-ended questions, allow the caregiver to respond without the guidance of cued responses. Open-ended questions allow for a great deal of insight into family caregivers’ viewpoints because they do not restrict the responses of the family caregivers (Austrom et al., 2014). Unrestricted methods can be used prior to and after attending education programs and support services. Goals and unmet needs of family caregivers are much more documented with unrestrictive methods after attending education programs and support services in focus groups (Hinton et al., 2006; Samia et al., 2012). The current literature review uses research from focus group findings to learn better about the goals and unmet needs of family caregivers after attending education programs and support services. Focus groups are a method and a design approach used to gather information on caregivers’ perspectives, opinions, and beliefs during or after attending education programs or support services (Boots et al., 2015). Focus groups are an invaluable source of information on goals and unmet needs of family caregivers.

Taken together, the comparison of when and how goals and unmet needs are elicited can inform researchers and clinical professionals on ways to provide the most suitable services to better serve family caregivers. The methods by which the goals and unmet needs are elicited may provide further insights about family caregivers. A better understanding of family caregiver goals will provide insights on how best to create tailored and flexible education programs and support services to maximize the quality of care provided by family caregivers and minimize negative health outcomes (Trivedi et al., 2014). A review of the literature revealed six domains of goals and unmet needs of family caregivers of persons with dementia. They include (1) education and information, (2) managing dementia-related symptoms, (3) managing stressors and health, (4) assistance with care, (5) role changes due to changing care needs, and (6) raising
awareness within the care context.

2.1.1 Education and Information about Dementia

Education and information encompassed goals and unmet needs for gaining knowledge about dementia and associated symptoms, understanding the changes that should be expected over time due to the progression of dementia, learning strategies to provide care specific to each type of dementia, and attending education and support groups specific to different phases of caregiving (Chui et al., 2010; Diehl-Schmid et al., 2013; Ducharme et al., 2011; Farran et al., 2002). Goals and unmet needs for education and information were common concerns of family caregivers of persons with dementia prior to and after attending education programs and support services. The need for more education and information was elicited through restrictive methods and unrestrictive methods (Black et al., 2013; Ducharme et al., 2009; Gaugler et al., 2004; Samia et al., 2012; Tanner et al., 2015).

**Gain More Knowledge about Dementia.** When family caregivers disclosed their unmet needs prior to education programs and support services via restrictive methods, they expressed their greatest unmet needs were related to information on resource referrals and access to more dementia education sessions (Black et al., 2013; Tanner et al., 2015). Goals or unmet needs of family caregivers after attending education and support services provide us with a rich understanding of the types of education and information family caregivers need. When unrestrictive methods were used after attending education programs and support services, family caregivers expressed the desire to find professional support and information that would help them to learn about the progression of dementia and related behaviours (Chui et al., 2013; Diehl-Schmid et al., 2013; Ducharme et al., 2003; Farran et al., 2002; Gaugler et al., 2004; Samia et al., 2012). Family caregivers often reported concerns about the future and feared that current caregiving skills would be insufficient as the syndrome progressed or as their caregiving situation changed (Samia et al., 2012). Education and information also encompassed a variety of goals about dementia education. Interestingly, family caregivers specifically reported goals and unmet needs about receiving more education
and information about communication only after attending education programs and support services and through unrestrictive methods. Family caregivers wanted to learn communication techniques to help their relatives with dementia or wanted to develop strategies to communicate with persons with dementia to maintain a relationship after attending education programs and support services (Ducharme et al., 2003). In light of this evidence, it is apparent that unrestrictive methods provide more insights into family caregivers’ needs; the restrictive methods limited the responses of family caregivers and do not enable the family caregivers to explain their need for specific education programs or support services. Therefore, it is difficult to ascertain if the unmet needs listed in restrictive methods are the only unmet needs of family caregivers of persons with dementia.

2.1.2 Managing Dementia-Related Symptoms

Family caregivers feel a responsibility to manage dementia-related symptoms such as assisting with ADLs or supporting cognitive impairments (Black et al., 2013; Tanner et al., 2015; Farran et al., 2002; Koenig, Steiner, & Pierce, 2011; Steiner et al., 2016). Goals and unmet needs pertaining to dementia-related symptoms include: how to address cognitive decline, assisting with ADLs and IADLs, and managing irregular sleep routines and safety concerns. Goals and unmet needs for managing dementia-related symptoms were gathered from restrictive methods and unrestrictive methods, prior to and after attending education programs and support services.

Cognitive Decline. Family caregivers wanted to know how to manage and support neuropsychiatric symptoms and cognitive decline in persons with dementia prior to and after attending education programs and support services (Black et al., 2013; Tanner et al., 2015; Farran et al., 2002; Koenig et al., 2011; Steiner et al., 2016). Knowledge about cognitive decline was an unmet need or goal when restrictive or unrestrictive methods are used. When restrictive methods prior to education programs and support services were used, family caregivers wanted their relative with dementia to have more cognitive awareness of the day of the week, to be aware of social events on specific days, and to have a better understanding of when the family caregiver is out
of the house (Kerssens et al., 2015). Coping with forgetfulness or confusion exhibited by persons with dementia was a frequent area of unmet needs for family caregivers with restrictive and unrestricted methods (Farran et al., 2002; Koenig et al., 2011; Steiner et al., 2016). Family caregivers were able to be more specific in areas of need for cognitive decline when unrestricted methods were used after attending education and support programs. Dealing with repeating questions or actions, losing, hiding, or taking things, loss of sense of time, auditory or visual hallucinations, stubbornness or uncooperativeness of the persons with dementia were all areas of unmet needs expressed by family caregivers using unrestricted methods after attending education programs and support services (Steiner et al., 2016). Additionally, family caregivers wanted strategies to deal better with verbal aggression, physical aggression, and uninhibited behaviour of their relatives with dementia using unrestricted methods after attending education programs and support services (Farran et al., 2002).

**Assisting with ADLs and IADLs.** Goals and unmet needs to assist and to support ADLs and IADLs of their relatives with dementia were often elicited with restrictive methods. However, assisting with ADLs and IADLs remained an area of unmet needs of family caregivers prior to and after attending education programs and support services. Family caregivers wanted their relatives with dementia to increase food intake, to improve overall mood, to engage in meaningful activities, and to complete routines independently (Kerssens et al., 2015). Family caregivers wanted to learn communication approaches to assist with ADLs and IADLs after attending education programs and support services because skills such as grooming, eating, and leisure activities deteriorated for their relatives with dementia (Ducharme et al., 2003). ADLs and IADLs appeared to be an ongoing unmet need of family caregivers of persons with dementia prior to and after attending education programs and support services with restrictive methods and unrestricted methods.

**Sleep.** Lack of sleep or disturbed sleep schedule was a less common concern of family caregivers. Family caregivers wanted their relative with dementia to learn to fall asleep smoothly with restrictive methods prior to education programs and support
services (Kerssens et al., 2015). However, with unrestrictive methods after attending education programs and support services, family caregivers shifted the unmet need for their relative’s sleep to focus on sleep routine because of their relative’s sleep problems (Austrom et al., 2014).

**Safety.** Safety of persons with dementia and the family caregivers was a frequent area of goals and unmet needs voiced by family caregivers only with unrestrictive methods after attending education programs and support services. The need to oversee safety and monitoring of relatives with dementia safety due to the loss of mobility, cognitive functioning, memory impairments, and awareness of unsafe situations were unmet needs of family caregivers (Austrom et al., 2014). Family caregivers were very concerned about safety for themselves and persons with dementia. Wives above the age of 70 had more safety concerns for their own safety and their relatives with dementia, had lower self-efficacy to manage safety issues, and were less effective at redirecting their relative with dementia to a safer place (Samia et al., 2012). Family caregivers desired skills to maintain safety for persons with dementia, but also wanted to learn how to find balance in order to give their relative an appropriate amount of independence (Karlsson et al., 2015; Samia et al., 2012).

### 2.1.3 Managing Stressors and Health

Goals and unmet needs for managing stressors and health predominantly came up when unrestrictive methods were used. Rarely did goals and unmet needs for managing stressors and health arise with restrictive methods due to the limitations of the method. Family caregivers are a vulnerable group who experience high levels of stress and burden (Gaugler et al., 2004). They have expressed the need to manage their own emotions and stressors associated with caring for persons with dementia (Ducharme et al., 2011; Farran et al., 2002; Koenig et al., 2011; Steiner et al., 2016). Although caregivers expressed the need for information, they also expressed they were overwhelmed and anxious by the information they received (Chui et al., 2011). Family caregivers were confronted with negative emotions because of misunderstanding of the syndrome manifestations and lack of acceptance of dementia (Boots et al., 2015). Goals
and unmet needs in the domain managing stressors and health included managing stress and anxiety, support of someone to talk to, and self-care.

**Managing Stress and Anxiety.** *Prior to* education programs and support services, family caregivers chose goals and unmet needs for mental health care and general health care of the relatives with dementia (Black et al., 2013; Tanner et al., 2015). The use of restrictive methods limited family caregivers’ responses and resulted in the focus of the goals and unmet needs to be directed towards persons with dementia. The restrictive methods did not allow family caregivers to express goals or unmet needs for themselves or their expressions remained quite general. In unrestrictive methods *after* attending education programs and support services, family caregivers disclosed low levels of emotional support (Ducharme et al., 2011) and expressed a need for reassurance about the care they provided (Ducharme et al., 2003). Family caregivers admitted emotional issues related to care (Austrom et al., 2014) and were stressed or anxious out of fear for their own safety (Farran et al., 2002). Additionally, unexpected costs associated with caregiving caused stress and anxiety for family caregivers (Austrom et al., 2014). Goals and unmet needs for future concerns about grief was a topic of stress and anxiety only apparent with unrestrictive methods (Ducharme et al., 2003). Goals and unmet needs for stress and anxiety were not only related to the dyad but others in the family unit as well. Stress and anxiety of family caregivers was compounded by other relatives’ health issues, other relatives’ financial or marital stress, or conflicted relationship with adult children (Austrom et al., 2014). This further display of stress and anxiety of family caregivers of persons with dementia also included stress and anxiety related to balancing the needs of other family members.

**Social/Emotional Support.** Family caregivers wanted referrals to support groups to understand better caregivers’ emotional needs, psychological symptoms, or stress (Chui et al., 2011; Hinton et al., 2006). Only *after* attending education programs and support services family caregivers said they wanted to learn how to ask for help and needed to learn how to accept help from other family members (Samia et al., 2012). Family caregivers who reflected on the earlier stages of dementia caregiving agreed it
would have been useful to have someone to talk to about dementia and could have helped with the acceptance process (Boots et al., 2015). Family caregivers wanted more communication from professional caregivers. Family caregivers expressed the need for emotional support; shared communication between the professional caregivers and family caregivers is vital for the health of the family unit (Chui et al., 2011; Karlsson et al., 2015). Family caregivers expressed interest in goal development to address the social isolation they experienced (Schinkothe et al., 2015).

**Self-care.** Goals and unmet needs about self-care were voiced after attending education programs and support services using unrestricted methods. Family caregivers who expressed the importance of self-care, however, also admitted to not always taking the time to look after themselves. After attending education programs and support services, many family caregivers had goals and unmet needs for strategies to help with making more time for themselves and paying attention to their own self-care (Samia et al., 2012).

Self-care may not be a focus for family caregivers because education programs and support services do not always teach strategies that focus on self-care (Samia et al., 2012). Additionally, self-care is an area of goals or unmet needs of family caregivers because there may be a lack of professional support to manage self-care (Samia et al., 2012). Family caregivers shared that they needed to find a balance in their personal lives but were unsure how to find balance (Ducharme et al., 2003). Female family caregivers were more likely than male family caregivers to struggle with self-care (Ducharme et al., 2003).

2.1.4 Additional Assistance with Care

Family caregivers expressed the need for support from professionals because of increased dependency due to the progressive nature of dementia (Gaugler et al., 2004, Samia et al., 2012). Additional assistance with care involved goals and unmet needs of family caregivers for assistance with providing medications and navigating the system. Goals and unmet needs in this domain were predominately from unrestricted methods after attending education programs and support services.
**Medications.** Family caregivers expressed the need for in-home help with administering medications and understanding the health of the relatives with dementia after attending education programs and support services with unrestricted methods (Hinton et al., 2006). Some family caregivers expressed that they needed assistance with administrating medications. However, family caregivers expressed goals to encourage their relatives to take their medicine independently prior to attending education programs and support services (Kerssens et al., 2015).

**Navigating the system.** Family caregivers still needed advice from professionals about problem solving skills after attending education programs and support services (Ducharme et al., 2011). Family caregivers were unsure how to access resources and were unsure how to navigate through the support systems in a timely manner (Karlsson et al., 2015; Samia et al., 2012). This was evident by the expressed unmet need of knowing where and how to access the appropriate resources at the suitable time (Samia et al., 2012). The specialized services that aligned with specific unmet needs of family caregivers were not easily accessible when they required the services, and thus the needs remained unmet after attending education programs and support services (Karlsson et al., 2015). When family caregivers received professional advice, they wanted the professionals to be creative and flexible when offering advice (Karlsson et al., 2015). Moreover, family caregivers stressed the importance of professionals having the ability to relate to the situations of the caregivers’ experiences (Karlsson et al., 2015). That is, family caregivers want professionals with plenty of work-related experience working with people who have dementia. Family caregivers expressed an unmet need to learn about the health care system, to receive information to access health care services, and to find appropriate services in order to make informed decisions for their relative with dementia with unrestricted methods after attending education programs and support services (Austrom et al., 2014; Ducharme et al., 2003).

2.1.5 **Role Changes Due to Changing Care Needs**

Family caregivers felt they were a valuable resource when it came to providing care for a relative with dementia (Samia et al., 2012). However, they also conveyed
feelings of uncertainty because of the variability of different trajectories for dementia (Samia et al., 2012). Programs that aimed to educate and to train family caregivers about dementia have yet to respond to the changing needs of family caregivers of persons with dementia (Samia et al., 2012). Care needs of relatives with dementia change due to the progression of the syndrome(s) and, therefore, the goals and unmet needs of family caregivers vary across caregiving situations (Boots et al., 2015). Family caregivers stressed the importance of tailored education and training programs at different phases of caregiving and professional guidance to support their individual needs with unrestrictive methods after attending education groups and support services (Boots et al., 2015; Karlsson et al., 2015).

**Changing Roles.** A diagnosis of dementia may lead to changes of roles within the family unit and sometimes cause relationship strain (Aneshensel et al., 1995; Austrom et al., 2014). Family caregivers have admitted they experienced feelings of uncertainty about assuming the caregiving role after attending education programs and support services (Steiner et al., 2016). Caregiving experiences varied among caregivers and with stages of the syndrome. Caregivers expressed a need to learn new caregiving techniques as the caregiving context and needs change (Chui et al., 2011). Family caregivers continued to have unmet needs about new responsibilities and how to best support their relatives throughout different stages of caregiving (Koenig et al., 2011). Family caregivers of persons with dementia shared that they experienced many changes and found it difficult to cope due to unmet needs over the course of caregiving for persons with dementia (Boots et al., 2015; Hinton et al., 2006). Family caregivers needed to understand better the changing relationship between themselves and their relative and needed to feel better supported by professionals (Koenig et al., 2011; Steiner et al., 2016). In addition to taking on new care responsibilities and learning to provide effective care, family caregivers also expressed the need to find meaning in the caregiving role when asked about unmet needs after attending education and support services using unrestrictive methods (Ducharme et al., 2003). A need to understand and to accept the role transitions and the new responsibilities was an unmet need of family
caregivers after attending education and support services (Austrom et al., 2014). Family caregivers of persons with dementia felt the role of a ‘caregiver’ was difficult to adapt to, which often led to spending time alone or with professional caregivers (Boots et al, 2015).

2.1.6 Raising Awareness of Dementia

Family caregivers sometimes felt they would have benefitted from positive reinforcement or validation from external networks. In order for this to have been achieved, family caregivers expressed the need to spread awareness about dementia to doctors, nurses, police, and judges about the nature of dementia (Diehl-Schmid et al., 2013). Raising awareness of dementia was only an unmet need when unrestrictive methods were used after attending education and support services.

**Understanding dementia beyond the dyad.** In addition to the changes within the dyad, family caregivers had unmet needs based on the imbalance of family relationships with children (Vernooij-Dassen et al., 2010) and extended family (Ducharme et al., 2003). Family caregivers held negative emotions towards other family members who were unwilling to help with their relatives with dementia. Family caregivers had expressed the need for extended family to better understand dementia-related symptoms, the added caregiving responsibilities, and the progression of dementia for persons with dementia with unrestrictive methods after attending education and support services (Ducharme et al., 2003). Spousal caregivers disclosed they would have liked their children to visit more often to support the family unit and their relative with dementia (Austrom et al., 2014). Family caregivers expressed the unmet needs to have family members- typically children or siblings- assist with caregiving tasks or at least become more aware of dementia (Samia et al., 2012).

2.1.7 Summary of Goals and Unmet Needs of Family Caregivers of Persons with Dementia

The goals and unmet needs of family caregivers after attending education programs and support services have been investigated far more often than the goals
and unmet needs of family caregivers prior to attending education programs and support services. Methods used for eliciting goals and unmet needs prior to education program and support services often used restrictive methods for collecting data. Restrictive methods focused on the needs or symptoms for person with dementia or restricted the responses of family caregivers and were less specific to the needs of family caregivers. Family caregivers gave responses in the manner that was set out by the researchers or clinicians who had program aims in mind. Restrictive methods rarely gave the option for family caregivers to expand on the unmet needs listed in the measure. Unrestrictive methods gained insights onto the family unit to spread awareness of dementia versus the focus solely into the unmet needs of the relatives with dementia. Family caregivers wanted to understand better the timing of care for their relatives with dementia to provide the best care possible (Gaugler et al., 2004). Goals and unmet needs related to education and information were much more specific when unrestrictive methods were used after attending education programs and support services. Education programs and support services should align program outcomes to the goals and unmet needs of family caregivers (Wilz, Schinkothe, & Soellner, 2011). Family caregivers are an integral component of the caregiving team as they provide the majority of care; therefore, it may be of significance to further investigate the goals and unmet needs of family caregivers with unrestrictive methods prior to attending education programs and support services.

