

UNDERSTANDING POSITIVE ASPECTS OF THE CAREGIVER EXPERIENCE IN
DEMENTIA: A META-INTEGRATION AND QUALITATIVE INVESTIGATION

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ABSTRACT

This dissertation includes two studies designed to explore the positive aspects of providing care to someone living with dementia. The work reported here provides a knowledge base that benefits future research by allowing for a greater degree of consistency in labels, measures, and definitions of positive aspects, as well as by informing theoretical models of caregiving. The label ‘positive aspects’ is used in this work to refer to experiences or outcomes that are perceived by a caregiver to be positive in nature, and related to fulfilling the caregiver role.

Study one is a meta-integration of the quantitative and qualitative research on the positive aspects of caregiving for someone living with dementia. Eight databases were systematically searched, and 80 studies were included in the study. Quantitative dataset synthesis revealed common relationships between measures of positive aspects and other caregiving factors. Qualitative dataset synthesis revealed factors that underlie, facilitate, and hinder positive aspects. Synthesizing the qualitative and quantitative datasets I elaborated on relationships between caregiving factors and provided a holistic account of the phenomenon, including conditions for the experience of positive aspects of caregiving.

Study two is a qualitative investigation into caregivers’ perceptions and experiences of positive aspects of caring for someone living with dementia. The findings from study two lend support to study one findings of the factors that underlie, facilitate, and hinder the experience of positive aspects of caregiving. Study two findings provide insight into the relationship between positive aspects of caregiving and caregiver age, caregiver/care recipient relationship, and years spent caregiving.

The findings of this dissertation may be used to inform models of caregiving, future research, and caregiver intervention programs. Through this work I elaborate on how caregiver factors, caregiving environment factors, and the complex interplay between the two impact caregivers’ experience of caregiving. I suggest the use of neutral models of caregiving that emphasize caregiver appraisal of the caregiving experience, as opposed to models of negative or models of positive caregiving outcomes. These findings highlight facilitating positive appraisal of the caregiving role and caregiving demands as a point of intervention for caregivers.

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parameters of the caregiver/care recipient relationship. Caregivers model for us what it means to *show up* for one another; they remind us that so much can fall away in difficult times and what we are left with, is each other.

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1. GENERAL INTRODUCTION

Dementia is the leading cause of functional impairment in older adults (Agüero-Torres et al., 1998; World Health Organization [WHO], 2017). Advanced aging is associated with an increased risk of developing dementia and, in the context of a growing aging population worldwide, care for persons diagnosed with dementia is a growing concern (WHO, 2017). Informal caregivers provide the majority of care to persons living with dementia (Alzheimer Society of Canada, 2010; Prince et al., 2013) and supporting caregivers in their role is of increasing importance. Typically, primary care becomes the responsibility of unpaid and untrained friends or family members (often a spouse or adult child), and these care providers are known as informal caregivers (hereafter, caregiver(s); Alzheimer Society of Canada, 2010; Prince et al., 2013).

Research investigating the experience of caring for a relative/friend with dementia has revealed negative outcomes and experiences associated with caregiving and has shown that compared to non-caregivers, informal caregivers demonstrate greater physical and psychological strain (Pinquart & Sörensen, 2003; Pinquart & Sörensen, 2007), conceptualized as caregiver burden. Research also indicates that there are positive aspects of caring, with caregiver reports of personal gain and satisfaction in the role (e.g., Lloyd, Patterson, & Meurs, 2014; Peacock et al., 2010). Current understanding of the positive aspects, however, is limited by variations in the conceptualization of positive aspects, challenges associated with measuring positive aspects, and limitations in caregiver models and frameworks to theoretically integrate positive aspects of caregiving into the caregiver experience.

In the current work, I rely on a post-positivist approach and the use of a newer method of scientific investigation to gain a holistic account of what is known of the positive aspects of caregiving in current literature. Meta-integration is a research method that brings together two lines of scientific inquiry: quantitative and qualitative. Through this method, I aggregated and synthesized extant literature on positive aspects of caregiving in order to decipher how positive aspects are conceptualized, measured, and related to other variables of the caregiver experience. Furthermore, I assess what facilitates and hinders the experience of positive aspects of caregiving. The findings from the meta-integration are explored further through investigation of caregivers' experiences and perceptions of the positive aspects of caregiving, using a qualitative design. It is anticipated that the findings of this work will inform future directions for research in

positive aspects of caregiving as well as intervention programs to support persons caring for a relative/friend with dementia.

The general introduction of this dissertation will provide the reader with an understanding of dementia and informal caregiving. Following this will be an overview of scientific inquiry, a statement regarding the researcher's philosophical perspective, and description of quantitative and qualitative scientific endeavors. Theory and method of meta-analysis and meta-synthesis will follow, and the general introduction will culminate with a discussion on meta-integration. The dissertation work includes two studies, which are presented in manuscript format and follow the general introduction. This dissertation culminates with a general discussion regarding the implication of these findings on future research, models of caregiving, and caregiver intervention programs, as well as considerations for quantitative and qualitative research.

1.1 Dementia

Advanced aging is associated with an increased risk of developing dementia: a progressive neurodegenerative disease that leads to a decrease in one's independence in daily functioning and an ever-increasing level of care (Lezak, Howieson, Bigler & Tranel, 2012). Every year after age 65, the prevalence of dementia in a population increases, affecting a large proportion of older adults (Lezak, et al., 2012). While evidence suggests stabilizing and even decreasing incidence in some countries (Wu et al., 2017), global estimates predict rising prevalence of dementia. Globally, it was estimated that 47 million persons were living with dementia in 2015 and this figure is expected to rise to 75 million by 2030, and 132 million by 2050 (WHO, 2017).

Dementia refers to a clinical syndrome caused by a range of neurodegenerative diseases differentiated by the associated brain abnormalities, mechanism of degeneration, and patterns of symptomology (Lezak et al., 2012). Dementia types can be categorized as cortical dementia (i.e., affecting the neocortex in early stages) and subcortical dementia (i.e., affecting subcortical structures in earlier stages)¹. The following is an overview of the different types of dementia. Understanding the variation in the age of onset, the symptomology, and the nature of progression across the dementia types allows one to appreciate how different types may affect the experience of dementia for those living with the disorder and their family members/friends.

¹ Some researchers suggest the distinction between cortical and subcortical dementia may be an oversimplification, as dense interconnections within the brain complicate notions of functional organization.

1.1.1 Types of Dementia

Dementia due to Alzheimer's disease. It is estimated that dementia due to Alzheimer's disease (AD) accounts for over 66% of diagnosed cases of dementia (Lezak et al., 2012; Rossor et al., 2016). AD is a cortical dementia that is associated with progressive degeneration of nerve cells originating in the entorhinal cortex and hippocampus of the medial temporal lobes (Lezak et al., 2012; Rossor et al., 2016) and with time, extending to the parietal and prefrontal areas (Lezak et al., 2012). Hippocampi and medial temporal lobes are integral to the formation of new episodic memories (i.e., newly learned information). Thus, a hallmark of the disease is impaired learning and consolidation within episodic memory (in later stages deterioration of the intellect and personality occurs) (Lezak et al., 2012; Rossor et al., 2016). Age is the greatest risk factor for developing AD, with the vast majority of cases occurring after age 60, but it has appeared in people as young as 30 (referred to as young onset AD) (Rossor et al., 2016). Due to episodic memory difficulties, persons with dementia may demonstrate behaviours such as repeated questioning, challenges with disorientation to time and place, and safety concerns (e.g., wandering, leaving stove on, etc.; Kales, Gitlin, & Lyketsos, 2015).

Frontotemporal dementia. Dementia due to frontotemporal lobar degeneration, also referred to as frontotemporal dementia (herein, FTD), describes a cortical dementia that affects the frontal and temporal lobes in the earlier stages (Lezak et al., 2012). It is estimated that FTD accounts for approximately 20 to 50% of young onset cases of dementia (Cardarelli, Kertesz, & Knebl, 2010). The onset of FTD is typically insidious and the progression of the disease tends to be slow. Four FTD subtypes have been identified: frontotemporal dementia behavioural (or frontal) variant, semantic dementia, logopenic progressive aphasia² and primary progressive aphasia (also referred to as progressive non-fluent aphasia). The behavioural variant of FTD (FTD-bv) is associated with changes in personality and social functioning. Persons diagnosed with FTD-bv may begin to act in socially inappropriate ways, their temperament may change, and they may begin engaging in odd or characteristically atypical behaviours. They tend to demonstrate a lack of insight and a paucity of empathy toward others (Lezak et al., 2012; Rossor et al., 2016).

² There is controversy about the categorization of logogenic progressive aphasia within the rubric of FTD, as the pathophysiology is that of Alzheimer's disease (Gorno-Tempini, et al., 2008).

In semantic dementia, the temporal lobes are affected more than the frontal lobes (Lezak et al., 2012) resulting in impaired object recognition, word knowledge, word finding, and language comprehension (in the absence of impairment in memory or other cognitive dysfunctions) (Lezak et al., 2012; Rossor, et al., 2016). Logopenic variant is associated with slow speech, impaired comprehension, and repetition and is considered a form of primary progressive aphasia (Gorno-Tempini et al., 2008).

The left temporal lobe is the primary site of degeneration in primary progressive aphasia. Thus, primary progressive aphasia describes a gradually progressive decline in speech, typically beginning with anomia (inability to recall object names) and progressing to impaired grammatical structure and language comprehension (Lezak et al., 2012; Rossor, et al., 2016). Persons diagnosed with primary progressive aphasia may live without memory impairment for two to 10 years (Lezak et al., 2012).

Dementia with Lewy Bodies. Dementia due to Lewy body³ disease or dementia with Lewy bodies (DLB) is a cortical dementia that is suspected to account for approximately 20% of dementia cases (Lezak et al., 2012; McKeith et al., 1992). The hallmark symptoms of DLB are extrapyramidal motor signs (most commonly muscular rigidity, but other symptoms of parkinsonism are possible), visual hallucinations, and notable fluctuations in cognitive functioning with dysfunction in attention, executive functioning, and visuospatial ability (Lezak et al., 2012; Rossor et al., 2016). DLB is associated with motor impairment, impairment in activities of daily living, behavioral and emotional problems, and diagnostic difficulties (Leggett, Zarit, Taylor, & Galvin, 2010). Typical age of onset for DLB is 50 years and the progressive decline tends to be rapid, relative to other dementias (Lezak et al., 2012).

Subcortical dementias. Subcortical dementia refers to diseases wherein degeneration begins in structures located deep within the brain. These structures have important connections to areas of the brain, particularly the frontal lobes (Blumenfeld, 2010; Lezak et al., 2012). Given the connection to the frontal lobes, there is a behavioural set of symptoms associated with subcortical dementias that includes cognitive slowing, problems with attention and concentration, problems in executive functioning (i.e., multitasking, problem solving, etc.), visuospatial abnormalities, and retrieval deficits in memory ability (Lezak et al., 2012). In

³ Lewy bodies are comprised of a protein called alpha-synuclein. The disease gets its name from the neurologist who discovered the abnormal protein deposit, Dr. Friederich Lewy, in 1912 (National Institute on Aging).

addition to emotional symptoms such as depression and apathy, there are behavioural symptoms associated with changes in personality (Lezak et al., 2012; Rossor et al., 2016). The constellation of behavioural symptoms may help to differentiate cortical and subcortical dementias (Lezak et al., 2012).

Subcortical dementias lead to motor disorders that, once present, may serve to differentiate cortical from subcortical dementia types. Movement disorders affect the extrapyramidal motor system of the brain; this system includes subcortical structures such as the basal ganglia, subthalamic nucleus, and substantia nigra (Blumenfeld, 2010; Lezak et al., 2012). The extrapyramidal system modulates movement and governs muscle tone and posture; dysfunction of this system can lead to excessive involuntary movement (known as *dyskinesia*), halting, or slowing of directed movement (known as *akinesia*, or *bradykinesia*) (Lezak et al., 2012). There are three major subcortical dementias: Parkinson's disease, Huntington's disease, and progressive supranuclear palsy (Lezak et al., 2012). The following will be a discussion of each.

Parkinson's disease. Bradykinesia (i.e., slowness in movement) and rigidity are hallmark symptoms of the movement disorder known as Parkinson's disease (PD). PD is associated with dopamine depletion involving the substantia nigra of the basal ganglia. The average age of onset for PD is 50 years (Lezak et al., 2012) and PD is estimated to affect .4% of the Canadian population (Statistics Canada, 2018). The first sign of PD is often a resting tremor that typically begins in one hand and, as the disease progresses, the movement symptoms begin to affect the limbs; shuffling gait and forward lean is typical in persons with PD (Lezak et al., 2012; Rossor et al., 2016). Facial muscles are also affected, resulting in an absence of facial expression, and eventually affecting speech (Lezak et al., 2012; Rossor et al., 2016). PD leads to cognitive impairment; when cognitive decline is sufficient in magnitude, it is referred to as dementia due to PD (or PDD). The neuropsychological profile resembles that of frontal dysfunction and cognitive slowing, and symptoms of depression are common (Lezak et al., 2012; Rossor et al., 2016).

Huntington's disease. Huntington's disease is a neurodegenerative disease associated with motor disturbances, cognitive impairment, and psychiatric disorders (Lezak et al., 2012; Rossor, et al., 2016). Symptoms can emerge in any one of these domains first and vary in degree of severity from one individual to another. Motor disturbance in HD is excessive involuntary motor movement, referred to as hyperkinesia (Lezak et al., 2012). The cognitive deficits

associated with HD are comparable to those of frontal lobe dysfunction, namely impairments in self-initiation, poor behavioural regulation, poor planning and organization, and changes in personality. Additionally, changes in personality may occur (Rossor et al., 2016) with depression developing in approximately 38-50% of persons living with HD (Lezak et al., 2012). HD has a high hereditary competent. As an autosomal dominant disorder, offspring of persons with HD have a 50% chance of developing the disorder (Lezak et al., 2012). A typical age of onset for HD is in the early 40's and the course of the disease is typically 15 to 20 years (Lezak et al., 2012).

Progressive supranuclear palsy. Progressive supranuclear palsy (PSP) is a progressive degenerative disease that affects the subcortical structures (i.e., basal ganglia and upper portion of the brain stem). As interconnections between the subcortical and cortical structures break down, pre-frontal functioning is compromised (Lezak et al., 2012; Rossor et al., 2016). Unlike Huntington's disease, PSP is not hereditary. Typical age of onset is in the 60's with the course of disease lasting 6 to 10 years (Lezak et al., 2012). Cognitive and behavioural changes often begin early and include problems with concentration, word finding, and other memory impairments (Lezak et al., 2012; Rossor et al., 2016). Apathy and inertia are common behavioural changes, as are irritability, depression or euphoria, disinhibition, and emotional incontinence such as uncontrollable laughing or crying (Lezak et al., 2012).⁴

1.1.2 Dementia Care

Due to the variability across dementia types in terms of onset, symptomology, and progression, it follows that the experience of providing care would vary as a function of dementia type. For instance, the onset of dementia during pre-retirement years can result in added financial consequences for persons living with dementia and their families; in addition, providing long-term care has been associated with greater burden for caregivers (Pinquart & Sörensen, 2003). Changes in personality and behaviour in the care recipient have been found to be associated with greater levels of burden in caregivers of persons living with dementia (Mioshi et al., 2013; Riedijk et al, 2006). Caregivers of persons living with dementia experience unique challenges and opportunities as they adjust to care needs that are progressive and variable in nature. The uniqueness of dementia caregiving provides special opportunities for the experience of positive aspects. Some research indicates that caregivers of persons living with dementia may

⁴ Like corticobasal degeneration (another movement based degenerative disorder), PSP overlaps with FTD, but not all persons with PSP are considered under the rubric of FTD.

experience personal growth on their journey of care. For instance, as caregivers learn to adjust to the progressive care needs of someone living with dementia, an aspect of their character becomes emphasized, or they learn new things about their character (e.g., Peacock et al., 2010).

Furthermore, they can experience changes in their life philosophies (e.g., Sanders, 2005) and become present focused (van Wezel, et al., 2016). Thus, individual caregiver characteristics notwithstanding, the above demonstrates that care needs and symptomology of persons living with dementia will result in varied experiences for the caregiver. Understanding the caregiver experience is central to efforts aimed at supporting caregivers in their care role. An increasingly important endeavour, as research suggests that the frequency of informal caregivers is on the rise (e.g., Prince et al., 2013). The following provides a description of informal caregivers in general, followed by a discussion of informal caregivers of persons living with dementia.

1.2 Informal Caregivers

Whereas the term ‘formal caregiver’ describes paid, trained, professional workers of an organization, ‘informal caregiver’ describes untrained, unpaid persons (typically a family member or friend) who become the primary caregiver to a person living with a chronic illness (in this body of work, the term ‘caregiver(s)/caregiving’ refers to informal care unless otherwise specified). Assistance and support of one family member or friend to another can be a mutual, normal, and healthy part of relational interaction, however, caring for persons living with certain types of chronic illnesses is a more involved role that often cannot be reciprocated (Brodaty, 2007). Caregiving in this capacity is often unexpected and may require considerable time and energy. The caregiving role can involve uncomfortable or unpleasant tasks that are physically, psychologically, socially, and financially taxing for the caregiver (Biegel & Schulz, 1999; Pinquart & Sörensen, 2003; Pinquart & Sörensen, 2007). Caregivers may aid in a variety of activities ranging from using the telephone, shopping, and doing laundry, to basic activities of daily living such as feeding, bathing, and dressing (Biegel & Schulz, 1999; Pinquart & Sörensen, 2003). The intensity of caregivers’ responsibilities may vary, and the time required to fill the role is dependent upon the illness and illness severity, with some caregivers having limited involvement (e.g., a few hours per week) and others providing 24 hours of care per day (Biegel & Schulz, 1999; Statistics Canada, 2017). The care provided by caregivers allow the care recipient to remain in the community and supports the care recipients’ independence, and promotes their physical, psychological, and spiritual health (Brodaty, 2007; Goetzingerg, 2008).

By providing unpaid care and keeping care recipients in the community, caregivers serve not only those in need, but society as a whole. Caregivers act as gatekeepers to health and social services, manage estate and finances, and delay long-term institutionalization for care recipients (Brodaty, 2007). Therefore, in the context of limited health care services, maintaining and supporting the well-being of caregivers is important on a political, social, and economic front (van Durme, Macq, Jeanmart, & Gobert, 2012).

Recent estimates regarding informal caregivers in North America indicate that approximately 29% of Americans and 28% of Canadians are providing care to a family member or friend living with a long-term health condition, disability needs, and/or aging needs (Caregiving in the United States; National Alliance for Caregiving in collaboration with AARP; November 2009; Statistics Canada, 2012). On average, informal caregivers provide approximately 20 hours of care per week, which translates into an estimated saving of \$375 billion for the United States healthcare system. In Canada, it is estimated that unpaid caregiving makes a significant economic contribution by saving the health care system approximately \$25-26 billion per year (Hollander, Liu, & Chappell. 2009). Although it is difficult to ascertain the prevalence and cost of informal caregiving globally (due to differences in health care systems, family structures, and societal values, for example, what constitutes caregiving, family role expectations, etc.), suffice it to say that the need for informal care is expected to rise. An unprecedented increase in the aging population is occurring globally and some evidence suggests that the incidence of dementia is rising on a global level (Prince et al., 2013; WHO, 2017).

1.2.1 Caring for persons living with dementia. Research indicates that providing formal care (i.e., social and health services) to persons living with dementia is a challenge globally, and informal care has been the main mode of care for persons with dementia (e.g., Alzheimer Society of Canada, 2010; Prince et al., 2013). Global estimates suggest that in 2015, 47 million persons were living with dementia (WHO, 2017) and this figure is expected to rise to 75 million by 2030, and 132 million by 2050 (WHO, 2017). It is estimated that 16 million Americans are providing informal care to someone living with dementia (Alzheimer's Association, 2018). Canadian caregivers for persons living with dementia provided approximately 230 million hours of informal care in 2008 and this is projected to increase to approximately 380 million hours per year by 2018 (Alzheimer Society of Canada, 2010). European estimates indicate that the cost of care for persons diagnosed with dementia was

approximately 160 billion pounds in 2008, and 56% of this was cost associated with informal caregiving (Wimo et al., 2011). Australian reports indicate that approximately 30 million people were living with dementia in 2009 and 75% of care for these persons was provided by a family member or friend (Brodaty & Donkin, 2009). Research suggests that roughly 60% of persons living with dementia reside in developing countries, and the informal care profiles (i.e., caregivers are commonly spouses or children with a higher proportion of female caregivers) are comparable to those of Western countries (Brodaty & Donkin, 2009).

1.2.2 Conceptualizing the caregiver experience. Although research indicates that there are positive aspects of caregiving, most conceptual models of the caregiving experience assume that living with chronic illness is stressful for both the caregiver and care recipient. Thus, stress theory is commonly applied to caregiver research and popular conceptualizations of the caregiver experience (i.e., caregiver burden or caregiver stress) are informed by stress-process based theory (e.g., Chwalisz, 1996; Pearlin, et al., 1990). Stress-process theory posits that stress is the result of an interaction between personal characteristics and situational factors (Lazarus & Folkman, 1984). Specifically, the theory suggests that when one is met with an objective demand they appraise their ability to contend with the demand, and if they feel they are unable to cope they experience stress and related negative psychological outcomes (Lazarus & Folkman, 1984).

In relation to caregiving, Pearlin and colleagues (1990) posit that stress represents a dynamic and ongoing process that directly affects the physical and psychological outcomes associated with caregiving. Chwalisz (1996) describes a general model of caregiving largely informed by stress theory. This model suggests sequential relations between environmental (or external) and subjective (or internal) components that moderate stress. In the model, the care recipient's physical disability or problem behaviours are considered an external stressor for the caregiver. The caregiver's appraisal of the external stressor (e.g., "Can I deal with this challenge?") may lead to either an increase in perceived stress (should they conclude they cannot contend with the stressor) or the challenge is appraised as being benign or even positive. When a caregiving challenge is perceived as stressful, there is an increased risk for the caregiver to experience negative emotion such as depression or anxiety, which can have physical effects such as loss of sleep or appetite, and may increase risk of physical or psychological illness (Biegel & Schulz, 1999). The physical effect of lack of sleep and poor diet may affect the caregiver's appraisal of external stressors experienced in the future, wherein the caregiver feels less able to

cope with the challenges presented to them (Biegel & Schultz, 1999; Chwalisz, 1996). In a cyclical fashion, stress emerging from a perceived inability to meet caregiving challenges may affect the caregiver's perception of the external caregiving stressor(s), exacerbating the perceived severity of the physical disability or problem behaviour (Chwalisz, 1996). As the caregiving experience is assumed stressful, caregiver research has predominantly focused on the negative aspects (e.g., depression, anxiety, and psychological distress), or caregiver burden, and factors that serve to mediate negative aspects of caregiving.

Negative aspects of caregiving. Conceptually, caregiver burden is comprised of two components: objective burden and subjective burden. Objective burden describes the observable changes in the care recipient's physical and psychological health, and external factors such as financial strain, changes in routine, social activities, and living arrangements (Braithwaite, 1992; Chwalisz, 1996). Subjective burden, on the other hand, refers to the caregiver's negative reaction to objective burden (Braithwaite, 1992; Chwalisz, 1996). Importantly, objective and subjective burden do not share a one-to-one, linear relationship. Instead, subjective burden is moderated by a number of caregiver characteristics and reflects the caregiver's subjective experience of objective burden (Braithwaite, 1992; Chwalisz, 1996).

Indeed, as predicted by models of caregiving, perceived stress has been found to be a consistent predictor of negative psychological outcomes, such as depression and anxiety, as well as negative physical outcomes, such as migraines (Chwalisz, 1996; Pinguart & Sørensen, 2003). Chwalisz (1996) proposed combining theories of stress with empirical findings of subjective burden research, as a preliminary model of caregiver burden. The Perceived Stress Model of Burden posits that age, gender, previous history, and appraisal of the care needs of the recipient influence the caregiver's perceived stress (Chwalisz, 1996). Research regarding this model found that perceived stress was the strongest predictor of perceived mental health, and caregivers' coping abilities and social support are moderators of perceived stress in caregivers (Chwalisz, 1996). Because perceived stress directly affects both mental and physical health status, it is reasonable to surmise that coping and social support are integral to a caregiver's experience of burden. This is in keeping with stress-based models of caregiving that include coping as a mediator of negative outcomes (i.e., Pearlin's stress-process model). Yet, based on this model, it is not clear whether coping and social support relate to positive aspects of caregiving. Some researchers suggest that certain methods of coping facilitate positive aspects of caregiving, or

may be positive aspects themselves (e.g., Farran, 1997). Indeed, overreliance on stress theory to conceptualize caregiving has made it difficult to know where positive aspects ‘fit’ within the caregiving experience, and thus has contributed to the paucity of positive aspects research and the incomplete understanding of the phenomenon.

Positive aspects of caregiving. Initially, caregiver research was in keeping with a long history of identifying and treating pathology, but as researchers began to question what it means for persons to be psychologically well, interest in the positive aspects of caregiving emerged (Kramer, 1997). Working with the notion that there is more to mental health than the absence of pathology, Ryff and colleagues (1998) forwarded six aspects of well-being: personal growth, purpose in life, autonomy, environmental mastery, positive relations with others, and self-acceptance. Investigations into the positive aspects of caregiving reveal positive aspects that closely reflect these six aspects of well-being. For instance, a recent integrative review of quantitative and qualitative studies pertaining to the positive aspects of caregiving in dementia posits four domains of positive aspects including personal accomplishment and gratification, mutuality in a dyadic relationship, increased family cohesion and functionality, and personal growth, and purpose in life (Yu, Cheng, & Wang, 2018). Unfortunately, unlike caregiver burden, there is a lack of consistency in the labels and definitions of the positive aspects of caregiving (Kramer, 1997; Yu et al., 2018).

Recent review of qualitative literature reported a number of conceptualizations of positive aspects, such as role satisfaction (i.e., feeling satisfied with doing a good job of caring), emotional rewards, personal growth (e.g., increased patience, increased self-respect and self-awareness), competence and mastery (i.e., learning new skills), faith/spiritual growth, relationships gains (i.e., improved/intensified bond with care recipient), sense of duty, and reciprocity (i.e., satisfaction in giving back to the care recipient; Lloyd, Patterson, & Muers, 2014; Peacock et al., 2010). These outcomes are consistent with Ryff and colleagues’ (1998) aspects of well-being, but how these might be related to other aspects of the caregiver experience, such as caregiver burden, remain equivocal.

Kramer (1997) posited that the lack of consistency, or contradictory findings, regarding the relationship between positive aspects and other caregiver variables is due to a lack of guiding theory or framework. An extensive review of the literature revealed that many studies investigating positive aspects of caregiving were conducted atheoretically (Kramer, 1997). When

theory was applied, it was most common for positive aspects to be situated within stress-based models of caregiving and referred to as ‘caregiver appraisals’ rather than distinct objective outcomes (Kramer, 1997). Some researchers continue to adapt stress-based models to include positive aspects (Lloyd et al., 2014). Others prefer to consider positive outcomes as a separate dimension of the caregiver experience as findings show that positive and negative outcomes are, at best, loosely correlated and have distinct predictor variables. Thus, such researchers maintain that positive aspects need not be conceptualized within a framework of negative outcomes (e.g., Carbonneau, Caron, & Desrosiers, 2010; Lloyd et al., 2014).

Some researchers argue that the lack of clarity in the positive aspects research is due to a reliance on quantitative research approaches that study measurable phenomena (Farran et al., 1991; Lloyd et al., 2014). Compared to pathological or negative outcomes, positive aspects are difficult to measure as the expression of positive aspects tend to be individualized and subjective in nature (Farran et al., 1991). Qualitative research approaches are better positioned to capture the nuances and subjective elements of the experiences of positive aspects. Although there are researchers who adhere strongly to one approach over another, researchers increasingly acknowledge that each approach brings its strengths and weakness to the pursuit of knowledge and it is becoming more common to view quantitative and qualitative approaches as complementary to one another rather than in opposition (Sandelowski, Voils, & Barosso, 2006). The following provides an overview of the theory of science, wherein differing philosophical stances on reality and obtaining knowledge will be discussed. Following will be a discussion on quantitative and qualitative approaches to science and the philosophical underpinning of these and their respective approaches.

1.3 Science and Research

Despite the connotations of the word ‘science’ (i.e., ‘truth,’ ‘fact’), all scientific knowledge is presupposed by a set of beliefs and assumptions about the world. A discussion of these beliefs and assumptions is necessary before considering and comparing quantitative and qualitative veins of scientific research.

1.3.1 Ontology. Stemming from the Latin roots *onto* meaning being and *logy* referring to ‘the study of,’ ontology is the philosophical study of existence or being. Ontology grapples with such ideas as ‘what is the nature of existence and the structure of reality’ (Crotty, 1998; Frost, 2011). For example, does reality exist outside of the mind or does the world materialize through

our perception of it? More clearly, does an object exist when it is not being perceived through the human eye and understood with the mind? *Realism* is an ontological perspective that posits that reality exists outside of the mind (Crotty, 1998). *Nominalist* or *idealist* perspectives suggest that reality is ‘intra-mental’, that is, reality is born out of the mind and there is no ‘real’ external reality (Crotty, 1998; Hannes & Lockwood, 2011). *Relativism* holds that reality is constructed intersubjectively with meanings derived from social knowledge and individual experience (Hannes & Lockwood, 2011). What is considered to be reality greatly affects pursuit of knowledge; it informs what knowledge is worth pursuing and how to obtain knowledge. Such considerations are important for consumers of science. Concerning the current endeavour, for instance, to understand what is known of the phenomenon of positive aspects of caregiving, one must understand the assumptions that contextualize the knowledge. When considering the wealth of the scientific literature, it is important to consider what can and cannot be revealed about the phenomenon of positive aspects of caregiving, given the assumptions out of which the knowledge from each study was born. Of equal consequence to the ontological consideration of ‘what is the nature of existence’ is the consideration of ‘what is the nature of knowledge’ (Crotty, 1998).

1.3.2 Epistemology. Stemming from the Latin roots of *episteme* meaning ‘knowledge’ and *logy* referring to the ‘the study of,’ epistemology describes perspectives on *how we know what we know* (Crotty, 1998; Frost, 2011). An epistemological perspective provides a philosophical framework for what kinds of knowledge are possible and how to attain knowledge that is ‘legitimate’ and adequate (Crotty, 1998). There are a number of epistemological perspectives and some lend themselves exclusively to a realist ontological perspective while others may apply to realist and nominalist/idealist/relativist perspectives.

Objectivist epistemology. The objectivist epistemological perspective posits that reality is observable and measurable; it exists outside of the mind (realism) (Crotty, 1998; Darlston-Jones, 2007) and it can be known through objective measurement and observation. *Positivist* and *objectivist* epistemology are comparable wherein positivist perspective assumes that reality is knowable through scientific observation and scientific method (i.e., experimentation).

Post-positivist epistemology. The post-positivist epistemological perspective holds that reality exists outside of the mind, however, the human perceptual apparatus is imperfect therefore our experience of, and knowledge of, reality is inherently imperfect or incomplete.

Reality is probabilistically knowable through use of scientific method/observation and the truths of reality can be approximated but never truly known.