Research of family caregivers and persons with dementia is not a novel area of research. However, relatively few studies acknowledge the goals and unmet needs of family caregivers prior to education programs and support services. Among those studies that do, the needs of family caregivers are discussed after attending education programs or support services or often focus on the person with the diagnosis of dementia. Further, methods to collect information on goals and unmet needs often restrict the response of family caregivers which may, in turn, limit the understanding of the goals or unmet needs of family caregivers. Family caregivers may respond in accordance to suggested needs such as learning about dementia-related symptoms. As
a consequence, family caregivers are unable to reflect on their personal situations to develop goals relevant to their caregiving context. In addition, the needs within the caregiving context may change over the course of the caregiving career. It is important to examine the caregivers’ goals at different phases of the caregiving career to understand better the dynamic nature of caregiving and to support family caregivers.

2.2 The Importance of Support Services that Address Goals of Family Caregivers

In 2010, US$604 billion world-wide was spent on dementia care (WHO, 2012). It is estimated that the Canadian government spends $15 billion on dementia care (Alzheimer Society Canada, 2010). Costs for dementia care are five times greater than non-dementia caregiving costs (Alzheimer Society Canada, 2015). Family caregivers play a vital role in the health care system because they support their relatives with dementia in addition to providing unpaid care (Alzheimer Society Canada, 2015; Marziali et al., 2010; Steiner et al., 2015). In 2011, it was estimated that family caregivers provided 19.2 million hours of unpaid care to a relative with dementia. These unpaid hours would have cost the health care system $1.2 billion if a caregiver had been paid for the care hours (Alzheimer Society Canada, 2015). Family caregivers are necessary in saving health care dollars if the family caregivers are supported and can provide proper care to their relative with dementia.

Researchers and community service providers in dementia care have created education programs and support services for family caregivers of relatives with dementia. Alzheimer Society Canada developed strategies to improve the lives of persons with dementia and their family caregivers and to increase public awareness of dementia and the services available (Alzheimer Society Canada, 2010). Education programs and support services have been created to address adverse emotional, psychological, and health effects that are associated with caregiving for persons with dementia (Gaugler et al., 2010). The aims of education programs tend to target reducing the negative impact of caregiving by providing information on topics such as progression of dementia and management of dementia-related behaviours (Sorensen et al., 2002).
In contrast, caregiver support programs tend to focus on building a sense of network and provide emotional support to family caregivers. Both types of programs attempt to build behavioural competencies and intend to enhance coping strategies which possibly could reduce the economic costs associated with caregiving (Alzheimer Society of Canada, 2010). Economic costs associated with caregiving may be lowered if we have a better appreciation of family caregivers’ unmet needs because education programs and support service can align with the needs of the family caregivers, and thus, lead to more effective program and service outcomes (Alzheimer Society Canada, 2010). Dementia care needs are much greater compared to the care needs of any other chronic condition (Black et al., 2013). Therefore, supporting caregivers of persons with dementia is a valuable component of any comprehensive strategy to address the challenges of living with dementia and to lower costs associated with dementia caregiving (Family Caregiver Alliance, 2015; Gaugler, Kane, Kane & Newcomer, 2005). Looking at goals of family caregivers is a way to learn about the unmet needs.

It is estimated that by 2040 education programs and support services that aim to reduce caregiver burden will result in 12,270 fewer Canadians being relocated to long-term care homes (Alzheimer Society of Canada, 2010). Providing education and counselling to family caregivers can delay long-term care admissions for persons with dementia by an average of 557 days and can improve the quality of life for family caregivers and their relative with dementia (Alzheimer Society Canada, 2015; Graff et al., 2008). Family caregiver education and training typically address medical problems, problematic behaviours, deterioration in activities of daily living, declines in cognition, inappropriate social interactions, mobility and falling challenges, and concerns for future care for the family member with dementia (Bouwens, Van Heigten & Verhey, 2008). However, many of these education programs were created with limited understanding of caregiver needs and concerns from the perspective of family caregivers (Black et al., 2013; Ducharme et al., 2009; Gaugler et al., 2005; Johnston et al., 2011; Steiner et al., 2016). It remains unclear which types of programs best meet the diverse needs of individual family caregivers (Aneshensel et al., 1995; Gaugler et al., 2005; Keady &
Nolan, 2003). Assessing the needs of family caregivers is rarely done by health care and social service agencies because the focus is primarily on the unmet needs of the person with dementia (Gaugler et al., 2004). Family caregivers express the importance of creating individual goals in order to meet the unmet needs of their family unit (Schinkothe et al., 2015; Wilz, et al., 2011). A better understanding of family caregivers’ goals and unmet needs is essential to lessen caregiver burden or strain and will help advance effective and efficient targeted education programs and support services for family caregivers (Marziali et al., 2010).

2.3 Conclusion

The literature review presented the goals and unmet needs of family caregivers of community-dwelling persons with dementia and how goals and unmet needs vary depending when they are assessed and how they are assessed. Analyses of the studies showed that family caregivers are pivotal and will be the primary source of care as the dementia population world-wide continues to increase over the next several decades. An understanding of caregivers’ goals and challenges across the caregiving career is vital to optimizing the health care system and to improving the quality of caregiver programs and supports as caregivers’ goals and care needs change over time (Steiner et al., 2016). It is crucial to gain a better understanding of the caregivers’ goals and challenges at different stages of the caregiving career. Caregiver education and training programs and support services that address unmet needs are necessary because they are a source of coping resources, emotional support, information on the progression of dementia, and affirmation of proper care (Glozman, 2004) for family caregivers. However, an understanding of goals and unmet needs of family caregivers of persons with dementia prior to education programs and support services is limited based on the current published literature. It is difficult, at present, to be certain of the program effectiveness if goals of the participants do not align with program outcomes. Due to the progressive nature of dementia, stressors and unmet needs change over the caregiving career. It is crucial to align the goals or unmet needs of the family caregivers with the outcome of the program at the appropriate time (Austrom et al, 2014). It has been hypothesized
that an increase in effectiveness of programs could be possible when program objectives align with caregivers’ goals (Bogardus, Bradley, Williams, Maciejewski, Gallow, & Inouye, 2004; Zarit & Femia, 2008). Awareness of programming at different phases of caregiving may ease some uncertainties associated with caregiving. Family caregivers’ goals and unmet needs should to be taken into consideration when developing family-centric protocols (Marziali et al., 2010), in addition to learning about the goals and unmet needs within the different phases of caregiving. Understanding family caregivers’ goals and satisfying family caregivers’ unmet needs will increase program effectiveness, which could decrease negative outcomes for family caregivers (Aminzadeh et al., 2005).

Researchers advocate for family-centered dementia care to ensure family caregivers are given the support needed to provide quality care to their relatives with dementia, which will increase the likelihood of a healthier family unit (Tanner et al., 2015). Focus groups emphasized the importance of support for family caregivers and persons with dementia. Therefore, family-centric plans for education programs and support services should take place (Karlsson et al., 2015). Education programs should acknowledge the different phases of caregiving and the different roles of family caregivers when developing education programs and support services for family caregivers of persons with dementia (Samia et al., 2012). Family caregivers expressed that their needs change over time. It is imperative to use a dynamic approach to tailor support services to the needs of family caregivers of relatives with dementia at different phases of caregiving (Montgomery & Kosloski, 2013; Zarit & Femia, 2008). Personalized goal setting that includes the family caregivers is crucial when managing chronic illnesses such as dementia (Glozman, 2004). Yet, incorporating caregiver goals is not common practice for education programs and support services. Education programs and support services may prove to be more successful if program objectives align to the caregivers needs (Bogardus et al., 2004; Zarit & Leitsche, 2001). Family caregivers can maintain their caregiving roles longer when provided with proper support. In turn,
persons with dementia can stay at home longer and the health care system can benefit because of lowered cost of government funded living (Koenig et al., 2011).

2.4 Research Questions

The primary aim of the current study was to investigate the goals set by family caregivers of community-dwelling persons with dementia prior to an education and training program. The secondary study aim was to investigate whether the goals varied across the caregiving career. A better understanding of family caregivers’ goals across the caregiving career may lead to more effective education and support groups, and thus, lower costs associated with dementia care, lower caregiver burden, and increased length of time the persons with dementia stays in the family home. The following research questions (RQs) were examined:

RQ#1: What are the expressed goals of family caregivers of community-dwelling persons with dementia prior to an education and training program?

RQ#2: How do the expressed goals of family caregivers of community-dwelling persons with dementia prior to an education and training program vary across the caregiving career?
Chapter 3

3 Methodology

The purpose of the study was to use conventional content analysis to describe the goals of family caregivers of community-dwelling persons with dementia prior to an education and training program and to gain insights about how the goals vary across the caregiving career. There is little published research that uses unrestricted methods to identify the goals of family caregiver of persons with dementia prior to attending education programs and support services (Boots, Wolfs, Verhey, Kempen & de vught, 2015; Hinton, Chambers, Velasquez, Gonzalez & Haan, 2006; Samia, Hepburn & Nichols, 2012). In other words, there are few findings in the published literature that describe the goals and unmet needs from the perspective of family caregivers of persons with dementia using data collection methods that do not limit the response of family caregivers.

Conventional content analysis is used to describe a phenomenon especially when there is limited existing theory or research literature on the phenomenon (Hsieh & Shannon, 2005). Categories and codes are not pre-determined when using conventional content analysis but instead the categories and codes emerge from the data (Hsieh & Shannon, 2005). Inductive category development is possible when researchers (e.g., SB and MYS) submerse themselves in the data to help develop new insights (Hsieh & Shannon, 2005; Krippendorff, 2004). The purpose of this chapter is to describe the education and training program used in a larger study, to outline the process used to capture and analyze the goals of participants in the program, to provide a rationale for the use of conventional content analysis, and to explain how relationship identity of participants was gathered.
3.1 The Family Caregiver Enhanced Training Education Dataset

3.1.1 The Education and Training Program

The current study was part of a larger six-week education and training program for family caregivers of community-dwelling persons with dementia called The Family Caregiver Enhanced Training (FaCET) program. It was developed collaboratively by researchers at Western University and clinicians at a community partner agency. FaCET was based on the Need-driven, Dementia-Compromised Behaviour theory, which highlights the importance of background and proximal factors that contribute to the expression of responsive behaviours in persons with dementia (Kovach, Noonan, Schlidt, & Wells, 2005). Background factors include non-modifiable factors such as neurological factors, cognitive factors, general health, and psycho-social factors. Proximal factors include modifiable factors such as personal factors (e.g., emotions, physiological need states, functional performance), physical environment (e.g., lighting, noise level, temperature), and social environment (e.g., people in the environment and the interactions of the people) (Algase et al., 1996). FaCET targeted the proximal factors by enhancing caregivers’ skills in addressing cognitive-communication challenges, helping with activities of daily living, addressing responsive behaviours, and understanding and recognizing delirium. The FaCET study was funded via a peer-review process with funds from the Behavior Supports Ontario program.

3.1.2 Participants

Ethics approval for FaCET was obtained from Western University’s Ethics Review Board (HSREB file number: 106097; Appendix A). Inclusion criteria (Appendix B) for the study included: 18 years or older, completed education programs offered by the local Alzheimer’s Society or a day program offering outreach services to family caregivers, provided care for a person with dementia for at least four hours a week, able to attend all training sessions, had sufficient communication skills in English to participate in the training program and data collection, and gave consent to audio and video recording of training sessions. These inclusion criteria ensured that participants held similar levels of
knowledge and understanding of dementia prior to enrolling in FaCET. Thirty participants met inclusion criteria before they attended the first session. Participants were divided into Group A and Group B based on their availability to attend all training sessions. Group A included 16 participants and Group B included 14 participants.

3.1.3 Procedure

FaCET was conducted at a day program offering outreach services for family caregivers in London, Ontario. Outcome measures for the larger study were completed at baseline, post-training, and three-month follow-up (See Table 1). Only data from pre-training baseline data collection were used to answer the primary and secondary research questions of the current study.

Table 1. Education and Training Program Schedule

<table>
<thead>
<tr>
<th>Data collection</th>
<th>Week 1</th>
<th>Weeks 2-5</th>
<th>Week 6</th>
<th>Week 18</th>
<th>Weeks19-22</th>
<th>Week 23</th>
<th>Week 35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group A</td>
<td>Pre-train baseline</td>
<td>Training Exposure</td>
<td>Post-train outcomes</td>
<td>3-months follow-up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group B</td>
<td>Pre-train baseline</td>
<td></td>
<td></td>
<td></td>
<td>Training Exposure</td>
<td>Post-train outcomes</td>
<td>3-months follow-up</td>
</tr>
</tbody>
</table>

Free respite care was provided to relatives with dementia; this enabled participants to attend all training sessions. All participants met with the research team to review the letter of information (Appendix C). All participants were informed of possible risks and benefits related to the education and training. All participants signed a consent form (Appendix D) in accordance with the Human Ethics Review Board process requirements at Western University. Thereafter, they completed questionnaires that included writing down their goal(s). Participants were asked the following questions: (a) “What are your goals relevant to your care situation with your relative with dementia?” and (b) “What would you like to address through the education and training program?” Participants sat independently and in a room free of distractions. A team of researchers and clinical professionals encouraged participants to reflect on their...
caregiving context. However, the researchers and clinical professionals did not suggest or shape goals of the participants. Phase of caregiving was included as one of the question in the questionnaire package. Phase of caregiving was measured using pie charts that visually displayed the extent to which their relationship identity was represented by the familial role versus the caregiver role (see Figure 1).

**Figure 1. Phases of Caregiving**

![Figure 1. Phases of Caregiving](image)

3.2 Research Design- Analysis

3.2.1 Content Analysis

Content analysis is the “research technique for making replicable and valid inferences from texts (or other meaningful matter) to the context of their use” (Krippendorff, 2004, p.18). The methodology dates to the 17th century, yet, the term content analysis was not used in English until 1941 (Krippendorff, 2004). Content analysis has recently become more common in health studies due to its trustworthiness (Hsieh & Shannon, 2005). It enables new insights by extending the knowledge of the human experience (Hsieh & Shannon, 2005; Krippendorff, 2004).
Content analysis allows flexibility when interpreting data. However, it also creates some uncertainty due to the different approaches that can be used. Methodology using content analysis falls within a continuum of qualitative content analysis to quantitative content analysis. Researchers move back and forth along the continuum to gain the most insight into the understanding of the data (Holsti, 1969). Qualitative content analysis focuses the attention of the context and the characteristics of the communicated messages or the contextual meaning of the text to yield better insights of the speaker in context (Holsti, 1969; Hsieh & Shannon, 2005). Text data may be in verbal, print, observations, or print media (Hsieh & Shannon, 2005). Quantitative analysis allows for the analysis of qualitative data by aiming to classify data in numerical terms based on frequency of terms or categories of qualitative data (Holsti, 1969).

Despite the range of use and definitions of content analysis, content analysis enables objectivity and systematic analyses (Holsti, 1969). Objectivity is expressed by systematic guidelines involved to analyze data at each step. Researcher decisions are required with content analysis. Therefore, it is imperative for the researcher to follow guidelines that reduce researchers’ subjective biases. These guidelines allow for other researchers to follow the same procedure and to arrive at the same conclusions about content units (word, theme, paragraph, etc.), categories, and codes (Holsti, 1969; Krippendorff, 2004). Further, triangulation allows for the completion of reliability checks to gain objectivity (Budd, Thorp & Donohew, 1967). Systematic analysis allows for the inclusion or exclusion of data in a rule governed manner. For data to be included or excluded it must fall within the consistent rules.

Content analysis is used when data accessibility is a problem or data may be limited. In addition, it can be used in a non-artificial manner. Surveys, interviews, questionnaires, or observations may create artificial situations in which data may not be gathered from the real perspective of the participant (Holsti, 1969). Content analysis allows for a “non-reactive” and “nonobtrusive” manner for analyzing data (Holsti, 1969; Krippendorff, 2004). Content analysis allows for a sample of the population to be analyzed and inferences made to the larger population (transferability) if, and only if,
the sample is representative of the population and characteristics of the population are described in detail (Holsti, 1969).

### 3.2.2 Types of Qualitative Content Analysis

There are three types of qualitative content analysis that fall along the continuum of qualitative to quantitative content analysis: conventional content analysis, directive content analysis, and summative content analysis. Conventional content analysis allows direct information from participants to emerge and does not include a preconceived notion of categories to fit participants’ responses in a mold of what already exists. Categories are derived from the unique responses of participants instead of prior research findings (Hsieh & Shannon, 2005). Researchers read over the text data numerous times to achieve a sense of the data in its entirety. Initial coding is done by data being read word by word to decide repeating concepts. This is done so by highlighting keyword that describes the concept. The researcher makes notes of concepts and thoughts of the data. During this process, codes begin to emerge, often directly from the text (Hsieh & Shannon, 2005). Codes are then sorted into meaningful categories. Categories can be combined based on the relation of the codes. Definitions of each category and subcategory are developed. The navigation of coding methods should be supported by the theory and research questions (Holsti, 1969); categories must reflect the research questions. In order to do so, coding units must be defined and operational definitions of categories must occur (Holsti, 1969). An operational definition “is a valid representation of the analyst’s concepts, and it is sufficiently precise that it guides coders to produce reliable judgments” (Holsti, 1969, p. 95).

Directive content analysis is driven by prior research or theory about a phenomenon (Hsieh & Shannon, 2005). Directive content analysis is often referred to as deductive content analysis because it is guided by an existing theoretical framework (Hsieh & Shannon, 2005). Initial coding and operational definitions of categories are gathered from the preexisting theory (Hsieh & Shannon, 2005). Data collection involves open ended interview questions, and then followed with targeted questions about the predetermined categories (Hsieh & Shannon, 2005). A researcher can target questions
to gain a better response that fits within the predetermined categories. Rank order is used to compare frequency of codes to explain the more frequent codes in order to extend the theory.

Summative content analysis involves quantifying words; the meaning of the word is not explored, but the usage is explored (Hsieh & Shannon, 2005). Manifest content analysis, a type of quantitative content analysis, is used if the analysis stopped at the point of determining the frequency of certain words or content (Hsieh & Shannon, 2005). Summative content analysis extends past frequencies of words and involves a process of interpretation of content (Holsti, 1969; Hsieh & Shannon, 2005).

3.2.3 Conventional Content Analysis

Conventional content analysis was used in the current study to analyze family caregiver goals because it enabled the researcher (SB) to evaluate data systematically by categorizing information to identify key categories and patterns. Coding, the “process whereby raw data are systematically transformed and aggregated into units which permits precise descriptions of relevant content characteristics” (Holsti, 1969, p.94), was completed by two coders (SB and MYS). The coders were trained in the rules of coding which allowed the coders to create a link between the participants’ goal data and the theoretical framework in which derived the research questions at hand.

Description of terms of conventional content analysis:

**Context unit.** The context unit is the context of the coding unit. The context unit provides the coder with enough understanding to provide the background information necessary to grant appropriate coding, must be exhaustive, and mutually exclusive (Budd et al., 1967; Krippendorff, 2004).

**Coding unit.** The coding unit is the smallest segment of textual matter that sets limits on the information (Krippendorff, 2004). The most common coding units are a word; a theme or code; a paragraph (Budd et al., 1967; Holsti, 1969; Krippendorff, 2004). Counting words provides the researcher with the easiest way to display objectivity, though it does not provide as much insight as other methods (Budd et al.,
Counting codes proves to yield more information. Further, codes are related to the categories because it describes a unit of information (Budd et al., 1967; Holsti, 1969; Krippendorff, 2004). A paragraph as a coding unit can be problematic when it includes more than one subject or more than one direction. Language is complex; therefore, it is necessary for the researchers to use systematic methods to analyze the data. Using paragraphs as coding units would be better suited to provide more insight about a general idea (Budd et al., 1967).

**Categories.** Categories are developed so they can accurately answer the research questions (Budd et al., 1967). Combining categories after coding is possible, but dividing a category after coding is less manageable. Categories should be added when they align with the research questions (Budd et al., 1967; Holsti, 1969). In order to ensure categories are mutually exclusive, every category must be thoroughly and explicitly defined (Budd et al., 1967; Holsti, 1969).

3.2.4 Method used to Address the Primary Research Question: Steps of Conventional Content Analysis

Conventional content analysis was used to answer the primary research question: What are the expressed goals of family caregivers of community-dwelling persons with dementia prior to an education and training program? Conventional content analysis began with the formation of a research question. An appropriate sample was selected to answer the research question. The success of content analysis was dependent largely on the coding process. Analyst triangulation refers to the use of more than one researcher to code and agree on codes and categories (Patton, 1999) (see Figure 2). Analyst triangulation was achieved by two coders (SB and MYS). Interrater validation of the coding process took place between two coders and independent coding resulted in 82% agreement of codes. Coding differences were discussed until there was 100% agreement on codes and categories. A coding scheme was used to code goals. This led to the organization of data into categories based on operational definitions. Development of good coding scheme was central to
trustworthiness in research using content analysis.

**Steps of the Coding Process:**

1. Goals of participants from FaCET were typed into a Microsoft word document.

2. Data were read thoroughly so the coder (SB) was familiar with the content and context units.

3. Basic coding began by organizing large sections of text into much fewer context units. Communication unit (C-unit) segmentation rules (see Appendix E) were used to segment raw data into appropriate context units. C-unit segmentations involved breaking goals into independent clauses (Appendix E).

4. For the purpose of answering the primary research question, two coders (SB and MYS) reviewed coding units. Each segmented goal was assigned a code that resembled the goal as closely as possible (i.e., Goal: “to feel more hopeful about the future”; Code: Positive outlook). As coding occurred, development or revision of codes took place (refined and revised in accordance with conventional content analysis method).

5. Analyst triangulation of comparing codes of segmented goals was used to establish trustworthiness. Two coders (SB and MYS) compared codes of segmented goals. Agreement of 100% between two coders was achieved before continuing to next steps. Discussion and revisions occurred one time to resolve discrepancies of codes.

6. Categories were created from the codes of segmented goals and were derived through analysis. Preliminary categories were noted by reading the codes of the segmented goals several times.

7. Categories were defined operationally. Coders were more likely to agree if categories were clearly defined and agreed upon.

8. Analyst triangulation of comparing categories was established. Agreement of 100% between two coders (SB and MYS) was achieved before continuing to next steps.

9. Triangulation of sources was achieved by comparing goals of Group A and Group B. Triangulation of sources ensured categories were relevant to both groups.

10. Finally, inferences were made to answer the research questions (Hsieh & Shannon, 2005; Krippendorff, 2012).
3.2.5 Method used to Address the Secondary Research Question: Goals within Phases of Caregiving

After completing conventional content analysis of goal data, the secondary research question was answered. During conventional content analysis, categories of goals were defined operationally and included codes in a Microsoft excel spreadsheet. Relationship identity was listed beside the goal after each segmented goal that was given a code and assigned to a category. Relationship identity was identified by participants from pre-training baseline data collection. Participants were shown a figure (see Figure 1) and asked to choose a phase of caregiving that best represents their relationship with their relative with dementia. Relationship identity of participants was kept on a separate document until all goals were assigned a code and category in order to maintain objectivity and minimize researcher bias. The researcher (SB) looked for patterns of relationship identity at the category level and at the code level. Frequency of relationship identity was tallied for each category and code. Relationship identity was described in terms of three groups: 1) familial role primarily (see Figure 1a and 1b), 2) caregiver role primarily (see Figure 1d and 1e), and 3) equally the familial and the
caregiver roles (see Figure 1c). Inferences were made by assessing how many goals were written by participants for different relationship identities for each category and code.
Chapter 4

4 Findings

The primary research aim of the current study was to investigate the goals set by family caregivers of community-dwelling persons with dementia prior to an education and training program. The secondary research aim of the study was to investigate whether the goals varied across the caregiving career. Data from the current study were gathered from the Family Caregiver Enhanced Training (FaCET), a larger education and training program study. Conventional content analysis was used to investigate the primary research aim. The secondary research aim was answered by looking for patterns between relationship identity of participants and category of goals that was established using conventional content analysis.

Table 2 presents descriptive information on the demographic characteristics of participants. Participants were assigned to Group A or Group B based on their availability to attend all sessions. Group A consisted of 13 women and three men. Group B consisted of nine women and five men. The average age of participants in Groups A and B was 63 years of age and 64 years of age, respectively. The average age of participants’ relatives with dementia from Groups A and B was 76 years of age and 64 years of age, respectively. Fifty-six percent of participants from Group A had completed university or graduate course work and 65% from Group B had completed university or graduate course work. Participants in both groups were primarily Caucasian. Thirty-eight percent of participants from Group A worked part-time or full-time, whereas 50% of participants from Group B worked part-time or full-time. Forty-four percent of the participants from Group A and fifty percent of the participants from Group B rated their self-health as “good”. Only one participant from Group A rated his/her self-health as “very poor”. In both groups, more than 85% of the participants lived in the same household as their relative with dementia.

Participants from Group A expressed one to five goals. Participants from Group B expressed one to three goals. From Group A, five participants identified with the familial
role primarily (see Figure 1a and 1b), eight participants identified with the caregiver role primarily (see Figure 1d and 1e), and three participants identified equally with the familial role and the caregiver role (see Figure 1c). From Group B, one participant identified with the familial role primarily (see Figure 1a and 1b), eleven participants identified with the caregiver role primarily (see Figure 1d and 1e), and two participants identified equally with the familial role and the caregiver role (see Figure 1c).

Table 2. Demographic Data

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Group A (n=16)</th>
<th>Group B (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex of CG</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men:</td>
<td>18.8%</td>
<td>34.7%</td>
</tr>
<tr>
<td>Women:</td>
<td>81.3%</td>
<td>64.3%</td>
</tr>
<tr>
<td><strong>Age of CG</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age:</td>
<td>63</td>
<td>64</td>
</tr>
<tr>
<td>Range</td>
<td>43-77</td>
<td>52-75</td>
</tr>
<tr>
<td><strong>Education of CG</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grades 9-11:</td>
<td>12.5%</td>
<td>7.1%</td>
</tr>
<tr>
<td>High school graduate:</td>
<td>18.8%</td>
<td>14.3%</td>
</tr>
<tr>
<td>Some university:</td>
<td>12.5%</td>
<td>14.3%</td>
</tr>
<tr>
<td>University graduate:</td>
<td>37.5%</td>
<td>50%</td>
</tr>
<tr>
<td>Graduate coursework:</td>
<td>18.8%</td>
<td>14.3%</td>
</tr>
<tr>
<td><strong>Ethnicity of CG</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian:</td>
<td>93.8%</td>
<td>92.9%</td>
</tr>
<tr>
<td>Other:</td>
<td>6.3%</td>
<td>7.1%</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Works full-time:</td>
<td>31.3%</td>
<td>21.4%</td>
</tr>
<tr>
<td>Works part-time:</td>
<td>6.3%</td>
<td>14.3%</td>
</tr>
<tr>
<td>Retired but works part-time:</td>
<td>0%</td>
<td>14.3%</td>
</tr>
<tr>
<td>Fully retired:</td>
<td>56.3%</td>
<td>42.9%</td>
</tr>
<tr>
<td>Homemaker:</td>
<td>6.3%</td>
<td>7.1%</td>
</tr>
<tr>
<td><strong>Self-rated health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very good:</td>
<td>12.5%</td>
<td>21.4%</td>
</tr>
<tr>
<td>Good:</td>
<td>43.8%</td>
<td>50%</td>
</tr>
<tr>
<td>Fair</td>
<td>37.5%</td>
<td>21.4%</td>
</tr>
<tr>
<td>Poor:</td>
<td>6.3%</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Living situation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives in the household with PWD:</td>
<td>87.5%</td>
<td>85.7%</td>
</tr>
<tr>
<td>Lives with another relative:</td>
<td>12.5%</td>
<td>14.3%</td>
</tr>
<tr>
<td><strong>Relationship identity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Familial role, primarily:</td>
<td>31%</td>
<td>7%</td>
</tr>
<tr>
<td>Caregiver role, primarily:</td>
<td>50%</td>
<td>79%</td>
</tr>
<tr>
<td>Equally familial and caregiver roles:</td>
<td>19%</td>
<td>14%</td>
</tr>
<tr>
<td><strong>Length of caregiving</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-12 months:</td>
<td>6.3%</td>
<td>7.1%</td>
</tr>
<tr>
<td>12-24 months:</td>
<td>25%</td>
<td>14.3%</td>
</tr>
<tr>
<td>24 months –5 years:</td>
<td>37.5%</td>
<td>64.3%</td>
</tr>
<tr>
<td>5 years or more:</td>
<td>31.3%</td>
<td>14.3%</td>
</tr>
<tr>
<td><strong>Age of PWD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age:</td>
<td>76</td>
<td>73</td>
</tr>
<tr>
<td>Range:</td>
<td>55-92</td>
<td>57-90</td>
</tr>
</tbody>
</table>
### Characteristics

<table>
<thead>
<tr>
<th>Relative who receives care</th>
<th>Group A (n=16)</th>
<th>Group B (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husband:</td>
<td>43.8%</td>
<td>42.9%</td>
</tr>
<tr>
<td>Wife:</td>
<td>12.5%</td>
<td>28.6%</td>
</tr>
<tr>
<td>Mother:</td>
<td>43.8%</td>
<td>14.3%</td>
</tr>
<tr>
<td>Father:</td>
<td>0%</td>
<td>14.3%</td>
</tr>
</tbody>
</table>

*CG= Family Caregiver **PWD= Person with Dementia

### 4.1 Results: Description of Categories of Goal Data

Participants expressed individualized goals during pre-training baseline data collection (i.e., Week 1) of FaCET. Participants were encouraged to write as many goals as they had based on their caregiving context. Participants’ goals were segmented into coding units using C-unit Segmentation Rules (see Appendix E). Conventional content analysis was used to analyze 59 coding units. The results of conventional content analysis yielded 27 codes (see Appendix F). Each code was analyzed by coders (SB and MYS) and was clustered into five categories that emerged from the data. The five categories listed from most frequent to least frequent, were: (1) managing caregiver’s emotions, (2) enhancing relationships, (3) developing skills, (4) supporting outlook of a relative with dementia, and (5) learning about dementia. Categories, subcategories, and codes are listed in Table 3 for clarity. What follows is explanation of each category and definitions of codes to provide support for the findings.
<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory Codes</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing Caregiver’s Emotions</td>
<td>Encourage a Positive Outlook</td>
<td>1. Patience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Understanding</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Caregiver coping</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Positive outlook</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Acceptance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Direction</td>
</tr>
<tr>
<td></td>
<td>Negative Emotions of the Caregiver</td>
<td>1. Anger</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Ease anxiety</td>
</tr>
<tr>
<td>Enhancing Relationships</td>
<td>Enhancing the Relationship within the Caregiving Dyad</td>
<td>1. Communication within the dyad</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Meaningful activities for the dyad</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Enjoy the relationship of the dyad</td>
</tr>
<tr>
<td></td>
<td>Enhancing the Relationship with Others</td>
<td>1. Balance needs of others</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Socialize with others</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Support another caregiver</td>
</tr>
<tr>
<td>Developing Skills</td>
<td>n/a</td>
<td>1. Communication skills to manage behaviours</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Enhance caregiver skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Skills for activities of daily living</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Manage situations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Address conflicts</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Confidence in caregiver skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Control symptoms of relative with dementia</td>
</tr>
<tr>
<td>Supporting Outlook of a Relative with Dementia</td>
<td>n/a</td>
<td>1. Calm distress of relative</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Help relative adjust</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Help relative with acceptance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Quality of life for relative</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Maintain relative’s independence</td>
</tr>
<tr>
<td>Learning about Dementia</td>
<td>n/a</td>
<td>1. Dementia knowledge</td>
</tr>
</tbody>
</table>
4.1.1 Managing Caregiver’s Emotions

The category labelled as managing caregiver’s emotions was defined operationally as caregivers’ expressions of emotions (positive or negative) that were the result of, or influenced by, caring for a relative with dementia. The category captured goals that reflected participants’ emotions towards caregiving. The category labelled as managing caregiver’s emotions was the most frequently cited category that emerged from the dataset. The category included eight codes for 22 goals. The eight codes in the category of managing caregiver’s emotions were: (1) patience, (2) understanding, (3) anger, (4) positive outlook, (5) caregiver coping, (6) acceptance, (7) ease anxiety, and (8) direction. Participants expressed goals that reflected a desire to have a more positive outlook for the future or expressed goals that addressed their negative emotions. Two subcategories were created to differentiate between the types of emotions the participants experienced: (1) encourage a positive outlook and (2) negative emotions of the caregiver (see Table 3).

4.1.1.1 Encourage a Positive Outlook

The subcategory labelled as encourage a positive outlook was defined as goals that encourage the capacity to accept or to tolerate a change in behaviour of persons with dementia while the family caregiver maintains a level of optimism for his/her caregiving context. The subcategory included six codes for 18 goals. The codes were: (1) patience, (2) understanding, (3) positive outlook, (4) caregiver coping, (5) acceptance, and (6) direction.

What follows is a description of the codes for the subcategory. The first code, patience, was defined as the family caregivers’ ability to tolerate annoyance or misfortune, without complaint, loss of temper, or irritation (Canadian Oxford Dictionary, 2017). Patience was the most frequently expressed code in the dataset. The code was assigned to six goals. The specificity of patience for the goals varied among participants. Goals ranged from wanting patience in general (e.g., “become more patient”-participant 02_07) to sustaining patience while attending to the care needs of their relative with
dementia (e.g., “keep having patience to give him the care he needs”-participant 02_11). Moreover, some participants were very specific with the area they wanted to achieve more patience. For example, one participant wrote “to develop more patience with our communication”-participant 01_14.

The second code, understanding, was defined by the family caregivers’ sympathetic awareness of behaviours exhibited by persons with dementia. Similar to specificity for patience goals in the code, understanding, ranged from a general desire to be more understanding to more specific goals that focused on understanding the experiences of their relative with dementia. Participants wrote goals “be a better and more understanding caregiver”-participant 02_07 or “to be understanding”-participant 01_02. Whereas, other participants wanted to understand better the emotions of their relative with dementia and respond accordingly. This was illustrated in the goals “to understand their feelings”-participant 01_06 and “to be able to respond with understanding to calm their fears (real/imaginary)”-participant 01_09.

The third code, caregiver coping, was expressed as family caregivers’ abilities to deal with responsibilities, problems, or difficulties in a calm and successful manner. Participants wanted to cope with their own feelings about caregiving or they needed to manage their own emotions to support their relative with dementia better. This was illustrated in the goals “help me cope better”-participant 02_07 and “develop coping skills to help deal with my family member’s depression when they ask me for an early exit”-participant 01_16.

The fourth code, positive outlook, was defined as family caregivers’ desire to be hopeful and optimistic for the future. The goals assigned to the code, positive outlook, were: “to be more hopeful for the future”-participant 01_01 and “to keep morale higher”-participant 01_10. Participants wanted to learn how to manage the caregiving context in a more positive and successful manner. One participant wrote the goal “I want to get on with it positively”-participant 01_07.

The fifth code, acceptance, was defined by family caregivers’ willingness to recognize and come to terms with the changes in their relative due to dementia-related
impairments. The code, acceptance, included a sense that participants wanted to accept the situations that have changed in their caregiving context and wanted to have a positive outlook moving forward. Acceptance, for the purpose of categorizing goals, involved family caregivers’ ability to accept a situation without feeling they needed to fix or modify the caregiving context. Participants wrote “I want to just accept it”-participant 01_07 and “I want to accept better what is happening and not feel I have to fix things”-participant 02_04.