Constructionist epistemology. Constructionist epistemological perspective diverges from the aforementioned epistemologies in that it suggests multiple realities, each of which is valid and true and none of which represents a real reality outside the mind. Constructionism suggests that reality is constructed by the mind and is thus local and specific (ergo, multiple). More specifically, one's perception of reality is shaped by individual characteristics and an individual's social experience (Crotty, 1998). As one learns language, for example, one's understanding of her or his surrounding (i.e., reality) is shaped by the words and meaning of the words one learns to ascribe to the surroundings. Therefore, knowledge occurs through human interaction and is passed down through generations. 'Reality' is continually re-constructed by the individual throughout her/his existence and interactions with others and the world.

1.3.3 Quantitative research. The objectivist and positivist/post-positivist epistemologies lend well to quantitative research endeavors. Quantitative research seeks to explain and predict human phenomena. To do so, researchers operationalize human phenomena by reducing the complex phenomena into a measurable construct known as a psychometric measure. For example, researchers may devise a measure of caregiver satisfaction by including a number of items pertaining to satisfaction and having caregivers answer on a multipoint Likert scale (e.g., a five-point range of answers from highly applicable to not applicable). This transforms the caregivers' satisfaction into a measured and quantifiable unit, or a number. In order to ensure the quality of their measures, researchers establish validity and reliability in their measures. From a post-positivist perspective, the quality of a measure refers to how able and how consistent the measure is at approximating 'real' reality.

Validity. A construct refers to a conceptualized phenomenon or attribute, for example, positive aspects of caregiving. Construct validity refers to the extent to which an instrument measures what it is intended to measure, where construct refers to a phenomenon or attribute (e.g., positive aspects of caregiving). Evidence for validity is commonly gathered through three areas of validity: content, concurrent, and predictive validity. *Content validity* refers to the degree to which the measure captures and reflects the construct. Evidence for content validity is gathered through consideration of the definition of the construct, the purpose of the measure, and the items of the measure (i.e., the wording, the process of development and selection of the

items, etc.) (Cook & Beckman, 2006). *Concurrent validity* refers to the degree to which a measure correlates with an established measure of the same construct (e.g., scores on a new measure of caregiver satisfaction should correlate highly with scores on established measures of satisfaction). *Predictive validity* refers to whether scores on a measure can predict scores on a related criterion measure (e.g., a high score on a measure of satisfaction predicts well-being in caregivers).

Historically, once the construct validity of a measure has been established, it is considered a good measure of the construct it represents. Researchers have recently criticized this approach to establishing validity by arguing that it is not the measure itself, but rather the conclusions/interpretations drawn from the measures' scores that need cumulative evidence for validity (Cook & Beckman, 2006). Thus, Cook and Beckman (2006) argue that validity must be established on a study by study basis. They forward five areas of validity evidence: content validity, response process (assessing the actions and thought processes of the persons responding to the measure), internal structure (scores intended to measure a single construct, should yield homogenous results), relations to other variable (i.e., concurrent validity), and consequences (relating unintended measure outcomes (e.g., gender differences in response patterns) back to the construct). Finally, in establishing the quality of a measure, researchers consider *reliability* of the measure. This is the degree of reproducibility and consistency in the scores of the measure scores. Reliability is necessary for a measure to have adequate evidence for validity, however, it alone does not indicate the quality of a measure.

Validity is also considered in relation to the experimental design of a study. *Internal validity* refers to degree of rigor and control applied to the experiment of a study. For example, when researchers wish to investigate whether psychotherapy improves caregiver satisfaction, they may devise an experiment wherein they have two groups of caregivers. One group serves as the control and the other group undergoes psychotherapy. The researcher will compare caregiver satisfaction scores for each group both before and after the treatment group receives psychotherapy. To ensure, however, that any observed difference in the satisfaction scores post-treatment are due to psychotherapy, the researcher will want to control for confounding variables. For example, researchers must make sure that the two caregiver groups are similar to one another in characteristics that could influence caregiver satisfaction, such as age, relationship to care recipient, gender, time spent caregiving, etc. Another way in which a researcher may

exert control in the experiment is to ensure that the psychotherapy for each participant in the treatment group is administered in a systematic way, so that each participant has a similar psychotherapy treatment/experience. This kind of rigor and control bolsters internal validity of the experiment and strengthens the findings of a study.

External validity refers to the degree to which the findings from a study can be applied outside of the laboratory, referred to as generalizability. Practices that bolster external validity include those that promote development of a sample that is representative of the population (e.g., random sampling), and those that promote research designs that approximate real life (e.g., treatment duration and administration that is practical in the real world). Strengthening the internal validity of a study design means exerting greater control thus decreasing external validity as the study characteristics are less representative of the ‘real world.’ Quantitative research tends to prioritize knowledge gained through the highly rigorous, internally valid research design of randomized control trials as opposed to prioritizing generalizability (Steckler & McLeroy, 2008).

Quantitative researchers use measures with strong validity and reliability and rigorous research designs to test hypotheses about the construct under study. Quantitative methods use statistical analysis to make ‘sense of’ and draw conclusions about the quantified data. For example, a researcher may take caregivers’ scores on a measure of satisfaction and a measure of well-being and, through statistical analysis, deduce whether a relationship between the two exists. In essence, the researcher is testing the hypothesis that caregiver satisfaction is related to caregiver well-being. Indeed, hypothesis testing is the crux of quantitative research and null hypothesis testing is the method by which researchers ascertain the significance of the statistical findings.

Null hypothesis statistical testing. Quantitative researchers use statistical inference to understand and offer a prediction of their experimental data. Null hypothesis statistical testing (NHST) is a method of statistical inference that allows researchers to determine the significance of their data findings. In NHST, two data sets are typically compared (e.g., data from caregiver satisfaction scores and data from caregiver well-being scores) and a hypothesis regarding the two (e.g., higher caregiver satisfaction will be related to higher caregiver well-being) is proposed. An alternative hypothesis, the null hypothesis, holds that no relationship between the two data sets exists (e.g., caregiver satisfaction is unrelated to caregiver well-being). Through statistical

analysis, the relationship between the two obtained data sets (i.e., caregiver satisfaction and caregiver well-being data sets) is analyzed and the outcome is compared to what might be expected by chance (i.e., what is the likelihood that the observed relationship between these two measures has occurred by chance). A long established, albeit arbitrary, level of significance known as the *p*-value indicates whether the null hypothesis is supported or not. The *p*-value of 0.05 is a commonly used gauge of statistical significance (Cohen, 1995). Statistical analyses that produce a *p*-value less than 0.05 indicate that the probability of obtaining the current data by chance is less than 5 in 100. Researchers take this to mean that the observed data is then supportive of the proposed hypothesis (e.g., a relationship between caregiver satisfaction and well-being exists) and the null hypothesis (e.g., no relationship exists) is rejected.

NSHT is not without its critics and a common concern with this method of inference relates to the underlying premise. The major premise of null hypothesis significance testing *should* be: if the null hypothesis is correct, then these data cannot occur. Given that these data have occurred, then the null hypothesis is false (Cohen, 1995). Critics argue, however, that this is not the premise of NHST; rather, the premise is probabilistic: if the null hypothesis is true, then these data are highly *unlikely* (Cohen, 1995). The problem is that a probabilistic premise makes the conclusion invalid or non-sensible (Cohen, 1995). Furthermore, Cohen argues that although researchers believe that they are ascertaining the probability of the data occurring given that the null hypothesis is true, what is actually being tested is the probability that the null hypothesis is true, given the data. While these appear to be semantic variations of the same statement, statistically they are entirely different questions (Cohen, 1995). For these and other concerns regarding NHST, some researchers suggest the use of effect sizes to facilitate statistical inference of their data. For example, finding a statistically significant relationship between scores on two measures suggests that a ‘real’ relationship exists. Effect sizes provide more information on the ‘real’ relationship by providing a sense of the magnitude or strength of the relationship as indicated by the statistical outcome.

Effect size estimates are commonly derived from correlation coefficients and standardized mean differences between two variables of interest. Effect sizes indicate the magnitude of the observed relationship, which is important in interpretation. Rather than relying on an arbitrary level of statistical significance (i.e., $p < 0.05$) to judge their data, the magnitude of the observed effect size indicates the *significance* of the finding. If given a large enough sample,

statistically significant relationships between variables will often be found. On the other hand, if the associated effect size is small in a large sample, evidence of the relationship is weak. If a moderate to large effect size is found in a smaller sample, it strengthens the conclusion that a relationship between the two variables exists (i.e., when the ‘sample parameter’ of the effect size becomes an estimate of the ‘population parameter,’ which some argue is the actual estimate of reproducibility; it is modified by the n from which it was obtained).

1.3.4 Qualitative research. Whereas quantitative research answers questions concerning associations and magnitude in human phenomena, qualitative research addresses the question of *what* is a human phenomenon (Wertz et al., 2011). The aim of qualitative investigation is to gain an in-depth understanding of the phenomenon under study from the perspective of people who live that phenomenon. In a sense, while quantitative research focuses on measurement and analysis of relationships between variables (i.e., getting the ‘whats’ of phenomena), qualitative research focuses on the processes (i.e., gaining access to the ‘whys,’ the how, in addition to the ‘whats’ of phenomena) (Ellet & Beausang, 2002; Wertz et al., 2011). This includes understanding not only the phenomena as a whole and how people experience the phenomena, but an understanding of the parts and processes that make up the whole (Wertz et al., 2011). Qualitative research can be compatible with post-positivist and constructionist perspectives and, although less common, can also be compatible with the positivist perspective (Myers, 1997). While there are a number of different qualitative approaches, qualitative researchers are generally interested in persons’ lived experiences, behaviours, and emotions, as well as social movements and cultural phenomena rather than the measured ‘objective’ representations of these (Strauss & Corbin, 1990). Qualitative researchers understand that the act of inquiry affects the phenomena under study and they either aim to take account of ‘this effect’ and separate it from analysis as best they can, or it is incorporated wholly, becoming part of data and interpretive output. In this way, ontologies that accept that there is no ‘real’ reality that is accessible to humans in its pure form (realism) or that reality is continuously constructed (idealism/relativism), are most consistent with qualitative endeavours.

Indeed, it is the experience and the accounts of individuals that are commonly the ‘reality’ of interest in qualitative investigations. The following provides a cursory summary of qualitative methods as outlined by Ellet & Beausang (2002). *Ethnography* is a type of qualitative research that focuses on the description (rather than explanation) of social influence on people

and the cultural basis of group identity (Ellet & Beausang, 2002). *Critical Social theory*, is a qualitative research approach that focuses on social context and social logic, with a focus on oppressed and marginalized groups of people to effect change (Ellet & Beausang, 2002). *Content analysis* is mainly used in qualitative research although quantitative applications are also possible (e.g., Krippendorf, 2004). Content analysis is a versatile qualitative approach that aims to describe the basic content of qualitative data (i.e., interview transcripts, etc.). *Narrative analysis* is a method applied to narrative stories or people's meaningful accounts of their experiences; it focuses on the structure (e.g., chronological order) of the narrative and the meaning (i.e., interpretation) of individual accounts (Ellet & Beausang, 2002). The *phenomenology* approach provides a rich and thick description of phenomena, and may interpret an experience as it is constructed by those involved, including the research analyst (Ellet & Beausang, 2002). Finally, *Grounded Theory* is a common method of qualitative investigation; the method aim is to generate theory, often pertaining to such human phenomenon as social relationships, behaviors in groups, and social processes (Noble & Mitchell, 2016). Qualitative data are commonly gained through open or semi-structured interviews, but can also include observation, archival records (e.g., journals, letters, newspaper articles, etc.), social media, and so on. Contrary to quantitative approaches, qualitative research incorporates varying levels of creativity and subjectivity into the analysis and interpretation of the data. As such, it is difficult to assess the quality of qualitative work against measures of quality for quantitative research (Ellet & Beausang, 2002).

Quality. Historically, attempts have been made to establish the validity and reliability of qualitative studies, but some argue the quantitative conceptualizations of validity and reliability (i.e., quality) are ill suited for qualitative endeavours. Researchers Lincoln and Guba (1985) provide one approach (among many) to evaluate qualitative research. The researchers offer five aspects of validity criterion for qualitative research: credibility, transferability, dependability, trustworthiness, and authenticity (Lincoln & Guba, 1985). *Credibility* may be thought of as the 'trueness' of the findings and this is best established through member checks (that is, another researcher in the study double checking analysis) (Seale, 1999). *Transferability* is similar to generalizability or external validity (Seale, 1999). *Dependability* is similar to the concept of reliability and refers to the degree to which a new researcher would be able to follow the method and analysis and come to similar conclusions. Auditing, wherein the researcher reports in detail,

their thought processes surrounding their choices and conclusions made during data collection and interpretation, is central to establishing dependability. Auditing is a reflexive process that lends to the trustworthiness of the finding of a study and facilitates establishing the five aspects of validity. In this context, *trustworthiness* means a detailed account of the potential influence of the researcher on the data, such that readers can gauge for themselves the trustworthiness of the veracity of the analysis. It is worth noting, however, that the notion of trustworthiness is incompatible with constructionist epistemology. Indeed, the idea of ‘truth,’ in general, is inconsistent with idealist/relativist ontologies and associated epistemologies; thus, *authenticity* takes the place of credibility and trustworthiness (Seale, 1999). When researchers show that they have represented a range of different realities, then authenticity has been established (Seale, 1999).

Quantitative and qualitative research. Traditionally, there has been tension between quantitative and qualitative research approaches. Initial psychological research pursuits were fundamentally qualitative in nature. As advancements in other scientific disciplines emerged, psychology began fighting for a place in the ‘hard’ sciences (e.g., physics, chemistry), which led psychological research to emphasize empirically based science (Duncan & Reese, 2012). This effort was representative of the received view in science at the time that privileged objectivist/positivist ontological perspectives and epistemological frameworks that supported rigorous research designs, empirical outcomes, and cause and effect conclusions. More recently, some psychology researchers have recognized the limitation of quantitative work in advancing knowledge of complex human phenomena and have turned to qualitative research approaches to address this (Flick, 2002). While some still consider qualitative work to be practically limited in its utility (i.e., lack of generalizability), others argue that the rich knowledge born out of such work provides a more holistic understanding of phenomena and can be used to inform quantitative findings and inspire new avenues of research. Indeed, a newer research method, meta-integration, has emerged that aims to bring together the findings of quantitative and qualitative work to expand and enrich the understanding of psychological phenomena. Given the historical tension between quantitative and qualitative researchers, meta-integration that combines findings from quantitative meta-analysis and qualitative meta-synthesis is not without its critics. Nevertheless, the potential benefits and advancement born from meta-integration

warrants the effort. Understanding the quantitative and qualitative approaches is an important foundation to understanding meta-integration.

1.4 Meta-Analysis

When researchers aim to study a particular aspect of a phenomenon, it can be difficult to obtain and maintain a working knowledge of *all* relevant research findings (Schulze, 2004). This is problematic to the scientific goals of accumulating and advancing knowledge. Consequently, researchers developed methods of systematically gathering and statistically synthesizing empirical findings related to a particular research area or question (Cooper, 2010; Schulze, 2004). Meta-analysis, first defined in 1976, has since become a burgeoning area of research in and of itself, and a commonly used statistical tool applied in most scientific disciplines (Schulze, 2004). Aggregating and making sense of a vast number of related empirical findings not only provides a solid understanding of what is known about the research area/question, but also identifies the areas that need further inquiry. Furthermore, meta-analyses may generate new knowledge and have proven to be useful in the development of theory (Cooper, 2010; Schulze, 2004).

There are a number of approaches and frameworks of meta-analyses, but a basic method is common across all approaches. Meta-analyses consist of two parts: a systematic review of the literature pertaining to a particular field of study/research question (e.g., caregiver satisfaction and caregiver well-being) and high order statistical aggregation of the literature findings (Cooper, 2010; Schulze, 2004). The systematic review process is a highly detailed and thorough stepwise endeavour. The meta-analyst must detail their actions entirely, noting the words/phrases used when searching databases, the sequential order in which the terms were searched, the data bases searched, as well as the decision to include and method of obtaining grey literature (e.g., unpublished studies), and so on. Virtually every decision and action made by the meta-analyst must be documented, such that the process may be replicated to produce the same outcomes (literature sample). The meta-analyst details how many relevant articles were identified and explains the inclusion and exclusion criteria used to determine the studies that will be incorporated in the meta-analysis. Each study detailed in the literature sample is referred to as a primary analysis.

Primary analyses yield findings related to individuals (i.e., participants) and their outcomes scores and correlations that emerge from individual data. The meta-analyst extracts all

relevant data from each study, which includes, for example, sample characteristics, treatment methods, experimental methods, measures, study outcomes, and so on. In essence, for a meta-analysis, studies in the literature sample act as the participants and study findings serve as data points from participants. Generally, meta-analysts perform transformations of the primary correlational data of each study where the data are translated into a measure of effect size common across the studies. This allows the overall effect size for the relationship of interest to be computed, which is essential in order to communicate the degree of strength of the relationship. In sum, meta-analyses are capable of incorporating a large number of studies with various findings (e.g., no relationship found, weak relationship found, strong relationship found) about a certain topic (e.g., caregiver satisfaction and caregiver well-being) and produce an aggregated product that communicates whether the relationship exists, and if it does, how strong the relationship is.

How data are aggregated and what analyses are performed depends upon the framework chosen, which is dependent upon the research area and the research question (Cooper 2010; Schulze, 2004). For instance, if a researcher believes that there is a universal effect size, the researcher may opt for the fixed effects model. The *fixed effects model* assumes that the effect size observed from the literature sample is due to one factor and assumes that differences in study characteristics do not contribute to the observed effect in a meaningful way (Hedges & Vevea, 1998; Schulze, 2004). Certainly, this is a strong assumption and the fixed effects model has been criticized (Cooper, 2010; Schulze, 2004), but nevertheless it remains one of the most frequently used meta-analysis methods (Hedges & Vevea, 1998; Schulze, 2004).

The *random effects model* is also a commonly used method of meta-analysis and it addresses the concern of across study variance. Comparable to the fixed effects model in most respects, the random effects model introduces a variance variable to account for the error associated with differences across the studies, which may contribute to the observed effect size (Cooper, 2010; Hedges & Vevea, 1998; Schulze, 2004). Compared to fixed effects models, random effects models are ideal when literature samples are small with notable variation or differences across the sample of studies. Other meta-analysis methods include *mixture models* and *hierarchical linear models*. *Mixture models* account for the possibility that a subset of the literature sample will have correlation coefficients born from a different universal factor (i.e., a latent factor that influences correlation coefficients) and the aim is to explain how the

distribution of the correlation coefficients emerges (Schulze, 2004; van Houwelingen, Arends, & Stijnen, 2002). *Hierarchical linear models* of meta-analysis, similar to mixture models, incorporate other variables that may affect correlation coefficients. Unlike mixture models, these variables are known, observed, explanatory variables and as follows, this model can be considered an extension of the mixture model (van Houwelingen, Arends, & Stijnen, 2002). Choosing the model or framework for one's meta-analysis, is highly dependent on the question being asked (e.g., "what is the overall magnitude of this one to one relationship being investigated?") and the theory and literature regarding the construct/relationships of interest (e.g., "theory and literature suggest that a relationship is highly affected by certain variables and these must be included in the analysis"). Concerning the current endeavour, meta-analysis will provide insight into how positive aspects relate, if at all, to other caregiving factors (for example, caregiver burden, years spent caregiving, etc.) and in doing so, will illuminate how positive aspects 'fit' into the greater caregiving experience.

1.5 Meta-Synthesis

With the relatively recent increase in qualitative research, there has been a call to develop means of synthesizing qualitative findings (Hannes & Lockwood, 2007), parallel to the trend within quantitative research. Some researchers refer to the synthesis of qualitative findings as a *meta-summary*, a *meta-study*, a *meta-data-synthesis*, or a *meta-synthesis* (Paterson, 2012). For the purposes of this dissertation, I will refer to the systematic literature review and synthesis of qualitative work as meta-synthesis. By providing a broad overview of a particular area of research, meta-synthesis can reveal powerful explanations, provide greater generalizability, and increased levels of abstraction (Sherwood, 1999) that allows researchers to revise, or refute, extant theories and understanding of human phenomenon (Hannes & Lockwood, 2007). Unfortunately, as compared to meta-analysis wherein approaches stem from similar philosophical perspectives, meta-synthesis is met with unique challenges as qualitative approaches are often differentiated on fundamental levels (Dixon-Woods et al., 2005; Sandelowski, Voils, & Barroso, 2006).

Qualitative approaches may differ on ontological positions (e.g., realist, idealist, and relativist), epistemological perspectives (e.g., objectivist, post-positivist, and constructionism), as well as theories and methodologies (e.g., grounded theory, phenomenology, etc.; Dixon-Woods et al., 2005; Sandelowski et al., 2006). Such differences make the synthesis of qualitative work a

daunting enterprise and, some researchers argue, a theoretically inconsistent enterprise. Nevertheless, the potential gains of a meta-synthesis have prompted researchers to devise methods to combat the difficulties associated with this endeavour (Hannes & Lockwood, 2011). Meta-syntheses may provide a means to explore differences and similarities across settings, populations, and methods/perspectives; generate new models, theories, and hypotheses; identify gaps or ambiguity in extant literature; provide historical overview and understanding of phenomena; and complement meta-analysis findings (Hannes & Lockwood, 2011).

The Cochrane collaboration, which developed standardized methods of quantitative synthesis, forwarded a method of qualitative synthesis somewhat analogous to meta-analysis in terms of perspectives on quality and the accumulation of knowledge (Hannes & Lockwood, 2011). The Cochrane collaboration emphasizes the importance of using qualitative studies that have been shown to be credible, trustworthy, and include a critical appraisal tool (Hannes & Lockwood, 2011), although these methods have been criticized for adhering too closely to values and perspectives common to the quantitative enterprise (and inconsistent with qualitative enterprise). Regardless of method, meta-synthesis approaches all (1) involve a team of researchers, (2) investigate a number of primary qualitative studies, and (3) organize and synthesize according to their respective theoretical perspective and research objectives (Yager, 1982).

Meta-synthesis methods can be differentiated according to whether they are aggregative or interpretive in nature. Aggregative meta-synthesis methods use the findings from systematic literature reviews to identify themes or similar descriptors in order to produce a general description of the phenomenon under study (Hannes & Lockwood, 2011). Aggregative synthesis methods do not consider the context under which individual study findings occur. These methods have been identified as: *meta-summary*, *thematic analysis*, *content analysis*, *case survey*, *qualitative comparative analysis*, and *Bayesian meta-analysis* (Hannes & Lockwood, 2011). Conversely, interpretive synthesis methods extend simple aggregation of individual study findings by considering the study context in relation to findings and through interpretation are able to advance knowledge by providing new models or theory of the phenomenon under study (Hannes & Lockwood, 2011). Such methods are identified as: *meta-study*, *narrative synthesis*, *narrative summary*, *formal grounded theory*, and *meta-ethnography* (Dixon-Woods et al., 2005; Hannes & Lockwood, 2011).

Methods of meta-synthesis can also be differentiated based on epistemological stance. Epistemology for an aggregative method is realism, whereas interpretive methods are in line with idealism/relativism epistemology (Hannes & Lockwood, 2011). The degree of iteration involved in an analysis procedure also helps to differentiate synthesis methods; some require a high degree, circular, and iterative process (e.g., meta-study, formal grounded theory) common to interpretive methods. Aggregative methods of synthesis have a low level or absent iterative process; instead they adopt a highly structured manner of selecting, organizing, and reporting on individual study findings (Hannes & Lockwood, 2011).

The method of meta-synthesis chosen, then, is dependent upon the research question or study aim. If a researcher aims to develop theory or discover new insight into a phenomenon, interpretive methods of synthesis are appropriate. If the aim is to produce a concrete and descriptive understanding of the phenomenon, a more aggregative synthesis approach is appropriate.

1.6 Meta-Integration

Following the recent advent of research synthesis is a novel synthesis method that combines findings from quantitative meta-analysis and qualitative meta-synthesis, known as mixed meta-synthesis, mixed research synthesis, or meta-integration (the latter label will be used in this dissertation; Crandell, Voils, & Sandelowski, 2012; Gough, Thomas, & Oliver, 2012; Kavanagh et al., 2012; Paterson, 2012; Sandelowski, Voils, & Barroso, 2006; Frantzen and Fetters, 2015). I use the label meta-integration, which describes the systematic review of quantitative and qualitative research pertaining to a particular phenomenon and the integration of the results from both a qualitative meta-analysis and qualitative meta-synthesis pertaining to a particular research question (Dixon-Woods et al., 2005; Frantzen & Fetters, 2015). The aim of meta-integration is to combine data from the two research approaches to produce a summation or holistic account of the phenomenon under study. Certainly, the philosophical, theoretical, and methodological challenges encompassed in qualitative meta-synthesis are also of concern in meta-integration. There are ‘purists’ who consider quantitative and qualitative science as completely distinct, producing fundamentally different forms of knowledge. These ‘purists’ claim that combining qualitative and quantitative science is like combining apples and oranges, (Glass, 2000) leading to non-sensible conclusions. Others (myself included) view the advent of mixed methods and meta-integration as a third research paradigm, to be considered alongside

quantitative and qualitative endeavours (e.g., Dixon-Woods et al., 2005; Frantzen & Fetters, 2015; van Wesel, Boeiji, & Alisic, 2015).

The proposed ability of meta-integration to refute, refine, and expand on theory, as well as summarize and advance knowledge in a particular field, was promising enough to lead some researchers to take on the task of resolving the methodological issues related to the ‘difference problem’ in combining quantitative and qualitative work. A number of synthesis tools are being studied and refined, as research into methods of study synthesis continues (Dixon-Woods et al., 2005; Sandelowski et al., 2006). Meta-integration tools can be categorized as segregated designs, integrated designs, and contingent designs (Sandelowski et al., 2006).

Segregated designs. Maintaining the conventional binary between quantitative and qualitative research, *segregated* mixed-meta designs assume that (1) quantitative and qualitative studies and related findings are entirely different entities that must be treated separately, (2) quantitative and qualitative works are easily differentiated from one another, and (3) each requires specific methods of analysis, due to their fundamental difference (i.e., synthesis of quantitative work requires methods designed solely for synthesizing quantitative findings and synthesis of qualitative work requires methods designed solely for synthesizing qualitative findings; Sandelowski et al., 2006). A segregated method of synthesis is suitable when synthesis outcome is intended to be a configuration, not assimilation, of the research findings (Sandelowski et al., 2006).

Segregated designs address complementarity and configuration in mixed-meta synthesis. According to segregated studies, each research approach is fundamentally different and asks/answers fundamentally different questions, therefore the findings from each approach can only serve to complement the other (Onwuebuze & Teddlie, 2003; Sandelowski et al., 2006). Thus, segregated designs provide complementary function wherein findings from one approach may serve to elaborate on or elucidate findings from the other (Sandelowski et al., 2006). As the findings of quantitative and qualitative work are seen as different, segregated designs configure research findings. By configuring the findings, meta-integration provides a coherent and whole account of the phenomenon or research question under study (Onwuebuze & Teddlie, 2003; Sandelowski et al., 2006).

Integrated designs. *Integrated designs*, do not view quantitative and qualitative research approaches as fundamentally different but rather as producing findings that are easily

transformed from quantitative to qualitative and vice versa (Dixon-Woods et al., 2004; Sandelowski et al., 2006). Such designs assume that, (1) differences between quantitative and qualitative approaches do not warrant separate analyses or syntheses of their findings, (2) quantitative and qualitative works are not necessarily easily distinguished from one another, (3) both share a common research domain that can address the same research questions and purposes, and (4) both quantitative and qualitative findings can be produced from either quantitative or qualitative methods (Sandelowski et al., 2006). Integrated meta-integration designs are suitable when synthesis is intended to produce assimilated (versus configuration) research findings (Gough, Thomas, & Oliver, 2012; Sandelowski et al., 2006). Accordingly, in integrated designs, the obtained literature sample is grouped based on the synthesis *not* the research method (i.e., quantitative/qualitative) and findings are transformed to facilitate assimilation. Integrative designs use *quantitizing* transformation to translate qualitative findings into quantitative form and *qualitizing* transformation to translate quantitative findings into qualitative form (Onwuegbuzie & Teddlie, 2003). These transformation techniques are commonly used in mixed method designs, which incorporate quantitative and qualitative methods. An example would be transforming qualitatively derived themes into predictor variables, (e.g., frequency counts of themes; quantitizing) or transforming quantitative correlations into themes, typologies, or case profiles (e.g., caregivers with low satisfaction scores versus caregivers with high satisfaction scores [qualitizing] ; Onwuegbuzie & Teddlie, 2003; Sandelowski et al., 2006).

Contingent Designs. Finally, *contingent designs* of mixed-meta synthesis describe a cycle of systematic review until a comprehensive synthesis is formed to answer the research question under study (Sandelowski et al., 2006). In this design, a synthesis of research is completed on a group of studies pertaining to a particular area of research, and the findings from the synthesis inform on a subsequent systematic review and synthesis, whose findings then inform on another review to answer yet another research question, and so on (Sandelowski et al., 2006). Contingent designs may or may not draw a clear distinction between quantitative and qualitative work and related findings. A contingent design may be segregated if the synthesis goal is to configure the findings into a theoretical or narrative product, or, contingent designs may take an integrated approach if the research question can be answered by the amalgamation of the quantitative and qualitative findings (Sandelowski et al., 2006).

Method Conclusion. In sum, choices regarding research approaches (quantitative/qualitative), methods of synthesis, and methods of meta-integration are largely based upon the research question, as well as the theoretical and literature-based knowledge of the phenomenon under study. Researchers who strongly adhere to certain ontological and epistemological perspectives may have difficulty studying in research approaches and using methodologies inconsistent with their views. Increasingly, however, researchers are accepting the relative merits and limitations of both quantitative and qualitative approaches, understanding that there may be many ways to come to know ‘reality.’ Research into methods that bring quantitative and qualitative work closer together and allow the findings from each to inform one another are advancing. These methods are moving toward the goal of providing holistic accounts of current knowledge and areas of growth within particular fields of study.

1.7 General Introduction Conclusion

The aim of this dissertation is to gain an understanding of the current knowledge of positive aspects of dementia caregiving. This includes labels, definitions, and measures used for positive aspects; how positive aspects are related to other caregiving variables; and how positive aspects ‘fit’ in to the greater caregiver experience. A recent integrative review of quantitative and qualitative studies pertaining to the positive aspects of caregiving in dementia was conducted by Yu and colleagues (2018). Yu and colleagues (2018) conducted a systematic review and narrative synthesis on 41 studies pertaining to the positive aspects of caregiving in dementia, and identified four domains of positive aspects of caregiving (personal accomplishment and gratification, feelings of mutuality in a dyadic relation, an increase in family cohesion and functionality, and a sense of personal growth and purpose in life) and three conditions that facilitate the emergence of positive aspects (personal and social affirmation, effective cognitive emotional regulation, and contexts that favour finding meaning). The researchers posit that the positive aspects of caregiving in dementia is a multi-dimensional construct best understood through multi-paradigm perspective, including models of stress and coping, and meaning making (Yu et al., 2018). The first study of this dissertation used a comprehensive search strategy and meta-integration analysis to further elucidate the phenomenon of positive aspects of caregiving. It was anticipated that the meta-integration would extend the findings of Yu and colleagues (2018) to reveal common conceptualizations, labels, definitions, and measures used to describe and investigate positive aspects of caregiving, as well as the relationships between positive

aspects and other caregiving variables. The complexity of the caregiving experience and the emergence of positive and negative aspects within the caregiving experience was illuminated through in-depth integration of the findings from meta-synthesis of quantitative studies and meta-synthesis of qualitative studies. The findings of study one were used to inform study two, a qualitative investigation of caregivers' perceptions of and experience of positive aspects in caregiving. In the general discussion, the findings of these studies are considered in relation to conceptual models of caregiving, caregiver intervention programs, and areas of future research.