The last code in the subcategory was direction. The code, direction, was defined as family caregivers’ desire to gain guidance to manage emotions and situations in their caregiver context better. For example, the goal “I need a sense of direction”-participant 02_02, highlighted the participant’s desire to gain skills or knowledge to address their feelings of uncertainty. The participant wanted direction to navigate their caregiving context better and sought the support of others. He/she needed direction on how to provide care to his/her relative with dementia.

4.1.1.2 Negative Emotions of the Caregiver

The subcategory labelled as negative emotions of the caregiver included goals that were defined as the family caregivers’ desire or ability to manage undesirable emotions of family caregivers in their caregiving context. Participants who expressed goals in this subcategory did not blame their relatives with dementia. Instead, participants created goals that allowed them to take responsibility for their negative emotions. Goals reflected participants’ desire to modify their own behaviour in response to their relatives’ dementia-related behaviours. Codes included in the subcategory labelled as negative emotions of the caregiver were: (1) anger and (2) ease anxiety.

What follows is a description of the subcategory labelled as negative emotions of the caregiver. The first code, anger, was defined as feelings of frustration or annoyance of family caregivers. Participants wrote goals to be “less angry”-participant 01_03 or “less frustrated”-participant 02_03. The code, anger, included goals that reflected participants’ feelings of being upset when unable to control situations (i.e., responsive
behaviours) in their caregiving context. One participant wrote “I want to control my anger with my family member’s negative behaviour”-participant 01_05. This illustrated that the participant wanted to manage his/her feelings of anger when interacting with his/her relative with dementia. Further, it displayed that participants wanted to address their negative emotions. The goals for the code, anger, displayed that participants acknowledged their negative emotions but also recognized the importance of addressing such negative emotions through their involvement in the education and training program.

The second code, anxiety about caregiving, was defined as lessening the feelings of worry of the family caregiver. One participant wrote the goal, “to ease anxiety about my ability to manage my family member’s progression through Alzheimer’s disease”-participant 01_12. This displayed the participant’s worry about his/her own ability to manage symptoms of his/her relative through the progression of dementia.

4.1.2 Enhancing Relationships

The category labelled as enhancing relationships was defined operationally as the increase or improvement in quality or value for the relationships and activities between the family caregiver and relative with dementia (caregiving dyad) or between the caregiving dyad and others. Participants expressed goals that encouraged activities for the caregiving dyad or for the family unit and friends. The category labelled as enhancing relationships was the second most frequently expressed category that emerged from the dataset. The category, enhancing relationship included six codes for 15 goals. The six codes were: (1) communication within dyad, (2) meaningful activities for the dyad, (3) enjoy the relationship of the dyad, (4) balance needs of others, (5) socialize with others, and (6) support another caregiver. Two subcategories were created to differentiate between the types relationships. The subcategories illustrated that the caregiving situation was not limited to the caregiving dyad but, also, included other relationships. The subcategories were: (1) enhancing the relationship within the caregiving dyad and (2) enhancing the relationship with others (see Table 3).
4.1.2.1 Enhancing the Relationship within the Caregiving Dyad

The subcategory labelled as enhancing the relationship within the caregiving dyad was defined as family caregivers’ need or desire to enhance their relationship and increase the amount of activities with their relative with dementia. Goals included in the subcategory labelled as enhancing the relationship within the caregiving dyad reflected participants’ desire to engage in activities with their relative with dementia to improve their relationship. Three codes emerged for 12 goals. Codes included in the category were: (1) communication within the dyad, (2) meaningful activities for the dyad, and (3) enjoy the relationship of the dyad.

The first code, communication within the dyad, was defined as family caregivers’ desire to learn new skills to communicate effectively with their relative with dementia to enhance the relationship of the caregiving dyad. The code, communication within the dyad, included goals that reflected participants’ desire to learn communication strategies that will help improve understanding of their relative with dementia. A better understanding by the relatives with dementia will allow them to participate in a reciprocal discussion to enhance the caregiving relationship. One participant wrote the goal “to communicate competently even when lethargy slows things to a crawl”-participant 01_10. The goal illustrated participants wanted to learn to communicate effectively when communication breakdowns caused by dementia-related impairments occurred. The code, communication within the dyad, also included goals such as: “to be more effective in engaging with my family member in conversation”-participant 01_08, “to improve the quantity and quality with our communication”-participant 02_12, and “to learn new tools for conversing with my relative with dementia”-participant 01_03.

The second code, meaningful activities for the dyad, was defined as family caregivers’ desire to provide meaningful and engaging activities for the caregiving dyad. The value of doing activities together is illustrated in the goals, “I want to learn more about activities we can do together that are meaningful to each of us”-participant 01_05 and “to have more activities at home to keep us both stimulated and engaged...”
together”-participant 02_01. Participants found benefit or fulfillment in doing activities together.

The third code, enjoy the relationship of the dyad, was defined as family caregivers’ need to take pleasure or delight in shared activities for the caregiving dyad. The goals assigned to the code, enjoy the relationship of the dyad, did not focus on dementia-related impairments. The code included goals that focused on the reciprocity of the relationship between the family caregiver and his/her relative with dementia. Goals such as “enjoy each other’s company (laugh more, tease a little)”-participant 01_06 and “to be pleasant towards each other”-participant 01_07 illustrated participants’ need to engage in a mutual exchange with their relative with dementia.

4.1.2.2 Enhancing the Relationship with Others

The subcategory labelled as enhancing relationship with others was defined operationally as the importance of the relationship and activities between the caregiving dyad and those outside of the caregiving dyad (i.e., family and friends). Goals in the subcategory, enhancing the relationship with others, focused on maintaining relationships with other family members and friends outside of the caregiving dyad. The three codes in the subcategory labelled as enhancing the relationship with others were: (1) balance needs of others, (2) socialize with others, and (3) support another caregiver.

The first code, balance needs of others, was defined as family caregivers’ abilities to satisfy their own needs or meet the needs of family member’s other than the relative with dementia. Participants acknowledged that it was important to tend to their own needs and the needs of other family members. This was illustrated in the goal, “learn to balance the needs of my family and self”-participant 01_10.

The second code, socialize with others, was defined by family caregivers’ goals for the caregiving dyad to interact and to maintain relationships with others. The code, socialize with others, reflected family caregivers’ desire to attend outings or to interact with others outside of the caregiving dyad. This was illustrated in the goal “visiting friends more often”-participant 01_06. The participant did not specify if he/she wanted to visit friends with or without his/her relative with dementia. Based on the coding
context, coders believed the goal assigned to the code, socialize with others, was an expressed goal for the caregiving dyad to do together.

The third code, support another caregiver, was defined as family caregivers’ desire to assist a family member outside of the caregiving dyad. One participant wanted to provide her mother with support in a manner that she would feel more confident managing her husband’s dementia-related behaviours. This was illustrated in the goal, “support and coach my mother to address my family member's (PWD) angry outbursts” - participant 02_05. The code, support another caregiver, revealed the caregiving context can involve other caregivers that need support.

4.1.3 Developing Skills

The category labelled as developing skills was defined operationally as the family caregivers’ desire to learn skills to manage the dementia-related impairments. The category included seven codes for 12 goals. Goals within the category focused on the family caregivers’ desire to learn new skills and strategies so they can provide better support and better manage the impairments of their relative with dementia. This was illustrated in the goal, “I want to learn skills and strategies as my family member continues to deteriorate” - participant 02_10. The category labelled as developing skills included the following codes: (1) communication skills to manage behaviours, (2) enhance caregiver skills, (3) skills for ADLs, (4) manage situations, (5) address conflicts, (6) confidence in caregiver skills, and (7) control symptoms of relative with dementia (see Table 3).

The first code, communication skills to manage behaviours, was defined as the family caregivers’ desire to improve communication to manage reactions from their relatives with dementia. Participants’ goals included acknowledging the behavioural symptoms of dementia. The code, communication skills to manage behaviours, focused on the participants developing communication skills to manage responsive behaviours (e.g., resistance to ADLs) or to manage dementia-related impairments. Participants recognized the importance of learning better communication skills to reduce the frequency of dementia-related behaviours. This was illustrated in the goals “better
communication to get a better reaction and cooperation from my family member”- participant 02_14 and “improve communication to alleviate stress regarding taking meds and ADLs”- participant 02_09. Participants also wanted to learn skills that would make them more confident with communication breakdowns. This was illustrated in the goal “to feel more confident I can handle communication issues as they arise”- participant 01_15.

The second code, enhance caregiver skills, was defined as family caregivers’ goals to develop skills so they can manage dementia-related impairments through the progression of dementia. The code, enhance caregiver skills, involved goals that addressed family caregivers’ ability to learn what to do at each stage. Participants recognized the loss of skills of their relative with dementia. They expressed their desire to support their relative with dementia as his/her skills deteriorate. For example, this was illustrated in the goal, “I want to understand what I need to do at each stage”- participant 02_10.

The third code, skills for ADLs, was defined as family caregivers’ desire to learn skills and strategies that are successful when helping their relative with dementia with ADLs. Participants wanted to identify signs that their relative with dementia was willing to accept help with ADLs. This was illustrated in the goal “seeing signs that my family member will let others assist her with daily activities better”- participant 01_11.

The fourth code, manage situations, was defined as family caregivers’ need to regulate the caregiving context. Participants wrote goals that reflected the importance of learning new strategies that worked for experienced family caregivers. For example, the goal “things to try that have been successful for others”- participant 02_02 displayed the desire to learn strategies that have been effective for other family caregivers.

The fifth code, address conflicts, was defined as family caregivers’ desire to learn skills and strategies that will help them when dealing with conflicts with their relative with dementia. Participants wrote goals such as “I want to acquire skills and strategies to head off conflicts in areas that matter (e.g., no smoking indoors)”- participant 02_13.
The sixth code, confidence in caregiving skills, was defined as family caregivers’ beliefs that they have the ability to manage responsive behaviours exhibited by their relative with dementia. Participants were realistic in understanding behaviours exhibited by their relative with dementia. However, they wanted to gain more confidence in their abilities to deal with responsive behaviours. This was illustrated in the goal, “to feel more confident I can handle behaviour issues as they arise” - participant 01_15.

The remaining code in the category labelled as developing skills was the code control symptoms of their relative with dementia. The code was defined as the family caregivers’ need to exercise restraint over the dementia-related behaviours of their relative with dementia. The code reflected participants’ desire to have the power or influence over the behaviours exhibited by their relative with dementia. This was illustrated in the goal “I want to learn how to control negative behaviour” - participant 01_05.

4.1.4 Supporting Outlook of a Relative with Dementia

The category labelled as supporting outlook of a relative with dementia was defined operationally as the ability to provide emotional support to their relatives with dementia and to be able to calm their fears. Participants wrote goals that acknowledged the emotions of their relative with dementia. Codes in the category labelled as supporting outlook of a relative with dementia revealed participants’ concern for the negative feelings of their relative with dementia (e.g., distress). The category included five codes for eight goals. Codes included in the category of supporting outlook of persons with dementia, were: (1) calm distress of relative, (2) help relative adjust, (3) help relative with acceptance, (4) quality of life for relative, and (5) maintain relative’s independence (see Table 3).

The first code, calm distress of relative, was defined as family caregivers’ desire to calm the fears and anxiety of their relative with dementia. Participants who expressed goals assigned to the code, calm distress of relative, were concerned for their relative with dementia and wanted to support his/her emotional needs. An example of a
goal included in the code was, “to be able to calm my family member’s anxiety and anger problems”-participant 01_13.

The second code, help relative adjust, was defined as family caregivers’ desire to help their relative adapt to the new situations as a result of impairments caused by dementia. Participants wanted to support their relative with dementia and wanted to ensure he/she was adapted and comfortable with situations that will arise due to the progression of dementia. This was illustrated in the goal “to help my family member be better adjusted”-participant 01_07.

The third code, help relative with acceptance, was expressed as family caregivers’ emotional support to help their relative with dementia understand and accept the nature and progression of the syndrome. Participants felt it was important for their relative with dementia to accept the new situations. This was illustrated in the goal “to help my family member be accepting of the situation that is”-participant 01_07.

The fourth code, quality of life for relative, was defined as improving or maintaining the standard of health, comfort, and happiness experienced by the relative with dementia. Participants wanted to support their relative with dementia over the progression of the syndrome which meant supporting his/her quality of life. One participant wrote “to give my family member a good quality of life for each stage changes”-participant 01_11.

The final code was maintaining relative’s independence. The code was defined as family caregivers supporting their relative with dementia in the least intrusive manner to give their relative the opportunity to complete a task partially or fully by him/herself. Participants appreciated the importance of encouraging independence of their relative with dementia. This was illustrated in the goal “to support my family member in ways that do not make them more resentful of dependency (driving, financial etc.)”-participant 02_05.

4.1.5 Learning about Dementia

The category labelled as learning about dementia was defined operationally by the family caregivers’ desire to gain knowledge and understanding of dementia and the
related symptoms. This category was distinct from the category labelled as developing skills because the category labelled as learning about dementia involved the participants’ desire to learn about dementia and the associated symptoms instead of learning skills to manage and deal with the associated symptoms. The category labelled as learning about dementia was the least frequently expressed. The category labelled as learning about dementia elicited one code and two goals. The code was: (1) dementia knowledge (see Table 3).

The code, dementia knowledge, was defined as family caregivers learning facts and information about dementia that would increase awareness and understanding of the syndrome. Participants acknowledged they did not have a strong understanding of dementia. Therefore, they created goals that would increase their understanding and knowledge of dementia. More specifically, participants wanted to learn and to understand why their relative with dementia engaged in responsive behaviours. This was illustrated in the goal “clearly understand the problems with dementia”-participant 02_02. Participants wanted to become aware of the reasons for dementia-related symptoms. An example that illustrated the code dementia knowledge was “a better understanding of my family member’s behaviours and reactions”-participant 01_01.

4.2 Results: Goals across Phases of the Caregiving Career

The secondary research question sought to examine how family caregivers’ goals varied across the caregiving career. Relationship identity is represented by the extent to which the familial and caregiver roles comprise one’s identity across the caregiving career (Montgomery & Kosloski, 2013). Relationship identity, as noted previously, refers to the measurement extent to which participants viewed their relationship in terms of familial and caregiver roles. Prior to entering the education and training program (FaCET), participants selected a relationship identity based on the caregiver identity theory (see Figure 1). Participants who chose either Figure 1a or Figure 1b had a relationship identity that included the familial role primarily. Participants who chose either Figure 1d or Figure 1e had a relationship identity that included the caregiver role.
primarily. Participants who chose Figure 1c had a relationship identity that included the familial and caregiver roles equally. Table 4 includes categories and codes of goal data derived from conventional content analysis and the number of occurrences of different relationship identities for each code.
Table 4. Relationship Identity of Categories and Codes

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Code</th>
<th>Familial Role Primarily</th>
<th>Caregiver Role Primarily</th>
<th>Equally Familial &amp; Caregiver Roles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enhancing Relationships</td>
<td>Enhancing the Relationship within Caregiving Dyad</td>
<td>Communication within dyad</td>
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<td>3</td>
<td>1</td>
</tr>
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<td></td>
<td>Meaningful activities for dyad</td>
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</tr>
<tr>
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<td></td>
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<td>0</td>
<td>1</td>
</tr>
<tr>
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<td>Enhancing the Relationship with Others</td>
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<td>0</td>
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<td>Socialize with others</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Support another caregiver</td>
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</tr>
<tr>
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<td></td>
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<tr>
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<td>4</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Understanding</td>
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<td>4</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Caregiver coping</td>
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<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Positive outlook</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acceptance</td>
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<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Direction</td>
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<tr>
<td></td>
<td>Negative Emotions of the Caregiver</td>
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<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ease anxiety</td>
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</tr>
<tr>
<td></td>
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<td>TOTAL</td>
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<td>14</td>
<td>5</td>
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<tr>
<td>Developing Skills</td>
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<td>Communication skills to manage behaviours</td>
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<td>4</td>
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</tr>
<tr>
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<td></td>
<td>Enhance caregiver skills</td>
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<td>Skills for ADLs</td>
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<td>Manage situations</td>
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<td>Address conflicts</td>
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<td>Confidence in caregiver skills</td>
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<td></td>
<td>Control symptoms of relative with dementia</td>
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<td>0</td>
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<td>Code</td>
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<td>Caregiver Role Primarily</td>
<td>Equally Familial &amp; Caregiver Roles</td>
</tr>
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4.2.1 Categories Reflecting the Familial Role Primarily

The following describes the categories that reflect the familial role primarily. The category labelled as enhancing relationships was most frequently written by participants who viewed themselves in the familial role primarily. However, it is important to note the variability within this category in terms of which goals were endorsed by participants in various phases of the caregiving career. As mentioned in the previous section, there were a total of 15 goals in this category labelled as enhancing relationship. Seven of these goals were written by participants who identified with the familial role primarily (Figure 1a and 1b), five goals were written by participants who identified with the caregiver role primarily (see Figure 1d and 1e), and three goals were written by participants who identified equally with the familial role and the caregiver role (see Figure 1c). The subcategory, enhancing the relationship within the caregiving dyad, included codes in which participants identified with various relationship identities. For example, the code, communication within dyad, included goals written by participants that identified with the familial role primarily, the caregiver role primarily, and identified equally with the familial and the caregiver roles. Whereas, the subcategory, enhancing the relationship with others, included the codes balance needs of others and socialize with others, which encompassed goals written only by participants who identified with the familial role primarily.

Enhancing relationships was not the only category of goals for participants who identified with the familial role primarily. Participants with the relationship identity of familial role primarily, also had goals for the categories labelled as managing caregiver’s emotions, supporting outlook of a relative with dementia, and developing skills. These categories were not frequently expressed by participants with the relationship identity of the familial role primarily. However, the findings highlight family caregivers having different goals of varying importance across the caregiving career. For example, the code, calm relative’s distress, was included in the category labelled as supporting a relative with dementia. The code included four goals. Two of the four goals were written by participants who identified with the familial role primarily. Moreover, the code,
quality of life for relative, included goals only written by participants who identified with the familial role primarily. The category labelled as developing skills included one goal written by a participant who identified with the familial role primarily. The goal was skills for ADLs. Goals for the category labelled as learning about dementia were not expressed by participants who identified with the familial role primarily.