1.8 General Introduction References

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2. STUDY ONE ABSTRACT

Care for persons with dementia is largely provided by informal caregivers, and caregiving has been shown to be financially, socially, physically, and psychologically challenging, yet, newer research suggests that providing care can be associated with positive outcomes. I aimed to provide a holistic account of the literature on positive aspects of caregiving with a meta-integration, which includes systematic search and synthesis of quantitative, qualitative, and mixed-methods research. Older age, being a spouse caregiver, caregiving as a man, and non-Caucasian caregiver race/ethnicity, were associated with higher scores on quantitative measures of positive aspects of caregiving. Higher scores on positive aspects of caregiving were also found with higher caregiver social support, faith/spirituality, feelings of competency, and subjective health. In contrast, high levels of caregiver education, high levels of burden and distress, low psychological health, and more care recipient problem behaviours and symptoms were factors associated with lower scores on measures of positive aspects of caregiving. Qualitative synthesis analysis identified factors that underlie positive aspects, including caregiver characteristics and tendencies as well as motivations in caregiving, and factors that facilitate, such as feeling appreciated, and having social support, and factors that hinder the experience of positive aspects in caregiving, such as feelings of loss and isolation. Based on these findings I suggest there are conditions for experiencing positive aspects in caregiving that relate to both internal factors (i.e., pertaining to the caregiver) and external factors (i.e. pertaining to the caregiver/care recipient relationship and caregiving environment). Conditions for positive aspects falter when caregivers' experience loss and isolation within the caregiver role.

2.1 POSITIVE ASPECTS OF THE CAREGIVING EXPERIENCE: A META-INTEGRATION

The following manuscript has been submitted for publication. In order to do so, the manuscript was divided into two parts, with the first manuscript, titled *Positive Aspects of the Caregiving Experience: A Meta-Integration of the Qualitative and Quantitative Literature of Informal Caregivers for Persons with Dementia Part One of a Two-Part Review*, submitted to *Dementia: The international journal of social research and practice*, with the following authorship: Branger, C. & O'Connell, M. E.. The second manuscript, titled *Positive Aspects of the Caregiving Experience: A Meta-Integration of the Qualitative and Quantitative Literature of Informal Caregivers for Persons with Dementia Part Two of a Two-Part Review*, was submitted to *Journal of Applied Gerontology*, with the following authorship: Branger, C. & O'Connell, M. E.. The primary author, C. Branger, conducted the research and is the author of the following manuscript. M. E. O'Connell served as a second coder in the research process, and provided revision of the current document. M. E. O'Connell managed the revisions necessary to submit this work for publication, which included reduction in content and division of the manuscript into two independent manuscripts.

The well-being of family members and friends who become the primary caregiver of someone living with dementia is important in the context of a growing aging population and increasing rates of dementia. In 2015, it was estimated that 47 million persons were living with dementia globally and this figure is expected to rise to 75 million by 2030, and 132 million by 2050 (World Health Organization [WHO], 2017). Research indicates that care for persons with dementia is largely provided by informal caregivers (i.e., family members and friends; hereafter, caregivers) who are untrained and unpaid for the care they provide (Prince et al., 2013). In the context of limited health care services for the growing number of persons living with dementia, caregiver research continues to be an active field of study with efforts commonly aimed at identifying and addressing the negative aspects of caregiving.

Caregiving for a loved one with dementia has been shown to be challenging on financial, social (e.g., Brodaty, 2007), physical, and psychological fronts (e.g., Pinquart & Sörensen, 2003). Research has provided conceptual models and frameworks of the caregiving experience (e.g., Pearlin et al., 1990; Chwalisz, 1996) and has shown that caregivers of persons with dementia demonstrate higher levels of physical and psychological strain compared to other caregiver types and non-caregivers (Pinquart & Sörensen, 2003). Some research, however, has shown that there are positive aspects associated with caring for a loved one with dementia including, but not limited to, feelings of personal gain and satisfaction (e.g., Lloyd, Patterson, & Muers, 2014; Peacock et al., 2010). Research into the positive aspects of caregiving is growing, but it remains fraught with variations in labels and challenges in measurement and conceptualization. For instance, positive aspects may be referred to as gains (e.g., Morano, 2003;

Yap et al., 2010), satisfaction (e.g., de Labra et al., 2015), personal growth (e.g., Lloyd, Patterson, & Meurs, 2014), and finding meaning (e.g., Butcher et al., 2016; Farran, et al., 1991). Measures of positive aspects of the caregiver experience range from finding meaning (e.g., Blume, 1999), to caregiver gains (e.g., Fabà, Villar, Giuliani, 2017), to measures of hassles and uplifts (e.g., Kinney & Stephens, 1989), to family role reward (e.g., Gonzalez et al., 2014), and positive aspects of caregiving (e.g., Cheng et al., 2012). Each construct represents some fraction of positive aspects of caregiving, and consequently, each construct is measured somewhat differently. As such, it is difficult to define the range of experiences that constitute positive aspects of caregiving. Without a comprehensive understanding of what is currently known of positive aspects and how these aspects are conceptualized and measured, advances in salutogenic caregiver research is limited. Without a comprehensive understanding of the positive aspects of caregiving, intervention programs for caregivers may risk working to diminish negative aspects of caregiving while missing the opportunity to bolster positive aspects.

The purpose of the current work is to gain a holistic account of the state of research on the positive aspects of caregiving. To this aim, this work will use a novel method of investigation, *meta-integration*, to synthesize findings from quantitative, qualitative, and mixed-methods qualitative literature on positive aspects of caregiving. For the purpose of this study, I define positive aspects as those experiences and outcomes (e.g., benefits, gains, growth, and satisfactions) perceived by the caregiver to be positive in nature, and related to fulfilling the caregiver role

2.1.1 Conceptual Models of the Caregiving Experience

Commonly, conceptual models of the caregiving experience assume that living with chronic illness is stressful for both the caregiver and care recipient. Accordingly, stress theory is often applied to such models, which posits that stress is the result of an interaction between personal characteristics and situational factors (Lazarus & Folkman, 1984). More explicitly, stress theory suggests that when individuals are met with an objective demand (e.g., a caregiving task), they appraise their ability to adapt to the demand and, should they feel unable to cope with the demand, they experience stress and related negative psychological outcomes (Lazarus and Folkman, 1984). Building on this theory, Pearlin and colleagues (1990) posit that stress represents a dynamic and ongoing process that directly affects the physical and psychological outcomes associated with caregiving. Similarly, Chwalisz (1996) describes a general model of

caregiving that suggests sequential relations between environmental and internal components/characteristics that moderate stress. While such models have proved useful for investigating and understanding the negative aspects of caregiving, these models have considerable difficulty accounting for the positive aspects of the caregiving experience.

Efforts have been made to expand on the stress-based model of caregiving to incorporate positive aspects of caregiving, including aspects of caregiving that are mediators or coping methods (e.g., Pearlin et al.'s Stress-Process model, 1990). Others have suggested that positive aspects of caregiving must be modeled separate from conventional models (e.g., Carbonneau, Caron, & Desrosiers, 2010; Lloyd, Patterson, & Muers, 2014). Nevertheless, the current state of knowledge regarding caregiver experience is imbalanced, with a predominant focus on negative aspects and considerably less known about the positive aspects. Some researchers argue that overreliance on stress theory to conceptualize caregiving has made it difficult to acknowledge and investigate positive aspects, leaving this side of the caregiving experience understudied and poorly understood (Kramer, 1997). I argue that understanding positive aspects of the caregiver experience is equally as important as the negative aspects for development and refinement of interventions.

Research into positive aspects of the caregiver experience is founded in research on what it means to be psychologically well (Kramer, 1997). Ryff and colleagues (1998) suggested six aspects of well-being: personal growth, purpose in life, autonomy, environmental mastery, positive relations with others, and self-acceptance. Interestingly, extant literature on positive aspects of caregiving reveal positive outcomes highly reflective of Ryff and colleagues' aspects of well-being (e.g., Yu, Cheng, & Wang, 2018).

A recent review of qualitative literature reported a number of positive outcome conceptualizations from caregiving, such as role satisfaction (i.e., feeling satisfied with doing a good job of caring), emotional rewards, personal growth (e.g., increased patience, increased self-respect and self-awareness), competence and mastery (i.e., learning new skills), faith/spiritual growth, relationships gains (i.e., improved/intensified bond with care recipient), sense of duty, and reciprocity (i.e., satisfaction in giving back to the care recipient; Lloyd et al., 2014). Some researchers argue the variations in labels used for positive aspects, conceptualizations of positive aspects, and instruments used to measure positive aspects is due to a lack of a guiding theory and framework of positive aspects of caregiving (Kramer, 1997). Others suggest that the lack of

clarity and consistency is due to a reliance on quantitative research approaches that study measurable phenomena (Lloyd et al., 2014). Compared to pathological or negative outcomes, positive outcomes are difficult to measure as the expression of these tend to be individualized and subjective in nature (Farran, 1991). Nevertheless, the body of work regarding positive aspects of caregiving is growing. A method of bringing this work together to form a coherent understanding of the state of knowledge in this area is needed to facilitate knowledge development and advances in the field.

Indeed, a recent integrative review of quantitative and qualitative studies pertaining to the positive aspects of caregiving in dementia synthesizes the findings of the two lines of inquiry revealing domains of positive aspects (i.e., feelings of accomplishment and gratification, feelings of mutuality in a dyadic relationship, increase of family cohesion and functionality, and a sense of personal growth and purpose in life) and conditions that facilitate the emergence of positive aspects (personal and social affirmation, effective cognitive emotional regulation, and context that favour finding meaning in the caregiving experience; Yu et al., 2018). Feelings of accomplishment and gratification result from feelings of competence in caregiving, particularly when the caregiver perceives that the care recipient is comfortable and that the care recipient's well-being is improving due to the caregiver's efforts (Yu et al., 2018). Mutuality in the dyadic relationship reflects the caregiver's appreciation for the relationship they have with the care recipient and being attuned to subtle positive responses from the care recipient that may signal love, affection and appreciation (Yu et al., 2018).

Increased family cohesion and functionality is described as the caregiver's perception that the experience of caregiving can present an opportunity to enhance the family's cohesion through modelling caregiving for younger generations, demonstrating filial responsibility, and working together to provide care for the care recipient (Yu et al., 2018). Finally, the domain of personal growth and change in character and life philosophy reflects a response to the challenges of caregiving that allows caregivers to see themselves as 'more patient,' 'more caring,' 'more emotionally intelligent and sensitive to needs of others,' and 'more humble' than previously thought (Yu et al., 2018). This domain also reflects a reorganization of priorities in life, wherein family is prioritized over material goods or wealth (Yu et al., 2018). Yu and colleagues (2018) forward three conditions that facilitate positive aspects, including personal affirmation (i.e., a caregiver's perceived performance in the caregiving role and the importance of preparedness in

improving sense of adequacy in the role), effective cognitive emotional regulation (i.e., cognitive re-framing that facilitates positive thinking, changes the perception of the caregiving situation to one that is more uplifting, and refocus to adaptive strategies such as making choices, being grateful, and using humour), and finding meaning (i.e., intrinsic motivations to provide care, good dyadic relationships, and positive religiosity).

The narrative synthesis of quantitative and qualitative studies thus provides some clarity and a framework for understanding positive aspects of caregiving. What remains unclear is the common labels, definitions, and measures of positive aspects in literature; what is known of the relationship between positive aspects and other caregiver and care recipient factors; and how positive aspects of caregiving ‘fit’ within the greater caregiver experience (including negative aspects). Using meta-integration, a method of investigation that not only synthesizes but integrates findings from quantitative and qualitative studies, I aim to address questions of consistency and variation in labels, definitions, and conceptualization of positive aspects of caregiving, as well as further elucidate the factors that underlie positive aspects, factors that facilitate the emergence of positive aspects, and factors that hinder the experience of positive aspects in caregiving.

2.1.2 Meta-Integration

Meta-integration is a method of investigation that encompasses quantitative meta-analysis and qualitative meta-synthesis. Historically, there has been a divide between quantitative and qualitative work. Stemming from different ontological and epistemological perspectives, the two approaches have been viewed as entirely different species of scientific research (Sandelowski, Voils, & Barroso, 2006). However, the divide between quantitative and qualitative research is narrowing. Methods that incorporate both quantitative and qualitative approaches (e.g., mixed-method study designs) and integrate knowledge derived from each line of inquiry are becoming increasingly popular. Given the variations in approach (i.e., quantitative, qualitative mixed study design), labels, definitions, measurements, and relationships investigated, I use meta-integration to investigate the current state of positive aspects literature and to elucidate the phenomenon of positive aspects of providing care to someone living with dementia.

2.2 Method

The current research endeavour is exploratory; consequently, I concluded that a configuration of the findings (i.e., segregated [Cooper, 2009] or convergent [Sherwood, 1999]) meta-integration design would be more appropriate than assimilation (Cooper, 2010; Frantzen & Fetters, 2016). I relied on the models of meta-integration described by Frantzen and Fetters (2016). Frantzen and Fetters (2016) compared published methods of synthesizing work from quantitative, qualitative, and mixed method studies. Models of meta-integration are differentiated by the inclusion or exclusion of mixed-methods studies (inclusion of mixed-methods require *advanced* model designs, rather than *basic* models designs), and the use of data transformation (e.g., a researcher might choose to transform quantitative data into qualitative data and conduct a convergent qualitative meta-integration; Please see Appendix A). I chose an advanced model over the basic model due to the inclusion of mixed method studies. Further, given the exploratory nature of this research, I determined that models of integration that included data transformation (transforming quantitative data into qualitative data and vice versa, for synthesis purposes) would be inappropriate, as I did not want to privilege any one line of inquiry (i.e., quantitative or qualitative). In the chosen model of meta-integration, the mixed methods studies are fractionated, that is, quantitative data and qualitative data from mixed method studies are extracted and added to quantitative and qualitative datasets, respectively (see Appendix A). The protocol for this meta-integration has been published and accurately describes how the current meta-integration was conducted. For more details on the methodological approach and process, please refer to our published protocol of the meta-integration (Appendix A; Branger, O'Connell, & Peacock, 2018).

Working from a post-positive epistemological perspective, I conducted an advanced meta-integration that included conducting the systematic search, inclusion and exclusion screening process, intra-method synthesis-analysis (quantitative analysis, and qualitative synthesis), inter-method synthesis (integration of quantitative and qualitative data set findings), organization of results, assessment of fit, and conclusions. The Mixed Methods Appraisal Tool (MMAT) was designed for the appraisal stage of systematic literature reviews that include quantitative, qualitative, and mixed-methods studies (Pace et al., 2012). The MMAT provides a means of assessing reliability in qualitative studies, quantitative studies, randomized control studies, and mixed methods studies with outcome scores that provides comparability across quantitative, qualitative, and mixed methods studies (Pace et al., 2012). The (MMAT) was used

to describe the methodological quality of each study, but quality was not used for inclusion/exclusion criteria, nor was it used to weight the findings of studies differently. The purpose of the present meta-integration was to establish what is known of positive aspects of caregiving, how they are labeled, conceptualized, measured, and investigated, regardless of the quality of the investigations.

2.3 Results

The liberal, comprehensive search strategy conducted on eight databases returned 3,706 references, leaving 3,374 after removing duplicates. Figure 1 includes a PRISMA diagram of the stages of exclusion that led to the final references, which were comprised of 50 quantitative approaches, 19 qualitative approaches, and 3 mixed methods approaches. The initial search was conducted in December 2017, and each data base was searched in June 2019 and September 2019 to identify new references. The recent searches were limited to those published after the completion of the original search (December 2017). The titles and abstracts were screened for inclusion. Eight new references were identified and included in the meta-integration, for a total of 56 quantitative approaches, 21 qualitative approaches, and 3 mixed methods.

2.3.1 Intra-Method Synthesis Analysis

I developed a coding manual for the data extraction phase (Appendix B) and 15% of the original (December 2017 search) 72 references were randomly selected for coding and data extraction by a second coder. The purpose of the second coder (MEO) was to ascertain the degree of agreement, to improve rigor, and to address potential issues of bias. There was over 90% agreement and discrepancies resulted from ambiguity in differences between highly related variables; therefore, once discussed, 100% agreement was reached. References were divided into quantitative and qualitative datasets. Mixed methods studies underwent fractionation, wherein quantitative data and qualitative data were extracted and entered into respective databases. The decision to fractionate was based on the findings that the mixed-methods studies did not have a high degree of integration regarding the quantitative and qualitative findings (Frantzen & Fetters, 2016).

Quantitative Intra-Method Synthesis Analysis

Fifty-six quantitative studies and three mixed-methods study were included in the quantitative dataset, for a total of 59. Table 2.1 provides a summary of the primary quantitative studies/references, including the Study ID numbers (e.g., QT#) that will be used throughout this

work to refer to the primary references. Fifty-one of the 59 studies were scholarly articles and two were dissertations/theses. The years of publication ranged from 1989-2019, with peak publications in positive aspects literature in 2012. The majority of the studies (61.0%) originated from United States of America (USA) and 94.3% of all studies' populations were community dwelling caregiver/care recipient dyads. The majority of studies (58.5%) stated that the care recipients were diagnosed with some form of dementia, and of these, 20.8% of studies were based on caregivers of persons living with dementia due to Alzheimer's disease (AD), or a combination of AD and other dementias (17%). One study included caregivers of persons with mild cognitive impairment, and one study included caregivers of persons living with Huntington's disease (1.8%). Most commonly, caregiver populations were mixed including spouses and adult caregivers; 79.6% of the primary studies included spousal caregivers, 50.9% included adult children, and 47.2% included other family members or friends.

Some of the studies (40.6%) reported using racially/ethnically diverse samples and were conducted in the USA, most commonly including African American, Hispanic American, and Caucasian American caregivers. Thirteen percent of the studies were based on a racially/ethnically diverse caregiver samples from a comprehensive longitudinal study conducted in the USA (Resources for Enhancing Alzheimer's Caregiver Health; REACH), with a sample of 1,222 caregivers from six sites across the country. The majority of the studies (88.1%) were correlational, with four studies reported to be descriptive, and three to be experimental. The following begins with findings pertaining to measurement and definition of positive aspects, followed by a summation of the findings pertaining to relationships between positive aspects, caregiver factors, and care recipient factors.

Positive Aspects Definitions and Measures

A description of each measure can be found in Table 2.2. The majority of studies referred to positive aspects as 'positive aspects of caregiving' (49.1%). Otherwise, labels such as 'positive outcomes' (9.4%), 'gains' (9.4%), 'satisfactions' (8.4%), or other labels (20.3%) were used. These other labels included, 'positive psychological resource' (1 study), 'caregiver reciprocity' (1 study), 'caregiving benefits' (1 study), 'finding meaning' (2 studies), 'perceived rewards' (2 studies), 'positive appraisal', (2 studies), 'posttraumatic growth' (1 study), and 'uplifts' (1 study). Furthermore, in one study, it was not clear what label the researchers were using outside of their measure.

Positive aspects definitions. Of the 59 quantitative studies, 12 (20.3%) did not provide a clear definition of the positive aspects. Of those that did, the majority (48.8%) of definitions described positive aspects as factors of, or perceptions of, the caregiving experience that could benefit the caregivers' experience of self and or experience of life. Other definitions describe positive aspects as diminishing negative aspects, for instance reducing stress and burden. In this way, positive aspects were positioned opposite of negative aspects. Fewer studies described positive aspects as overall satisfaction due to the experience of caregiver. Lastly, others indicated that positive aspects were a means of making meaning and coping within caregiving.

Positive aspects measures. A summary of the measures, primary reference description of the measures' properties, and reported evidence for the measures can be found in Table 2.2. The measures, including: Positive Aspects of Caregiving (PAC; Tarlow et al., 2004), Careers' Assessment of Satisfaction Index (CASI; Andrén & Elmståhl, 2005), Caregiver Satisfaction Scale (CSS; Kramer, 1997), Caregiver Satisfaction Scale revised (CSSR; Lawton, Moss, Hoffman, & Perkinson, 2000), Caregiver Reciprocity Scale (Carruth, 1996), Caregiver Appraisal Tool (Chang, Brecht, & Carter, 2001; Lawton, Kleban, Moss, Ravive, & Glicksman, 1989), Family Role Reward Scale (Gonzalez et al., 2014), Finding Meaning Through Caregiving Scale (FMTCS; Farran et al., 1991), Scale for Positive Aspects of Caregiving Experience (SPACE; Grover, Nehra, Malhorta, & Kate, 2017), Caregiving Gratification Scale (Kajiwatra, Nakatni, Ono, & Miyakoshi, 2015), Caregiving Hassles and Uplifts scale (Kinney & Stephens, 1989), Gains in Alzheimer's Care Instrument (Yap et al., 2010), Benefit Finding Scale (BFS; Luszczynska et al., 2012), Personal Growth subscale of the Hogan Grief Reaction Checklist (Hogan, Greenfield, & Schmidt, 2001), Meaning Through Caregiving (MTC; Noonan and Tennstedt, 1997), and Picot Caregiver Rewards Scale (PCRS; Picot, 1994) were used and nine studies used study specific measurement of positive aspects.

The most commonly used measure across the 59 studies was the PAC measure and it was used in 21 (35.5%) of the studies. Reported evidence for the reliability and validity for the PAC was strong and Cronbach's Alpha was often provided. The PAC was translated into Chinese, Portuguese, and Iranian, with the latter demonstrating good inter-rater reliability (no evidence presented for former). The PAC is available in 9 and 11 item versions. The items pertain to caregivers' mental and affective states and are most commonly found to reflect two factors: Self-Affirmation and Outlook on Life (QT26, QT28, QT36, QT39, QT41, QT62). The next most

commonly used measure was FMTCS and it was used in six (11.3%) of the studies. The FMTCS is a 43-item scale that addresses three factors: loss and powerlessness (19 items), provisional meaning (making meaning from every day events) (19 items), and ultimate meaning (spiritual meaning) (9 items). The CSS was used in four (7.5%) of the studies. The CSS is a 15-item scale pertaining to long-term satisfaction, such as finding purpose and meaning in caregiving. Finally, the Gains in Alzheimer's Care Instrument (GAIN) was used in three (5.7%) of the studies. GAIN is a 22-item scale pertaining to five domains of caregiving: industry, identity, intimacy, generativity, and ego integrity. All reported evidence of validity and reliability was comparable across the most common measures; however, evidence presented for PAC was the most consistent and strong across studies, with a Cronbach's alpha range of 0.80-0.95.

Relationships between Caregiver/Care Recipient Factors and Positive Aspects

Gender and positive aspects of caregiving. In this work I refer to gender rather than sex. Gender is increasingly accepted as a psychological construct situated within a cultural and social context (Pflum, et al., 2015). While it was not explicitly stated in primary studies whether researchers were referring to sex or gender when describing participant characteristics, the omission of biological data in the primary studies indicates the construct being considered was gender rather than sex. Further, it was clear in discussions regarding differences between men and women that the primary studies were referring to psychosocial differentiations (e.g., traditional gender norms for provision of care), rather than biology. Data from 16 (27.1%) out of the 59 studies either investigated the relationship between caregiver gender and positive aspects of caregiving (47%), or reported data that could be used to calculate the effect size between the two variables (53%). The average MMAT score for these studies was 68.2%, with a mode of 75% and a range of 25% to 100%. The measures used in these investigations included: Positive Aspects of Caregiving measure (PAC; 10 of the studies [62.5%]); Meaning Through Caregiving Scale (MTC) and Finding Meaning Through Caregiving Scale (FMTCS; two studies [12.5%]); Scale for Positive Aspects of Caregiving Experience (SPACE; one study [.06%]); Caregiver Satisfaction Scale Revised (CSSR; one study [6.2%]); Caregiver Assessment of Satisfaction Index (CASI; one study [6.2%]); and study specific measures (two studies [12.5%]). Eight of the 16 studies analyzed the relationship between gender and positive aspects of caregiving using Pearson correlation coefficient, '*r*'. Only one study (QT11) found a significant correlation between gender and PAC scores ($r = -.110, p < .010$) with men coded as '0' and women coded as

'1' indicating that, in this sample, caregiving as a man gender was associated with higher PAC scores. Effect size was calculated for four studies. A small effect size was found in one study using a study specific measure of caregiver gain (QT78: $d = 0.225$, CI 95% = $-0.5542 - .1032$) and a medium effect size was found in two studies using the PAC scale (QT62: $d = .303$, CI 95% = $0.1578-0.4472$; QT57: $d=.728$, CI 95% = $0.5188-0.9371$). Confidence intervals for the third calculated effect size included zero and the study used the satisfaction measure CSS (QT15: $d = .02$, CI 95% $-0.410-0.370$). In sum, these data indicate a small to medium effect size of gender and positive aspects of caregiving as measured by PAC scale, wherein caregiving as a man is associated with higher PAC scores.

Age and positive aspects of caregiving. Nineteen (32.2%) out of the 59 primary studies either investigated the relationship between age and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score for these studies was 66.2% with modes 50% and 75% and range of 50% to 100%. These studies used the following measures: Positive Aspects of Caregiving (PAC) in ten studies (52.6%); Caregiver Satisfaction Scale (CSS; three studies) and its revised version (CSSR; one study) in four studies (22%); The Picot Caregiver Rewards Scale (PCRS) in one study (5%); the Caregiver Assessment of Satisfaction Instrument (CASI) in one study (5%); the Caregiver Gratifications scale (CGS) in one study (5%); the Meaning Through Caregiving (MTC) in one study (5%); and study specific measures in one study (5%). Significant and positive Pearson correlation coefficients between age and positive aspects were reported for a study specific measure of positive aspects (QT70; $r = 0.230$, $p < 0.10$); PAC (QT39; $r = 0.240$, $p < 0.05$), CSS (QT33; $r = 0.280$, $p < 0.05$), CGS (QT30; $r = 0.164$, $p < 0.01$), and CASI (QT01) subscales of 'purpose' ($r = 0.236$, $p < 0.01$) and 'appreciated' ($r = 0.240$, $p < 0.01$). Three studies reported significant negative correlations between age and positive aspects, as measured by PAC (QT28; $r = -0.120$, $p < 0.05$; QT76; r not reported, $p = 0.005$) and CSSR (QT15; $r = -0.238$, $p < 0.05$). The effect size of the relationship between age and positive aspects was calculated for two studies: PCRS (QT66; $d = 0.471$, CI 95% = $0.0346- 0.907$) and PAC (QT57; $d = 0.057$, CI 95% = $-0.202-0.134$).

In sum, these data indicate that five of studies investigating the relationship between age and positive aspects found significant positive correlations of small magnitude, indicating that older age is associated with higher scores on measures of positive aspects. However, a significant negative correlation was reported in three studies, indicating that as age increased, scores on

measures of positive aspects decreased. Support for the magnitude in effect size of the relationship between age and positive aspects was found in one study calculation, wherein a small effect size was found.

Race/Ethnicity and positive aspects of caregiving. I chose to use both race/ethnicity to discuss these findings. It was unclear how primary studies determined group membership among participants. Ethnicity refers to social and cultural identity and an individual's sense of membership in an ethnic group can be variable and highly individualized (Fenton, 2013). The primary studies investigated differences among African American, Hispanic American, and Caucasian American groups and different ethnicities can exist within each one of these but such ethnicities were not detailed in the primary studies. Any discussion in the primary studies regarding differences among these groups, however, were psychosocial in nature not biological. While the term 'race' can be thought to reflect group classification based on physical attributes such as skin colour, eye colour, and so forth, contemporary critics of the race/ethnicity terminology divide argue that both race and ethnicity are social constructs (Song, 2017). Given the omission of report of ethnic groups in the primary studies, the complexity of the conceptualization of race, and the importance of a social emphasis in the discussion of the experience of caregiving, I will refer to race/ethnicity in this work. Eight (14%) of the 59 primary studies either investigated the relationship between race and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT for these studies was 68%, with modes 50% and 75 % and a range of 25% to 100%. These studies used the following measures: Positive Aspects of Caregiving (PAC) in five studies (63%); the Finding Meaning Through Caregiving Scale (FMTCS) in one study (13%); and a study specific measure was used in two studies (25%). The race/ethnic groups investigated across these studies were Hispanic American, African American, and Caucasian American.

Two studies reported significant Pearson correlation coefficients (QT56; PAC and Caucasian American and African American race groups ($r = 0.220, p < 0.05$); FMTCS with African American and Caucasian American caregiver groups on Provisional meaning ($r = 0.200, p < 0.010$) and Ultimate Meaning $r = 0.38, p < .01$). Calculated effect sizes indicate small to medium effects sizes for PAC with the following race/ethnic identities: Caucasian American and African American (QT62: $d = 0.537, CI 95\% 0.3982-0.6751$; QT57: $d = 0.443, CI 95\% = 0.2862-0.5994$; QT56: $d = 0.444, CI 95\% = 0.2833-0.6044$; QT27: $d = 0.260, CI 95\% = 0.0079-$

0.5129; QT11: $d = .561$, CI 95% = 0.45-0.673), African American and Hispanic American ($d = 0.028$, CI 95% = -0.1545-0.2113), and Hispanic American and Caucasian American Caregivers (QT62: $d = .499$, CI 95% = 0.3362-0.662; QT57: $d = 0.570$, CI 95% = 0.4121-0.7277; QT11: $d = 0.683$, CI 95% = 0.571-0.796). A study specific measure with Caucasian American and African American Caregiver effect size was calculated (QT54: $d = 0.915$, CI 95% = 0.191-1.638). Another study specific (QT14) measure of positive aspects by race group effect size was calculated for Caucasian American and African American caregivers by subscale of personal gain ($d=0.725$, CI 95% = 0.472-0.976) and competency ($d = 0.687$, CI 95% = 0.4363-0.938). In sum, these data reveal small to medium correlations and effects sizes for the relationship of race/ethnicity and positive aspects. The primary data indicate that African American caregivers score higher on measures of positive aspects than Caucasian American caregivers. Hispanic American caregivers score higher on measures of positive aspects than Caucasian American caregivers.

Caregiver employment and positive aspects of caregiving. Only one study investigated caregiver employment status and positive aspects of caregiving. The MMAT score for this study was 75%. The study investigated the correlation between caregivers' employment status and scores on PAC. The study (QT15) reported that the correlation was not significant, but did not report the raw data or statistical outcomes. No other studies report data to support effect size calculation for this relationship.

Caregiver level of education and positive aspects of caregiving. Nine (15%) of the 59 primary studies either investigated the relationship between caregiver years of education and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score for these studies was 60%, with a mode of 50% and a range of 25% to 100%. Positive Aspects of Caregiving (PAC) was used in 3 studies (33%), Caregiver Satisfaction Scale (CSS) (2) and its revised version (CSSR; 1) were used in three studies (22%), The Picot Caregiver Rewards Scale was used in one study (PCRS) (11%), the Scale for Positive Aspects of Caregiving Experience (SPACE) was used in one study (11%), and one study utilized a study specific measure (11%). Five of the studies report a significant, negative Pearson correlation coefficient for caregiver years of education and positive aspects, as measured by PAC (QT11: $r = -0.320$, $p < 0.01$), PCRS (QT66: $r = -0.370$, $p < .001$), CSS (QT34: $r = -0.350$, $p < 0.01$; QT03: $r = -0.247$, $p < 0.05$) and SPACE (QT23: $r = -0.344$, $p < 0.010$). In sum, these data indicate that

the more years of education a caregiver has, the lower they tend to score on measures of positive aspects.

Relationship type and positive aspects of caregiving. Twelve (20%) of the 59 primary studies either investigated the relationship between caregiver/care recipient and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score for these studies was 73%, with a mode of 75% and a range of 50% to 100%. Positive Aspects of Caregiving (PAC) was used in five studies (42%), Caregiver Satisfaction Scale (CSS) was used in one (8%) study, Meaning Through Caregiving measure (MTC) was used in one study (8%), Finding Meaning Through Caregiving Scale (FMTCS) was used in one study (8%), Caregiver Assessment of Satisfaction Instrument (CASI) was used in one study (8%), a subscale of Personal growth belonging to the Hogan Grief Reaction Checklist was used in one study (8%), and two studies used study specific measures (17%).

Three studies reported Pearson correlation coefficients for the relationship between caregiver/care recipient relationship type and positive aspects. One study reported significant negative correlations, indicating that spousal relationship type was associated with higher scores on the MTC (QT52: $r = -0.170$, $p < 0.001$). Effect sizes were calculated for nine studies, and the effect size confidence intervals that did not include zero are as follows. Small effects sizes were found for the relationship between relationship type and PAC (QT62: (Husband vs Wife) $d = 0.430$, $CI\ 95\% = 0.2443-0.6156$; (Husband vs Child) $d = 0.254$, $CI\ 95\% = 0.0756-0.4733$); Personal Growth subscale of Hogan Grief Reaction Checklist (QT48: (Spouse vs Children) $d = 0.302$, $CI\ 95\% = 0.0221-0.5813$; and FMTCS (QT37: $d = 0.570$, $CI\ 95\% = 0.097-1.04$). These data indicate an association between caregiver/care recipient relationship type and positive aspects of caregiving of small magnitude, wherein spousal caregivers have a tendency to score higher on measures of positive aspects as compared to adult children or other caregivers. In one study, husbands were found to score higher on measures of positive aspects than wives (QT62), consistent with findings pertaining to the relationship between caregiver gender and positive aspects (wherein men tend to score higher).

Duration of caregiving and positive aspects of caregiving. Eleven (19%) of the 59 primary studies investigated the relationship between duration of caregiving in years, and positive aspects of caregiving. The average MMAT score for these studies was 63%, with a mode 50% and a range of 45% to 100%. Positive Aspects of Caregiving (PAC) was used in three

studies (27%), the Finding Meaning Through Caregiving Scale (FMTCS) was used in one study (9%), the Caregiver Gratification Scale (CGS) was used in one study (9%), and two studies used study specific measures (18%). Three of the studies report significant Pearson correlation coefficients for the relationship between caregiving duration and positive aspects. Two significant negative correlations were found (QT65: $r = -0.100, p < 0.05$; QT45: $r = -0.246, p < 0.05$), indicating that the greater number of years spent caregiving, the lower the scores on measures of positive aspects. On study (QT4QL7) report a significant positive correlation ($r = 0.330, p < 0.05$), indicating that greater number of years spent caregiving was associated with higher scores on the PAC.

Care recipient dementia severity and positive aspects of caregiving. Fifteen (25.4%) of the 59 primary studies either investigated the relationship between care recipient dementia severity and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score for these studies was 74.5%, with a mode of 75% and a range of 50% to 100%. Positive Aspects of Caregiving (PAC) was used in four studies (26.6%), Caregiver Satisfaction Scale (CSS) (3) and its revised version (CSSR) (1) were used in four (26.6%) studies, Finding Meaning Through Caregiving Scale (FMTCS) was used in one study (8%), Caregiver Assessment of Satisfaction Instrument (CASI) was used in two studies (13.3%), Gains in Alzheimer's Care Instrument (GAIN) was used in one study (6.6%) the Caregiver Gratifications Scale (CGS) was used in one study (6.6%), and four studies used study specific measures (26.6%). Twelve of the studies investigated the relationship between dementia severity and positive aspects. Three studies reported significant Pearson Correlation coefficients. Two of the studies found a negative association between dementia severity and positive aspects (QT24: $r = -0.30, p < .01$; QT79: $r = -0.26, p < .001$), indicating higher scores on a measure of Daily Care Bother (QT24, QT79) was associated with lower scores on the PAC and CSS with dementia severity measured by ADL (QT33: $r = 0.250, p < 0.05$). Another study reported a positive correlation (QT02: $r = 0.171, p < 0.05$) indicating that higher scores on a measure of dementia severity was associated with higher scores on the subscale of 'purpose' on the CASI measure. Effect size was calculated for three studies and all revealed a small to medium effect size between dementia severity and positive aspects.

Using the measure of GAIN, an effect size for dementia severity was calculated (QT36: (mild severity) $d = 0.239, CI 95\% = 0.0256-.5052$; (moderate severity) $d = 0.400, CI 95\% =$

0.103-0.697; (severe) $d = 0.16$, $CI_{95\%} = 0.1025-.4124$); PAC (QT27: $d = 0.613$, $CI_{95\%} = 0.299, -0.9257$); and CSS (QT15: $d = 0.595$, $CI_{95\%} = 0.195-0.993$). In sum, these data indicate a small to medium magnitude of association between dementia severity and positive aspects of caregiving. Importantly, seven out of the 13 (54%) studies that investigated the relationship between positive aspects and dementia severity did not find a significant correlation. Further, these data indicate that a relationship between dementia severity and positive aspects of caregiving is not robust and significant findings indicate a negative relationship (i.e., when ADL impairment is high, scores on PAC measure tend to be lower). In one study, high scores on a measure of purpose were associated with greater dementia severity.

Care recipient behaviour and symptoms, and positive aspects of caregiving.

Fourteen (23.7%) out of the **59** primary studies investigated the relationship between care recipient behaviours/symptoms and positive aspects. The average MMAT score for these studies was **71.2%**, with a mode of 50% and a range of 50% to 100. These studies used the following measures: Positive Aspects of Caregiving (PAC) in seven studies (50%), Caregiver Satisfaction Scale (CSS) in two studies (16%), Caregiver Assessment of Satisfaction Index (CASI) in one study, the Caregiver Gratifications Scale (CGS) in one study (8%), the Gains in Alzheimer's Care Instrument (GAIN) in one study (8%), and two studies used a study specific measure (16%). Out of the 14 studies, nine reported statistically significant Pearson correlation coefficients. A significant negative relationship between dementia behaviours/symptoms and positive aspects was measured by PAC and reported (QT65: $r = -0.520$, $p < 0.010$; QT60: $r = -0.265$, $p < 0.05$; QT24: $r = -0.330$, $p < 0.010$; QT11: $r = -0.27$, $p < 0.01$; QT79: $r = -0.17$, $p < 0.001$). Similarly, negative and significant correlations between scores on PAC were found with subscales of the Revised Memory and Behavioural Problems Checklist (RMBPC), memory bother (QT41: $r = -0.190$, $p < .01$), disruptive occurrences ($r = -0.15$, $p < 0.01$), and bother due to disruptive occurrences ($r = -0.22$, $p < 0.01$). Significant negative correlation between GAIN and RMBPC was reported (QT38: $r = -0.170$, $p = 0.002$). One study using a study specific measure of caregiving benefits found a significant negative correlation with RMBPC (QT06: $r = -0.170$, $p < 0.05$). One study found a positive correlation between behavioural symptoms and the subscale of caregiver satisfaction, purpose (QT73: $r = 0.22$, $p < 0.01$). Five of the 12 studies (42%) did not find a significant correlation between care recipient behaviours/symptoms, and positive aspects. The majority of the significant correlations were medium sized (i.e., $r \sim 0.3$) and the

majority of significant correlations were negative, indicating that the greater the dementia related behaviours/symptoms exhibited by care recipients, the lower caregivers scored on measures of positive aspects.

Caregiver burden and positive aspects of caregiving. Twenty-six (44.1%) out of the 59 primary studies either investigated the relationship between caregiver burden and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score for these studies was 71%, with a mode of 75% and a range of 50% to 100%. These studies used the following measures: Positive Aspects of Caregiving (PAC) in ten studies (38%), Caregiver Satisfaction Scale (CSS) in three studies (13%), the Gains in Alzheimer's Care Instrument (GAIN) in three studies (13%), the Finding Meaning Through Caregiving Scale (FMTCS) in 2 studies (8%), the Meaning Through Caregiving (MTC) measure in one study (4%), the Caregiver Assessment of Satisfaction Instrument/Index (CASI) in two studies (7%), the Caregiver Gratifications scale (CGS) in one study (4%), the Scale for Positive Aspects in Caregiving Experience (SPACE) in one study (4%), the Caregiver Appraisal Tool (CAT) in one study (4%), and two studies used a study specific measure (8%). Eighteen out of the 26 studies (69%) reported a significant negative Pearson correlation coefficient for the relationship between caregiver burden and positive aspects. Studies measuring the relationship between burden and PAC scores reported a significant negative association between the two variables (QT65: $r = -0.160, p < 0.01$; QT41: $r = -0.160, p = 0.001$; QT26: $r = -0.440, p < 0.010$; QT24: $r = -0.420, p < 0.01$; QT22: $r = -0.239, p < 0.05$; QT09: (PAC Iranian version) $r = -0.291, p = 0.001$; QT75: $r = -0.842, p < 0.001$; QT79: $r = -0.42, p < 0.001$).

Caregiver burden was significantly correlated with scores on measures of GAIN (QT64: $r = -0.150, p = 0.02$; QT38: $r = -0.160, p = 0.004$; QT17: $r = -0.2029, p < 0.01$), MTC (QT52: $r = -0.280, p < .001$), FMTCS (QT45: $r = -0.762, p < 0.01$; QT18: $r = -0.200, p < 0.01$), CGS (QT30: $r = -0.199, p < 0.01$), CAT (QT08: $r = -0.280, p = 0.013$), and SPACE (QT23: $r = -0.294, p = 0.030$). One study reported a significant positive association between burden and the purpose subscale of the CASI (QT73: $r = 0.20, p < 0.01$). One study did not report data because the relationship was not significant (QT28). Eight out of the 24 studies (33%) did not find a significant relationship between caregiver burden and positive aspects. The studies that did find a significant relationship reported negative relationships ranging from small to large, indicating

that when caregiver burden scores were higher, scores on measures of positive aspects were lower.

Caregiver distress and positive aspects of caregiving. Two (3%) out of the 59 primary studies either investigated the relationship between psychological distress and positive aspects, or reported data sufficient to calculate an effect size of the relationship. These studies used the Finding Meaning Through Caregiving Scale (FMTCS) and a study specific scale. The provisional meaning subscale of the FMTCS was found to significantly, negatively correlate with a measure of psychological distress (strain) based on caregivers reports of disruptive care recipient behaviour and the degree of distress the caregiver experienced in relation to that behaviour (QT54: $r = -0.280$, $p < .010$; MMAT score 50). The subscale of ultimate meaning did not correlate significantly. The study specific measure of positive aspects significantly, negatively correlated with a measure of negative affectivity in caregiving (QT18: $r = -0.410$, $p < 0.001$; MMAT score 100). In sum, these studies reveal small to medium significant inverse relationships between measures of positive aspects and measures of psychological distress, indicating that when psychological distress is high, scores on these measures of positive aspects are low.

Caregiver psychological health/wellbeing and positive aspects of caregiving.

Psychological health is differentiated from caregiver distress and commonly reflects measures of mood, whereas distress is a construct (like burden) that describes a reaction to caregiving. The average MMAT score for these studies was 70%, with a mode of 75% and a range of 50% to 100%. Psychological health was investigated in relation to positive aspects of caregiving in thirteen (22%) out of the 59 studies. These studies used the following measures: Positive Aspects of Caregiving (PAC) in seven studies (54%), Finding Meaning Through Caregiving (FMTCS) in two studies (4%), Gain in Alzheimer's Care Instrument (GAIN) in two studies (4%), and two studies used study specific measures (4%). Nine out of the 13 studies reported significant Pearson correlation coefficients. Seven studies reported significant negative correlations between measures of positive aspects and psychological health in terms of measures of depressive symptoms (QT60: $r = -0.337$, $p < .050$; QT41: $r = -0.260$, $p < 0.01$; QT26: $r = -0.250$, $p < 0.010$; QT21: $r = -0.270$, $p < 0.010$; QT18: (Provisional meaning) $r = -0.370$, $p < .010$, (Ultimate meaning) $r = -0.28$, $p < 0.01$) and general psychological health (QT38: $r = -0.270$, $p < 0.001$). Measures of psychological health that measured positive mental health (e.g., vitality, social

functioning), a significant positive correlation was reported (QT45: $r = 0.705$, $p < 0.01$). One study that used measures of anxiety also found a significant positive correlation with the positive aspects measure (QT56: $r = 0.220$, $p < 0.05$).

Forty-two percent of the studies investigating psychological health and positive aspects of caregiving did not report a significant correlation between the two constructs. Of those that did, the majority revealed a small but significant inverse relationship between depressive symptomology and scores on positive aspects measures. In sum, these data indicate that when caregivers score high on measures of depressed mood, they tend to score low on measures of positive aspects of caregiving. One study indicated that caregivers who scored high on a measure of anxiety also scored high on a measure of positive aspects (a small correlation). Other findings indicated a positive association between measures of positive psychological health and positive aspects.

Caregiver physical health and positive aspects of caregiving. Four (7%) out of the 59 primary studies either investigated the relationship between caregiver physical health and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score for these studies was 62%, with a mode of 50% and a range of 50% to 100%. These studies used the following measures: Finding Meaning Through Caregiving Scale (FMTCS) in two studies (50%), Caregiver Satisfaction Scale (CSS) in one study (25%), and a study specific measure in one study (25%). No studies reported significant correlations between the measures of positive aspects and measures of caregiver physical health.

Caregiver subjective health/well-being and positive aspects of caregiving. Eight (14%) out of the 59 primary studies either investigated the relationship between caregivers' subjective health/well-being and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The mean and mode MMAT scores for these studies was 75%, with a range of 50% to 100%. These studies used the following measures: Positive Aspects of Caregiving (PAC) in two studies (25%), Caregiver Satisfaction Scale (CSS) in one study (13%), the Caregiver Assessment of Satisfaction Instrument (CASI) in one study (13%), the Finding Meaning Through Caregiving Scale (FMTCS) in one study (13%), the Meaning Through Caregiving (MTC) measure in one study (13%), and two studies used study specific measures (25%). Out of the eight studies, four reported significant and positive correlations between measures of subjective health/well-being and positive aspects of caregiving (QT52: $r = 0.100$, p

< 0.05 ; QT41: $r = 0.140$, $p < 0.01$; QT05: $r = 0.485$, $p < 0.001$; QT01: $r = 0.343$, $p < 0.01$). Fifty percent of the studies that investigated the relationship between caregiver subjective health/well-being and positive aspects revealed no significant correlations. Out of those studies that found significant correlations, the data indicate a small, positive association. This means that caregivers who score high on measures of subjective health/well-being tend to score high on measures of positive aspects caregiving.

Caregiver support and positive aspects of caregiving. **Thirteen (22%)** out of the **59** primary studies either investigated the relationship between caregiver support and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score for these studies was 69%, with modes of 50% and 75% and a range of 50% to 100%. These studies used the following measures: Positive Aspects of Caregiving (PAC) in five studies (38%), Caregiver Satisfaction Scale (CSS) (3) and its revised version (CSSR; 1) in four studies (30%), the Caregiver Appraisal tool (CAT) in one study (7%), the Scale for Positive Aspects of Caregiving Experience (SPACE) in one study (7%), the Caregiver Assessment of Satisfaction Index (CASI) in one study (7%), and one study used a study specific measure (7%). Eight out of the 13 studies found a significant and positive Pearson correlation coefficient between measures of support and positive aspects of caregiving. Four studies used measures of social support and two of them revealed small scale positive correlations between measures of social support and positive aspects (QT 26: $r = 0.190$, $p < 0.01$; QT23: $r = 0.270$, $p < 0.05$), while the other two studies did not find a significant correlation.

Three studies investigated satisfaction with social support and positive aspects of caregiving and all revealed a small to medium sized significant, positive correlation (QT34: $r = 0.270$, $p < 0.05$; QT33: $r = 0.290$, $p < 0.05$; QT11: (satisfaction) $r = 0.190$, $p = .01$, (social interaction) $r = 0.55$, $p < .01$, (social support received) $r = 0.68$, $p < 0.01$). One study found that perceived emotion support was a predictor of scores on a measure of positive aspects (QT25). Social network size was found to have a significant and positive correlation with positive aspects (QT11: $r = 0.230$, $p = 0.035$). Finally, one study found instrumental support had a positive and significant correlation with positive aspects measures (QT39: $r = 0.250$, $p < 0.01$). One study (18%) did not find a significant correlations (QT28).

In sum, these data reveal that instrumental and social support have a small positive association with scores on measures of positive aspects of caregiving. Instrumental support and

social network size correlated significantly with positive aspects measures, but the most robust finding here is that caregivers' satisfaction with social support is significantly correlated with positive aspects measures. This indicates that the higher the level of a caregiver's satisfaction with social support, the higher they tend to score on measures of positive aspects.

Caregiver coping and positive aspects of caregiving. Ten (17%) out of the 59 primary studies either investigated the relationship between caregiver coping and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score of these studies was 70%, with a mode of 75% and a range of 50% to 100%. These studies used the following measures: Positive Aspects of Caregiving (PAC) in three studies (30%), Caregiver Satisfaction Scale (CSS) (3) in two studies (22%), the Gains in Alzheimer's Care Instrument (GAIN) in one study (11%), the subscale Personal Growth of the Hogan Grief Reaction Checklist in one study (11%), the Scale for Positive Aspects in Caregiving Experience (SPACE) in one study (11%), the Finding Meaning Through Caregiving Scale (FMTCS) measure in one study (11%), and two studies used a study specific measure (22%). All ten studies reported significant Pearson correlation coefficients. Consistently, maladaptive coping methods such as criticism toward care recipient (QT64: $r = -0.14, p = 0.03$), avoidance coping (QT23: $r = -0.276, p = 0.04$), emotive coping (QT05: $r = -0.32, p = 0.03$), and negative religious coping (e.g., feeling God is punishing the caregiver) (QT26: $r = -0.200, p < 0.01$) were found to have small negative correlations with positive aspects measures. Adaptive coping methods such as encouragement toward care recipients (QT64: $r = 0.35, p < 0.0001$; QT39: $r = 0.34, p < .001$), cognitive reframing (QT50: $r = 0.260, p = 0.05$), active management (QT64: $r = 0.42, p < 0.0001$; QT39: $r = 0.370, p < 0.001$; QT38: $r = 0.46, p < 0.001$), problem focused coping (QT34: $r = 0.420, p < 0.001$; QT05: $r = 0.359, p = 0.016$), and positive religious coping (e.g., God provides strength to caregiver) (QT26: $r = 0.31, p < 0.01$; QT79: $r = 0.32, p < 0.001$) were found to have a small positive correlation with measures of positive aspects.

Caregiver religiosity/faith and positive aspects of caregiving. Four (7%) out of the 59 primary studies either investigated the relationship between caregiver religiosity/faith/spirituality and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The mean and mode MMAT score for these studies was 75% with a range of 50% to 100%. These studies used the following measures: Positive Aspects of Caregiving (PAC) in three studies (75%) and the Meaning Through Caregiving (MTC) measure was used in one study (25%). All

four studies reported small, significantly positive Pearson correlation coefficients for the measures of religiosity and positive aspects of caregiving (QT56: $r = 0.0240$, $p < 0.05$; QT5253: $r = 0.230$, $p < .001$; QT39: $r = 0.340$, $p < 0.010$). One study found a significant correlation and further analysis indicated that spirituality may have a small effect on PAC by mediating the negative impact of subjective stressors on caregivers (QT28). In sum, these data indicate that caregivers who score high on measures of religiosity and spirituality tend to score high on measures of positive aspects of caregiving.

Caregiver competency/self-efficacy and positive aspects of caregiving. Five (8%) out of the 59 primary studies either investigated the relationship between caregivers' sense of competency/mastery of their role and positive aspects, or reported data sufficient to calculate an effect size of the relationship. The average MMAT score for these studies was 59%, with modes of 50% and 75% and a range of 45% to 75%. These studies used the following measures: Positive Aspects of Caregiving (PAC) in two studies (40%), Caregiver Satisfaction Scale (CSS) in one study (20%), the Meaning Through Caregiving (MTC) measure in one study (20%), and one study used Gains in Alzheimer's Care Instrument (GAIN) (20%). Three out of the five studies (60%) report a significant, small to medium positive Pearson correlation coefficient between positive aspects and a measure of self-efficacy (QT60: $r = 0.346$, $p < 0.01$), as well as caregiver competency (QT52: $r = 0.460$, $p < 0.001$; QTQL47: $r = 0.460$, $p < 0.01$). One study reported a significant negative correlation between sense of competency and GAIN measure (QT38: -0.270 , $p = 0.000$), while one study found no significant correlation (QT15). In sum, these data indicate a potential positive, small to medium association between caregivers' feelings of competency, mastery, or self-efficacy in the caregiving role and their scores on measures of positive aspects of caregiving.

Quantitative Intra-Method Synthesis Analysis Conclusion

In sum, the data from the primary quantitative studies indicate that positive aspects of caregiving are associated with the following caregiver attributes: perceived health and well-being (small effect size), age (small effect size), perceived social support (small effect size), caregiver religiosity and spirituality (small effect size), as well as self-reported competency, mastery, and self-efficacy in caregiving (small to medium effect size). In addition, higher scores on positive aspects of caregiving were associated with being a spousal caregiver (small effect size), caregiving men (small to medium effect size), or non-Caucasian Americans (i.e., African

American, Hispanic American; small to medium effect size). Positive aspects of caregiving were negatively associated with caregiver education level (small effect size), care recipient dementia severity (small to medium effects size, however, 54% of studies that investigated this relationship did not find significant correlation), dementia-related behaviours and symptoms (medium effect size), caregiver self-reported burden (small to large effect size), caregiver distress (small to medium effect size), and caregiver psychological health/well-being (medium effect size). Evidence for both positive and negative association with positive aspects were found for duration of caregiving. No significant relationship between measures of positive aspects and caregiver employment status or caregiver physical health were found.

Qualitative Intra-Method Synthesis Analysis

The 21 qualitative references were read and data pertaining to study characteristics, as well as the ‘findings/results’ sections of the primary studies were extracted and entered into a study summary and data extraction document. The average MMAT score for these studies was 62% with a mode of 75% and a range of 25% to 100%. A summary of the primary qualitative references can be found in Table 2.3 along with their corresponding study ID numbers (e.g., QL#), which will be used for the remainder of the document to reference a primary study. Each document was read through and the ‘findings/results’ section underwent line by line coding. In the first read through, I made notes regarding similarities, contrasts, and reoccurring themes across the studies’ findings. Towards the end of the first reading, I identified 24 codes and generated themes related to those codes. In the subsequent readings, I identified an additional seven codes.

The final analysis resulted in four overarching categories that incorporated a total of twenty-six themes. The categories were identified by reviewing the themes; it was apparent that certain themes seemed to group together and reflect a particular facet of the phenomenon, yet each theme was distinct from one another. The categories identified were: ‘Positive outcomes/aspects,’ ‘Factors that underlie positive aspects,’ ‘Facilitating factors,’ and ‘Hindering factors.’ One theme was identified that did not fit into any of the four categories. I identified the theme *positive and negative*, which reflected data that indicated the co-occurrence of positive and negative aspects within the caregiving experience.

Positive and Negative. The complexity of the caregiving experience is captured in the theme of *positive and negative*. Within this theme, some data pertain to the co-occurrence of

negative and positive emotions, while other data reflect the negative and positive aspects in contrast to one another and, in some cases, as dependent upon one another. Negative and positive emotions were reported as being intertwined. For instance, study findings indicate that caregivers report the experience of pain, anguish, and anger, while also experiencing feelings of love and compassion (QL02, QL09, QL18, QL77, QL80).

Other studies reported on the contrast of negative and positive aspects, indicating that positive aspects emerge from the process of experiencing negative aspects (QL04, QL34, QL54). In a similar way, other studies revealed that when caregivers report on their negative experiences, they seem to be setting the stage to report on their positive experiences (QL33). Together, these data reveal that caregivers may be able to identify positive emotions related to the caregiving experience through contrast, by identifying the negative emotions. The data denote that caregivers sense an inherent connectedness between negative and positive aspects. It appears that report of the positive aspects of caregiving is incomplete when not situated or contextualized within the greater caregiver experience (i.e., in relation to the challenges and negative aspects of caregiving).

The Category ‘Positive Outcomes’

Four themes under the category of positive outcomes were identified. Outcome refers to the beneficial outcomes of providing care that exist under the overarching label of positive aspects. These themes largely reflect improvement and change. Many primary studies reported *improved relationships* between family members, *improved quality of relationships between the caregiver and care recipient*, and caregivers’ *personal growth* and *change in philosophy*.

Improved relationships. The theme of improved relationships was identified in 33% primary studies. These data reflect the notion that challenges associated with a family member living with dementia provide the opportunity for family members to come together and work towards the common goal of supporting the care recipient. Evident by the following excerpt, many primary studies reported that caregivers found support from others to be motivating and important in their ability to continue caregiving.

Having a family member with dementia provided an opportunity for families to spend more time together and become closer in ways that otherwise may not have been possible. QL37

Some studies reported that caregivers reflected on the importance of forgiveness in their relationships. Forgiveness seemed to be crucial in improving their relationships with other family members and with the care recipient.

Improved quality of caregiver/care recipient relationship. The theme of improved caregiver/care recipient relationship was identified in 29.7% of primary studies. Some studies reported that the increased time spent together and the closeness inherent in providing care led to a higher quality of relationship between the caregiver and care recipient. Some studies reported that the constant change associated with dementia prompted caregivers to re-evaluate what was important. For some caregivers, this meant forgiving past issues with the care recipient. Other studies reported that greater focus and appreciation for the present time with the care recipient led to a deepening of the relationship.

Personal growth. Improvement by way of *personal growth* was identified in 69% of the primary studies. Many of the primary studies reported caregivers' *personal growth* as a positive aspect or outcome of caregiving. For instance:

The caregivers indicated that many gains they experienced were associated with personal growth and internal changes that had only occurred because of their caregiving role. ...AD [Alzheimer's disease] creating new dimensions in their lives, as well as highlighting elements of their personality that they previously had not recognized. QL45

Personal growth was commonly described as learning something new about oneself; for instance, common reports included improved sense of competency, gaining practical skills, and becoming proficient at problem solving. Enhancing inherent qualities of their personality and/or virtues was also frequently reported in primary studies. For instance, improved patience was reported with notable frequency, as well as other virtues such as humility.

Change in Philosophy. In addition to improvements, themes related to changes in personal life philosophies and perspectives/daily practices emerged from the analysis. Approximately 29% of primary studies presented reports of caregivers' experiencing a change in their life philosophy. Commonly, change in philosophy reflected a shift in caregivers' perception of what was important in life. For example, one study reported that material wealth and individual status was no longer a primary focus for caregivers as they began to realize that time

with their care recipient was limited. The importance of relationships became central in their lives.

Caregivers also indicated that they felt caregiving had become a “blessing” for them and allowed them to “re-evaluate” their lives and the directions that they were heading in, personally and professionally. QL45

Frequently reported was a newfound propensity toward ‘being present.’ The reports of these primary studies indicated that caregivers seem to develop a new appreciation for time and the passage of time. Given the progressive nature of dementia and the changes in the care recipients’ lucidity or personality, the studies’ findings indicate that caregivers become more present focused as opposed to future oriented.

Awareness of the present moment and acceptance were also important to the caregivers who offered advice. Staying in the moment, living each day at a time, and embracing oneself were common themes for caregivers. QL33

The Category ‘Factors Underlying Positive Aspects’

In the analysis of the primary qualitative studies, the category factors that underlie positive aspects was found to be comprised of two sub-categories: *ways of being* and *motivators*. The *ways of being* subcategory is made up of themes pertaining to characteristics/tendencies of caregivers. The *motivators* sub-category is comprised of themes pertaining to factors that seems to motivate or sustain caregivers in their roles.

Ways of being. The sub-category ways of being was comprised of four themes. The ‘ways of being’ themes represent caregivers’ characteristics, tendencies, and behaviours that were identified as integral to the experience of the positive aspects of caregiving. Analysis of the primary studies revealed positive aspects were commonly associated with *gratitude, choice in attitude, acceptance, and being other focused.*

Gratitude. The theme of gratitude was identified in 57% of the primary studies. Commonly embedded within caregivers’ interview excerpts was a tendency toward optimism, and perhaps this facilitated the experience or report of gratitude that was prevalent in the primary studies. Gratitude related to both being present and appreciating the positive aspects of everyday, ordinary events. For instance, according to some primary study data, caregivers reported gratitude in knowing the care recipient was clean and fed. At other times, gratitude referred to being grateful for what remained in contrast to what was lost (e.g., in the caregiver/care

recipient's relationship, in the care recipient's abilities, and changes in the care recipient's personality). Therefore, caregivers have reported gratitude for the time they still have with the care recipient, for moments of lucidity in the care recipient, and for the fact that the care recipient is physically present (even though her or his personality may be altered). In particular, gratitude for what was still possible (e.g., the activities they could still enjoy, the abilities the care recipient could still manage independently), in the context of progressive decline, was a common finding.

By accepting their situation and choosing a positive attitude, these caregivers were able to see beyond their loss and focus on their blessings instead. These attitudes were expressed as being thankful, being optimistic, feeling blessed, focusing on the positive, taking joy in the moment and finding humor in things.

QL46

Choice in Attitude. Closely related to the theme of gratitude was a common theme of *choice in attitude*, which was identified in 53% of the primary studies. The findings indicated that many caregivers believed they had a choice in how they responded to the caregiving situation. The caregivers believed that this choice would largely dictate how difficult or satisfying the experience of caregiving would be. Choice related to the following domains: response to caregiving demands, in response to behaviours and symptoms of the care recipient, choice in response to caregiving as a whole, the experience of becoming a caregiver, and the associated impacts on life and identity, were found in the primary studies. The notion of cognitive reframing was commonly reported in relation to the *choice in attitude* theme, and some studies indicated that caregivers learned to practice cognitive reframing.

Caregivers talked about practicing a positive approach to caregiving. Although this approach may have been related to a natural tendency, it was still apparent from the data that active work was conducted to maintain and support a positive attitude toward the caregiving role and the care recipient. Several caregivers described the importance of dwelling on the positives and avoiding thoughts about potential negative outcomes. QL11

Acceptance. I identified the subtheme of *acceptance* in 43% of the primary studies. Here, acceptance was in relation to accepting the diagnosis and the realities of the disease, accepting the caregiving role and the tasks involved, and accepting losses. Accepting loss pertained to loss

in a number of respects: losses in the caregiver/care recipient relationship, changes in aspects of a care recipient's personality, loss of a care recipient's abilities, and knowledge of eventually losing the care recipient. Accepting loss pertaining to self was present in the data; caregivers learned to accept loss of pre-caregiving life, loss of identity, and loss of freedom. This theme seemed to highlight a release of control by caregivers. The data indicate that acceptance was important in allowing caregivers to 'let go' and be adaptable, because dementia is a process that is progressive in nature and presents new challenges and unpredicted changes.