4.2.2 Categories Reflecting the Caregiver Role Primarily

The following provides a descriptive explanation of the categories that reflect the caregiver role primarily. Participants who chose Figure 1d or Figure 1e represent those who view their relationship identity to include the caregiver role primarily. The category labelled as managing caregiver’s emotions was most frequently expressed by participants identified with the caregiver role primarily. The category labelled as developing skills was the second most frequently expressed category of goals for participants who identified with the caregiver role primarily. The category labelled as learning about dementia included goals only written by participants who identified with the caregiver role primarily. The category labelled as supporting outlook of a relative with dementia was least frequently expressed by participants who identified with the caregiver role primarily (see Table 4).

The category labelled as managing caregiver emotions was predominately endorsed by those who see themselves in the caregiver role primarily. For example, the code, understanding, encompassed all goals written by participants who identified with the caregiver role primarily. Further, the subcategory negative emotions of the caregiver did not include any goals written by participants who identified with the familial role primarily (see Table 4). The code, patience, included four goals written by participants who identified with the caregiver role primarily and two goals written by participants who identified equally with the familial and caregiver roles. The code, patience, was not written by participants who identified with the familial role primarily. This shows lack of patience is more likely to be expressed goals for participants who identify with the caregiver role primarily.
The category labelled as developing skills was endorsed predominately by those who see themselves within the caregiver role primarily. For example, the code, enhance caregiver skills, encompassed all goals written by participants who identified with the caregiver role primarily. Additionally, one of the more frequently occurring codes in the dataset, communication skills to manage behaviours (see Appendix F), was written predominately by participants who identified with the caregiver role primarily. Many of the codes (skills to manage situations, skills to address conflicts, control symptoms of relative, enhance caregiver skills, and confidence in caregiver skills) included goals solely written by participants who identified with the caregiver role primarily.

The category labelled as learning about dementia was endorsed only by those who see themselves within the caregiver role primarily. As mentioned in the previous section, there were only two goals in this category. All goals were written by participants with a relationship identity for the caregiver role primarily. The code, dementia knowledge, encompassed all goals written by participants who identified the caregiver role primarily.

The category labelled as enhancing relationships was most frequently expressed by participants who identified with the familial role primarily. However, the category was still a concern of participants who identified with the caregiver role primarily. Participants, who identified with the caregiver role primarily included in the category labelled as enjoy relationships, had goals for the codes communication for the caregiving dyad and meaningful activities for the dyad. The code communication for the caregiving dyad was more frequently expressed by caregivers who identified with the caregiver role primarily than participants who identified with the familial role primarily.

4.2.3 Categories Reflecting the Relationship Identity Equally for the Familial and Caregiver Roles

The relationship identity that participants identified equally for the familial and caregiver roles reflects a transition in relationship identities. Participants who chose Figure 3c can move towards a relationship identity of familial role primarily or caregiver role primarily depending on the unmet needs and resources available in their caregiving
context (Montgomery & Kosloski, 2013). The category labelled as supporting outlook of persons with dementia encompassed a near even distribution of relationship identities across the caregiving career. As Table 4 indicates, there were a total of 7 goals in this category. Three of these goals were written by participants with a relationship identity that included the familial role primarily, two goals were written by participants who identified with the caregiver role primarily, and three goals were written by participants who identified with the familial role and the caregiver role equally (see Table 4). The code, calm distress, included two goals endorsed by participants with the relationship identity of the familial primarily and two goals endorsed by participants with the relationship identity of the caregiver role primarily. The code, quality of life, was written by a participant who identified with the familial role primarily. The codes, help relative adjust, help with acceptance, and maintain relative’s independence, were endorsed only by participants who identified equally with the familial role and the caregiver role (see Table 4).
Chapter 5

5 Discussion

The purpose of the current study was to investigate the goals set by family caregivers of community-dwelling persons with dementia prior to an education and training program. The secondary study aim was to investigate whether the goals varied across the caregiving career. This study is unique because previously published studies have not examined the goals expressed by family caregivers using unrestrictive methods prior to their involvement in education programs and engagement in support services (Bangerter et al., 2017). Additionally, it is the first to examine how the goals of family caregivers of community-dwelling persons with dementia vary across the caregiving career. Conventional content analysis was used to gain an understanding of the goals set by family caregivers prior to an education and training program. Caregiver identity theory informed the measurement of participants’ relationship identity. Specifically, earlier phases of the caregiving career are characterized by relationships where the familial role comprises a large part of the relationship identity (see Figure 1a and 1b). Later phases of the caregiving career are characterized by relationships where the caregiver role comprises a large part of the relationship identity (see Figure 1d and 1e).

The findings of this study provide insight into the relationship between goals of family caregivers of persons with dementia and how their goals vary across the caregiving career. Five categories of goals emerged from the current study. Findings of the current study revealed the goals of family caregivers vary by relationship identity. This chapter provides a discussion of the results, significance and implications for education programs and support services, the limitations and strengths of the current study, and recommendations for future research.

5.1 Goals of Family Caregivers of Persons with Dementia

The current study used an unrestrictive method to gain information about the goals of family caregivers of a relative with dementia prior to an education and training program. An unrestrictive method permitted family caregivers to express goals without
being confined to pre-defined goals or predetermined unmet needs as listed in an assessment tool. The use of an unrestricted method minimized researcher and clinician influences on participants’ goals. The use of an unrestricted method was intended to provide new information about goals of family caregivers of persons with dementia prior to the education and training program. Participants were encouraged to consider their individual caregiving context and to think about goals that were relevant to them. The individual caregiving context, as mentioned in previous chapters, is the environment in which family caregivers manage care needs of their relative with dementia, the living arrangement, and education programs and support services available (Montgomery & Kosloski, 2013). For example, it may include the needs as a result of the impairments of a relative with dementia, the resources available for the caregiving dyad, or work and family conflicts for the family caregiver. Overall, the findings revealed five categories of goals expressed by family caregivers of a relative with dementia: (1) managing caregiver’s emotions, (2) enhancing relationships, (3) developing skills, (4) supporting outlook of a relative with dementia, and (5) learning about dementia. What follows is a discussion of the five categories that emerged from the data using conventional content analysis.

5.1.1 Category: Managing Caregiver’s Emotions

Findings from the current study revealed family caregivers most frequently expressed goals for the category labelled as managing caregiver’s emotions overall. Goals were classified by two subcategories labelled as a) encourage a positive outlook and b) negative emotions of the caregiver, both aimed at providing better care.

5.1.1.1 Encourage a Positive Outlook

Participants most frequently expressed goals in the subcategory labelled as encourage a positive outlook, which focused on dealing with their own emotions positively. This included goals that addressed empathy towards their relatives’ feelings or actions and ability to tolerate difficult situations without getting upset. For example, participants felt goals that targeted being more patient or understanding would help
them to provide quality care to their relative with dementia. Goals included in the subcategory labelled as encourage a positive outlook demonstrated that family caregivers are attuned to the need to increase their positive emotions. Goals that encourage a positive outlook indicate participants’ ability to be reflective of their emotions and the care they provide their relative with dementia. Participants are able to recognize they want to be more positive with their emotions (e.g., more patient or less angry). Self-reflection allows participants to address their feelings that affect the caregiving experience. Addressing goals that encourage a positive outlook can make the caregiver career for family caregivers a more enjoyable experience. Additionally, family caregivers who have a positive outlook for the caregiving context experience less negative health outcomes (Tarlow et al., 2004).

The subcategory labelled as encourage a positive outlook included goals for two novel codes, (a) patience and (b) positive outlook, which were not evident in research based on the parameters of the literature review (Black et al., 2013; Chui et al., 2011; Ducharme et al., 2011; Farran et al., 2002; Koenig et al., 2011; Steiner et al., 2016). Goals for the codes, patience and positive outlook, may have been a focus of participants in the current study because goals were elicited without the restriction of an assessment tool or guidance of researchers or clinicians. Moreover, collecting goals prior to an education and training program can influence the type of goals participants express. For example, they may have assumed that expressing their goals prior to a training program may influence the direction and content of that program. Alternatively, participants may have sought support services because they felt some negative effects of caregiving such as feelings of impatience.

Patience was the most frequently expressed code for goals in the category labelled as managing caregiver’s emotions. This shows that family caregivers are very concerned with developing or maintaining patience through difficult caregiving activities prior to attending an education and training program. Further, it demonstrates that family caregivers want to manage feelings of impatience or intolerance more effectively. Participants may have chosen to participant in FaCET because they were distressed and
wanted to manage their caregiving context better. Participants who expressed goals for patience may have experienced high levels of objective, stress, or relationship burden. For example, participants may lack patience because their caregiving duties infringe on their time or care tasks exert a large impact on their personal lives (Bailes et al., 2016). Participants may also lack patience because they feel emotionally distressed by their caregiving experience (Bailes et al., 2016). Therefore, participants wrote goals to maintain or sustain patience. Difficulty maintaining patience throughout the caregiving career can contribute to relationship burden because of the strain within the caregiving dyad (Montgomery et al., 2000). Participants want to focus on modifying their own emotions to support their relative with dementia to manage their caregiving context and address sources of caregiver burden.

The code, positive outlook, illustrated that family caregivers were aware their responsibilities for their relative with dementia will continue, and increase in intensity. Therefore, they wanted to have a positive approach to care provision. Goals for the code, positive outlook, indicate hopefulness. This illustrates there is an expectation that dementia-related behaviours of their relative will progress but participants wanted to maintain or sustain a positive attitude for their caregiving career. Maintaining a positive outlook of family caregivers is important because negative feelings, such as depression, are associated with greater levels of caregiver burden (Adelman et al., 2014). Family caregivers who experience positive aspects of caregiving have healthier relationships with their relatives with dementia, experience less negative health outcomes, and have high levels of satisfaction in the caregiver role (Brodaty & Donkin, 2009).

Addressing goals relevant to positive outlook and patience holds promise for improved caregiving experiences, increased meaning in the caregiver role, and lowered negative caregiving health outcomes (Brodaty & Donkin, 2009; Cheng, Mak, Lau, Ng, & Lam, 2016; Hirdes, Freeman, Smith & Stolee, 2012). Research in palliative care, revealed family caregivers who maintained a positive outlook had significantly lower levels of caregiver distress and found more meaning in their caregiver role compared to family caregivers who did not have a positive outlook (Hirdes et al., 2012). Research on family
caregiving for persons with Alzheimer’s disease, which did not report on goals and unmet needs, documented the importance of having patience to enhance family caregivers’ feelings of validation, especially when they could exercise patience in difficult situations (Cheng et al., 2016). Education programs and support groups that target enhancing positive emotions of family caregivers may prove to be more effective in minimizing negative caregiver health outcomes, such as caregiver burden.

The codes, caregiver coping, acceptance, and direction, were assigned to goals in the current study. In previous research, family caregivers expressed goals for caregiver coping, acceptance, and direction (Boots et al., 2015; Hinton et al., 2006; Farran et al., 2002; Kerssens et al., 2015; Koenig et al., 2011). Caregiver coping, acceptance, and direction were goals that were expressed using both restrictive and unrestrictive methods. Therefore, family caregivers identified these goals independently and with the guidance of researchers. Moreover, caregiver coping, acceptance, and direction were unmet needs that were expressed by family caregivers prior to and after attending education programs or support services. This illustrated that family caregivers of persons with dementia have unmet needs for these codes even after receiving support. This further shows that education programs and support services do not always address the goals and unmet needs of family caregivers at the most appropriate time. It is crucial to target goals that address family caregiver’s emotions because family caregivers are essential to the long-term care system and delaying long-term care placement of persons with dementia. It is imperative to offer support services that address family caregivers’ emotions to enhance the caregiving career. Addressing goals that encourage a positive outlook, such as acceptance, patience, and understanding, can minimize the negative emotions experienced by family caregivers (Brodaty & Donkin, 2009; Cheng et al., 2016; Hirdes et al., 2012).

5.1.1.2 Negative Emotions of the Caregiver

Goals in the subcategory labelled as negative emotions of the caregiver were less frequently expressed by participants than goals in the subcategory labelled as encourage a positive outlook. The goals in the subcategory labelled as negative
emotions of the caregiver indicate that participants wanted to minimize their own negative feelings related to caregiving. For example, participants wanted to control their anger with their relatives’ behaviours or wanted to be less reactive to impairments of their relative with dementia. The codes that encompassed goals related to anger, reflected the participants’ desire to modify their own behaviour in response to situations in their caregiving context. Although goals for the subcategory labelled as negative emotions of the caregiver were less frequent, they highlight the fact that family caregivers experience anger, frustration, and anxiety in their caregiving context and/or with interactions with their relative with dementia. The negative emotions experienced by family caregivers, results in poor health outcomes for family caregivers or premature relocation to long-term care homes for relatives with dementia. Previous research that reported negative emotions, such as lack of acceptance, led to increased negative health outcomes for family caregivers (Boots et al., 2015). Minimizing negative caregiver health outcomes and attaching meaning to the caregiver role can benefit family caregivers and their relative with dementia (Hirdes et al., 2012). Family caregivers need education and support services that teach strategies to minimize negative emotions, and increase positive emotions, to ultimately, make the caregiving career more gratifying for the caregiving dyad.

Anger and frustration were codes that emerged from the current study that were not reported in the existing research on goals and unmet needs of family caregivers based on the parameters of the literature review. However, this does not mean that family caregivers of persons with dementia do not experience feelings of anger and frustration in their caregiving context. Anger and frustration may be indicators of the inability to change the caregiving situation or deal with a caregiving task or responsibility such as grooming, dependence, or safety concerns. Indeed, the general caregiving literature provides evidence that family caregivers admitted stress of caregiving related to safety concerns, cognitive decline of their relative with dementia, and irregular sleep routines (Austrom et al., 2014). Further, literature on goals and unmet needs of family caregivers illustrated family caregivers experience negative
emotions because other family members are unwilling to help with the caregiving responsibilities (Ducharme et al., 2009). “Emotional issues” and “negative emotions” were general descriptors used in the literature to describe anger and frustration from family caregiver experience (Austrom et al., 2014; Ducharme et al., 2009).

The code, ease anxiety, was assigned to one goal in the current study. Although participants in the current study did not frequently report goals for anxiety, it does not mean they did not experience anxiety. The caregiving literature is replete with reports of anxiety among family caregivers of persons with dementia (Ducharme et al., 2009; Koenig et al., 2011; Whitlatch et al., 2001). Previous research reported family caregivers’ anxiety extended beyond the caregiving dyad and included anxiety over other relatives’ health issues (e.g., sister’s health), other relatives’ financial or marital stress (e.g., daughter’s marital problems), or conflicts in relationships with adult-children (Austrom et al., 2014). Participants in the current study may not have felt anxiety prior to entering the education and training program because they knew they would receive support to address their concerns. Alternatively, family caregivers may have felt anxious, however, their expressed goals may be more specific to address negative emotions in their caregiving context. In turn, the goals may address feelings of anxiety. For example, goals for better coping, positive outlook, and acceptance may be ways family caregivers chose to address anxiety in their caregiving context.

Goals of participants in the current study align with the stressors and mediators within the Stress Process Model (Pearlin et al., 1990). The Stress Process Model (Pearlin et al., 1990) offers important insights into the differential needs and goals of family. The goals expressed by family caregivers in the current study provide further support for the different types of stress that occur in individual caregiving contexts. The category labelled as managing caregiver’s emotions illustrates how caregiving demands impact the emotions of family caregivers of persons with dementia. Participants in the current study did not explicitly have goals “to manage stress”. However, goals for the category labelled as managing caregiver’s emotions, reflects negative emotions of family caregivers. Further, premature relocation to a formal care setting for a relative with
dementia is likely if family caregivers’ goals remain unmet (Reinhard et al., 2016). Providers of education programs and support services need to inquire about unmet needs that can cause stress for family caregivers (Reinhard et al., 2016). Methods that gain more knowledge on goals and unmet needs of family caregivers either focus on the person with dementia, are guided or influenced by researchers, or lack the perspective of family caregivers (Bangerter et al., 2017). Gaining a deeper understanding of family caregivers’ goals for education programs and support services prior to receiving the services may address primary stressors more effectively.

The category labelled as managing caregiver’s emotions, frequently had goals that displayed secondary intrapsychic strains, especially for competence and gain. Competence and gain involve the ability to find inner growth as they face challenges (Pearlin et al., 1990). Family caregivers in the current study expressed goals that encouraged a positive outlook and addressed negative emotions of the caregiver. The findings from the study reflected the participants’ desire to grow as they faced challenges in their caregiving context. Further, these findings displayed participants are invested in modifying their own behaviour to achieve better outcomes for the caregiving dyad. The desire of participants to find inner growth is promising for more effective education programs and support services. The findings from the current study reveal family caregivers are open to achieve inner growth where, in turn, secondary stressors such as intrapsychic strains can be addressed.

The Stress Process Model also includes mediators that can buffer the impact of primary and secondary stressors on family caregivers’ well-being (Pearlin et al., 1990). For example, mediators such as social support and coping can lessen the negative impact of stressors (Brodaty & Donkin, 2009). Participants in the current study expressed goals for caregiver coping. Coping represents the actions of family caregivers in response to their caregiving situation (Pearlin et al., 1990). Coping can be manifested in three dimensions: (1) ability to manage the situations, (2) ability to manage the meaning of the situations, and (3) ability to manage stress symptoms. As mentioned previously, family caregivers who have a positive outlook are able to find meaning in the
caregiving role and experience fewer negative caregiver health outcomes (Cheng et al., 2016; Hirdes et al., 2012). Findings from the current study revealed participants want to learn how to cope better with their caregiving context. Goals that encourage a positive outlook and address negative emotions of family caregivers display they want to manage the situations in their caregiving context more effectively. The category labelled as managing caregivers’ emotions displays the need for family caregivers to manage stress symptoms. Goals and unmet needs of family caregivers of persons with dementia are being recognized as a crucial component to address negative health outcomes of family caregivers and premature relocation to long-term care homes for relatives with dementia (Bangerter et al., 2017; Feinberg, 2017; Reinhard et al., 2016). Providers of education programs and support services should aim specific supports to the goals of family caregivers in terms of managing caregiver’s emotions. Better skills to manage caregiver’s emotions can minimize stressors relative to caregiving, resulting in a more satisfying caregiving experience (Brodaty & Donkin, 2009).