Caregivers expressed acceptance of caregiving and the situation in general through different phrases. Independent of the specific content of the story, these phrases indirectly communicated that they were taking things in stride. QL53

Other focused. Finally, the theme *other focused* was identified in 52% of primary studies. The data indicates that caregivers often concerned themselves with the well-being of the care recipients and derived pleasure from being able to do things for the care recipients, as well as create moments of happiness for the care recipients. Being other focused emerged in objective ways and in more nuanced examples. For instance, caregivers sacrifice their time and preferred activities to meet the demands of caregiving. This is an objective example of putting the care recipients' needs before their own. However, some studies indicated more nuanced ways of being other focused. For example, caregivers making choices that increased their own psychological burden (e.g., increased worry about well-being of care recipient), but improved or maintain the care recipients' quality of life (e.g., allowing care recipient to live in home, rather than move to long-term care). A caregiver taking the perspective of the care recipient when the care recipient is exhibiting behavioural symptoms provides another example of being other focused.

In summary, they [caregivers] were more inclined to consider how the care recipient might be experiencing the situation, rather than assuming that the problematic behaviours were intentional...Caregivers reported satisfaction, regardless of whether the care recipients' stability or progress, was directly related to what the caregiver did. And when the care recipients were working hard themselves, engaging in activities believed to be beneficial, attempting self-care, or helping with daily chores, caregivers expressed appreciation or gratitude. QL08

Motivators. The sub-category of motivators is comprised of themes pertaining to factors that serve to motivate and sustain caregivers in their role. The themes largely pertain to interpersonal relationship with care recipient, and intrapersonal factors, such as values and internal motivators.

Responsibility and commitment to relationship. The most common subtheme relating to motivating factors was *responsibility and commitment* to the care recipient or caregiver/care recipient relationship. This subtheme was identified in 62% of the primary studies. The data revealed that a sense of responsibility to the care recipient is central to continuing care. The responsibility subtheme was identified in studies of both spousal and adult children caregivers. Some primary studies reported that caregivers' marriage vows were the reason the former provided care to the care recipient. Other studies indicated that caregiving was an opportunity for caregivers to show their love, commitment, and respect for their partner. Some studies reveal a sense of duty or filial piety as central to adult children's decision to provide care. Culture was indicated as impacting motivation to care, with primary studies reporting cultural norms surrounding filial piety and responsibility of care as caregivers' reasons for caregiving. Still, a common finding was the notion of "if not me, then who?" While this could be understood as 'obligation' rather than responsibility, the data revealed that there was a sense among some adult caregivers that they were the most appropriate person to take on the caregiving role, as they would provide a certain level of care for their parent. Thus, the data reflect a motivation to go beyond providing the needed care and to ensure high quality care. Therefore, I conceptualized this as responsibility to relationship, rather than obligation.

Underlying these active attempts to sustain a positive attitude seems to be a continued commitment to the marriage and spouse, even though the care recipient's personality and behaviours had changed significantly. QL11

Reciprocity. The subtheme of reciprocity was identified in 47% of the primary studies. The theme of *reciprocity* is closely related to *responsibility and commitment* in that it is linked to the caregiver/care recipient relationship. Rather than an extension of the relationship, *reciprocity* seems to reveal a switch, or, shift in the pre-caregiving roles between the caregiver and care recipient. For instance, some studies reveal that husbands are pleased to have the opportunity to care for their wives, who provided care, support, and nurturing to the family unit over the years. In this way, the husbands accepted a shift in the responsibility of care, and data indicated they

were pleased to repay their wives by caring for them. Commonly, caregivers were motivated to provide care in the way that the care recipient had historically cared for them. This was frequently the case in adult children caregivers. Some studies reported caregivers' pleasure in being able to show their love and care to the care recipients this way. Other studies reported that caregiving heightened caregivers' appreciation for the care the parent had given them, and thus, they appreciated the opportunity to provide good care to their parent.

An interesting and central theme that arose in many of the interviews, both with spouses and with children, was that they had shared so much and received so much, in a psychological sense, from the ill family member. Now it was very natural to return or "pay back" some of that, and this was based on their own free will. QL01

Love. The theme of *love* was identified in 19% of the primary studies. In some studies, *love* was given as the reason for providing care, and in others, it was reported as what gave meaning to providing care. In other studies, *love* seemed to reflect an action or even a product. For example, primary studies indicated that, because caregiving was objectively demanding and taxing, performing the caregiving role either validated, or made visible, the caregiver's love for the care recipient.

Husbands, distinctly, reported finding meaning in being able to return the love that they had received during their married lives. QL46

Some caregivers saw stretching their patience and tolerance, no matter how difficult the situation was, as a validation of their love for the care recipient. QL08

Altruism. The theme of altruism was identified in 29% of primary studies. The theme of altruism reflected a motivation to provide care driven by a sense of moral responsibility to other human beings. While altruism can have many meanings, including secular ones, the meanings I found in my analysis were mostly used in a religious context; thus it is this usage that I focus my analysis on. In many of the studies, altruism was closely related to spirituality and religious beliefs. In these cases, the data reflected caregivers' sense that they were doing God's work and working for a higher power; there was a reason for dementia and caregiving coming into their life. Other studies reflect caregivers' sense of morality as a motivator. Here, it seemed that providing care to a human being in need (rather than a focus, on the responsibility to

caregiver/care recipient relationship) was of central importance. The data revealed a sense of moral, human responsibility to give to someone in need, and there was satisfaction in being strong enough to assume the responsibility.

Caregivers' philosophies of what caregiving means and why it is important varied. For some people, it was a question of morality and that it was the right thing to do; for others, it was the value and appreciation of every moment, as these moments were limited. QL53

Modeling behaviour. Another motivating factor, identified in 14% of the primary studies, was a desire to model providing care and respecting older adults, to the younger generations. Modeling caregiving was about modeling good care, but also seemed to be about communicating values and teaching morals to the younger generations. Some studies revealed that caregivers also thought about their own future and their needs as they age. The caregivers believed that modeling caregiving was a way of influencing their children to provide care to them in the future.

Most daughters were also mothers and wanted to use this experience with their children to teach them the importance of good caregiving. QL33

Caring for an older adult parent with dementia was acknowledged as a way to demonstrate to caregivers' children what may be expected of them in the future in the event that caregivers themselves may require care. QL37

Passing on knowledge. A desire of caregivers to be able to help other caregivers by sharing knowledge and advice was a theme identified in 14% of the primary studies. Caregivers were motivated to extend the meaning they had found in caregiving to benefit others. There was a sense in the data that there was a desire to balance out the challenging, or at least unexpected, changes that come along with a dementia diagnosis and providing care by creating positive outcomes of the experience, such as helping others. In this way, the experience of dementia and providing care could be made more meaningful by helping other caregivers and care recipients.

Being able to use their experiences to comfort and help other caregivers engendered feelings of empowerment and usefulness. When caregivers could help others this way (passing on knowledge to other caregivers), they sensed a larger purpose to what they had gone through. QL08

Sense of purpose. Finally, a sense of purpose was identified as a motivating factor in 14% of the primary studies. For some, becoming a caregiver restored daily purpose in their lives because they had matured through other life roles such as their career or parenting. In other reports, the theme reflected that caregivers found a greater sense of purpose in the caregiving role. The reports indicated that caregivers benefitted, or experienced satisfaction, from being able to assume the caregiving role and meet the needs and ensure the well-being of another human being.

A number of caregivers confessed that their caregiving motivations were less selfless. The gradual loss to other aspects of their life through providing care meant that caregivers were dependent on their role, providing purpose in life.

QL57

A sense of purpose helped caregivers identify with the role and commit to it, and was strengthened with increased knowledge of things that can be done to improve management of the care recipient. QL08

The Category ‘Factors Facilitating Positive Aspects’

Facilitating factors are differentiated from underlying factors in that they represent externally located factors, rather than intrinsic qualities, characteristics, or motivations. Many facilitating factors relate to interpersonal interactions, such as *connecting and communicating with care recipient, social support, feeling appreciated*. Other facilitating factors are more individual or caregiver related, such as *practicing self-care, faith and spirituality, as well as the utility of knowledge, preparation, and routine* in improving the caregiving experience.

Connecting and communicating. The data indicated that the ability to connect and communicate with the care recipient was important in the experience of caregiving. The theme of connecting and communicating was identified in 24% of the primary studies. In some studies, connecting and communicating was discussed in relation to making adjustments in communication as connection and communication became more challenging. Connection became more difficult due to changes in care recipients’ memory and identity and communicating became limited due to the care recipients’ changes in language abilities. Other reports reflect the importance of spending time with care recipient and appreciating their company.

Connecting with the loved one for whom the caregiver is providing care is a key experience of engagement. Caregivers often saw the opportunity to forge or sustain this connection as the essence of what gave meaning to caregiving. The relationships were complicated, anger and arguments happened, and both sides could initiate them, but connecting gave meaning to caregiving even if it fluctuated. The relationships were also not always equal or reciprocal, and varied with time, with the severity of dementia, and with other events in their lives. QL53

Feeling appreciated by care recipient. The theme of the importance of feeling appreciated by the care recipient was identified in 29% of the primary studies. The data indicated that, even in the context of losses in care recipient identity and caregiver/care recipient pre-caregiving relationship, appreciation and acknowledgement of the caregiver's work by the care recipient was important. Some reports indicated that appreciation helped caregivers feel that they were doing a good job. Other reports indicated that it was satisfying when care recipients (CR) showed appreciation because this communicated that the care recipient understood what the caregiver was doing for them.

Importantly, a deep sense of satisfaction was expressed when the caregiver felt that the CR appreciated what the caregiver was doing for him or her, whether or not the CR was able to express it. QL08

Social support. In 43% of the primary studies, social support from family members, friends, community, and formal healthcare staff emerged as important in improving the caregiving experience. The data indicated that social support was a means of coping for some caregivers. Support from caregiver groups was a frequent finding that reflected the importance of knowing that others were experiencing similar challenges in caregiving. Indeed, support seemed to ameliorate feelings of isolation for the caregiver.

Some caregivers felt able to continue as long as they received support from family. One caregiver felt her husband's ability to bring humour into a situation alleviated tension caused by the extent of her mother's (recipient) decline and the consequential demands this elicited. QL57

Humour. Humour emerged as a theme in 29% of primary studies. Humour was often reported as a positive response to the caregiving situation and was closely related to 'choice' in

attitude and working to remain positive and optimistic. These data indicated that the ability to find humour in caregiving improved the experience of caregiving.

Many participants talked about how humour became an inherent part of their lives with their care- recipients, and how it helped them balance the positive and negative. QL33

Faith and spirituality. Faith and spirituality was a theme identified in 45% of primary studies. The data indicated that faith and spirituality may have a number of functions within the caregiver experience. Faith and spirituality may serve as motivators to provide care, as a method of coping, and as a way to provide strength to caregivers. Some studies indicated that a recognition of faith, or a deepening of faith and spirituality, was a positive outcome for caregivers.

Feelings of fulfilment seem to be strongest among family carers who emphasize these religious and cultural obligations more strongly. They say that they derive a great deal of strength and support from their religion and it makes them able to keep going independently for longer. QL54

One of the greatest gains experienced by the caregivers in this study was an increased feeling of spirituality and for some, a closer relationship with God. QL45

Self-care. The theme of self-care was identified in 24% of the primary studies. The data indicated that self-care was reported as a means of establishing balance in the caregivers' lives. The reports revealed that caregivers believed that engaging in self-care improved their caregiving abilities and would sustain them in their role, which would benefit the care recipient. In one primary study, learning how to practice self-care was reported as an area of personal growth for caregivers whose histories were marked by putting others' needs first.

Trying to maintain other interests such as gardening, religious meditation, or singing in a choir. These were deliberate activities caregivers remained engaged in to maintain balance in their lives. QL46

Knowledge, preparation, and routine. Knowledge, preparation, and routine were subthemes that reflected factors that appeared to decrease strain and stress, as well as facilitate caregivers on the day to day. In 38% of the primary studies, *knowledge* about the symptoms and the progression of dementia was a theme identified as being important in how caregivers

responded to caregiving. Some reports indicated that knowledge about dementia allowed caregivers to attribute challenging behaviours and symptoms to the disease, rather than the care recipient. This helped to ameliorate caregivers' negative responses to the symptoms. Other reports indicated that caregivers who have difficulty understanding the care recipients' behaviours struggled to report positive aspects. Data denoted that knowledge about dementia may facilitate caregivers in accepting the care recipients' changes, understand the care recipients' behaviour, and prepare for future changes. The importance of preparation and routine was frequently reported in the studies. Preparing for the changes seemed to be integral to facilitating acceptance in caregivers and allowing them to adjust to changes in day-to-day life and over the course of the illness. Many primary studies (24%) reported *routine* as being an important aspect of the caregiver experience. These data indicated that caregivers believed that routine benefits the care recipient by creating stability and predictability. Routine simplified day-to-day life for the caregiver.

When the [care recipient] responded well to something they [caregiver] did, they felt a sense of mastery and a confirmation that they were serving their purpose well. Caregivers talked a lot about how they put the relative on a schedule of activities and dealt with various issues confronted on a day-to-day basis including behavioural problems and impaired abilities. For instance, caregivers learned to speak more slowly and gently, use simple sentences, and repeat or rephrase instructions if necessary. QL08

The Category 'Factors Hindering Positive Aspects'

Factors identified as potentially hindering the experience or emergence of positive aspects in caregiving were identified. Most commonly, they were identified through contrast. That is, during the analysis process, I identified factors that seemed to be present in positive aspects, (e.g., social support, and connection/communication), highlighting how the experience of positive aspects might be hindered when those factors are absent (e.g., isolation). The hindering factor themes (*loss, isolation, and relationship dynamic*) were identified in the primary studies' findings and suspected to be related to positive aspects because they represented the opposite, or absence of factors identified as being central to, or facilitating the positive aspects.

Loss. Loss was identified in 52% of the primary studies. Loss in these data pertained to many different aspects. There was loss of access to the care recipient which reflected the

challenges associated with the loss of the pre-caring relationship and the loss of the care recipient's roles, reported in these studies. This led to losses in the interpersonal relationship, loss of activities, and loss of shared memories between the caregiver and care recipient. In this way, the interpersonal aspects of loss could be understood as the opposite of the identified facilitating factors of communication and connection. Loss of freedom and loss of identity for the caregiver was also reported in the findings and closely associated with the loss of social engagements and access to social spaces the caregiver used to inhabit (e.g., career, community).

Isolation. Closely related to loss was the theme of isolation which was identified in 29% of the primary studies. According to the studies, isolation sometimes referred to physical isolation associated with providing care in the home. Other reports reflected an existential isolation, wherein caregivers felt alone in their experience. The findings regarding the importance of social support (either through friends, family, or support groups) in facilitating positive aspects, highlights how feelings of isolation may negatively impact the experience of the positive aspects.

Their parents were no longer parents who could be supportive and provide them with advice and security. QL01

Some family carers point out that they feel lonely because they have less time for their own social contacts and activities. These are principally family carers who handle the care for a family member with dementia alone and are not supported by other family members. QL54

Pre-caregiving relationship dynamic. The quality of the pre-caregiving relationship between the caregiver and care recipient was identified as a potential hindering factor in 10% of the primary studies. The data indicated that caregivers who reported a difficult or strained pre-caregiving relationship with care recipient, struggled to report positive aspects of caregiving. In the primary studies that reported improved quality of relationships as a positive outcome of caregiving, it was common for there to be report of a strong pre-existing relationship between the caregiver and care recipient, or the process of the caregiver forgiving and relinquishing past issues with the care recipient. The process of forgiveness can be complicated by the presence of dementia, as a care recipient's identity and memory are affected and the nuances of the interpersonal relationship between caregiver and care recipient change. The impossibility of forgiveness may hinder positive experiences in providing care.

The abuse, hurt or mistrust from the previous existing relationship, affected how these caregivers viewed their spouses' behaviour in the present. Instead of attributing behaviour or words to the disease as those in the other two groups did, the negative group caregivers perceived that their negative experience was a reflection of the care recipients' continuous negative behaviour. QL02

Qualitative Intra-Method Synthesis Analysis Conclusion

In sum, the synthesis analysis of the qualitative data revealed that positive aspects in the primary studies broadly reflect changes and improvements. Changes occur in the form of changes in philosophies of life and values, whereas improvements reflect improvements in relationships, personal growth, and self-awareness. Through data analysis I identified factors that underlie positive aspects that include factors related to caregivers' internal characteristics, tendencies, and internal motivating factors. The accounts of caregivers that reported experiencing positive aspects of caregiving tended to also include the themes of optimistic thinking and practicing gratitude. The accounts of caregivers reporting positive aspects also tended to include themes of being other focused, concerning themselves with the experience of others. The caregiver's accounts indicated that they perceived attitude was a choice and worked to practice gratitude and find appreciation for the positive aspects of life. The accounts of caregivers who reported positive aspects indicated the caregivers were motivated by a sense of responsibility, either to the care recipient or to a higher purpose. They appreciated the opportunity to give back and to reciprocate the care that they received, or witnessed the care recipient provide. Caregivers who reported experiencing positive aspects of caregiving were sometimes motivated by altruism and love. Some caregivers touted love as the reason to provide care and some viewed providing care as love in action. Caregivers were motivated to model good caregiving and values to younger generations and to extent the meaning found in caregiving to benefit others, by sharing their caregiving experience with new caregivers.

These data suggest that connection is important in improving the caregiver experience, whether this is continued connection and communication with the care recipient, or connection through social support. Faith and spirituality support some caregivers in their role, and some view a deepening of faith as a positive outcome of caregiving. The experience of positive aspects may be hindered by overwhelming feelings of loss and isolation in the caregiving experience. Positive aspects may also be hindered when caregivers do not feel appreciated for their work or

when the pre-caregiving relationship between the caregiver and care recipient was difficult. In sum, these findings reflect that caregivers' perspectives are central to the caregiving experience. For example, cognitive reframing emerged frequently in the data and appeared to be an important tool for coping with caregiving demands and facilitating positive experiences in caregiving.

2.3.2 Inter-Method Synthesis Analysis

Meta-integration organization and fit. I created visual displays of the intra-method findings for each data set and considered the findings of each data set in relation to one another. This included reorganizing and configuring the findings in relation to one another. For instance, I juxtaposed objective versus subjective factors (e.g., caregiver age, versus self-report measure), caregiver versus care recipient factors (caregiver subjective health versus dementia related behaviours and symptoms), and caregiving versus interpersonal factors (e.g., duration of caregiving versus caregiver/care recipient relationship). I decided to present the combined findings of the data sets in terms of negative associations and positive associations between caregiving factors and positive aspects; this distinction seemed to map well to both the quantitative and qualitative syntheses and bring the findings of the two data sets together in a wholesome and meaningful way. The findings of the two data sets displayed good fit, indicating many similarity and complementary findings across the two syntheses.

Lower positive aspects of caregiving. Quantitative data set synthesis revealed that scores on self-report measures of positive aspects shared an inverse relationship with subjective measures of caregiver burden, distress, and (negative) psychological health/well-being (QT18, QT21, QT26, QT41, QT60, QT73). Assuming that subjective measures of caregiver burden, distress, and psychological health were representative of caregivers' experiences of caregiving and their psychological state, these data indicated that caregivers who perceived themselves to be experiencing burden and who endorsed symptoms of psychological distress were less likely to simultaneously endorse experiencing positive aspects of caregiving.

Qualitative dataset synthesis revealed that caregivers perceived a choice in attitude in how they responded to caregiving as a determinant of whether the caregiving experience as a whole was satisfying or negative (QL05, QL08, QL11, QL17, QL37, QL46, QL53, QL57). Facilitating choice in attitude is active cognitive re-framing, practicing optimistic thinking, and focusing on positive aspects of caregiving (QL08, QL53). Thus, "choice in attitude" is an

effortful endeavour, and many factors could impact on one's ability to do so. Such factors included those related to the caregiving realities (duties and demands) and caregiver factors (psychological state). Caregiver burden is commonly conceptualized as the subjective burden caregivers experience when they perceive they are unable to meet the objective caregiving demands (Chwalisz, 1996). Thus, when dementia severity and problematic, dementia-related behaviours/symptoms are high, objective demands increase and caregivers' perceived ability to manage or respond to the demands and symptoms may be reduced, leading to increased perceived (or, subjective) burden (Chwalisz, 1996). Caregiver burden, distress, and psychological strain may tax the psychological resources required for caregivers to do the effortful work needed for 'choice in attitude,' or even for practicing gratitude and acceptance.

Further, quantitative synthesis findings reveal that caregivers' feelings of competency, mastery, and self-efficacy in the caregiving role were positively associated with positive aspects (QTQL47, QT52, QT60). Theoretically, if burden emerges from perceived inability to meet demands, then those caregivers who reported high levels of burden are less likely to endorse feelings of competency, mastery, and self-efficacy in the caregiving role. Thus, the negative association between caregiver burden/distress/psychological strain and measures of positive aspects may be partially explained by decreased cognitive/psychological resources. More explicitly, taxed cognitive and psychological resources would impact caregivers' abilities to engage in behaviours that underlie positive aspects (such as cognitive re-framing, choice in attitude, acceptance, and gratitude) and may impact feelings of capability within the caregiver role (e.g., competency, mastery), which facilitate the experience of positive aspects. Indeed, qualitative synthesis data indicated that feelings of mastery, competency, and self-efficacy were related to the positive outcome of personal growth (QL08, QL37, QL45).

In the current findings, problem behaviours and symptoms were found to have a negative association with measures of positive aspects (QT06, QT11, QT24, QT38, QT41, QT60, QT65, QT73). Problem behaviours and symptoms are difficult to address; they have been linked to caregiver burden scores (Branger et al., 2017) and may impact caregivers' feelings of competency and self-efficacy in the role. The current quantitative synthesis revealed that years spent caregiving showed both a negative (QT 45, QT65) and positive association (QTQL47) with measures of positive aspects of caregiving. It is possible that gaining experience with caregiving might increase skill and efficacy, and thereby lead to more positive experiences in caregiving.

Conversely, it is possible the progressive nature of dementia means increasing level of care, or changes in the nature of care demands, and initiation or intensification of problem behaviours and symptoms. In this way, it may be that some caregivers' sense of competency and mastery diminished as the disease progresses, thereby explaining the negative association between years spent caregiving and positive aspects. In a similar way, caregiver burnout is associated with increased psychological strain (Takai, et al., 2009), which may impact on the cognitive resources required to engage in behaviours that underlie positive aspects. Thus, this too might explain the findings of negative correlations between years spent caregiving and positive aspects scores.

Quantitative synthesis data revealed that some studies reported a negative association between scores on positive aspects measures and caregiver age (QTQT15, QT28, QT76), although the majority of the studies indicate a positive association (QT01, QT30, QT33, QT39, QT70). In considering the quantitative synthesis finding that spousal caregiver/care recipient relationship was associated with higher positive aspects scores (QT48, QT62), it is possible that the finding of a negative relationship between age and positive aspects scores is confounded by relationship type. Nevertheless, based on these data, the explanation for how age and positive aspects relate remains unclear.

Higher positive aspects of caregiving. Quantitative synthesis revealed positive associations between scores on measures of positive aspects and caregivers' responses on subjective measures pertaining to *subjective health/well-being, coping, competency/mastery, and self-efficacy in the caregiving role*, as well as measures of *religiosity/spirituality*, and *social/instrumental support*. The assumption is made that caregivers' responses to these measures provides an accurate reflection of their experiences in caregiving.

Subjective health and well-being. Quantitative synthesis revealed that high scores on subjective measures of psychological health and well-being, as well as 'positive' measures of psychological health and well-being (i.e., not measures of depressed mood) are associated with high scores on measures of positive aspects (QT01, QT05, QT41, QT52, QT74). Thus, the findings are interpreted as indicating that those who perceived themselves to be in good physical/psychological health endorsed higher levels of positive aspects (or vice versa). Such findings are expected, given the above discussion regarding the negative association between psychological distress and positive aspects of caregiving. Interestingly, physical health was not found to correlate significantly with positive aspects of caregiving, but these data indicated that

the caregivers' perceptions of (subjective appraisal) their health correlated significantly with measures of positive aspects. The disparity between actual and perceived physical health as they relate to scores on measures of positive aspects may indicate a latent factor influencing caregivers' self-reports of the caregiving experience. For instance, it is possible that persons with optimistic dispositions tend to score higher on measures of health, well-being, and positive aspects as a function of their personality. Self-care was reported in one qualitative study as facilitating positive aspects of caring (QL45). Quantitative data revealed that adaptive coping methods of engaging in pleasurable hobbies and activities (a form of self-care) were associated with higher scores of positive aspects (QT39). Together, I interpret the findings to suggest that engaging in self-care may facilitate experiences of positive aspects of caregiving. This facilitation may occur directly, or through affecting caregivers' subjective and psychological health/well-being.

Coping. Quantitative data synthesis revealed that maladaptive coping methods related to lower scores on measures of positive aspects (QT05, QT23, QT26, QT64), while adaptive coping methods related to higher scores on positive aspects measures (QT23, QT26, QT34, QT39, QT50, QT64). Maladaptive coping methods include, but are not limited to, avoidant, emotive, and critical behaviours toward the care recipient. These coping methods are inconsistent with qualitative synthesis findings related to factors that underlie positive aspects, such as being 'other-focused' (QL01, QL02, QL08, QL11, QL17, QL33, QL37, QL46, QTQL47, QL53) and finding 'acceptance' within the caregiving role (QL02, QL08, QL18, QL33, QL35, QL37, QL46, QL53, QL57). Adaptive coping methods revealed in the quantitative dataset include problem-focused methods, encouragement, and engaging in self-care. In consideration of qualitative synthesis findings, these coping methods were consistent with the facilitating factor of 'knowledge and preparation,' as well as the factors underling positive aspects, being 'other focused,' and practicing 'acceptance.' Encouragement may also serve to benefit the caregiver/care recipient relationship, and was found to be a positive aspects outcome factor in the qualitative synthesis findings (QL02, QL35, QL77).

Competency/mastery. The finding of a positive association between caregiver competency, mastery, self-efficacy, and positive aspects is supported by the qualitative synthesis findings that revealed that feelings of competency, mastery, and self-efficacy in the caregiving role was a positive outcome of the caregiving experience (QL37, QL45) related to personal

growth. Caregivers reported that they learned what they were capable of and experienced personal growth by meeting the demands and facing the difficult aspects of caregiving. The facilitating factor of ‘knowledge and preparation’ is also related to caregiver competency, mastery, and self-efficacy (QL08). Qualitative data revealed that the experience of caregiving was improved by having knowledge about dementia, the progression of the disease, related behaviours and symptoms, and what to expect in the future. Furthermore, knowledge was important in being able to prepare for the changes (QL01, QL02, QL08, QL33, QL37, QL46, QL53, QL57, QTQL47). Knowledge was also beneficial in allowing caregivers to attribute problematic behaviours and symptoms to the disease rather than the care recipient, which improved their experience of caregiving (QL02). Further, qualitative synthesis data indicated that caregivers’ desired to pass on the knowledge they had gleaned from caregiving in order to benefit new caregivers (QL01, QL33, QL37). Passing on knowledge was identified as a motivating factor underlying positive aspects, and highlights the importance of knowledge and preparation in the caregiving experience. In sum, feelings of competency, mastery, and self-efficacy may be related to personal growth. Therefore, these feelings are a positive outcome of caregiving and may be influenced by knowledge and preparation, a factor that facilitates positive aspects. Caregivers may find motivation in caregiving through passing on knowledge that has facilitated the efficacy, competency, and mastery of their role.

Faith and Spirituality. The quantitative synthesis revealed a positive association between scores on measures of religiosity/spirituality and measures of positive aspects of caregiving (QT39, QT52, QT53, QT56). This finding is in keeping with qualitative synthesis data that revealed religiosity and spirituality as facilitating factors in positive aspects. Faith and spirituality were reported to be giving meaning to the caregiving experience, contributing to caregivers’ sense of fulfilling a greater purpose (QL08, QL33, QL57, **QL77**). Altruism was reported in connection to religiosity in some primary studies (QL34) and qualitative synthesis data revealed *altruism* to be a motivating factor related to positive aspects (QL05, QL34, QL35, QL46). Positive religious coping was identified by one study as facilitating positive aspects, wherein caregivers’ faith allowed them to feel accompanied by God in their caregiving work (QT26). The outcome factor, *personal growth*, incorporated spiritual growth and growth in faith (QL34, QL45). In a similar way, negative religious coping, identified as perceiving God as punishing and the caregiving role as a form of punishment (QT26), was associated with poorer

caregiver outcomes and decreased scores on measures of positive aspects. In sum, these data indicate that strong faith and religiosity/spirituality may facilitate caregivers' experience of positive aspects, either by experiencing a deepening of their faith, by providing a means to finding meaning/support in the role, or as a positive coping resource for caregivers.

Caregiver/care recipient relationship. Quantitative synthesis revealed that the spousal relationship was associated with higher scores on measures of positive aspects than adult children or other family members or friends (QT37, QT48, QT62). Qualitative synthesis revealed that responsibility and commitment to the caregiver/care recipient relationship was an important factor underlying positive aspects. Responsibility to the care recipient was reported in adult children, too (QL01, QL18, QL77), but commitment to the relationship was often reported in relation to the marriage vows (QL11, QL35, QL46). Specifically, there seemed to be a commitment to stay with the care recipient through the tough times, as there had been many good times (QL11, QL37). 'Responsibility/commitment' was identified as one of the motivating factors underlying positive aspects of caregiving. 'Love' was also found to be a motivating factor underlying positive aspects. More specifically, caregiving was perceived as a means of demonstrating one's love for the care recipient or was seen as 'love in action' (QL11). For some spouses, upholding the commitment to their partner and fulfilling the caregiving role made their love for the care recipient tangible (QL08, QL46). Quantitative synthesis revealed some studies showed that older age was associated with higher scores on positive aspects, and that this could be confounded by the spousal relationship. For one male caregiver (QL08), caring for his wife provided him with the opportunity to reciprocate the care and love his wife had provided to himself and their children throughout the years. Adult children who report a sense of responsibility and commitment, as related to the caregiving experience, tend to report a sense of 'who else' would do it and a desire to fulfill the role to ensure good quality care for their parent (QL08). There is some indication in the qualitative dataset that when it comes to responsibility and commitment for adult children, these are more closely related to altruistic and reciprocity themes. Whereas for spouses, the theme of responsibility and commitment reflects their devotion to the relationship and to their vows, and spouses may see caregiving as an expression and extension of their love for the care recipient.

2.3.3 Meta-Integration Conclusions

The conditions for positive aspects. Based on the findings of this meta-integration I suggest there are conditions for positive aspects in caregiving. These conditions related to both internal factors (i.e., pertaining to the caregiver) and external factors (i.e. pertaining to the caregiver/care recipient relationship and caregiving environment). The data revealed that internal factors that helped create the conditions for the experience of positive aspects in caregiving were 1) caregiver disposition and tendency toward optimistic thinking, practicing acceptance, gratitude, and cognitive-framing, 2) caregiver religiosity and spirituality, 3) values and morals that serve to motivate and sustain caregivers, 4) feelings of competency, self-efficacy, and mastery, and 5) adaptive coping styles. External factors that helped create the conditions for the experience of positive aspects were, 1) a good pre-caring relationship dynamic with the care recipient, 2) communication and connectedness with the care recipient, 3) feeling appreciated by the care recipient and others, 4) support (i.e., social support and, to a lesser degree, instrumental support), 5) time for self and self-care, and 6) knowledge, preparation, and routine.

Conditions for positive aspects faltered when caregivers experienced loss and isolation within the caregiver role. Loss and isolation undermined feelings of connectedness and communication with the care recipient, and support from others. When feelings of loss were predominant, acceptance became more difficult. Feelings of loss of access to the care recipient may have emerged due to changes in personality and the emergence of problematic behaviours and symptoms in the care recipient. Loss of access to the care recipient or loss in the caregiver/care recipient relationship not only contributed to general feelings of loss and isolation but may have also undermined feeling connected to and appreciated by the care recipient, as well as reduced communication with the care recipient. Experiencing problematic behaviours and symptoms can influence feelings of isolation, as the caregiver's experience becomes increasingly foreign to the caregiver's peers and other family members. Problematic behaviours and symptoms in the care recipient affects feelings of caregiver burden and distress, and together this cycle may impact the caregiver's psychological and emotional resources. When psychological and emotional resources are taxed, engaging in cognitively effortful activities such as cognitive re-framing, practicing acceptance, and gratitude becomes more difficult, thereby undermining the conditions for experiencing positive aspects.

2.4 Meta-Integration Discussion and Conclusions

I used meta-integration to synthesize and elaborate on literature pertaining to positive aspects of caregiving for someone living with dementia. The findings of this meta-integration are consistent with the finding of a recent integrative review of positive aspects literature conducted by Yu and colleagues (2018). Yu and colleagues posit four domains of positive aspects (i.e., feelings of accomplishment and gratification, feelings of mutuality in a dyadic relationship, increase of family cohesion and functionality, and a sense of personal growth and purpose in life) and conditions that facilitate the emergence of positive aspects (personal and social affirmation, effective cognitive emotional regulation, and context that favour finding meaning in the caregiving experience) (Yu et al., 2018). The domains of personal accomplishment and gratification largely align with feelings of competency and satisfaction in the caregiving role, conceptualized in this meta-integration as factors that underlie positive aspects. Increased family cohesion and functionality, as described by Yu and colleagues (2018), closely aligns with improved relationships (both between the caregiver and care recipient, and with caregiver's other family members), modeling behaviour, and demonstrating filial piety describes the motivating factors that underlie positive aspects in this study. The domain of mutuality in the dyadic caregiver/care recipient relationship, identified by Yu and colleagues (2018), describes the importance of the pre-caregiving relationship, the current relationship, and communication and connection that were identified as factors that facilitate the experience of positive aspects in the current study. Yu and colleagues (2018) identified conditions for positive aspects including personal and social affirmation, which aligns with the importance of social support and feelings of self-efficacy as facilitating factors in the experience of positive aspects. The conditions of effective cognitive and emotional regulation describe choice in attitude, practicing gratitude, practicing acceptance, and use of humour and align with the 'ways of being' factors identified as underlying aspects in this study. Finding meaning emerged in Yu and colleagues' (2018) integrative review as a condition for positive aspects and, based on the current findings, I would situate finding meaning with the practices of choice in attitude, practicing gratitude, and changes in life philosophy. I found that the current meta-integration provided support for the previous integrative review findings and served to extend and expand on the work of Yu and colleagues. The current meta-integration provides information on the use of labels, definitions and measures of positive aspects which is important for creating consistency in future investigations into the positive aspects of caregiving. In addition, the current work includes a detailed account of the

factors that underlie and affect the experience of positive aspects, identifying and illuminating the relationships between caregiver factors, care recipient factors, and positive aspects of providing care to someone living with dementia.

The association between some caregiving factors and measures of positive aspects, however, were not explained or elaborated on by the findings of this study. Quantitative synthesis revealed that men caregivers tend to score higher on measures of positive aspects as compared to women caregivers. Caregiving literature included in this meta-integration pertains to the psychological and social aspects of caregiving. Thus, I discuss the psychological construct of ‘gender.’ The finding of a gender difference on measures of positive aspects is somewhat analogous to findings in the literature wherein women caregivers are found to score higher on measures of caregiver burden than men (Gallicchio, Siddiqui, & Langenberg, 2002; Torti et al., 2004). It is difficult to ascertain, with the current findings, why it may be that men tend to score higher on measures of positive aspects. Some theories suggest a response bias, wherein men caregivers are less likely than women caregivers to report experiencing burden and strain (Verbrugge & Madans, 1985). Other studies indicate that men caregivers use instrumental support (formal and informal supports) more than women caregivers do, perhaps reducing the amount of objective burden they experience; however, other findings do not support this notion (Pinquart & Sörensen, 2006). The current qualitative data provided some insight, with findings indicating that perhaps the motivating factors of both ‘responsibility/commitment’ and ‘reciprocity’ are common in men caregivers. In heterosexual relationships, wherein traditional gender roles of provision of care are upheld, motivation of reciprocity in caregiving might be more applicable to men than women. Provision of care has traditionally been a gendered role relegated to women (Wheatley, Lawton, and Hardill, 2018). It might be that for some men, caregiving provides a novel means of expressing ‘love’ in an overt manner.

The association between race/ethnicity and measures of positive aspects was not well explained or elaborated on in the meta-integration findings. Quantitative syntheses revealed that African American caregivers and Hispanic American caregivers score higher than Caucasian American caregivers on measures of positive aspects. The finding is somewhat analogous to literature wherein Caucasian American caregivers tend to score higher on measures of burden and distress than African American and Hispanic American caregivers (Torti et al., 2004). Research investigating race/ethnicity in relation to caregiver experience indicates that higher

degrees of religiosity and spirituality among African American and Hispanic American caregivers may explain higher scores on measures of positive aspects and lower scores on measures of burden as compared to Caucasian American caregivers (Sun et al., 2010). Religiosity has been found to be an important contributor to caregiver adjustment (Murray-Swank et al., 2006) or resilience (Dias et al., 2015). Resilience has been found to be a significant factor in caregiver outcomes (i.e., negative and positive aspects; Dias et al., 2015) and resilience researchers report differences in resilience scores across race/ethnicity groups (Gaugler, Kane, & Newcomer, 2007). Thus, it is possible that differences in psychological resilience and the potential benefits of religiosity on caregiver coping may explain differences in scores on positive aspects of caregiving across race/ethnicity groups.

Finally, age was most commonly found to have a positive relationship with measures of positive aspects in this work. Some studies reported the opposite and the relationship between age and positive aspects remained unexplained by the meta-integration findings. Similarly, findings on the relationship between years spent caregiving and measures of positive aspects were equivocal. Future research should investigate the relationship between age, caregiver gender, race/ethnicity, and duration of caregiving, on caregiver's experience of positive aspects.

Limitations. The limitations associated with this meta-integration include the inability to conduct meta-analysis on the quantitative data due to heterogeneity among primary references. Nevertheless, the narrative synthesis of the quantitative data did serve to inform on common significant associations between caregiving variables and measures of positive aspects. Further, the quality of the primary studies was assessed using the MMAT, however, quality scores were not used in this meta-integration to weight the findings of studies differently. In this way, findings from a poorly developed studied with a low MMAT quality score (e.g., MMAT score of 25) were given equal consideration in the analysis as those with a high MMAT quality score (e.g., MMAT score of 75). I chose not to use quality scores to weight findings because the aim of the research endeavor was exploratory. A primary goal of this meta-integration was to establish how, and in relation to what, positive aspects of caregiving have been investigated; consequently, I did not consider quality of study design. If a meta-analysis would have been possible, I would have considered weighting the findings based on quality scores. The meta-integration was largely conducted by one researcher. While 15% of primary references were screened, coded,

and analyzed by a second researcher, having more than one researcher throughout the entire process would have improved rigour.

Future directions. What remains unanswered by the meta-integration is the finding of a significant relationship between measures of positive aspects and age, race/ethnicity, and caregiver sex. Future research should aim to elucidate these relationships, as findings pertaining to how such caregiver characteristics impact scores on measures of positive aspects may inform intervention programs in important ways. That is, such research might indicate how conditions of positive aspects vary for caregivers depending on their, age, gender, or race/ethnicity. These findings would be directly applicable to intervention programs. Future research should further investigate the utility of the PAC measure in comparison to other measures of positive aspects, with particular focus on its cross-cultural sensitivity.

2.5 Study One References

References marked with an asterisk indicate studies included in the meta-integration (*APA Publication Manual*, 6th ed., section 7.27, p. 194).

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Table 2.1

Summary of Primary Quantitative References Included in Meta-Integration

Study ID	Reference	Purpose	Design	Sample	Measure	Findings	MMAT
QLQT05	Farran, C., Keane-Hagerty, E., Salloway, S., Kupferer, S. & Wilken, C. (1991)	Investigate the utility of an existential framework for understanding the caregiving experience.	correlational	Cross-cultural; n = 94; mixed relations; mixed sex; mean age 61.4	Finding Meaning Through Caregiving Scale (FMTCS)	No significant relationships between the endorsement of positive aspects, the duration of caregiving, problem behaviours, ADL impairment, and support of burden. Provisional meaning was found to have a significant and positive correlation with support, and no other significant relationships for PM were found. No significant relationships for ultimate meaning were found.	55
QT01	Abdollahpour, I., Nedjat, S., Noroozian, M., Yahya, S., & Mejdzadeh, R. (2017)	To develop and validate the Positive Aspects of Caregiving Questionnaire (PAC) in caregivers of patients with dementia in Iran.	correlational	Iranian; n = 132; mixed relations; mixed sex ; mean age 51.5	Positive Aspects of Caregiving Questionnaire (PAC)-Iranian	Content validity indices > .80, internal consistency (alpha = 0.785), and test–retest reliability (0.905). Item–total correlations confirmed good reliability of PAC. Two factors were identified by factor analysis: patient and caregiver relationship, and caregiver’s psychological well-being. Divergent validity and convergent validity were established. A high negative correlation between PAC and caregiver burden was found. A significant positive correlation between PAC and self-rated health was also found. Cronbach’s alpha for full scale was 0.785. Cronbach’s alpha for each factor was 0.71.	75

QT02	Andrén, S. & Elmståhl, S. (2005)	To investigate the CASI scale for factors pertinent to dementia caregiving and to study CASI's satisfaction factor in relation to measures of dementia severity (Berger and GBS), caregiver burden (CB), subjective well-being (NHP), and sense of coherence (individual resources; SOC).	correlational	Swedish; n = 153; mixed relations; mixed sex; mean age 62	Carers' Assessment of Satisfaction Index (CASI)	There was a significant association between CASI factors, increasing age, and deterioration of the care recipient's function. A negative association between caregiver/care recipient relationship and satisfaction was found, indicating the more distant the relationship the lower the satisfaction.	100
QT03	Baker, K. Roberston, N., & Connelly, D. (2010)	This study explores how facets of masculinity relate to male caregivers' appraisals of strain and gain in dementia care. Measures of gender identity (masculinity factor and femininity factor) and gender role conflict (success/power/competitiveness factor and restrictive affectionate behaviour between men factor) were investigated.	correlational	Race NR; n = 70; spouse relation; male caregivers; mean age 68.6	Caregiver Satisfaction Scale	Significant correlations between gains and gender role conflict; positive correlations between gains, success, power, competition, and 'restrictive affection between men' factors. Researchers suspect traditionally held beliefs surrounding gender and gender roles influenced reporting on the measure. Significant negative association between years of caregiver education and gain.	100
QT05	Blume, N. (1999)	A descriptive relationship seeking study's aim was to examine a theoretical model of potential positive appraisal resources and their effect on caregivers' well-being. Relationships between concepts, hope, finding meaning, coping, and sense of coherence (i.e., well-being) were investigated. Rather than positive aspects, the researchers investigated positive appraisal	correlational	Race NR; n = 45; spouse relation; mixed sex; mean age 73.7	Finding Meaning Through Caregiving Scale (FMTCS)	FMTCS subscales of loss/powerlessness, provisional meaning, and ultimate meaning were found to be significant predictors of caregiver well-being.	75

resources, which they comprised of hope, finding meaning, and coping.

QT06	Boerner, K., Schulz, R., & Horowitz, A. (2004)	This study investigated the predictive value of caregiver benefit on post-loss bereavement. Burden, health, depression, relationship, age, and gender in relation to caregiver benefit was investigated.	correlational	Race NR; n = 217; mixed relations; mixed sex; mean age 64	Study Specific	This study investigated the predictive value of positive aspects (conceptualized as caregiver benefit) on post-lost depression and grief. Results support the hypothesis: pre-loss caregiver benefit predicted post-loss grief but not depression. Pre-loss caregiving benefit was associated with higher levels of post-loss depression and grief.	75
QT07	Carruth, A. (1996)	To determine the extent to which caring for a parent living with dementia is similar or different from the experience of providing care to a parent without dementia.	correlational	89.1% Caucasian; n = 305 (mixed dementia and non-dementia caregivers); adult child relation; mixed sex; mean age NR	Caregiver Reciprocity Scale	Adult children of parents with dementia gave more direct instrumental and supervisory care, received more negative and fewer positive exchanges, and reported significantly lower levels of warmth and regard, intrinsic rewards of giving, and balance within family caregiving as compared to adult children of parents without dementia.	75
QT08	Chang, B., Brecht, M., & Carter, P. (2001)	To identify predictors of caregiver burden, satisfaction, depression, and social support.	correlational	Cross-cultural; n = 81; relations NR; mixed sex; mean age 67.5	Caregiver Appraisal Tool	Difficulty arranging support from confidante or friends significantly correlated with caregiver burden and depression and negatively correlated with satisfaction. The intensity of the social support network members was correlated with satisfaction.	75
QT09	Cheng, S., Lam, L., Kwok, T., Ng, N., & Fung, A. (2012)	To investigate self-efficacy in relation to other factors such as burden, depression, and positive appraisals/gains.	correlational	Chinese; n = 99; mixed relations; mixed sex; mean age 59.8	Positive Aspects of Caregiving (PAC)	Caregivers with higher self-efficacy in controlling upsetting thoughts had more positive gains and less burden when confronted with more behavioural problems. Self-efficacy in obtaining	100

						respite had direct effects on burden and depression, and self-efficacy in responding to disruptive behaviours had a direct effect on positive gains, but not moderating effects.	
QT11	Cho, J., Ory, M., & Stevens, A. (2016)	The study assessed the relationship between intrapersonal, interpersonal, organizational factors, and positive aspects of caregiving (as measured by PAC).	correlational	Cross-cultural; n = 642; mixed relations; mixed sex; mean age 60.0	Positive Aspects of Caregiving (PAC)	Findings indicate that Hispanic American and Black caregivers scored higher on the PAC measure than Caucasian American caregivers. Education, marital status, and using formal transportation services were significant predictors for PAC among Hispanic American caregivers. Age, education, caregiving duration, and received social support were significant for PAC among African American caregivers. Sex, education, being a spousal caregiver, satisfaction with social support, using help from a homemaker, visiting nurse services, and participating in support groups were significant among Caucasian American caregivers. Findings indicated that PAC varies significantly across the three studied racial/ethnic groups of family caregivers and that intrapersonal, interpersonal, and organizational factors relate uniquely to PAC.	100
QT14	Cox, C. (1998)	To investigate differences between African American and Caucasian American caregivers in relation to their status and functioning as well	descriptive	African American and Caucasian American; n = 228;	Study Specific	Scores indicate Caucasian American caregivers were more anxious, depressed, felt less competent, and experience less gain than African American caregivers.	50

		as care recipient status and functioning, before and after receiving respite care.		mixed relations; mixed sex; mean age 58		Caucasian American caregivers experienced further decline in gain and competency after respite.	
QT15	de Labra, C., Millan-Calenti, J., Bujan, A., Nunez-Naveria, L., Jensen, A., Peersen, M., mojs, E., Samborski, W., & Maseeda, A. (2015)	To investigate potential predictors of caregiving satisfaction in caregivers of people with dementia. Investigation included background characteristics and context (age, sex, education, marital status, relationship, employment, duration of caregiving), stress-related factors (dementia severity, burden, work related changes, caregiving competence), and mediators (social support and satisfaction with support).	correlational	Cross-cultural; n = 101; mixed relations; mixed sex; mean age 61.3	Caregiver Satisfaction Scale Revised (CSSR)	Having a consanguinity relationship (same blood) with the care recipient, suffering from lower levels of subjective burden, and managing individuals with severe cognitive impairment are the most important predictors of higher caregiving satisfaction. Significant correlations were found between satisfaction, age, caregiver/care recipient relationship, dementia severity, burden, and support from professionals (general practitioner, dementia supervisor).	75
QT16	Gonzalez, E., Polansky, M., Lipp, C., Gitlin, L., & Zuasniewski, J. (2014)	To investigate the efficacy of an intervention aimed at teaching resourcefulness on caregiver outcomes, including caregivers' emotional outcomes (anxiety and depression) and role outcomes (reward, strain, mutuality, and preparedness).	experimental	African American and Caucasian American; n =102; relations NR; sex NR; mean age NR	Family Role Reward Scale (FRRS)	FRRS correlated significantly with resourcefulness, as measured by the Self-Control Scale. No treatment effects on reward, role strain, and frequency of behaviour problems. Small to medium effects were shown for the intervention program on resourcefulness, anxiety, preparedness of the caregivers, and the frequency of behaviour problems in the care recipients.	75

QT17	Fabà, J., Villar, F., & Giuliani, F. (2017)	This study aimed to develop a new measure to evaluate gains associated with caregiving for a person with dementia.	correlational	Spanish; n = 152; mixed relations; mixed sex; mean age 63.0	Gains Associated with Caregiving scale (GAC) and Gains in Alzheimer's care Instrument (GAIN)	Final version of the GAC scale had 22 items which accounted for 47.94% of the total variance, and a sum of scores range from 0 to 66. The higher scores reflected a higher attribution of gains to the caregiving role. Regarding the concurrent validity of the scale, the correlation between the GAC and the GAIN was found to be positive, statistically significant, and strong ($r = 0.75$; $p < 0.001$). In terms of internal consistency, the Cronbach's alpha coefficient ranged from 0.81 to 0.89 for the domains, and it reached a value of 0.95 for the whole scale.	100
QT18	Farran, C., Miller, B., Kaufman, J., & Davis, L. (1997)	To investigate the relationship between finding meaning, caregiver stress/distress, and potential difference across racial groups.	correlational	African American and Caucasian American; n = 215; spouse relations; mixed sex; mean age 71.6	Finding Meaning Through Caregiving Scale (FMTCS)	The best predictors of caregiver depression included being Caucasian American, having poorer physical health, greater behavioural problems distress, greater task distress, and higher levels of care recipient impairment. Higher levels of subscale provisional meaning had an independent effect on lower levels of depression, but the effects of finding meaning were similar across race/ethnicity groups. Higher levels of provisional meaning had an independent effect on lower levels of role strain, but the effects of finding meaning were similar across race/ethnicity groups.	100

QT20	Fisher, G., Franks, M., Plassman, B., Brown, S., Potter, G., Llewellyn, D., Rogers, M., & Langa, K. (2011)	To compare the characteristics and outcomes of caregivers of adults with dementia and caregivers of those with cognitive impairment, but not dementia.	correlational	Cross-cultural; n = 169; mixed relations; mixed sex, mean age 60.4	Study Specific	Almost all caregivers for both groups (dementia and cognitive impairment/not dementia) reported some rewards from their caregiving experience, viewing themselves as more efficacious in a number of ways (e.g., feeling closer to the care recipient, feeling in control over the care recipient's well-being).	75
QT22	Gonçalves-Pereira, M., Carmo, I., Alves da Silva, J., Papoila, A., Mateos, R., & Zarit, S. (2010)	To analyze the link between knowledge and burden, as well as knowledge and positive caregiving experiences, in a Portuguese clinical setting.	correlational	Portuguese; n = 116; mixed relations; mixed sex; mean age 56.1	Positive Aspects of Caregiving (PAC)	Positive aspects of caregiving were valued by participants, as found in previous surveys (PAC scores were 41.7; SD =10.7). A significant and inverse relationship between PAC and Burden was found. No significant relationship between PAC and psychological health was found.	50
QT23	Grover, A., Nehra, R., Malhotra, A., & Kate, N. (2017)	To assess the positive aspects of caregiving and its correlates among caregivers of patients with dementia.	correlational	Indian; n = 55; mixed relations; mixed sex; mean age 49.3	Scale for Positive Aspects of Caregiving Experience (SPACE)	A negative correlation between SPACE, subjective burden, and burden of disruption of family interaction was found. Self-esteem and the social aspects of caring domain had a negative correlation with subjective burden. No other caregiver characteristics (presumably, age, sex, relationship, employment, etc.) or care recipient characteristics (mental status, and IADLS) were significantly correlated with SPACE total, or domains scores.	50
QT24	Harris, G., Durkin, D., Allen, R., DeCoster, J., & Burgio, L. (2011)	To investigate the mediating effect of exemplary care on caregiver appraisals and emotional outcomes. Exemplary care was defined as	correlational	Cross-Cultural; n = 621;	Positive Aspects of Caregiving (PAC)	A significant, inverse relationship was found between PAC, care recipient behavioural problems and symptoms, and dementia severity. A significant, positive	75

		“communicating to the care recipient that they are loved, respected, and worthy of special consideration”.		mixed relations; mixed sex; mean age 59.6		relationship with exemplary care (EC) was found. EC explained the relations between each subjective appraisal variables (symptoms, severity and burden). Enacting the EC behaviours may lead directly to the experience of positive emotions by facilitating meaning-based coping appraisals within the stress process model.	
QT25	Harwood, D., Barker, W., Ownby, R., Bravo, M., Agüero, H. & Duara, R. (2000)	To investigate predictors of positive (satisfaction) and negative (burden) appraisals among Cuban American caregivers.	correlational	Cuban American; n = 40; mixed relations; mixed sex; mean age 60.9	Caregiver Satisfaction Scale	Positive and negative caregiver appraisals share a common predictor, perceived emotional support, but they are largely determined by independent factors. Care recipient psychopathology, caregiver gender, and perceived physical health showed no relationship with positive caregiving appraisal. Satisfaction was predicted by caregiver age and perceived emotional support, with older age and higher levels of support linked to greater satisfaction.	50
QT26	Heo, G. (2014)	To investigate the relationships between religious coping, positive aspects of caregiving, social support, burden, and depression in caregivers of persons living with dementia due to AD.	correlational	Cross-cultural; n = 648; relation NR; mixed sex; mean age 61.0	Positive Aspects of Caregiving (PAC)	A significant inverse relationship was found between PAC scores and negative aspects such as burden, depression, and negative religious coping. A positive relationship between PAC scores, social support, and positive religious coping was found.	75

QT27	Hilgeman, M., Allen, R., DeCoster, J., & Burgio, L. (2007)	To examine the influence of positive aspects as moderators of treatment outcomes over a 12 month period of time.	descriptive	African American and Caucasian American; n= 243; relations NR; mixed sex; mean age 60.8	Positive Aspects of Caregiving (PAC)	A significant effect of race/ethnicity on PAC was found with African American caregivers reporting higher levels of PAC scores across 12 months. A main effect of daily care burden across time was associated with increases in PAC scores. No significant effect of time on PAC was found, indicating that the passage of time did not impact PAC scores. Findings indicated that only daily care bother had a significant independent relation with PAC.	75
QT28	Hodge, D. & Sun, F. (2012)	To examine the effects of spirituality on positive aspects of caregiving.	correlational	Latin American; n = 209; relations NR; mixed sex; mean age 58	Positive Aspects of Caregiving (PAC)	Subjective stressors (burden, bother related to behavioural problems) had a direct effect on PAC; higher levels of subjective stress predicted lower levels of PAC scores. Objective stressors (dementia severity and behavioural problems) had no direct effect on PAC. Social support was not related to PAC. Spirituality was positively related to PAC.	75

QT30	Kajiwara, K., Nakatani, H., Ono, M., & Miyakoshi, Y. (2015)	To determine factors that influence the continuation of in-home caregiving for patients with dementia.	correlational	Japanese; n = 405; mixed relations; mixed sex; mean age 63.9	Caregiving Gratification Scale (CGS)	A significant and positive correlation between CGS, present continuation of care, and continuation with worsening symptoms was found.	50
QT31	Kinney, J. & Stephens, M. (1989)	To investigate the role of daily caregiving stressors (hassles) and small caregiving satisfactions (Uplifts) in the well-being of family caregivers.	correlational	Cross-cultural; n = 60; mixed relations; mixed sex; mean age NR	Caregiving Hassles and Uplifts Scale	The Caregivers Hassles and Uplifts Scale is a measure of appraisals. Caregiver gender was found to account for a significant proportion of cognitive uplifts ($p < 0.01$), with women reporting more. Uplifts were not significantly associated with any index of well-being. Uplifts related to activities of daily living and practical/logistical uplifts were significantly and positively associated with depression. The most satisfaction with care recipient behaviour was reported by younger caregivers who spent more time per day caring. Care recipient characteristics were found to be more predictive of hassles, and caregiver characteristics were stronger predictors of uplifts.	25

QT33	Kramer, B. (1993)	To investigate the interpersonal vulnerability variable (i.e., marital history and quality of the relationship prior to the onset of Alzheimer's disease), caregiver resources, and appraisals of stressors as predictors of both positive and negative outcomes.	correlational	99% Caucasian; n = 72; spouse relation; female sex; mean age 70	Caregiver Satisfaction Scale (CSS)	The study investigated cognitive appraisal, instrumental activities of daily living (IADLs), and care recipient memory and behaviour symptoms (MBPS). A significant and positive relationship was found between cognitive appraisal and depression. This suggests that appraising demands as highly stressful led to higher reported levels of depression. A significant and negative relationship between IADL, MBPC, and quality of life rating suggests that when demands were appraised as less stressful, the quality of life rating was higher. Appraisals were not significantly related to caregiver satisfaction. Dementia severity and social involvement satisfaction were significantly and positively correlated to caregiver satisfaction. Caregiver age, and quality of relationship prior to illness onset were significantly and negatively correlated with caregiver satisfaction. The quality of relationship between the caregiver and care recipient before the onset of Alzheimer's disease was found to have a significant negative relationship with caregiving satisfaction. This indicates that the greater the perceived quality of the relationship prior to the illness onset, the lower the perceived caregiver satisfaction.	50
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QT34	Kramer, B. (1997)	To investigate the differential predictors of negative (strain) and positive (gain) appraisals among husbands caring for wives with dementia.	correlational	Caucasian; n = 74; spouse relation; male sex; mean age 72	Caregiver Satisfaction Scale (CSS)	CSS was found to have a significant and positive relationship with satisfaction with social support and problem focused coping. A significant and negative relationship was found between CSS scores and caregiver level of education. No relationship was found between stressors and caregiver gain, suggesting that appraisal of gain is equally likely for husbands managing varying levels of stressors and challenging symptoms. In regard to the unexpected findings of the association between lower education and appraisal of gain, the author suggests that highly educated husbands may perceive a more striking difference in status between their previous job and the caregiving role.	50
QT36	Lee, M. (2005)	To examine the effects of active interventions on longitudinal changes of negative and positive caregiver outcomes, and test whether the effects of active interventions and longitudinal increase of stressors.	correlational	Cross-cultural; n = 482; mixed relations; mixed sex; mean age 68.5	Positive Aspects of Caregiving (PAC)	The initial status of PAC scores were predicted by gender (females reporting lower PAC before interventions), race/ethnicity (Hispanic American caregivers reporting higher PAC than Caucasian Americans before interventions), and satisfaction with social support (high satisfaction related to PAC). In contrast, dementia severity, behavioural problems, caregiver relationship, SES, and self-rated health did not have a statistically significant relationship with PAC before the intervention (except at one site, wherein	75

						spouses had lower PAC before intervention). No longitudinal change in PAC was found during 18 months and no difference in change of PAC was found between the active intervention and the control. No relationship was found between PAC and stressors.	
QT37	Lee, Y. & Bronstein, L. (2010)	To examine the role of culture in Korean-American dementia caregivers' finding meaning and to compare spouse and child caregivers on finding meaning scores.	correlational	Korean American; n = 65; mixed relations; mixed sex; mean age 63.8.	Finding Meaning Through Caregiving Scale (FMTCS)	Child caregivers had significantly higher FMTCS than spouses. Social support was the only significant predictor of FMTCS for both spouses and child caregivers.	50
QT38	Liew, T., Luo, N., Ng, W., Chionh, H., Goh, J., & Yap, P. (2010)	To explore factors associated with the experience of gains in dementia caregiving.	correlational	94.6% Chinese; n = 334; mixed relations; mixed sex; mean age 51.5	Gains in Alzheimer's care Instrument (GAIN)	Caregiver competence showed a significant negative relationship with GAIN. Competence was measured by the Short Sense of Competence Questionnaire that is comprised of three domains that measure satisfaction with the PWD as a recipient of care, satisfaction with one's performance as a carer, and the consequence of caregiving on the personal life of the carer.	75
QT39	Lim, J., Griva, K., Goh, J., Chionh, H. & Yap, P. (2011)	To examine the factors associated with negative and positive adjustment outcomes among Asian family caregivers of persons living with dementia.	correlational	Chinese; n = 104; mixed relations; mixed sex; mean age 49	Positive Aspects of Caregiving (PAC)	Age, instrumental support, religiosity/spirituality, active management, and encouragement coping strategies were positively related to PAC scores. The only significant predictor of PAC was encouragement. Religiosity/spirituality indirectly	100

						predicted PAC through the variable encouragement.	
QT41	Lou, V., Lau, B. & Cheung, K. (2015)	The study aimed to validate the psychometric properties of the PAC scale among Hong Kong Chinese informal dementia caregivers.	correlational	Chinese; n = 374; mixed relations; mixed sex; mean age 62.9	Positive Aspects of Caregiving (PAC)	A significant and negative relationship was found between PAC scores, psychological health, and depression. A significant and negative relationship was found between PAC scores and subscales of a measure of problem behaviours and symptoms. Subjective physical health was positively and significantly related to PAC. PAC two factor structure was confirmed including 'enriching life' and 'affirming self.'	75
QT42	Luszczynska, A., Durawa, A., Dudzinska, M., Kwiatkowska, M., Knysz, B. & Knoll, N. (2012)	Three studies investigated the effects of mortality reminders on reports of Post-traumatic Growth (PTG) and benefit finding among people living with life-threatening illness and their caregivers. Only the third study is noted in this meta-integration because it pertains to caregivers of persons with a neurodegenerative disease, namely Huntington's Disease.	experimental	Race/ethnicity NR; n = 50; mixed relations; mixed sex; mean age 43.2	Benefit Finding Scale (BFS)	Correlation analyses indicated that the level of benefit finding was unrelated to Huntington's Disease stages, caregivers' life satisfaction, or caregiver age. Caregivers reminded of their own mortality reported finding fewer benefits in caregiving than those who participated in the control group procedures.	50
QT43	Márquez-González, M., López, J., Romero-Moreno, R., & Losada, A. (2012)	To explore the relationships between spiritual meaning and social support from the religious community and problem behaviours, anger, and depression.	correlational	Spanish; n = 128; mixed relations; mixed sex; mean age 59.7	Finding Meaning Through Caregiving Scale (FMTCS)	Significant and negative associations between spiritual meaning, appraisals of caregiving demands, and anger were found. Support from a religious community was significantly and positively related to spiritual meaning.	75