5.1.2 Category: Enhancing Relationships

The category labelled as enhancing relationships was the second most frequent category of goals in the current study. This category reflected participants’ strong desire to enhance relationships between themselves and their relative with dementia. Additionally, it reflected participants’ desire to enhance relationships between the caregiving dyad and others. Goals in this category were divided into two subcategories: (a) enhancing the relationship within the caregiving dyad and (b) enhancing a relationship with others. The subcategory labelled as enhancing the relationship within the caregiving dyad were more frequent than the subcategory labelled as enhancing a relationship with others.

5.1.2.1 Enhancing the Relationship within the Caregiving Dyad

The subcategory enhancing the relationship within the caregiving dyad included goals for communication, activities, and enjoyment of each other’s company for the family caregiver and their relative with dementia. The most frequent code in the
category labelled as enhancing relationship was communication within the dyad. This revealed that participants were most concerned about improving communication to enhance the relationship between themselves and their relative with dementia. Communication impairments are common characteristics of dementia (DSM-V, 2013). Family caregivers wanted to develop and expand their communication skills to support their relative with dementia, but more importantly, to improve the conversation in the caregiving dyad. Communication is essential for meaningful activities and the enjoyment of the relationship between a family caregiver and his/her relative with dementia because it enables a connection and reciprocity (Savundranayagam & Orange, 2011). Therefore, communication is a central component to a strong relationship between the family caregiver and their relative with dementia (O'Connor et al., 2007).

Communication impairments result in relationship strain, caregiver burden, and distress (Small & Perry, 2013). Family caregivers are affected by communication breakdowns which may have negative consequences to the relationship, including a lack of, or change in, closeness in the relationship and caregiver distress (Pearlin et al., 1990; Savundranayagam & Orange, 2011). Communication impairments and ineffective communication strategies may lead to family caregivers feeling disconnected from their relative with dementia (Murray et al., 1999).

Education programs and support programs tend to focus on communication strategies for responsive behaviours or impairments of ADLs (Ducharme et al., 2009; Feinberg, 2017) instead of focusing on strategies that will enhance the relationship of the caregiving dyad. Communication to enhance relationships was a novel finding possibly uncovered with unrestricted methods prior to an education and training program. In previous studies, family caregivers wanted communication strategies to help their relatives with dementia (Ducharme et al., 2009). Family caregivers wanted to learn communication strategies to address behaviours and cognitive impairments which will be discussed in 5.1.3. Research acknowledged family caregivers wanted their relatives to engage in meaningful activities (Kerssens et al., 2015). Taken together, improved communication and meaningful activities may be viewed by participants as an
approach to enjoying relationships. Goals for the code enjoy the relationship are more general than goals for communication within the dyad. Participants wanted to increase the activities they do with their relative with dementia. Therefore, improved communication skills of the caregiver may elicit more mutual engagement in activities. Education programs and support services may be more effective in decreasing caregiving burden if communication strategies to enhance the relationship of the caregiving dyad are more of a focus. Further, improved communication skills in the caregiving dyad may prove to increase meaningful activities. Improved communication and increased meaningful activities can enhance the relationship in the caregiving dyad.

5.1.2.2 Enhancing the Relationship with Others

The subcategory labelled as enhancing a relationship with others was rarely expressed by participants in the current study. Goals in this subcategory revealed participants have goals outside the caregiving dyad. However, they were not frequently expressed prior to an education and training programs using unrestrictive methods. Participants in the current study expressed the goal to balance the needs of others outside the caregiving dyad and the goal to support other caregivers. The code, balance needs of others, was one of the less frequent codes in the current study. However, it was frequently reported in previous literature (Austrom et al., 2014; Ducharme et al., 2011). Family caregivers needed to find a balance in their personal lives (Ducharme et al., 2011) and in their caregiving duties (Austrom et al., 2014).

Participants in the current study wanted to support another caregiver. In contrast, previous studies report that primary caregivers felt resentment or conflict towards other family members because of lack of support or differences in caregiving strategies (Austrom et al., 2014). Findings in the current study showed that some participants were concerned about other caregivers (e.g., their mother), thereby illustrating the importance of support between primary and secondary caregivers. Adult-children may face additional stressors if one of their parents is caring for the other parent with dementia. Adult-children may have recognized their parents need support with caregiving responsibilities resulting in adult-children assuming the caregiver role to
help the primary caregiver who may be unable to provide quality care. Education programs and support services should keep in mind that family dynamics in a caregiving context may vary. Secondary family caregivers may face another set of barriers which may not have been explored thoroughly.

Persons with dementia become more dependent throughout the progression of dementia (Black et al., 2013). The increased dependency leads to a strain on the relationship and negative health implications for family caregivers (Pearlin et al., 1990). When relationships are challenged, family caregivers can perceive their care demands as being stressful and experience relational deprivation (Montgomery et al., 2016). Relational deprivation, which is the restructuring of the relationship between the caregiver and the relative with dementia and decreasing reciprocities (Pearlin et al., 1990), was expressed in goals from participants in the current study. Family caregivers in the current study wanted to focus on creating more reciprocity in the caregiving dyad and wanted to engage with others outside the caregiving dyad. According to the Stress Process Model (Pearlin et al., 1990) and the findings of the current study, family caregivers experience distress over the restructuring of the relationships. Therefore, education programs and support services need to address this cause of distress by supporting family caregivers to enhance relationships (Brodaty & Donkin, 2009).

Previous studies have reported that family caregivers of persons with dementia are at risk of social isolation (Gaugler et al., 2010; Schinkothe et al., 2015). Interestingly, participants in current study rarely had goals for socialization. It appeared participants were more concerned with improving the relationships between themselves and their relative with dementia versus being social with others. Relationships restricting the caregiving dyad were of more importance to family caregivers than relationships with those outside the caregiving dyad. Family caregivers are healthier when they enjoy the caregiving experiences, have a better relationship, and feel a reciprocal bond with their relative with dementia (Brodaty & Donkin, 2009). Findings from the current study support The Stress Process Model (Pearlin et al., 1990) subjective indicators of stress.
such as relational deprivation. Participants felt the effects of relational deprivation and wanted to address these areas of concern.

Education programs and support services should focus on strategies that will enhance the relationship between family caregivers and persons with dementia. Secondary role strain involves roles and responsibilities, such as work responsibilities and social constriction, outside the caregiving situation (Pearlin et al., 1990). Secondary intrapsychic stressors include loss of self, lack of caregiver competence, absence of caregiving gains, and guilt (Aneshensel et al., 1995; Pearlin et al., 1990). Secondary role strain was shown by participants in the current study as illustrated by goals included in the codes balance needs of others and socialize with others.

5.1.3 Category: Developing Skills

The category labelled as developing skills illustrated participants desire to learn and improve skills for caregiving-related tasks. The most frequently expressed code in the category was communication skills to manage behaviours. This finding displayed the significance of teaching communication skills that would allow family caregivers to manage communication impairments of a relative with dementia. This differentiated from the code communication within the dyad, in the category labelled as enhancing relationships, because the code communication skills to manage behaviours focused on developing task-related skills. The code, communication within the dyad, focused on increasing the quantity and quality of communication of the caregiving dyad. Participants wanted to gain skills that would teach them how to communicate better with their relatives with dementia. Specifically, participants wanted to learn skills to address dementia-related impairments, such as repeated questions from a relative with dementia. Additionally, they wanted to gain more confidence so they could handle communication issues accordingly. Participants in the current study were much more concerned with developing skills specific to communication compared to learning skills to manage situations in general. Findings from the current study illustrated participants are aware communication strategies will help with task-focused caregiving duties. This exemplified the importance of communication strategies to manage behaviours in
education programs and support services. The frequent goal of communication skills to manage behaviours illustrates family caregivers feel negative effects of behaviours. However, they feel they can modify the behaviours of their relative with dementia by learning better communication strategies. Further, it shows that family caregivers want to modify their behaviour to support their relative with dementia and improve the caregiving experience.

Consistent with previous literature on unmet needs, findings from the current study show family caregivers’ desire to develop skills (Diehl-Schmid et al., 2013; Ducharme et al., 2011; Farran et al., 2002). Family caregivers expressed the need to develop skills in communication to manage responsive behaviours, to manage conflicts, and to assist with ADLs through the progression of dementia (Diehl-Schmid et al., 2013; Ducharme et al., 2011; Farran et al., 2002). Similar to the current study’s findings, family caregivers needed skills to enhance their communication when managing responsive behaviours exhibited by their relative with dementia (Kerssens et al., 2015; Ducharme et al., 2009; Farran et al., 2002). Effective communication strategies may assist with conflict resolution. Moreover, family caregivers need help managing ADLs, such as feeding (Farran et al., 2002). ADLs and IADLs are often targeted in education programs and support services because they focus on the deterioration of skills of persons with dementia (Bouwens et al., 2008; Kerssens et al., 2015). Participants in the current study did not often express goals for ADLs, as indicated by its low frequency. When ADLs were a goal, participants expressed goals focused on gauging their relatives’ reactions before assisting with ADLs. Participants were focused on developing skills to support the autonomy and independence in their relative with dementia.

Findings from the current study revealed participants wanted to manage situations in their caregiving context and learn how to control symptoms. Developing skills to address the cognitive decline of persons with dementia and managing responsive behaviours more effectively was reported in the literature by family caregivers (Farran et al., 2002; Steiner et al., 2016). Findings from the current study and in previous studies suggest that family caregivers want to learn ways to understand the
changes that should be expected due to the progression of dementia and strategies to provide care specific to each type of dementia (Chui et al, 2010; Diehl-Schmid et al., 2013; Ducharme et al., 2011; Farran et al., 2002).

Goals for the category labelled as developing skills is likely an indication that caregiver experience objective burden. Objective burden includes time infringement on the lives of family caregivers (Savundranayagam & Montgomery, 2010). Family caregivers feel the effects of the caregiving responsibilities and want to develop skills to ease the impact. Higher levels of objective burden are associated with greater levels of cognitive and physical impairments which lead to increased dependency of persons with dementia (Diehl-Schmid et al., 2013). Goals for the category labelled as developing skills display an increase in caregiving responsibilities. Family caregivers feel the responsibility to provide care for their relative with dementia. In fact, professional hired help does not always relieve family caregivers’ objective burden (Bailes et al., 2016). Education programs and support services should be aware that family caregivers want to feel more confident in their own skills when providing care to their relative with dementia. Family caregivers want to provide care for as long as possible (Steiner et al., 2015). Therefore, it is imperative that education programs and support groups address goals for developing skills of family caregivers across the caregiving career.

Goals in the category labelled as developing skills illustrated family caregivers desire to address developing skills to manage impairments of their relative with dementia more effectively. Primary stressors are directly linked to the disease profile of family members with dementia and include factors such as functional status, communication impairments, and responsive behaviours (Pearlin et al., 1990). Distress caused by objective indicators may be resolved if family caregivers feel more prepared and have the skills to address the cognitive function of their relative with dementia. Education programs and support services that address objective indicators for problematic behaviours, such as repetitive questions and resistance to care, may lower negative caregiving outcomes if their family caregiver feels more prepared. As
mentioned previously, support is needed to provide family caregivers with the tools they need to manage their caregiving context.

5.1.4 Category: Supporting Outlook of a Relative with Dementia

Goals included in the category labelled as supporting the outlook of a relative with dementia illustrated participants’ concern for the wellbeing of their relatives with dementia. For example, participants most frequently expressed goals that would help them calm their relatives’ distress. Moreover, the category supporting outlook of a relative with dementia revealed family caregivers are concerned with how they can modify their actions in order to address anxiety or distress of their relatives with dementia. Anxiety and distress of family caregivers are often reported unmet needs (Austrom et al., 2014). However, the results from studies using unrestrictive methods prior to an education and training program revealed participants also experience these negative emotions as a result of their relatives’ anxiety and distress. These findings show that family caregiving does not solely include task-related duties. Family caregivers experience stress because of pressures to support the emotional needs of their relative with dementia. It may be of value to teach strategies to family caregivers to help calm distress or ease anxiety of their relatives with dementia. Addressing goals for the category labelled as support outlook of a relative with dementia not only addresses the unmet needs of support of family caregivers, but may prove to have positive effects on their relative with dementia. It may benefit the relationship of the caregiving dyad if a family caregiver is able to provide more emotional support to their relative with dementia. Education programs and support services should consider family caregivers’ goals for supporting outlook of their relative with dementia because displayed caregiver distress can occur outside of the impairments of their relative with dementia.

Goals and unmet needs for supporting the outlook of a relative were not evident within the parameters set by the literature review. In other words, this was a unique goal. Typically, family caregivers wanted to support their relative with dementia by fulfilling their unmet needs (Kerssens et al., 2015). Maintain independence was the only code from the current study’s findings that aligned with previous research on goals and
unmet needs of family caregivers for the category labelled as support outlook of relative with dementia. Family caregivers wanted to support their relative with dementia in a manner that did not make them resentful of dependency. They wanted to support their relative with dementia as much as needed by allowing their relative with dementia to remain as independent as possible. Family caregivers wanted skills to maintain safety for persons with dementia but found it difficult to find balance to give their relative an appropriate amount of independence (Karlsson et al., 2015; Samia et al., 2012).

The category labelled as supporting outlook of a relative with dementia aligns with stressors of family caregivers of persons with dementia (Pearlin et al., 1990). As mentioned in the previous sections family caregivers experience primary and secondary stressors as a result of their caregiving context. Family caregivers want help to provide better emotional support to their relatives with dementia. Additionally, intrapsychic factors such as personality and competence are indicators of caregivers’ stress (Brodaty & Donkin, 2009). Family caregivers who have the personality and competence to support the outlook of their relative with dementia may prove to be less effected by negative outcomes of caregiving for persons with dementia.

5.1.5 Category: Learning about Dementia

The category labelled as learning about dementia involved gaining knowledge and understanding of dementia and the related symptoms. Learning about dementia remained a goal of participants even though family caregivers in the current study attended an education program prior to enrolling in the education and training program. Participants in the current study wanted to learn about dementia and wanted to understand why their relative engaged in responsive behaviours. Although infrequently expressed, this category is significant because it shows that family caregivers want to learn more about dementia even if they have previously attended a dementia training program. In previous research, family caregivers of persons with dementia had goals and unmet needs to seek more education to gain an understanding of dementia and the progression of the syndrome with the use of restrictive methods (Black et al., 2013; Tanner et al., 2015) and unrestrictive methods (Chui et al., 2013;
Diehl-Schmid et al., 2013; Ducharme et al., 2003; Farran et al., 2002; Gaugler et al., 2004; Samia et al., 2012). Family caregivers wanted more information on resource referrals and education programs (Black et al., 2013; Tanner et al., 2015), wanted to gain a better understanding of behaviours of their relative with dementia (Samia et al., 2012), and wanted to learn about the progression of the syndrome (Chui et al., 2013; Diehl-Schmid et al., 2013; Ducharme et al., 2009; Farran et al., 2002; Gaugler et al., 2004). Education programs and support services to improve knowledge and understanding about dementia may address family caregivers’ distress when managing challenges related to the functional health of persons with dementia.

Learning about dementia illustrated that family caregivers want to learn about dementia as they experience changes in their relative with dementia. Seeing the impairments in a relative with dementia can be overwhelming which leads to increased needs for support from education programs and support groups (Thompson & Roger, 2013). Family caregivers want to provide care at home as long as possible (Pearlin et al., 1990; Savundranayagam, 2014). Therefore, education should be ongoing and available to family caregivers of persons with dementia. In order to provide more targeted care about dementia, developers of education programs and support services should consider the specific needs of learning about dementia. Family caregivers will witness many changes in their relative with dementia (Mendez & Cummings, 2003) and should have the opportunity to learn about the changes as they witness them.

Education programs and support services that address goals for dementia knowledge may increase the understanding of why their relative with dementia is exhibiting responsive behaviours. Improved knowledge and understanding of dementia may help address goals in the other categories previously mentioned. Learning about dementia is a background factor that may enhance caregivers’ skills and understanding (Pearlin et al., 1990). Learning about dementia may contribute to the effectiveness of developing skills, supporting outlook of a relative with dementia, enhancing relationships, and managing caregiver’s emotions. After family caregivers attend an education program on dementia, they are able to learn skills that address impairments
of their relative with dementia. Learning about dementia may improve caregivers’ understanding which can contribute to enhanced relationships between family caregivers and their relatives with dementia (Eifert, Adams, Dudley, & Perko, 2015).

5.2 Goals that Vary Across the Caregiving Career

The secondary aim of the current study was to investigate how the goals of family caregivers prior to an education and training program vary across the caregiving career. The needs of family caregivers have yet to be thoroughly recognized without the influence of researchers or clinicians (Bangerter et al., 2017). The needs of family caregivers vary over time, but, to date, education and training programs and support services have yet to respond to the changing needs of family caregivers (Samia et al., 2012). There is value in looking at the goals of family caregivers across the caregiving career to determine how education programs and support services can offer targeted support at the appropriate time (Reinhard et al., 2016).