						The relationship between spiritual meaning and anger was mediated through appraisals of problem behaviours, suggesting that spiritual beliefs might help caregivers to find meaning in the caregiving experiences and thus appraise care recipient behavioural problems as less stressful.	
QT45	McLennon, S., Habermann, B., & Rice, M. (2011)	To examine the role of finding meaning in caregiving as a way of coping and as a potential mediator of the effect of caregiver burden on caregiver health.	correlational	Cross-cultural; n = 84; relations NR; mixed sex; mean age 73.3	Finding Meaning Through Caregiving Scale (FMTCS)	Significant negative relationships were found between FMTCS, the duration of caregiving, and caregiver burden. A significant positive relationship was found between FMTCS scores and positive psychological health (including domains of vitality, social functioning, emotional role, and mental health).	50
QT46	Morano, C. (2003)	To examine how the appraisal of burden and satisfaction, as well as the perception of expressive support mediate the effects of caregiving on depression, somatic complaints, life satisfaction, and personal gain.	correlational	Hispanic Americans; n = 103; mixed relations; mixed sex; mean age 64	Study Specific	Appraisal of burden was found to mediate the effects of caregiving on depression and somatic complaints and had significant direct effects on life satisfaction. Appraisal of satisfaction did not have a mediating effect on any of the measures but did have a direct effect on depression and personal gain. Expressive support had a mediating effect on depression, as well as a direct effect on somatic complaints and life satisfaction.	75

QT48	Ott, C., Sanders, S., & Kelber, S. (2007)	To describe the grief and personal growth experiences of spouses and adult children of individuals with Alzheimer's disease and related dementias, as well as the factors contributing to these experiences.	descriptive	Race/ethnicity NR; n = 201; mixed relations; mixed sex; mean age 64.0	Personal Growth subscale of Hogan Grief Reaction Checklist	Level of social support, coping by cognitive reframing, and coping by religion significantly contributed to caregivers' personal growth. Level of depression contributed to a decrease in personal growth. Adult children caregivers scored higher on personal growth.	75
QT52	Quinn, C., Clare, L., McGuinness, T., & Woods, R. (2012)	To explore the associations between intrinsic and extrinsic motivations, the ability to find meaning in caregiving, as well as the pre-caregiving and current relationship quality.	correlational	Cross-cultural; n = 447; mixed relations; mixed sex; mean age 67.8	Meaning Through Caregiving (MTC)	The quality of the relationship before caregiving and the current quality of the relationship were found to have a significant and positive relationship with MTC. Motivation to care was found to have a significant and positive correlation with MTC, for both intrinsic and extrinsic motivations. Role captivity was found to have a significant negative relationship with MTC. The spouse relationship and subjective health were significantly and positively correlated to MTC and competence in caregiving. A separate study, based on the same sample and investigations, reported that religiosity and MTC have a significant positive relationship.	50

QT54	Rapp, S. & Chao, D. (2000)	To examine the contributions of caregivers' appraisals of role strain and role gain in predicting both positive and negative aspects of caregiver well-being.	correlational	African American and Caucasian American; n = 65; mixed relations; mixed sex; mean age 60.9	Gains in Alzheimer's care Instrument (GAIN)	A significant association between ethnicity and GAIN was found, with African American caregivers reporting greater GAIN. Significant negative correlations between GAIN, caregiver burden, negative affect were found. No significant relationships between GAIN and caregivers' age, sex, subjective health, positive affect, duration of caregiving, or care recipient dementia symptoms were found.	50
QT56	Roff, L., Burgio, L., Gitlin, L., Nichols, L., Chaplin, W. & Hardin, M. (2004)	To examine differences in positive aspects of caregiving across African American and Caucasian American caregivers.	correlational	African American and Caucasian American; n = 618 (REACH); mixed relations; mixed sex; mean age 61.8	Positive Aspects of Caregiving (PAC)	African Americans scored significantly higher on PAC than Caucasian American caregivers. African American caregivers scored lower on SES, reported less behavioural bother, scored lower on anxiety, and were more religious than Caucasian American caregivers. When investigated through a multiple regression analysis, the relationship between race/ethnicity and PAC was partly explained by African American caregivers' lower SES, lower behavioural bother, lower anxiety and higher religiosity scores.	75

QT57	Roth, D., Dilworth-Anderson, P., Huang, J., Gross, A., Gitlin, L. (2015)	Potential group differences were examined on the positive aspects of caregiving (PAC) scale at both the item and scale level.	descriptive	African American, Hispanic American, and Caucasian American; n = 642 (REACHII); mixed relations; mixed sex; mean age NR	Positive Aspects of Caregiving (PAC)	Significant differences in PAC by race/ethnicity indicated that African American and Hispanic American caregivers reported higher PAC scores than Caucasian American caregivers. Significant difference in PAC by gender revealed that males reported higher scores on PAC than females in this sample. No significant relationships or differences in PAC scores across age or relationship type (spouse versus non-spouse) were found.	75
QT58	Savundranayagam, M. (2014)	To investigate the impact of changes in help and changes in satisfaction with help on positive aspects of caregiving in a sample of spouse and child caregivers.	correlational	96% Caucasian; n = 462; mixed relations; mixed sex; mean age NR	Study Specific	Analysis revealed that increases in the amount of help and satisfaction with help was significantly linked with increases in caregiver rewards for adult children. Only increases in satisfaction with help were significantly related to increases in caregiver rewards for spouses. The author concludes that quality of support is important for both adult child and spousal caregivers, but the quantity of support is also important for adult children caregivers.	25
QT60	Semiatin, A. & O'Connor, M. (2012)	To examine the relationship between positive aspects of caregiving and self-efficacy among family members caring for a loved one with Alzheimer's disease.	correlational	Cross-cultural; n = 57; mixed relations; mixed sex; mean age 70	Positive Aspects of Caregiving (PAC)	PAC scores were significantly and negatively correlated with caregiver depression scores and dementia symptoms in care recipients. Self-efficacy and PAC scores were positively and significantly correlated.	50

QT62	Tarlow, B., Wisniewski, S., Belle, S., Rubert, M., Ory, M. & Gallagher- Thompson, D. (2004)	To assess a newly developed measure for the positive aspects of caregiving using a sample of dementia caregivers.	correlational	Cross-cultural; n = 1229 (REACH); mixed relations; mixed sex; mean age 62.2	Positive Aspects of Caregiving (PAC)	Factor analysis revealed two components in the nine-item measure, 'self- affirmation' and 'outlook on life.'	75
QT64	Yap, P., Luo, N., Yee, W., Chionh, H., Dip, A., Lim, J., Sco, L. & Goh, J. (2010)	To describe and validate a new scale, Gains in Alzheimer care Instrument (GAIN) and to measure gains in dementia caregiving.	correlational	Cross-cultural; n = 238; mixed relations; mixed sex; mean age 50.1	Gains in Alzheimer's care Instrument (GAIN)	GAIN and PAC were significantly and positively correlated. Encouragement and active management coping were significantly and positively correlated with GAIN. Criticism coping was negatively correlated with GAIN. Burden was found to have a negative and significant correlation with GAIN.	75
QT65	Yu, H., Wu, L., Chen, S., Wu, Q., Yang, Y. & Edwards, H. (2016)	To examine the mediating role of reciprocal filial piety (RFP) between the care recipient's behavioural and psychological symptoms of dementia (BSPD) and the caregiver's burden or gain among adult-child caregivers caring for parents with dementia in China.	correlational	Chinese n= 401; adult children relation; mixed sex; mean age 48.0	Positive Aspects of Caregiving (PAC)	Reciprocal filial piety and PAC were found to have a significant positive correlation. Negative and significant correlations found between the PAC score and number of years caregiving and number of hours caregiving.	75
QT66	Picot, S. (1994)	To use Choice and Social exchange Theory as a framework for identifying potential rewards of African American caregivers of demented elders.	correlational	African American; n = 83; mixed relations; female sex; mean age 58.9	Picot Caregiver Rewards Scale (PCRS)	A demographic variable that showed a significant correlation to PCRS was age, with older caregivers reporting more perceived rewards than younger caregivers. In addition, education was significantly and negatively related to PCRS where more education led to lower PCRS.	50

QT68	Butcher, H., Gordon, J., Woon, J., Perkhounkova, Y., Cho, J., Rinner, A. & Lutgendorf, S. (2016)	To investigate the effect of the Structured Written Emotional Expression (SWEE) on the ability to find meaning in caregiving and the effects of finding meaning on emotional state and psychological burden.	experimental	94.5% Caucasian; n = 91; relations NR; mixed sex; mean age 60.9	Finding Meaning Through Caregiving Scale (FMTCS)	A main effect of group indicated that the SWEE intervention was effective in facilitating meaning making. An improvement in Provisional Meaning scores was facilitated by having higher provisional meaning scores at pretest.	75
QT70	Monin, J., Schulz, R., & Feeney, B. (2014)	To examine whether compassionate love in both individuals living with dementia due to Alzheimer's disease and their spousal caregivers related to less caregiver burden, more positive caregiving appraisals, and less depressive symptoms for caregivers.	correlational	Cross-cultural; n = 58; spouse relations; mixed sex; mean age 71.1	Positive Aspects of Caregiving (PAC)	This study found that caregivers' report of compassionate love for the care recipient was significantly and positively related to PAC. Care recipients' compassionate love for the caregiver was significantly and positively related to PAC. In addition, a significant and positive relationship between caregiver age and PAC was found. A significant, negative relationship between PAC, burden, and depressive symptoms was found.	50
QT71	Daley, R., O'Connor, M., Shirk, S., & Beard, R. (2017)	To investigate the experiences of dyads taking either the We/Us/ or I/Me approach.	correlational	Race/ethnicity NR; n = 11; spouse relations; mixed sex; mean age 80.8	Positive Aspects of Caregiving (PAC)	No significant differences between groups on patient cognitive/functional ability, caregiver anxiety, depression, burden, or relationship satisfaction was found. However, We/Us caregivers expressed more positive aspects of caregiving than I/Me caregivers. The I/Me approach is not associated with differences in variables of patient cognitive status/functional ability, caregiver emotional health, perceived burden, or relationship satisfaction. Caregivers taking a We/Us approach,	75

						however, were able to identify more positive aspects of caregiving. This may be related to mutual compassion, a characteristic of the We/Us approach, which may be protective.	
QT72	Cohen, C., Colantonio, A., & Vernich, L. (2002)	To identify positive aspects of caregiving and examine how they are associated with caregiver outcomes.	correlational	Canadian; n = 289; relations NR; sex NR; mean age NR	Study Specific	Majority (73%) of caregivers could identify at least one specific positive aspect of caregiving. Positive feelings about caring were associated with lower scores on measures of depression, lower burden scores, and better self-assessed health.	36
QT73	Park, M. Choi, S., Lee, S., Kim, S., Kim, J., Go, Y., & Lee, D. (2018)	To explore how unmet needs and formal support may impact caregiver satisfaction and caregiver burden.	correlational	North Korean; n = 320; family caregivers; 60.3% female; mean age 65.7.	CASI- Short version.	Care recipient dementia related symptoms had a positive association with caregiver satisfaction. Caregiver satisfaction had a negative association with caregiver burden. Formal support had no significant effect on caregiver satisfaction.	83
QT74	Quinn, C., Nelis, S., Martyr, A., Victor, C., Morris, R., & Clare, L. (2019)	To identify the potential impact of positive and negative dimensions of caregiving on caregiver well-being and satisfaction with life.	Correlational	Race/ethnicity NR; n = 1283; mixed spouses and other family members; 68.7% female; mean age NR.	Positive Aspects of Caregiving (PAC)	Lower well-being was associated with perceiving fewer positive aspects of caregiving. Lower satisfaction with life was associated with perceiving fewer positive aspects of caregiving.	71
QT75	Riley, G., Evans, L., & Oyeboode, J. (2018)	To investigate the link between appraisals of relationship continuity and the negative and positive emotional impact if the caregiving role.	Correlational	White British ethnicity; n – 71; relations NR; 67% female; mean age 71.	Positive Aspects of Caregiving (PAC)	Higher relationship continuity between caregiver and care recipient was associated with more positive emotional responses (PAC).	57

QT76	Paul, C., Teixeira, L., Duarte, N., Pires, C. & Ribeiro, O. (2018)	To evaluate the impact of a psychoeducational intervention on positive aspects of care for caregivers of persons living with Alzheimer's disease.	Experimental	Portuguese; n = 187; relations NR; 56% female, mean age 78.4.	Positive Aspects of Caregiving (PAC)	Factors associated with positive aspects of caregiving were younger age of caregiver, and the presence of a secondary caregiver.	71
QT78	Polenick, C., Wexler Sherman, C., Birditt, K., Zarit, S. & Kales, H. (2018)	To determine how perceptions of purpose in life among persons living with dementia and their family caregivers are linked to caregiving gains.	Correlational	N = 153; family caregivers; 41.5% female; mean age 65.	Study specific	Caregivers' higher purpose in life was associated with greater caregiving gains. Care recipient purpose in life was associated with greater caregiver gains.	71
QT79	Fields, N., Xu, L., & Miller, V. (2019)	To investigate whether and how positive aspects of caregiving and religiosity buffer the association between caregiving burden and desire to institutionalize.	Correlational	Mixed race/ethnicity; n = 637; mixed relations: 82.9% female; mean age 60.	Positive Aspects of Caregiving (PAC)	PAC and religious coping were negatively associated with decision to institutionalize, only PAC was significant.	86
QTQL47	Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., & Corcoran-Perry, S. (2001)	To examine the relationships between caregivers' positive and negative subjective responses to caregiving and to increase the understanding of the experience of being a spouse caregiver for a person living with dementia.	correlational	Caucasian American; n = 50; spouse relation; mixed sex; mean age 73.3	Positive Aspects of Caregiving (PAC)	PAC scores were positively and significantly related to caregiver competence and years of caregiving. No significant relationship was found between caregiver age, gender, or negative aspects and PAC.	45

Table 2.2

Summary of Positive Aspects Measures

Study ID	Measure	Properties	Evidence
QT42	Benefit Finding Scale (BFS)	Randomly selected items from the BFS was used in one study. No data pertaining to the measure was provided.	NR
QT08	Caregiver Appraisal Tool (CAT)	Measures feelings toward the caregiving role (satisfaction/burden). 47 items on a 5-point Likert scale assessing burden, satisfaction, mastery, and caregiving impact as a global score. Burden and Satisfaction subscale extracted and used by original authors (the former 13 items with score range 13-65 and satisfaction, is 9 items with a score range of 9-45).	Cronbach's alpha = 0.72 (satisfaction)
QT07	Caregiver Reciprocity Scale (CRS)	22-item scale with four subscales: 1. warmth and regard (9 items); 2. intrinsic rewards of giving (5 items); 3. love and affection (4 items); 4. balance in family caregiving (4items).	NR
QT03	Caregiver Satisfaction Scale (CSS)	Original authors used five items from the caregiving satisfaction scale. Responses on a 5-point Likert scale with higher scores indicating greater gains.	Cronbach's alpha = 0.84

QT33	Caregiver Satisfaction Scale (CSS)	15 items pertaining to long-term caregiving satisfaction (such as “I feel there is more purpose and meaning in my life as a result of caring for my husband”). Responses on a 4-point scale with higher scores indicating greater satisfaction.	Validity and reliability of the measure: Standardized alpha coefficient = 0 .90
QT34	Caregiver Satisfaction Scale (CSS)	15 items pertaining to long-term caregiving satisfaction (such as “I feel there is more purpose and meaning in my life as a result of caring for my husband”). Responses on a 4-point scale with higher scores indicating greater satisfaction. Possible range 15-60.	Evidence for the validity and reliability of the measure: Standardized alpha coefficient of .90
QT15	Caregiver Satisfaction Scale Revised (CSSR)	6 items pertaining to different aspects of PAC: (1) global satisfaction helping the relative, (2) feeling closer to the patient, (3) enjoying being with the patient, (4) boosting the caregiver’s self-esteem, (5) delighting in the patient’s pleasure, (6) giving meaning to the caregiver’s life. Maximum score of 30, with higher scores indicating greater satisfaction.	NR
QT30	Caregiving Gratification Scale (CGS)	Eight items measuring positive appraisal of caregiving. Responses on a 4-point Likert scale (score range, 0-24).	The reliability and validity have been verified in Japan.
QT02	Carers' Assessment of Satisfaction Index (CASI)	20 item measure exploring diversity of caregiver rewards in caring for persons experiencing geriatric conditions including, but not limited to dementia. Responses ranging from (4) applies and provides quite a great deal of satisfaction, (3) applies and	NR

		provides quite a lot of satisfaction, (2) applies but does not provide a source of satisfaction, or (1) does not apply.	
QT73	Carers' Assessment of Satisfaction Index (CASI)	20 items capturing factors: purpose, pleasure, appreciation, and reward.	Cronbach's alpha = 0.91.
QT16	Family Role Reward Scale (FRRS)	Response on a 5-point scale that ranges from 'not at all' (0) to 'a great deal' (4), on items for example: "does caring for your family member allow you to preserve integrity?"	Cronbach's alpha = 0.93.
QT05	Finding Meaning Through Caregiving Scale (FMTCS)	Items pertaining to loss/powerlessness, provisional meaning, ultimate meaning. Scores below 90 are low, scores above 140 are high.	NR
QT18	Finding Meaning Through Caregiving Scale (FMTCS)	Comprised of three subs scales: loss and powerlessness, provisional meaning (PM), and ultimate meaning (UM). The 19 items of PM focus on CGs being able to enjoy what they still have in terms of a relationship with the CR, and 5 items of UM focus on the identification of a spiritual or religious belief system. Responses on a 5-point Likert scale ranging from strongly disagree (1), to strongly agree (5).	Cronbach's alpha = 0.88, and 0.91 for provisional and ultimate meaning, respectively.
QT37	Finding Meaning Through Caregiving Scale (FMTCS)	FMTCS response options are on a 5-point scale (0=strongly disagree-4 = strongly agree). Higher scores indicate greater meaning.	Cronbach's alpha = 0.84.

QT43	Finding Meaning Through Caregiving Scale (FMTCS)	Only includes 5 items pertaining to ultimate meaning. Responses from 0-4.	Cronbach's alpha = 0.92
QT45	Finding Meaning Through Caregiving Scale (FMTCS)	43 items in three subscales: Loss/powerlessness (19-items), Provisional meaning (19 items), and Ultimate meaning (5-items). Response on a 5-point scale (0-4), with higher scores indicating greater levels of finding meaning.	Cronbach's alpha= 0.80-0.91
QT68	Finding Meaning Through Caregiving Scale (FMTCS)	Reflects coping resources and coping responses. Participants complete the FMTCS, which is comprised of three sub scales: Provisional meaning, ultimate meaning, and powerlessness/loss. Responses on a 5-point scale with higher scores on provisional and ultimate meaning subscales indicating greater meaning and high scores on loss and powerless indicating stronger feelings of loss and powerlessness.	NR
QT17	Gains in Alzheimer's care Instrument (GAIN)	22-item scale pertaining to five domains: industry, identity, intimacy, generativity, and Ego integrity. Responses on a 4-point Likert scale, with scores ranging from 0-66 and higher scores reflecting a higher attribution of gains to the caregiving role.	NR

QT38	Gains in Alzheimer's care Instrument (GAIN)	10 items measure three of three components: (1) personal growth (patience, strength, self -gains and dementia caregiving awareness, knowledge); (2) gains in relationships (closer to PWD, family members and relate better to older people); (3) higher level gains (positive change in life philosophy, spiritual growth, altruism). A 5-point Likert response scale for each item and all items are summed.	Cronbach's alpha = 0.89.
QT64	Gains in Alzheimer's care Instrument (GAIN)	10-item scale with responses on a 5-point scale, where higher scores indicate greater gain (range 0-40).	Cronbach's alpha = 0.89, test-retest reliability coefficient was 0.70.
QT52	Meaning Through Caregiving	12-item Meaning in Caregiving Scale explored the positive aspects of care and ways in which caregivers can find meaning through the CG experience. Responses were on a 5-point scale with scores ranging from 12-60. Higher scores indicated a greater sense of finding meaning.	Cronbach's alpha = 0.88.
QT48	Personal Growth subscale of Hogan Grief Reaction Checklist	Number of items not reported. 1-5 response method, with higher scores indicating greater personal growth. Items represent forgiving, compassionate, tolerant, hopeful, and caring characteristics.	Cronbach's alpha = 0.88.
QT25	Philadelphia Geriatric Center Appraisal Scale- subscale satisfaction	A subscale of Philadelphia Geriatric Center Appraisal Scales with 5 items of appraised satisfaction (higher scores indicate higher satisfaction). *response method and score range unknown.	Cronbach's alpha = 0.69

QT66	Picot Caregiver Rewards Scale (PCRS)	24 items pertaining to short-term and long-term internal and external caregiving outcomes. Responses on a 5-point scale with scores ranging from 0-96 and higher scores indicating higher perceived rewards.	Alpha coefficient = 0.86.
QT50	Picot Caregiver Rewards Scale (PCRS)	24-items scale includes caregiver perceived pleasures, satisfactions, good feelings, and positive consequences. Responses on a 5-point scale and higher scores indicate greater rewards.	Construct validity assessed by factor analysis producing a single factor accounting for 43% of variance. Alpha coefficient, .86
QT09	Positive Aspects of Caregiving (PAC)	9 items on 5-point Likert scale. Scores range from 0 to 45, with higher scores indicating greater positive aspects.	Cronbach's Alpha = .84
QT11	Positive Aspects of Caregiving (PAC)	11 items answered on a 5-point Likert scale. Scores range from 1 to 44 with higher scores indicating higher levels of positive aspects.	Cronbach's alpha = .92
QT22	Positive Aspects of Caregiving (PAC)	11 items on a 5-point Likert Scale, where higher scores indicate 'higher satisfaction.'	NR
QT24	Positive Aspects of Caregiving (PAC)	9 items pertaining to a mental or affective state in the context of the caregiving experience. Responses on a 5-point scale response (0= disagree a lot – 4= agree a lot)	Cronbach's alpha = 0.92.

		Assesses the perception of benefits within the caregiving context such as feeling more useful and feeling appreciated. Scores range from 0-36 with higher scores indicating more positive appraisals of the CG situation.	
QT26	Positive Aspects of Caregiving (PAC)	9 items to assess how caregivers' subjectively perceived gains from providing care for the family member. Responses on a 5-point scale (0-4) with higher scores indicating higher levels of positive aspects. Psychometric analysis revealed a two factor structure with 'self-affirmation' and 'outlook on life' as underpinning the PAC.	Cronbach's alpha = 0.85
QT27	Positive Aspects of Caregiving (PAC)	9 items pertaining to perception of benefits within the caregiving context, such as feeling useful, feeling appreciated, and finding meaning. 5-point response scale (1-5) with higher scores indicating more positive appraisals. Score range from 9-45.	Cronbach's alpha = .89.
QT28	Positive Aspects of Caregiving (PAC)	9 items pertaining to the CGs mental or affective state assessing the perception of benefits in caregiving. Comprised of two factors: self-affirmation, and outlook on life.	Cronbach' alpha for subscales of self-affirmation and outlook on life: 0.88 and 0.85, respectively.
QT36	Positive Aspects of Caregiving (PAC)	11 items pertaining to PA. Addresses self-affirmation (SA) and outlook on life (OL). Summary score of this study, 9 items used, with a theoretical range of 9-45, higher scores indicate greater PAC.	Cronbach's alpha = 0.89. Discriminant validity calculated at initial (before intervention) PAC by Depression (CES-d), ($r = -0.181$, $p < .0001$).

QT39	Positive Aspects of Caregiving (PAC)	9 items pertaining to perceived gains in relation to the caregiving experience. Responses on a 5-point scale, higher scores indicating greater PAC. Two components: self-affirmation, and outlook on life.	Self-affirmation, and outlook on life. Cronbach alpha = .86 (self-affirmation), and 0.80 (outlook on life).
QT41	Positive Aspects of Caregiving (PAC)	9-item two-factor solution, including self-affirmation and outlook on life. Self-affirmation describes a confident and capable self-image brought by caregiving and the outlook on life factor describes enhanced interpersonal relationships and positive life orientation.	NR
QT56	Positive Aspects of Caregiving (PAC)	9 items assess caregivers' subjectively perceived gains from desirable aspects of, or positive affective returns from, providing care for their family member. Responses on a 5-point scale, with higher scores indicating greater PAC. Subscales of self-affirmation and outlook on life.	Cronbach's alpha = 0.88.
QT57	Positive Aspects of Caregiving (PAC)	11-item scale (modified from original 9 items), pertaining to the possible positive experiences associated with providing care. Responses on a 4-point scale with scores ranging from 0-44.	NR
QT60	Positive Aspects of Caregiving (PAC)	9 items pertaining to a caregiver's affective state in the context of the caregiving experience. Responses on a 5-point scale, with scores ranging from 9-45 and higher scores indicating more positive caregiving appraisals.	Reliability was alpha = 0.85.

QT62	Positive Aspects of Caregiving (PAC)	11 items phrased as statements about the caregiver's mental/affective state in relation to the caregiving experience. Answered on a 5-point scale. Higher scores indicate greater PAC.	Factor analysis reveal two factors: self-affirmation and outlook on life. Cronbach's alpha was 0.86, and 0.80, respectively and the total scale was .89
QT65	Positive Aspects of Caregiving (PAC)	Chinese version of the PAC. 9 items phrased as statements about the caregiver's mental/affective state in relation to the caregiving experience. Responses on a 5-point scale with a score range of 9-45, and higher scores indicating more positive feelings toward the caregiving experience.	NR
QT70	Positive Aspects of Caregiving (PAC)	"Positive appraisals of Caregiving" 11 items phrased as statements about the caregivers mental/affective state in relation to the caregiving experience. Responses on a 5-point scale with higher scores indicating greater caregiving benefit.	NR
QT71	Positive Aspects of Caregiving (PAC)	9-item scale requiring respondents to rate how much they agree with positive statements about mental and affective states related to the caregiving experience. Responses on a 5-point scale. Scores range from -35 to 45, with higher scores indicating more positive aspects of caregiving.	NR
QT74	Positive Aspects of Caregiving (PAC)	9 items rated on a 5-point Likert scale, with higher score indicating more positive appraisals of caregiving.	Cronbach's alpha = 0.91

QT75	Positive Aspects of Caregiving (PAC)	The PAC includes items assessing the sense of gratification and achievement from caregiving.	Cronbach's alpha = 0.95
QT76	Positive Aspects of Caregiving (PAC) Portuguese	11 items on a Likert scale of five points.	NR
QT79	Positive Aspects of Caregiving (PAC)	11 items on a 5-point Likert scale, with statements about the caregiver's mental or affective state, designed to assess the perception or beliefs within the caregiving context.	Cronbach's alpha = 0.92
QTQL47	Positive Aspects of Caregiving (PAC)	11 items phrased as statements about the caregiver's perceptions of good things that have arisen from the caregiving experience.	Cronbach's Alpha = 0.88
QT01	Positive Aspects of Caregiving Questionnaire-(PAC)Iran	Scale developed by a panel of psychiatrists, neurologists, psychologist, and content experts. The scale was initially 12 items but was reduced to 10 items after exploratory factor analysis. The response method to items is not reported.	Inter-rater reliability found to be good and item content validity was found to be greater than 80% after revision.
QT23	Scale for Positive Aspects of Caregiving Experience (SPACE)	44-item scale comprised of four domains: caregiving personal gains (14 items), motivation for caregiving role (13 items), caregiver satisfaction (8 items), self-esteem, and social aspect of caring (9 items). Responses on a 5-point Likert scale (0-4) with a 0-176 range. Total scores are calculated by dividing by the number of	Internal consistency, split-half reliability (Spearman-Brown coefficient/Guttman's split-half coefficient = 0.83), face validity (90% agreement on various items among experts), test-re-test reliability (intraclass correlation coefficient of

		items, thus 0-4 is the total score range. Higher scores indicate a more positive caregiving experience.	0.9-0.99 for various domains), and cross-language reliability (intraclass correlation coefficient of 0.92-0.98 for various domains).
QT06	Study Specific	11 items, 5-point Likert scale responses with higher scores indicating greater benefit.	NR
QT14	Study Specific	4 items pertaining to gain and 4 items pertaining to competency. Responses on a 4-point Likert scale ranging from (1) Very much to (4) Not at all pertaining to personal strengths, self-confidence, growth, and new learning. Competency and feeling of being able to adequately cope, using a 4 item scale (alpha = .74), with responses on a 1-4 point scale.	Cronbach's alpha for personal gain = .76
QT20	Study Specific	5 items developed for a national study to indicate a variety of caregiving rewards, including: feeling useful, feeling closer to the care recipient, feeling good about oneself, feeling able to handle most problems, and feeling that the care they providing kept care recipient from getting worse.	NR
QT46	Study Specific	Personal gain measured by a 4-item scale pertaining to what caregivers might have learned as a result of providing care (e.g., becoming more aware of your inner strength). Responses on a 4-point scale with higher scores indicating greater gains.	NR

QT54	Study Specific	11-item scale developed for the study and describes the possible benefit of the caregiver role (e.g., made you feel appreciated”). Responses of either ‘yes’ or ‘no’ with ‘yes’ items summed for a possible range of 0-11. Higher scores indicate greater gains.	NR
QT72	Study Specific	Caregivers were asked an open-ended question about positive aspects of caregiving. Caregivers responded yes or no to specific positive aspects. Caregivers were asked about caregiving in general. Responses on a smiling faces scale (7-point scale ranging from a happy to a sad face) to capture positive and negative feelings.	NR
QT78	Study Specific	Caregiver gains was assessed by the following items, with a four point Likert scale response: caregiving has made them more confident about their abilities; caregiving has taught them to deal with difficult situations; caregiving has brought them closer to the care recipient ; caregiving has given them satisfaction that the care recipient receives good care.	Alpha = 0.66
QLQT05	Study Specific	The researchers quantified the caregivers’ qualitative reports and themes of valuing PA. Range of 0-7.	NR

This table provides a summary of the measures used in the quantitative and mixed method studies included in the meta-integration. Included here is a description of the properties of each measure as reported by the primary study and reported evidence for the validity or reliability of the measure.

Table 2.3

Summary of Primary Qualitative References Included in Meta-Integration

ID	Reference	Purpose	Design	Sample	Label	Epist.	Method	Analysis	Findings	MMAT
QL01	Albinsson, L. & Strang, P. (2003)	The aim of this study was to focus on issues of freedom/responsibility, existential isolation, death, and meaning/meaninglessness.	Exploratory	20 Family members of persons in late stage dementia. 13 children, 4 spouses, and 2 other.	other	not stated	Interview: existential issues were approached through questions about what it was like to care for their relative with dementia, how often they visited the person, and what the visit was like.	The interview data were analyzed using a hermeneutic approach and in light of Yalom's definitions of four basic existential domains. The domains were used as preconceived categories, but 'emerged from the data.'	To take responsibility (faithfulness; paying back) for the person with dementia was generally perceived as rewarding, but in some cases, it was more a matter of duty with elements of guilt and obligation. Existential isolation dealt with the hampered or ended communication with a spouse or parent who was no longer able to communicate; no other relatives left in one's life or, the role-reversal (i.e., to parent your own parent). Thoughts about the impending death were affected by previous experiences, not only by the actual situation. Anticipatory grief was commonplace. Some informants described an increased awareness of the shortness of life, which made them live more intensely in the present. The illness itself was discussed in terms of meaninglessness. Still, many respondents were able to identify meaning in the past (memories), present (daily routines, positive aspects of responsibility), and future (to pass on the patient's lifework).	50

QL02	Shim, B., Barroso, J., & Davis. L. (2012)	To explore how the experiences of spousal caregivers of people with dementia differ.	Exploratory	21 spouse caregivers of persons living with dementia due to AD.	other	not stated	Secondary analysis of interviews	Content analysis; Manifest and Latent	Spousal caregivers of people with dementia can be encouraged toward more positive caregiving experiences through empathy-building interventions and enhanced understanding and acceptance of changes in the care recipient.	75
QL04	Butcher, H. & Buckwalter, K. (2002)	To examine how one can find meaning in the caregiving experience by transforming the exasperations of caring for a loved one living with dementia (due to AD and related disorders) into blessings.	Descriptive	1 spousal caregiver of someone living with dementia.	PA	not stated	Interview: the account used in this analysis is from one participant whose account captured the majority of the themes identified in that initial investigation	Hermeneutic analysis.	The caregiver constructs meaning by emphasizing particular aspects of her experiences including cherished memories, creating a happy life by living life intensely, and counting her blessings. While some caregivers naturally find such meaning, this study suggests that reading the narratives of others as well as writing about one's own thoughts and feelings can facilitate this meaning-making process. Structured, written emotional expression, in particular, fosters meaning-making, diminishes psychological distress, improves immune function, and promotes health and well-being.	50
QL05	Farran, C., Keane-Hagerty, E., Salloway, S., Kupferer, S. &	To investigate the utility of an existential framework for understanding the caregiving experience.	Exploratory	94 family caregivers of persons living with dementias, and dementia due to ad.	Pa	Not stated	Structured interview with use of both qualitative and quantitative methods.	Appears to include both inductive and deductive thematic analyses (potentially content analysis), using the categories	Results suggest that an existential framework provides an alternative paradigm for understanding the caregiving experience.	55

Wilken,
C. (1991)

associated with
the existential
paradigm to fit
data. Use of chi
square analysis to
analyze
subcategory
responses across
caregiver groups.