Relationship identity is the extent to which participants viewed their relationship in terms of the familial role and the caregiver role. The outer-most pie charts (see Figure 1a and 1e) represent a more stable relationship identity. Figure 1c represents a relationship identity that is in transition (i.e., familial role to caregiver role or caregiver role to familial role). The variability of family caregivers’ relationship identity displays the dynamic nature of the caregiving career. Further, the dynamic nature of caregiving is exemplified by the variability of family caregivers’ goals across the caregiving career (see Figure 3). The current study examined goals of participants who identified with the familial role primarily (see Figure 1a and 1b), the caregiver role primarily (see Figure 1d and 1e), and equally the familial and caregiver roles (see Figure 1c). Categories of goals of participants from the current study, using an unrestrictive method prior to an education and training program, are illustrated in pie charts reflected by participants’ relationship identity (see Figure 3).
Figure 3. Categories of Goals Reflected by Relationship Identity

5.2.1 Categories Reflecting the Familial Role Primarily

Figure 3 displays how goals from the current study vary across the caregiving career. Participants whose relationship identity comprised the familial role primarily most frequently expressed goals within the category labelled as enhancing relationships (see Figure 3a). This shows that family caregivers who are in the initial stages of the caregiving career are more likely to have goals for enhancing relationships by strengthening the reciprocities of the caregiving dyad. Maintaining strong relationships, especially for the caregiving dyad, was important for participants who identified with the familial role primarily. In other words, participants want to connect with their relative with dementia in terms of their familial roles such as adult-child and spouse/partner.

As mentioned in the previous section, strengthening familial relationships can have positive outcomes for family caregivers. Dyads with supportive relationships had significantly lower caregiver burden (Reblin et al., 2015). Positive caregiver health outcomes, such as higher caregiver self-esteem, lower caregiver burden, and fewer health problems, were associated with a stronger relationship with their relative (Reblin
et al., 2015). A positive relationship between family caregivers and persons with dementia is associated with increased well-being, better problem solving skills, lower burden, decrease in depressive symptoms, better mental health of the family caregiver, slower cognitive and functional decline, and fewer behavioural symptoms of the persons with dementia (Fauth et al., 2012). Healthy relationships between the family caregiver and persons with dementia are linked with positive aspects of caregiving, feelings of caregiver competence, and slower rate of cognitive decline in the persons with dementia (Brodaty & Donkin, 2009; Norton et al., 2009; Quinn et al., 2012; Reinhard et al., 2016). Positive relationships have beneficial outcomes for the caregiving dyad, such as less strain on the relationship. Higher levels of relationship burden may lead to the decision of family caregivers to relocate their relatives with dementia to a long-term care home (Savundranayagam et al., 2011). Program objectives that target enhancing relationships should be considered a vital component for education programs and support services because positive relationships result in healthier outcomes for family caregivers and their relative with dementia (Reblin et al., 2015; Reinhard et al., 2016).

Awareness of family caregivers’ goals that align with relationship identities can be a beneficial approach to offering education programs and support services to family caregivers and their relatives with dementia. Offering education programs and support services with objectives to enhance relationships to family caregivers who are in the earlier stages of the caregiving career, or who identify with the familial role, can improve health outcomes and build stronger relationships (Brodaty & Donkin, 2009; Norton et al., 2009; Quinn et al., 2012; Reinhard et al., 2016). Education programs and support services with the objective of enhancing relationships can teach family caregivers strategies to develop and maintain their relationships, ways to facilitate socialization, and techniques to balance the needs of family caregivers, their relatives with dementia, and others outside the caregiving dyad. Targeted support services offered in a timely manner may result in less negative health outcomes for family caregivers and relatives with dementia can stay at home longer (Feinberg, 2017).
Additionally, targeted support promises lowered costs to the health care system because services will be more effective in ordering targeted needs of family caregivers (Brodaty & Donkin, 2009).

Although enhancing relationships was the most frequently expressed category of goals from participants in the current study, goals for the categories supporting outlook of a relative with dementia, managing caregiver’s emotions, and developing skills were also goals of participants who identified with the familial role primarily. Supporting outlook of a relative with dementia and managing caregiver’s emotions were categories of moderate importance for participants in the current study (see Figure 3a). Both the categories supporting outlook of a relative with dementia and managing caregiver’s emotions involve the emotions and wellbeing of the family caregivers and their relatives with dementia. When participants identified with the familial role primarily, family caregivers are equally concerned with addressing goals for their emotions as they are for addressing their relatives’ emotions. In other words, family caregivers do not prioritize managing their own emotions over the emotions and outlook of their relative with dementia. Developers of education programs and support services should have an understanding of family caregivers’ priorities of goals and how they view their relationship identity. Teaching strategies for managing caregiver’s emotions and supporting outlook of a relative with dementia should be included in education programs and support services.

Developing skills was the least frequently expressed category of goals for participants who identified with the familial role. Often, family caregivers provide additional support outside the initial familial role in the earlier phases of the caregiving career. However, the caregiving duties are less intensive and family caregivers continue to identify with the familial role primarily (Montgomery & Kosloski, 2013). In other words, until the caregiving duties become more intensified, family caregivers do not consider themselves as caregivers. The current study provides further support that family caregivers who identify with the familial role primarily do not prioritize caregiving tasks and want to focus on relationships of the caregiving dyad and with others.
Based on the findings from the current study, learning about dementia was not a category of goals that was apparent for family caregivers who identified with familial role primarily. Family caregivers may not see the impairments in their relative with dementia in the earlier stages of the caregiving career and do not feel the need to learn about dementia. Participants who identified with the familial role did not want to gain more knowledge about dementia. Participants may not view their relative in terms of a diagnosis of dementia. Therefore, they want to support their relative by enhancing relationships or supporting emotions of the caregiving dyad.

5.2.2 Categories Reflecting the Caregiver Role Primarily

Participants whose relationship identity comprised the caregiver role primarily most frequently expressed goals for the category labelled as managing caregiver’s emotions. The category labelled as managing caregiver’s emotions reflected caregivers desire to be in control of their own emotions. Positive emotions can improve the caregiving experience and enhance the relationship of the caregiving dyad. Negative emotions, such as anger and anxiety, can negatively impact the caregiving experience (Fauth et al., 2012; Montgomery & Kosloski, 2013; Pearlin, 1990). Results from the current study revealed that family caregivers who identified with the caregiver role primarily most often wanted to control their own emotions. In fact, none of the participants who expressed goals on addressing negative emotions, such as anger, identified with the familial role primarily. This revealed family caregivers who experience anger no longer identify with the familial role primarily. The ramifications of negative emotions are impacting the caregiving experience and the relationship of the caregiving dyad. As caregiving duties increase in quality and quantity, or tasks are outside the relationship identity, family caregivers experience greater levels of caregiver burden (Montgomery & Kosloski, 2013). Participants who identified with the caregiver role primarily experience a wider range of emotions that need to be addressed in order to improve the caregiving experience. For example, as mentioned in Chapter 4, the code understanding, included goals only written by participants who identified with the caregiver role primarily. Family caregivers have a difficult time adjusting to the
additional caregiving responsibilities (Eifert et al., 2015). If family caregivers lack understanding and acceptance, they may be unwilling to attend education programs and support services available to support the needs of their relative with dementia at the most appropriate time (Eifert et al., 2015).

Negative caregiver’s emotions impact the caregiving career and may result in premature relocation to long-term care. Additionally, family caregivers who experience negative emotions contribute to higher costs in the health care system because they have poorer health and seek medical support more often for themselves and their relative with dementia (Adelman et al., 2014; Brodaty & Donkin, 2009; van der Lee et al., 2017). Negative emotions affect the quality of care provided (Aminzadeh et al., 2005) and can increase the likelihood of premature relocation to institutional settings for the family member with dementia (Alzheimer Society Canada, 2015; Luppa, Luck, Brahler, Konig & Riedel-Heller, 2008; Mittelman et al., 2006; Schulz, O’Brien, Bookwala & Fleissner, 1995). Family caregivers who lack effective coping skills to managing their caregiving context have lower self-efficacy, higher levels of depressive symptoms, anxiety, and higher rates of morbidity (Sorensen & Conwell, 2011).

The category labelled as developing skills was frequently expressed by participants who identified with the caregiver role primarily. This illustrates family caregivers have more goals for developing skills as they progress through the caregiving career. In the later phases of the caregiving identity theory, family caregivers begin to take on care tasks outside the initial familial role (Montgomery & Kosloski, 2013). Findings from the study are consistent with the caregiver identity theory because participants’ goals indicated that care tasks were increasing in quantity and intensity (Montgomery & Kosloski, 2013). The goals in the category labelled as developing skills focused on skills and strategies to manage behaviours and the progression of dementia. Thus, the participants want to develop more skills to address the impairments or caregiving duties. Further, as caregiving duties increase, family caregivers can experience more caregiver burden, especially when the tasks are discrepant from the relationship identity (Montgomery & Kosloski, 2013). Family caregivers may identify
with the caregiver role primarily because they are completing more tasks or they feel the pressures of more negative outcomes of caregiving. For example, a caregiver may feel impatience with their relative with dementia because of the time infringement of completing caregiving duties. This time infringement contributes to objective burden of the family caregiver (Savundranayagam & Montgomery, 2010). These findings are important because it illustrates family caregivers shift away from the familial role and to the caregiver role predominately when their priorities are managing behavioural difficulties and the progression of dementia. Family caregivers who are focused on skills to manage dementia-related impairments no longer identify with the familial role.

The category labelled as learning about dementia was expressed only by participants who identified with the caregiver role primarily. Family caregivers who have progressed in the caregiver career may need additional education programs to address the impairments of their relative with dementia. Family caregivers who identify with the familial role primarily may not express goals for learning about dementia because they still view their relative as the initial familial role (i.e., spouse or parent). This reveals family caregivers who identify with the caregiver role primarily are more likely to need services to manage their own stress. Participants who wrote goals included in the category labelled as learning about dementia identified with the caregiver role primarily. Participants who wrote goals included in the category labelled as learning about dementia may identify with the caregiver role primarily because they are doing tasks outside of the initial familial role. As persons with dementia become more dependent, the dyadic relationship with their family caregiver can become more challenging (Montgomery & Kosloski, 2013; Pearlin et al., 1990). Family caregivers experience negative outcomes as a result of lack of caregiver skills and competence (Pearlin et al., 1990). Learning about dementia may improve caregiver understanding which can lead to a positive relationship between family caregivers and their relatives with dementia (Eifert et al., 2015).
5.3 Value of Addressing Goals of Family Caregivers that Vary Across the Caregiving Career

The findings from the current study revealed that participants have goals for categories labelled as enhancing relationships, managing caregiver’s emotions, developing skills, and supporting outlook of a relative with dementia across the caregiver career (see Figure 3). The category labelled as enhancing relationships has the general distribution of higher frequency of goals by participants who identified with the familial role primarily and less frequently when participants identified with the caregiver role primarily. Managing caregiver emotions and developing skills becomes increasingly more expressed as family caregivers move through the caregiving career.

The category labelled as supporting outlook of a relative with dementia included goals written by participants who identified with all phases of the caregiving career. This indicates that family caregivers of persons with dementia are concerned about their relatives’ emotions, whether the family caregiver identified with the familial role primarily or with the caregiver role primarily. The general even spread of frequency of goals across the phases of the caregiving career informs us about the value of teaching family caregivers ways to support the outlook of the relative with dementia across the caregiving career. These findings have implications for the design of education programs and support services. In particular, such programs and services should take into account the caregivers’ desire to support the outlook of their relative with dementia throughout the caregiving career. Caregiver programs must not be limited to caregiver needs because their goals involve enhancing the experience of their relative with dementia. Moreover, these goals are relevant at all phases of the caregiving career. The category labelled as supporting outlook of a relative with dementia included goals that were generally spread across the caregiving career. Figure 3 illustrates that participants who identified equally with the familial and the caregiver roles were concerned with supporting outlook of a relative with dementia. Participants who identified with the familial role or identified equally with the familial and the caregiver roles more frequently expressed goals for the category supporting outlook of a relative with
dementia compared to participants who identified with the caregiver role primarily. However, supporting outlook of a relative with dementia remained a goal for participants who identified with the caregiver role primarily. This informs us that family caregivers are concerned about supporting outlook of their relative with dementia throughout the caregiving career. Family caregivers may be concerned with their relatives’ outlook because they notice a change in their behaviours or they are aware of impairments caused by dementia. Goals for the category supporting outlook of a relative with dementia reveal family caregivers are concerned about the emotions of their relative with dementia generally to the same degree throughout the caregiving career.

Assessing relationship identity of family caregivers of persons with dementia is a useful strategy to guide the delivery of education programs and support services (Montgomery & Kosloski, 2013). Family caregiving is a dynamic and iterative process that requires flexible support. Education programs and support services may be underutilized or less effective because of lack of targeted outcomes to the specific needs of family caregivers at the appropriate times (Montgomery & Kosloski, 2013; Reinhard et al., 2016). Significant changes in the caregiving context leads to a shift in relationship identity and can result in increased distress for family caregivers if family caregivers feel the caregiving duties exceed the initial familial role (Montgomery & Kosloski, 2013). For example, a daughter who provides caregiving duties to a parent, such as grooming, has higher distress because these tasks are not typical of the initial familial role. Moreover, in a progressive condition or syndrome, such as dementia, caregiving tasks may consume the relationship (Pearlin et al., 1990). Changes in the relationship due to stress can negatively impact the relationship between the family caregiver and persons with dementia, thus impacting the caregiving experience (Quinn, et al., 2012). When caregivers appraise care tasks to be discrepant with the relationship identity, the resultant distress is manifested as objective burden, relationship burden and stress burden (Montgomery & Kosloski, 2013).

Goals and unmet needs of family caregivers are a growing concern of policy
makers (Reinhard et al., 2016). However, there has yet to be a method that best assesses the unmet needs of family caregivers (Bangerter et al., 2017). Education programs and support services need to align program objectives with the goals and unmet needs of family caregivers. Yet, goals of family caregivers vary across the caregiving career. Further, goals vary in level of importance depending on the family caregivers’ relationship identity. To better support family caregivers, programs and services cannot occur in isolation. For example, they cannot focus on teaching communication skills without incorporating the following into their care plan: caregiving context (i.e., social support from other caregivers, level of impairment of the relative with dementia, etc.), the level of support the caregiver provides, the self-assessment of their goals, and their expectations/standards for their relationship with their family member with dementia. Addressing goals at a relevant time for family caregivers may prove to lower caregiver distress because the goals address the unmet needs and behaviours in the caregiving context. The influence of categories on other categories displays the benefit of offering multicomponent education programs and support services. No single intervention will adapt to the changing needs of family caregivers. Therefore, it may be beneficial to offer education programs and support services that address the specific needs across the caregiving career (Bangerter et al., 2017).

Education programs and support services that teach the development of skills may lead to improved understanding and patience. Negative emotions can arise from the caregiving context. Goals that address managing caregiving emotions can be targeted when family caregivers have developed skills to manage dementia-related impairments. Education programs and support services should better support managing caregiver emotions. Skilled family caregivers are more sensitive to the needs of their relative with dementia and respond more appropriately to the needs of their relative with dementia (Farran et al, 2003). Family caregivers may feel better adjusted to their caregiving context if they can understand their emotions and understand reasons for dementia-related impairments (Eifert et al., 2015). Uniform supports will not be effective in supporting family caregivers of persons with dementia because the
caregiving context is unique (Montgomery et al., 2016; Montgomery & Kosloski, 2013) and the needs vary across the caregiving career. Program effectiveness is challenged by the differing needs of family caregivers (Montgomery et al., 2016) for different relationship identities. The findings of this study provide insight into the relationship between goals of family caregivers of persons with dementia and goals across the caregiving career.

5.4 Limitations and Directions for Future Research

Although the findings of the study provide initial information about goals of family caregivers and how goals vary across the phases of caregiving, the findings are limited by study design and sample. The findings may not be generalizable because participants were limited to London, Ontario. Future research on goals of family caregivers of persons with dementia might consider expanding the number of participants by recruiting from a larger geographical location (e.g., rural vs. urban), more diverse ethnicity group (e.g., culturally and linguistically diverse – CALD groups) and different family caregivers (spouse vs. adult children vs. daughter and son in-laws). Additionally, future research must take into consideration family caregivers’ different experiences of previous education and training programs and how it may determine if categories of goals are consistent with findings of the current research. Participants in the current study previously had attended an education program. Goals in the category labelled as learning about dementia may be less frequent because of the previous education experience. Family caregivers who have not attended education programs may have more goals for learning about dementia.

Future research should consider how kinship may impact the categories of goals of family caregivers. The current study did not investigate how goals vary by kinship. Family caregivers may have different goals or identify with a different phase of the caregiving career depending on the relationship with their relative with dementia. Further investigation into kinship may provide a better understanding of goals of family caregivers of persons with dementia over the caregiving career. For example, spouses may have a different goal focus than adult-children or in-laws, or spouses and adult-
children may have similar goals but have a different relationship identity. The recent work of Purves and Phiney (2012) shows that different members of the same family can hold widely different perspectives on their needs/goals versus those of their relative with dementia.

Confirming the goals across the phases of the caregiving career might be undertaken by using directive content analysis. Directive content analysis is driven by prior research or theoretical frameworks about a phenomenon (Hsieh & Shannon, 2005). Initial coding and operational definitions of categories from the current research could be used to target questions to gain a better response to fit within the predetermined categories (Hsieh & Shannon, 2005). Using data from the current study, with the combination of directive content analysis, may further prove to provide validity for the types of goals and how goals vary across the phases of the caregiving career. In addition, a better understanding of family caregivers’ goals for different phases of the caregiving career may provide an extension of the caregiver identity theory. Further research can investigate categories of goals from the current study and determine if the categories are consistent with the different phases of caregiving career.

Goals of family caregivers were not weighted by level of importance. Goals of any kind were considered of value because research is limited on the types of goals prior to an education program (Black et al., 2013; Blom et al., 2015; Gallagher et al., 2011; Schinkothe et al., 2015). Future research should investigate the most important goals of family caregivers. Personalized goal setting may facilitate better education programs and support services that may target negative outcomes of caregiving more effectively (Toto et al., 2015). Goal attainment scaling (GAS) allows for the person with dementia and the family caregiver to express his/her desired goals, weigh the goals of importance and define levels of accomplishment (Bouwens et al., 2008). Focus on individualized treatment planning using GAS holds great potential because it personalizes goals, thus, maximizing the quality of life for persons with dementia and their family caregivers versus traditional global planning activities which attempt to cater to all needs of all individuals (Bouwens et al., 2008). GAS can be adapted to any level or domain of the
international classification of functioning, disability, and health thereby, covering all aspects of life as a whole (Bouwens et al., 2008), which would be beneficial for family caregivers of persons with dementia due to the dynamic nature of caregiving. Future research should consider using GAS when offering education programs and support services to design targeted interventions, to determine the effectiveness of the programs, and/or to determine what goals are of higher priority for family caregivers of persons with dementia.

5.5 Conclusion

A better understanding of the goals and unmet needs of family caregivers of persons with dementia is crucial for the future of family caregiver, agency providers and the health care system (Feinberg, 2017; Reinhard et al., 2016). What we do know about the goals and unmet needs of family caregivers is often a reflection of the needs of their relative with dementia (Bangerter et al., 2017). This study sought to identify the goals of family caregivers of persons with dementia and to examine how their goals vary across the caregiving career. A better understanding of family caregivers’ goals is essential to lessen negative health outcomes of family caregivers and will help advance targeted education programs and support services (Marziali et al., 2010). Family caregivers are an integral component of the caregiving team because they provide the majority of care. However, education programs and support services have yet to respond to the changing needs of family caregivers of persons with dementia (Samia et al., 2012). Consequently, family caregivers are unable to address negative health outcomes if the program is not relevant to them at the time the program is being offered. In addition, the needs within the caregiving context may change over the phases of the caregiving career. It is necessary to offer education programs and support services that are flexible, offered in a timely manner, and specific to the needs of caregivers (Ducharme et al., 2009; Gaugler et al., 2004; Vernooij-Dassen, Joling, van Hout, & Mittelman, 2010).

Primary and secondary stressors are components of The Stress Process Model (Pearlin et al., 1990). Findings from the current study reveal family caregivers of persons with dementia have goals that address primary and secondary stressors. Each caregiving
context is unique and includes varying levels of needs which contributes to inconsistent findings of education programs and support services (Montgomery et al., 2016). Education programs and support services need to gain a better understanding of goals of family caregivers of persons with dementia so their goals can be addressed to decrease negative health outcomes and increase positive care experiences. Moreover, more effective education programs and support services involve multicomponent programs to address the multiple areas of stress of family caregivers (Montgomery et al., 2016). Family caregivers have different priorities and needs at different stages of their caregiving career. The goals and unmet needs of family caregivers involve different categories of goals at different phases of the caregiving career. However, earlier phases may have more focus on relationship development, whereas, later phases focus on managing caregiver’s emotions or developing skills. Multicomponent programs for different relationship identities can address skill building and support the emotional impact for family caregivers. A decrease in the negative impacts of caregiving and improved program effectiveness may occur if multicomponent programs are offered to family caregivers when family caregivers require the support.

Education programs and support services that are flexible, timely, and targeted to the needs of the caregiver may prove to be a more promising avenue compared to standardized education program and support services (Gaugler & Teaster 2006). Learning about goals of family caregivers of persons with dementia and offering education programs and support services to target specific goals may prove to lessen negative outcomes (Montgomery & Kosloski, 2013). Education programs and support services should address the needs for learning about dementia, skill development, managing caregiver’s emotions, support outlook of a relative with dementia, and enhancing relationships. An understanding of goals of family caregivers of persons with dementia and changes across the caregiving career should be critical to minimize negative caregiver outcomes and increase program effectiveness (Steiner et al., 2016). Integrating goals of family caregivers based on relationship identity can prove to address family caregivers’ goals at appropriate times.
This study provides initial insights into family caregivers’ goals across the caregiving career. Due to the progressive nature of dementia and the changing needs of persons with dementia, family caregivers require different supports across the caregiving career (Keady & Nolan, 2003; Montgomery & Kosloski, 2013). Education programs and support services have been used to address negative outcomes associated with caregiving for persons with dementia, but, have yet to reveal consistent and significant results (Gaugler et al., 2010). Education programs and support services may be more suitable when family caregivers of persons with dementia are grouped together by similar goals or relationship identity (Gaugler & Teaster, 2006). Education programs and support services should align program outcomes to the goals of family caregivers at the appropriate time (Montgomery & Kosloski, 2013; Wilz et al., 2011).
References


methodological strategies and key recommendations. *Journal of Applied Gerontology, 00(0),* 1-15. DOI: 10.1177/0733464817705959


Appendices

Appendix A: Ethics Approval Form

Western University Health Science Research Ethics Board
HSREB Annual Continuing Ethics Approval Notice

Date: February 02, 2017
Principal Investigator: [Redacted]
Department & Institution: Health Sciences, Western University

Review Type: Delegated
HSREB File Number: 106097
Study Title: Building Family Caregiver Skills for Managing Behavioural Problems in Dementia: Development, Implementation, and Evaluation of a Novel Training Approach

HSREB Renewal Due Date & HSREB Expiry Date:
Renewal Due: 2017/12/31
Expiry Date: 2018/01/28

The Western University Health Science Research Ethics Board (HSREB) has reviewed the Continuing Ethics Review (CER) Form and is re-issuing approval for the above noted study.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice (ICH E6 R1), the Ontario Freedom of Information and Protection of Privacy Act (FIPPA, 1990), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

[Signature]
Ethics Officer, on behalf of [Redacted]

Western University, Research Support Services Bldg., Rm. 5150
London, ON, Canada N6G 1X9 t. 519.661.3036 f. 519.850.2466 www.uwo.ca/research/ethics
Appendix B: Inclusion Criteria

- Age 18 years or older
- Completed either the [First Link program](#) or the [Alzheimer's Outreach Services](#) Caregiver Education series
- Family caregiver of a person with dementia
- Provide at least four hours/week of caregiving responsibilities to a family member with dementia
- Able to attend all training sessions
- Sufficient communication skills in English to participate in the training program
- Consent to audio and video recording of training sessions
Appendix C: Letter of Information

**Project Title:** Building Family Caregiver Skills for Managing Behavioural Problems in Dementia: Development, Implementation, and Evaluation of a Novel Training Approach

**Principal Investigator:** Marie Savundranayagam, PhD, Western University, Faculty of Health and Rehabilitation Sciences

**Co-Investigators:** JB Orange, PhD, Western University, School of Communication Sciences and Disorders and Angela Roberts, PhD, Post-doctoral Fellow Lawson Health Research Institutes

**Research Partners:** Alzheimer’s Outreach Services, London Ontario

**Funding Sources:** Behavioural Supports Ontario and WCA, London, Ontario

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**Letter of Information**

**Invitation to Participate**

You are being invited to participate in a research study that evaluates the effectiveness of a family caregiver education and training program in reducing the frequency of and reactions to problem behaviours exhibited by your family member with dementia.

**Purpose of the Letter**

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

**Purpose of this Study**

The purpose of this study is to develop and to evaluate the effectiveness of a novel family caregiver-training program that addresses *proximal* factors vs. *background* factors. *Proximal* factors are those unmet physical needs, unmet psychological needs, environmental factors, and social factors that contribute to problem behaviours in dementia. In contrast, typical caregiver-education programs focus on *background* factors or the brain changes and associated declines in thinking and language abilities that are expected in dementia.

**Inclusion Criteria**

Individuals who meet the following criteria are eligible to participate in this study:

- Age 18 years or older
- Completed either the [First Link program](#) or the [Alzheimer’s Outreach Services Caregiver Education series](#)
- Family caregiver of a person with dementia
- Provide at least four hours/week of caregiving responsibilities to a family member with dementia
- Able to attend all training sessions
- Sufficient communication skills in English to participate in the training program
- Consent to audio and video recording of training sessions

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

**Study Procedures**
There will be a total of 40 participants in this study. Participants will be assigned randomly (i.e., like a flip of the coin) to one of two training sessions (Immediate and Delayed). The Immediate group will complete the training program first. The Delayed group will complete the training program second following the Immediate group. Participants in the Delayed group will participate in one additional study session.

If you agree to participate, you will be asked to complete the following tasks:
- Attend 7 (Immediate group) or 9 (Delayed group) study sessions;
- Consent to being video and audio recorded;
- Actively engage with other participants during training sessions;
- Practice using the skills learned in activities that simulate everyday behavioural problems exhibited by people with dementia;
- Complete a series of established questionnaires and assessments that measure caregiver depression, caregiver burden, dementia severity in your family member with dementia, frequency of and severity of reactions to problem behaviours, communication problems exhibited by and strategies used with your family member with dementia;
- Set weekly learning goals.

If you choose to participate, each study session will require approximately two hours of your time. All study sessions will be held at McCormick Home in London, Ontario.

Below is a brief description of each session:
- **Session 1**: Program overview and baseline program evaluation data collection
- **Session 2**: Improving communication interactions to prevent and to manage behavioural problems
- **Session 3**: Minimizing behavioural problems while meeting physical needs (e.g., activities of daily living, pain, and other health related issues)
- **Session 4**: Using Montessori-based activities to improve social engagement and minimize behavioural problems
- **Session 5**: Training caregivers in effective techniques for addressing and managing behavioural problems
- **Session 6**: Debriefing, reflection on goals, and post-program evaluation data collection

The following depicts the time involved for participating in the study.

<table>
<thead>
<tr>
<th>Training program</th>
<th>Weeks 1-6</th>
<th>Week 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time involved</td>
<td>Training: 2 hours/week</td>
<td>3-month follow-up: 2 hours</td>
</tr>
</tbody>
</table>
Possible Risks, Harms, and Inconveniences
There is a possible risk for fatigue given the length of the training sessions. Rest breaks and refreshments will be offered every 60 minutes or upon your request in order to minimize fatigue.
For some individuals, there may be a risk for stress or anxiety while completing the questionnaires and assessments. Providing rest breaks and having questionnaires/assessments presented by an experienced researcher are all steps that will help to minimize potential stress, anxiety, and/or discomfort.
The use of audio and video recording equipment can be uncomfortable for some individuals. Audio and video recording equipment will be placed as unobtrusively as possible to minimize the potential for stress and anxiety associated with this component of the training program.
A potential inconvenience is arranging respite care for your family member with dementia. The social workers at [institution] will assist you with this process if required. Respite care for your family member with dementia will be available, free of charge, during the training sessions through the [program] day program.

Possible Benefits
This research project may benefit you by increasing your:
- Knowledge and skills in managing and reacting to problem behaviours in dementia;
- Confidence in your caregiving skills;
- Opportunities to interact with a supportive group of professionals and caregivers;
- Knowledge of available resources to support caregiving processes.

Society as a whole may benefit from this project due to the fact that well-trained caregivers with knowledge and skills in managing problem behaviours in dementia may reduce the need to depend on community support agencies.

Compensation
You will not be compensated for your participation in this research.

Voluntary Participation
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you withdraw from the study, your data collected up until the point of your withdrawal will be kept in the study.

Confidentiality
All data collected will remain confidential and accessible only to the investigators of this study. Your personal health information will not appear on any of the research data. Given that the study will involve a group of individuals, full confidentiality cannot be guaranteed. Moreover, participant faces may be recorded on the video files. During the
course of the training session, it is possible that the video data may contain the first name of a participant. We are leaving the faces identifiable because emotions and reactions to the training may be uniquely conveyed through facial and gestural expressions.

The hardcopy paper research records of your data will be retained for 7 years and stored in the following manner: locked in a cabinet in a locked, secured office in the Aging and Communication Laboratory (Room 2208) in Elborn College at Western University. Electronic research records will be kept for 7 years and stored in the following manner: a secure, password protected, encrypted cloud file storage system. Audio and video data will be saved for 7 years and later archived on a secure drive at Western.

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

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

- Marie Savundranayagam, PhD: Phone (519) 661-2111 (extension 82215): Email msavund@uwo.ca
- JB Orange, PhD: Phone (519) 661-2111 (extension 88921); Email jborange@uwo.ca
- Angela Roberts, PhD: Email

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

Publication
If the results of the study are published your name and video images will not be used. The results of this study may be presented at research conferences or community meetings.

This letter is yours to keep for future reference.
Appendix D: Consent Form

**Consent Form**

**Project Title:** Building Family Caregiver Skills for Managing Behavioural Problems in Dementia: Development, Implementation, and Evaluation of a Novel Training Approach

**Study Investigators’ Names:**

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

Participant’s Name (please print):

_______________________________________________

Participant’s Signature:

_______________________________________________

Date:

_______________________________________________

Person Obtaining Informed Consent (please print):

_______________________________________________

Signature:

_______________________________________________

Date:

_______________________________________________
Appendix E: C-Unit Segmentation Rules

SEGMENTING UTTERANCES INTO C-UNITS

The analysis of oral language samples requires recorded speech to be divided into units. This document describes the rules for segmenting utterances into Communication units (C-units).

A C-unit:
- Is an independent clause with all of its modifiers
- Includes a main clause with all of its subordinating clauses attached to it
- Cannot be further divided without losing its meaning

A Clause:
- Can be the main clause or a subordinate clause
- Contains a subject (i.e. a noun phrase) and a predicate (i.e. a verb phrase)

Example of C-unit that contains a main clause only:

C The wife was angry.

Example of C-unit that contains a main clause and a subordinate clause:

C When the boy look/ed in the jar he saw that the frog was miss/ing.

Coordinating Conjunctions:
- Utterances containing a coordinating conjunction it should be separated into 2 C-units
- Coordinating conjunctions include: and, or, but, so (but not “so that”), and then, then

Example:

C The wife pack/ed her bag.
C and she left him.

Subordinating Conjunctions:
- Subordinating conjunctions link a main clause with a subordinate clause
- Utterances containing a subordinating conjunction should remain as 1 C-unit
- Subordinating conjunctions include: because, that, when, who, after, before, so (that), which, although, if, unless, while, as, how, until, like, where, since,
Example:
   C She came back because she crash/ed the car into a tree.

**Conjunction reduced:**
- Speakers use reduced conjunctions in order to increase efficiency of communication
- To recognize reduced conjunctions, look for C-units that begin with "and" and are missing a subject but contain a verb that refers to the subject mentioned in the previous C-unit

Example:
   C The wife went up to her room.
   C *CONJRED and pack/ed her bag.

*Note: when there is ambiguity about the subject, the *SUBJ code is used instead of the *CONJRED code

**References:**
Appendix F: Codes for Goals

<table>
<thead>
<tr>
<th>Code</th>
<th>Occurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication within the dyad</td>
<td>6</td>
</tr>
<tr>
<td>Patience</td>
<td>6</td>
</tr>
<tr>
<td>Communication skills to manage behaviours</td>
<td>5</td>
</tr>
<tr>
<td>Understanding</td>
<td>4</td>
</tr>
<tr>
<td>Calm distress of relative</td>
<td>4</td>
</tr>
<tr>
<td>Meaningful activities for the dyad</td>
<td>4</td>
</tr>
<tr>
<td>Anger</td>
<td>3</td>
</tr>
<tr>
<td>Caregiver coping</td>
<td>3</td>
</tr>
<tr>
<td>Positive outlook</td>
<td>3</td>
</tr>
<tr>
<td>Acceptance</td>
<td>2</td>
</tr>
<tr>
<td>Enhance caregiver skills</td>
<td>2</td>
</tr>
<tr>
<td>Enjoy the relationship of the dyad</td>
<td>2</td>
</tr>
<tr>
<td>Address conflicts</td>
<td>1</td>
</tr>
<tr>
<td>Balance needs of others</td>
<td>1</td>
</tr>
<tr>
<td>Confidence in caregiver skills</td>
<td>1</td>
</tr>
<tr>
<td>Control symptoms of relative with dementia</td>
<td>1</td>
</tr>
<tr>
<td>Dementia knowledge</td>
<td>1</td>
</tr>
<tr>
<td>Direction</td>
<td>1</td>
</tr>
<tr>
<td>Ease anxiety</td>
<td>1</td>
</tr>
<tr>
<td>Help relative adjust</td>
<td>1</td>
</tr>
<tr>
<td>Help relative with acceptance</td>
<td>1</td>
</tr>
<tr>
<td>Manage situations</td>
<td>1</td>
</tr>
<tr>
<td>Maintain relative’s independence</td>
<td>1</td>
</tr>
<tr>
<td>Quality of life for relative</td>
<td>1</td>
</tr>
<tr>
<td>Skills for ADLs</td>
<td>1</td>
</tr>
<tr>
<td>Socialize with others</td>
<td>1</td>
</tr>
<tr>
<td>Support another caregiver</td>
<td>1</td>
</tr>
</tbody>
</table>
Curriculum Vitae

Name: Shalane Basque

Post-secondary Education and Degrees:

Master of Science, Health and Rehabilitation Sciences
Western University
London, Ontario, Canada
2015-2017

Ontario College Graduate Certificate, Autism and Behavioural Science
St. Lawrence College
Kingston, Ontario, Canada
2010

Bachelor of Arts (Honours), Speech and Language Sciences
Brock University
St. Catharines, Ontario, Canada
2004-2008

Honours and Awards:

Western Graduate Research Scholarship
2015-2017

Kingston Foundation for Autism Spectrum Disorder Award
2010

Brock University Scholarship: Entrance Scholarship
2004

Related Work Experience

Lab Manager
Caregiver Research (CaRe) Lab
Western University
2016-Present

Program Coordinator
Person-Centered Communication for Homecare Staff
Western University
2016-Present

Teaching Assistant
Health Issues in Aging
Western University
2016-2017
Lab Manager
Ontario Neurodegeneration Research Initiative
Western University
2014-Present

Lab Transcriber
International Consortium of Communication, Aging &
Neurodegeneration
Western University
2013-Present

Research Associate
Family Caregiver Education Training
Western University
2014-2015

Research Assistant
Orange Lab
Western University
2013-2014

**Conferences & Research**


Basque, S., Savundranayagam, M.Y., Orange, JB., & Kloseck, M. (2016, October 21). *Discovering goals set by family caregivers of persons with dementia prior to a behavioural interventions.* Poster presentation at the 45th Annual Scientific and Educational meeting of the Canadian Association on Gerontology. Montreal, QC.