QL08	Cheng, S., Mak, E., Lau, R., Ng, N., & Lam, L. (2015)	To discover positive gains as constructed by family caregivers of relatives living with dementia due to ad.	Explorator y	57 primary caregivers (8 wives, 2 husbands, 42 daughters, 1 son-in- law, 1 nephew) providing at least 14 hours of care per week to a relative with physician diagnosed dementia.	Other	Not stated	Recorded diaries, transcribed verbatim. Caregivers instructed to report on the positive aspects that they experienced, up to three times per week.	Thematic analysis, inductive identification of codes and themes by two researchers independently, then consensus reached on any disparities.	Ten themes related to positive gains were identified: (a) insights about dementia and acceptance of the condition, (b) a sense of purpose and commitment to the caregiving role, (c) feelings of gratification when the care recipient was functioning relatively well, (d) mastering skills to handle the care recipient, (e) increased patience and tolerance, (f) cultivating positive meanings and humor amidst difficult circumstances, (g) letting go of things, such as when the care recipient's qualities had been lost or the personal agenda had become unrealistic, (h) developing a closer relationship with the care recipient, (i) finding support, and (j) feeling useful helping other caregivers.	75
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QL11	Donovan, M., & Corcoran, M. (2010)	To describe caregiving related beliefs, meanings, and actions identified by a group of uplifted, long-term spouses of people living with dementia due to ad or related dementia.	Exploratory	15 spousal caregivers of persons living with dementia who scored high on a measure of uplifts.	Pa	Not stated	Secondary use of interview data. The interviews were 90 minutes, on three occasions, over a period of six weeks.	Phenomenological approach.	Two primary themes of caregiver thinking and action: (1) engaging in positive behaviours and (2) making adjustments in attitudes.	50
QL17	Habermann, B., Hines, D. & Davis, L. (2013)	To explore the positive aspects experienced by adult children when providing care to their parent who has either parkinson's or ad.	Exploratory	34 adult children caregivers of a parent living with dementia due to ad (76%) or parkinson's disease (24%).	Pa	Not stated	Semi-structured interviews (3-60 minutes) regarding the challenges experienced as a caregiver along with the positive aspects or the satisfying experiences of being a caregiver.	Descriptive approach and "conventional content analysis". Themes or codes were data-derived and driven by the research questions rather than by a theoretical framework.	Results indicated that most caregivers had positive experiences. Three relationship-centered themes were identified: spending and enjoying time together, appreciating each other and becoming closer, and giving back care. A small number of caregivers could not identify positive experiences.	75

QL18	Harris, P. (1998)	To broaden the understanding of, and provide perspectives on son caregivers.	Exploratory	30 sons caring for a parent with dementia.	Po	Not stated	In-depth personal interviews lasting 1.5-2 hours with a general interview guide aimed at addressing: role as caregiver, stress and coping, interpersonal and family relationships, and meaning and motivation.	Content analysis, a six-step process completed by two researchers. Steps included: re-reading the transcripts, the devolvement of substantive codes, and grouping the codes into themes that emerged from the narratives and common issues that were identified through the interview guide questions.	The within-group analysis revealed common themes that emerged from the narratives: duty, acceptance, taking charge, common emotions, and work flexibility. The analysis also revealed these common issues: loss, sibling relationships, role reversal, coping strategies, and positive outcomes. The interviews also generated a typology of son caregivers that included such types as the dutiful son, the son who goes the extra mile, the strategic planner, and the son who shares the care.	50
QL33	Murphy, M. (2005)	To describe the positive or beneficial aspects of caregiving experienced by family caregivers of Alzheimer's patients.	exploratory	11 adult children caregivers of someone living with AD.	PA	not stated	Semi-structured interviews (60-90 minutes). Caregiving experiences as well as the positive caregiving experiences addressed.	Phenomenological method of analysis with content analysis. Line by line analysis is a method of analyzing each line of the transcript to highlight relevant meaningful comments.	Caregivers co-created narrative about their responsibilities, relationships, and the positive aspects of their experiences. Themes that emerged included positive approaches to deal with the stress of caregiving, positive motives, rewards, the creation of meaningful experiences, and the perceived benefits for the patients.	100

QL34	Netto, N., Goh, J. & Yap, P. (2009)	To investigate the gains experienced by family caregivers of persons with dementia. More specifically, how some caregivers are able to experience gains whilst shouldering the burden of caring for their loved ones with dementia.	Exploratory	12 family primary caregivers of persons living with dementia.	Gain	Not stated	In-person semi-structured interviews.	Selective transcription focused on answers to the research questions and issues that were directly related to dementia caregiving. Open coding used to conceptualize and categorize the raw data. Axial coding to review and examine the initial codes by dividing existing codes into sub-dimensions or combing several similar codes into a more general one. Finally, selective coding was done where the researcher, guided by major themes that had emerged, scanned the data and codes to look selectively for cases that illustrated themes and to make comparisons and contrasts.	All participants reported gains from caregiving. The most common gain was that of 'personal growth' which was comprised of being more patient/understanding, becoming stronger/more resilient, having increased self-awareness, and being more knowledgeable. Another theme that emerged was 'gains in relationships' whereby caregivers experienced an improvement in their relationship with the care recipient, with others in the family, or in their ability to interact with other older persons. The third gain experienced was that of 'higher-level gains' which encompassed gains in spirituality, a deepened relationship with God, and a more enlightened perspective in life.	50
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QL35	Paun, O. (2003)	To document and explore the experience of caregiving from the perspective of older women who are providing care at home to a spouse diagnosed with AD.	Exploratory	4 women caring for a spouse living with dementia due to AD or related dementia.	Other	Constructivist/naturalist	Combined feminist and phenomenological approach.	Tape recorded and transcribed 45-90 minute interviews. The researcher described a detailed method of analysis that included an audit trail.	Five major themes were found to define the fundamental structure of these women's experiences. The article addresses only findings pertaining to the fourth theme: making sense of the situation. The findings revealed aspects unique to older women's/wives' AD caregiving experience.	100
QL37	Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., Leipart, B. & Henerdon, S. (2010)	To use a strengths-based perspective to investigate and describe the positive aspects of caregiving identified by family caregivers of persons with dementia.	Exploratory	39 family caregivers of someone living with dementia, 82 % female, 44% under the age of 60, primarily spouses (56%), followed by adult children (33%).	PA	Constructivist/naturalist	Secondary analysis of data collected from a mixed methods study investigating the use and non-use of homecare and community-based services in family caregivers.	An interpretive, descriptive qualitative approach was used. Audio tapes of six focus groups and 3 individual interviews were transcribed verbatim. Transcripts were analyzed by the research team independently, and then each member's finding were discussed in the larger research group setting.	The researchers report that family caregivers can view their role as an opportunity to give back, to discover personal strengths, and to become closer to the care receiver.	75

QL45	Sanders, S. (2005)	To identify and compare the various types of strain and gain that is experienced by caregivers of individuals with AD.	Exploratory	85 spouse and adult child caregivers to persons with dementia.	Gain	Not stated	Caregivers were asked to respond to open-ended questions that were incorporated into a survey that included quantitative measures.	Grounded theory analysis of the findings and interpretations of the results.	All caregivers reported some experience of strain associated with their caregiving role. Majority of caregivers (81%) also reported that they had experienced gains during the time they were caregiving for a relative with AD. The 16 individuals who reported only strains were predominantly caregiving in isolation, without a great deal of assistance. These individuals did not differ from the other 69 caregivers in any identifying manner, such as gender, age, or race/ethnicity. The caregiver strains originated from worries and uncertainties, balancing multiple demands, and feeling overwhelmed with care, while spiritual growth, personal growth, and feelings of mastery produced feelings of gain.	50
QL46	Shim, B., Barroso, J., Gilliss, C. & Davis, L. (2012)	To investigate how spousal caregivers of individuals with dementia found personal meaning in their caregiving experience.	Exploratory	11 spousal caregivers of persons living with dementia.	Other	Not stated	Semi-structured interviews with open-ended questions.	Analyzed during the data collection period to inform subsequent interviews. The method shaped subsequent interviews to best answer the	Caregivers commonly had altruistic values, and the discipline to live by those values. They found meaning by believing in a choice of attitude and perceiving satisfaction in living according to their values in life. They had faith in a higher power, a strong sense of love for their spouses, and they derived strength from past challenges. Positive attitudes among caregivers of individuals with	50

								research questions.	dementia may be enhanced by sharing these stories and strategies.	
QLQT 47*	Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., & Corcoran-Perry, S. (2001)	To examine the relationships between caregivers' positive and negative subjective responses to caregiving and to increase the understanding of the experience of being a spouse caregiver for a person living with dementia.	Exploratory	50 spouses of persons living with dementia.	PA	Not stated	Semi-structured interviews.	Appears to be thematic analysis with a deductive approach. Study "variables" of interest were defined prior to qualitative analysis and codes reflective of these variables were applied to the data.	Positive aspects of caregiving and caregiving competence were significantly related to each other, as were the three measures of negative subjective responses. No significant correlations were found between any measures of a positive and negative subjective response suggesting the two types of responses are independent. The duration of caregiving was significantly related to positive aspects of caregiving, caregiver competence, and relational deprivation. Qualitative interview data revealed that participants simultaneously experienced caregiving as self-affirming, while also enduring losses and difficulties resulting from their caregiving role.	45
QL53	Todorova, I., Turner, H., Castaneda-Sceppa, C., Young, D. & Bonner, A. (2016)	To gain understanding of the meaning and experience of engagement for caregivers of individuals with dementia living in the community.	Exploratory	17 spousal caregivers of someone living with dementia (n= 14) who were children or other family member.	Other	Not stated	Semi-structured interviews were conducted either in-person or over telephone.	Interpretive Phenomenological Analysis.	Researchers identified the superordinate themes of connectedness, meaningfulness, acceptance, and vigilance. They conclude that caregiver engagement is a multidimensional phenomenon, with some dimensions being contextual and specific to caregiving. It is a relational concept, referring to a committed, vigilant, and meaningful relationship of caregivers and care recipients as active collaborators.	75

QL57	Williams, K., Morrison, V. & Robinson, C. (2014)	To use semi-structured interviews and photo elicitation to explore how family caregivers (1) make sense of caregiving and (2) cope with their circumstance.	Exploratory	12 family members and one friend caregiver of somebody living with a stroke (n = 5) or dementia (n = 8). One caregiver was male. Eight caregivers lived with the care recipient and five lived separately.	Other	Not stated	A cross-sectional qualitative design conducting in-person semi-structured interviews and using photograph elicitation.	Interviews were transcribed verbatim. Based on the large sample size, analysis took place at a group level, whereby recurrent themes (i.e., themes present in 50% or more of the transcripts) were included in the analysis. Themes that were interrelated were integrated to form major themes. Themes and subthemes were compared with original transcripts during the analysis and the write-up process to ensure validity.	Emerging themes included: (1) making sense of the illness such as the implications of receiving a diagnosis, caregiving motivations, and receiving support, and (2) coping with caregiving with the variance in coping depending on, in part, individual differences in sense making. Caregivers adopted active and information seeking techniques to deal with current problems and to increase their sense of control but adopted avoidant techniques when considering future logistics of caregiving and when feeling helpless due to the burden they faced. At times, caregivers looked on the bright side and made downward comparisons.	75
QL68	Smith, A. (1999)	To learn more about the process involved in living as a primary caregiver of an	Exploratory	6 caregivers of persons living with AD.	Satisfactions	Constructivist	Interviews	Grounded Theory.	Primary caregivers' stated needs, struggles, and satisfactions in caring for persons with Alzheimer's disease, and suggested what would help those most in providing the best possible care.	75

		Alzheimer's patient. In addition, the goal was to learn more about the needs of caregivers, the struggles faced, and the satisfaction experienced by caregivers.							ctioni st	
QL77	Ar, Y. & Karanci, N. (2017)	To investigate Turkish adult children caregivers' perceptions of Alzheimer's disease and caregiving experience.	Exploratory	20 primary adult children caregivers of persons living with AD.	Experiences	Not stated	Interviews	Interpretive Phenomenological Analysis.	Most caregivers viewed family disharmony as the cause of the disease. Caregivers reported positive changes during their caregiving experiences. Caregivers employ religious/fatalistic coping and benefit from social support.	
QL80	Pang, R. & Lee, D. (2019)	To explore the experience of spousal caregivers of persons with young onset dementia.	Exploratory	6 spousal caregivers of persons diagnosed with dementia before age 65 in Hong Kong.	Other	Not stated	Semi-structured interview	Qualitative Content Analysis	Three major categories identified: coming to terms with diagnosis, multiple unanticipated 'early' losses, and finding positives and meaning. Finding positive and meaning included acceptance, continuity of relationship quality, and finding meaning in reciprocity and faith.	

This table provides a summary of the qualitative studies included in the meta-integration. Study ID numbers with an asterisk denote mixed method references. 'Label' refers to the label used to refer to positive aspects. PA refers to 'positive aspects,' PO refers to 'positive outcomes,' Sat. refers to 'satisfactions', and 'Epist.' refers to the stated epistemology. Where possible, the stated

method of analysis was listed in this table. When primary references did not provide a label of method of analysis, a description of the analysis was provided. MMAT refers to the quality score the primary references were given on the mixed methods appraisal tool.

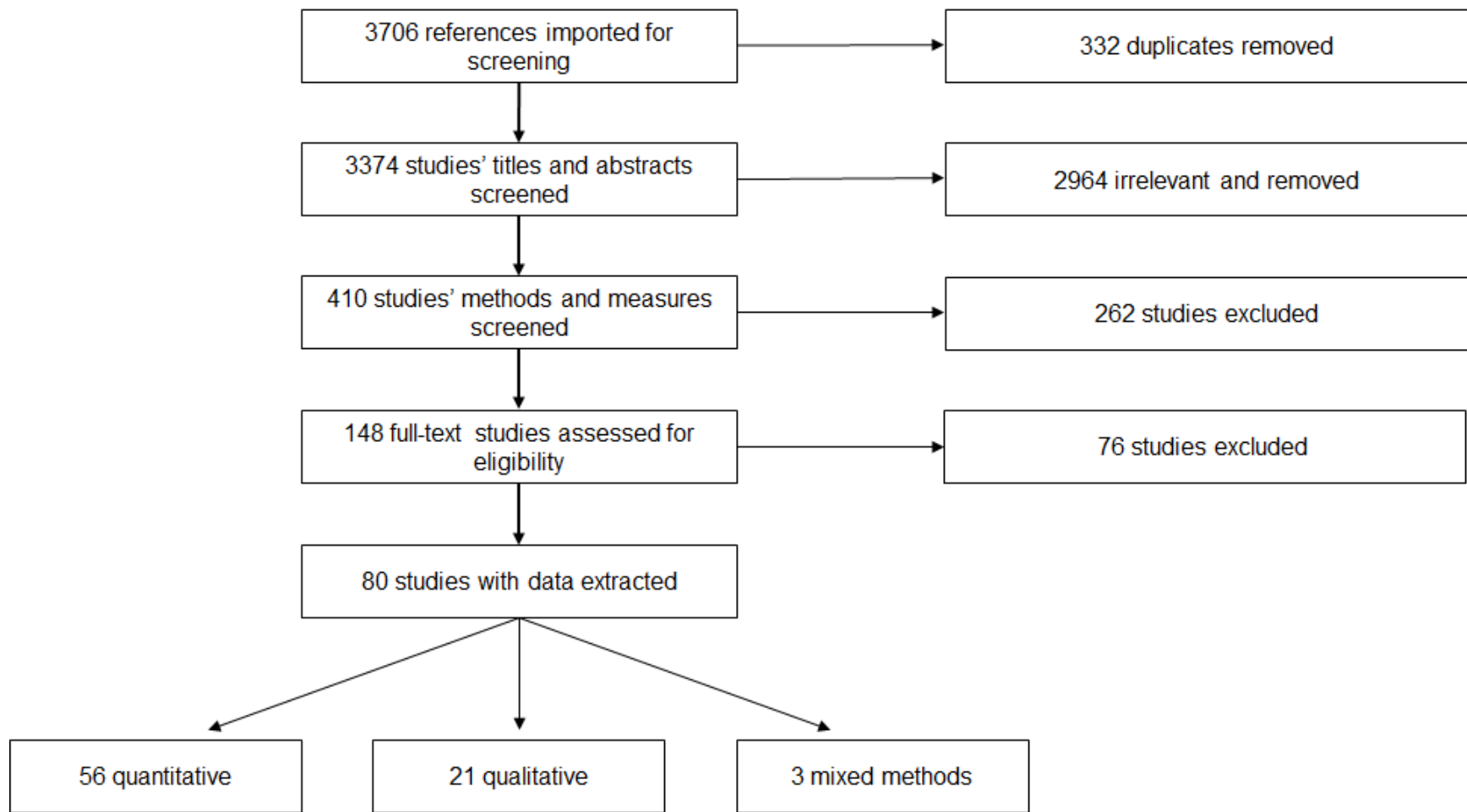


Figure 1. PRISMA diagram reflecting the screening process.

3. STUDY TWO ABSTRACT

This study investigated the perceptions and experiences of positive aspects of providing care to someone living with dementia in a sample of seven caregivers. Caregivers were interviewed using a semi-structured format and data were analyzed using thematic analysis. Quantitative data pertaining to factors known to impact the caregiver experience were considered in relation to the interview data. The findings included neutral, negative, and positive overall experiences to providing care. Persons with neutral experiences were often in the early stages of care and the data indicate that challenges in caregiving are important for experiencing the positive aspects. Negative overall experience was marked by a poor pre-caregiving relationship dynamic with the care recipient. Positive overall experience was related to viewing caregiving as a journey and process, rather than a departure from normalcy. Positive caregiver accounts revealed optimistic thinking, gratitude, and acceptance. All caregiver accounts revealed that caregivers were ‘other focused,’ placing emphasis on care recipients’ needs and well-being. All caregivers were able to report experiencing positive aspects of caregiving. The relationship between caregiver age, caregiver/care recipient relationship, years spent caregiving, and positive aspects were explored. These findings have important implications for future research on positive aspects of caregiving. The findings may be used to inform intervention programs that, in addition to diminishing negative aspects, aim to facilitate the experience of positive aspects of caregiving.

3.1 PERCEPTIONS AND EXPERIENCES OF POSITIVE ASPECTS OF CAREGIVING

This manuscript is in preparation for publication, with the following authorship: Branger, C., & O'Connell, M.E.. The following study was conducted by C. Branger and supervised by M.E. O'Connell. C. Branger is the author of this work, with revisions by M.E. O'Connell. M.E. O'Connell is preparing the current manuscript for submission, which includes changes in format.

Supporting informal caregivers of persons living with dementia is of increasing importance as Canada's aging population continues to grow and the prevalence/incidence of dementia continues to rise (Alzheimer's Society Canada, 2016). Although some evidence suggests stabilizing and even decreasing incidence in some countries (Wu et al., 2017), global estimates predict a rising prevalence (World Health Organization [WHO], 2017). It is projected that by 2038, informal caregivers (hereafter, caregivers) of persons living with dementia will provide approximately 756 million hours of unpaid care per year (Alzheimer Society of Canada, 2010), which relieves substantial burden on limited formal care services.

Intervention programs developed to support and sustain caregivers in their role are informed by research investigating the caregiver experience. Caregiver research has placed emphasis on understanding the negative aspects of caregiving with a predominant focus on factors that contribute to, and methods to diminish, caregiver burden (Walker, Powers, & Bisconti, 2016). Yet, caregivers vary greatly in their experiences of caring for someone living with dementia. While for some, the caregiving experience is construed as negative (Brodaty, 2007; O'Rourke & Tuokko, 2000; Pinquart & Sörensen, 2003), others report positive experiences and outcomes from providing care (e.g., Branger, Burton, O'Connell, & Morgan, 2014; Farran, 1997; Peacock et al., 2010). Relative to the negative aspects of providing care, much less is known of the positive aspects of caregiving. Literature reveals that positive aspects may diminish negative aspects of caregiving (e.g., Carbonneau, Caron, & Desrosiers, 2010), delay institutionalization of the care recipient into long-term care (Cohen, Gold, Shulman, & Zuccherro, 1994), and facilitate caregivers' personal growth and well-being (Carbonneau, Caron, & Desrosier, 2010; Kramer, 1997; Moen et al., 1995). While research has provided some insight into the phenomenon of positive aspects of caregiving, findings regarding positive aspects in relation to other caregiver and care recipient factors vary across the burgeoning area of research and are equivocal. Gaining a clear understanding of the nature of positive aspects and identifying factors that facilitate or hinder the emergence of positive experiences in caregiving will enhance

the conceptualization of the phenomenon, thereby advancing research and informing intervention and support programs for caregivers.

3.1.1 Caregiver Experience

The caregiver's experience of caring for someone living with dementia is impacted by numerous factors, including personal factors and factors related to the care recipient and care environment (Chwalisz, 1996; Pearlin et al., 1990). Commonly, care recipient factors have been found to be related to negative, rather than positive, aspects of caregiving. Research indicates that the age of onset of dementia is related to level of caregiver burden (Kaiser, & Panegyres, 2007). The type of dementia diagnosis can impact the caregiver experience (Miller et al., 2013). For instance, frontotemporal lobar degeneration has been found to be predictive of caregiver burden (Mioshi et al., 2013; Riedijk et al., 2006). The progressive nature of dementia results in ever-increasing care needs, and therefore not surprisingly, dementia severity has been found to be predictive of caregiver burden (Branger, Enright, O'Connell, & Morgan, 2017; Mioshi et al., 2013). Apathy in the care recipient (Branger et al., 2017), as well as behavioural and verbal aggression (Gallicchio et al., 2002; Gaugler et al., 2005), are factors found to be related to negative aspects of caregiving.

Caregiver factors known to impact the caregiver experience are related to both positive and negative aspects of providing care. For instance, a perceived lack of choice in assuming the caregiving role, referred to as role captivity, is associated with higher levels of burden and depressive symptoms (Noonan & Tennstedt, 1997; Walker et al., 2016). Intrinsic motivation to provide care and a low sense of role captivity are associated with finding meaning in the role (Quinn, Clare, & Woods, 2009). Avoidant-based methods of coping (i.e., coping that aims to pacify negative emotion) have been found to be associated with increased levels of burden (Neundorfer, 1991; Cooper, Katona, Orrell, & Livingston, 2006), whereas approach-based (i.e., solution focused) methods of coping are associated with positive experiences (Branger et al., 2014).

Competence, or mastery, is perceived by some caregivers as an opportunity to learn new skills that can be applied to all areas of life (Lloyd et al., 2014). Caregivers, as opposed to non-caregivers, may experience enhanced sense of purpose as they experience mastery in their caregiving role (Moen et al., 1995). High levels of caregiving competence and self-efficacy are associated with finding meaning in caregiving (Semiatin & O'Connor, 2012; Quinn et al., 2009).

A caregiver's perception of a high quality relationship with the care recipient before caregiving and during caregiving has been associated with finding meaning in the caregiving role (Quinn et al., 2009). Finding meaning in caregiving has been identified as important in the experience of positive aspects (Farran, 1997; Yu, Cheng, & Wang, 2018).

3.1.2 Positive and Negative Aspects of Providing Care

Although literature describes a relationship between positive and negative aspects of providing care, the nature (i.e., unidirectional, bidirectional, indirect) of the relationship is unclear. Some research indicates that positive aspects of caregiving might have a moderating effect between caregiver burden and depression (Walker et al., 2016). Caregivers' appraisals of strain and gain within the role have been found to be predictive of outcomes wherein positive appraisals demonstrate a buffering effect on negative appraisals of the role (Rapp & Chao, 2000). Positive aspects have been found to account for a significant proportion of variation in depression and self-esteem scores in caregivers (Noonan & Tennstedt, 1997) and findings indicate that positive aspects may serve to diminish negative aspects such as depression and anxiety (Pinquart & Sörensen, 2004).

An inverse relationship has been indicated wherein caregivers demonstrating high levels of burden and depression are low on measures of positive aspects and well-being (Walker et al., 2016) and high levels of positive reporting are associated with low reporting of depression burden and poor health in caregivers (Cohen, Colantonio, & Vernich, 2002). Nevertheless, a direct and inverse relationship between negative and positive aspects is not always supported in the literature (Lloyd et al., 2014). Evidence suggests that predictor variables for positive and negative aspects are rarely the same with fewer predictors of positive aspects identified (Pinquart & Sörensen, 2004). Some studies report that the correlation between positive and negative aspects is modest at best (Rapp & Chao, 2000).

It is possible that the relationship between positive and negative aspects is dialectical. Taking an existential perspective, some posit that the experience of one is not made possible without the experience of the other; evidenced by the simultaneous existence of caregiver distress and satisfaction, as well as hassles and uplifts (Farran, 1997). Although the nature of the relationship remains unclear, it is apparent that the caregiver experience is comprised, at least in part, by positive and negative aspects. The negative aspects of caregiving are well researched and

understood. Bolstering knowledge of the positive aspects will afford a well-rounded understanding of the caregiver experience as a whole.

Positive aspects of caregiving. Literature reveals a wide variety of labels used to describe positive aspects of providing care to someone living with dementia; common labels include gains, satisfaction, uplifts, personal growth, well-being, rewards, gratifications, and benefits (e.g., Kramer, 1997; Farran, 1997; Lloyd et al., 2014). Finding meaning in the challenges of caregiving appears to play an important role in the experience of positive aspects of caregiving (Farran, 1997; Yu et al., 2018). Qualitative investigation reveals that some caregivers perceive a choice, or decision, in how they respond to caregiving experiences; how the caregiver responds to the experience of powerlessness, loss, and suffering associated with caregiving is central to finding meaning and experiencing positive aspects of caregiving (Farran et al., 1991). The importance of choice emerged in a systematic review of positive aspects research. Findings revealed that a positive attitude, accepting the reality of the situation, and commitment to the caregiver/care recipient relationship are factors central to the emergence of positive aspects in caregiving (Lloyd et al., 2014).

Some studies revealed that reciprocity (i.e., the caregiver's opportunity to give back to the care recipient) facilitates the experience of positive aspects (e.g., Nolan, Grant, & Keady, 1996; Lloyd et al., 2014; Peacock et al., 2010). Commonly, caregivers report a sense of personal growth in the caregiver role by way of increased patience, self-respect, self-awareness (Lloyd et al., 2014), and personal discovery of inner strengths (Peacock et al., 2010). A recent integrative review of quantitative and qualitative studies pertaining to the positive aspects of caregiving in dementia posits four domains of positive aspects and three conditions for positive aspects. The four domains include: personal accomplishment and gratification, mutuality in a dyadic relationship, increased family cohesion and functionality, as well as personal growth and purpose in life. The three conditions include: personal and social affirmation/role fulfillment, effective cognitive and emotional regulation, and finding meaning in the caregiving (Yu et al., 2018)

Research has indicated factors (e.g., attitudes/choices) and processes (e.g., finding meaning) that facilitate the emergence of positive aspects, yet it is unclear how care recipient and caregiver characteristics might impact these factors and processes, thereby complicating the emergence of positive aspects. Investigating caregiver and care recipient factors in relation to positive aspects would provide insight into whether these factors impact positive experiences

and, by virtue of the relationship, illuminate the interplay between positive and negative aspects of caregiving. Exploring caregiver accounts of positive aspects of providing care to someone living with dementia would provide insight into the nature and role of positive aspects within the greater caregiver experience.

The purpose of this study is to build upon a previous meta-integration of positive aspect literature (Branger & O'Connell, 2019a, 2019b, submitted) wherein outcomes, facilitating factors, and hindering factors of positive aspects in caregiving were identified. The aim of the current study is to investigate caregivers' perceptions of and experiences of positive aspects of caregiving, including their sense of what positive aspects are, how positive aspects emerge in the caregiving experience, what facilitates the experience of positive aspects, and what hinders the experience of positive aspects.

I aimed to conduct a qualitative description study that included demographic and clinical data, design to further explore the meta-integration findings (Branger & O'Connell, 2019a, 2019b, submitted) of associations between positive aspects of caregiving and caregiver age, caregiver/care recipient relationship status, years spent caregiving, and caregiver burden. In addition, I explored associations between positive aspects of caregiving with care recipient factors, such as dementia severity, type of dementia diagnosis, and problem behaviors and symptoms. Based on positive aspects of caregiving literature, I expected that the majority of caregivers would be able to report positive aspects of providing care. I anticipated that caregivers who have difficulty reporting positive aspects would demonstrate one or more of the following: high levels of burden, distress, lower quality relationship, and high role captivity and that their care recipients would demonstrate high levels of dementia severity and mood/behavioural disturbances.

3.2 Method

Epistemology

I adhere to the post-positivist epistemology wherein a *true* reality is assumed to exist, but access to true reality is not possible; the human perceptual apparatus is imperfect and our experience and knowledge of reality is inherently imperfect or incomplete (Crotty, 1998). Researchers must approximate assumed true reality through use of scientifically designed measures and methods. In this study, positive aspects of providing care to someone living with dementia are assumed to be a real (true) phenomenon. I attempt to better understand positive

aspects through use of qualitative methods and quantitative measures to approximate the true phenomenon. Here, I assume that interview data reflect participants' experiences of providing care as it is assumed that a unidirectional relationship between language and meaning exists; when participants speak they are using language to articulate their experiences (Braun & Clarke, 2006). I assume that the measures used in this study are an approximation of a real phenomenon and in using the measure(s) data in relation to interview data, I am approximating and exploring a true relationship between any two real phenomena.

Participants

Participants of this study were recruited through affiliation with the Rural and Remote Memory Clinic (RRMC) of Saskatoon, Saskatchewan, Canada. The RRMC is a research clinic that provides interdisciplinary assessment for persons who are experiencing changes in memory and thinking and reside in rural and remote areas of Saskatchewan. Use of the RRMC caregiver sample has advantages due to the depth of data collected from the primary informal caregiver and the care recipient. Relevant to the current endeavour, RRMC data include age of dementia onset, type of dementia, dementia severity, mood/behavioural symptomology, and caregiver burden.

Eligible participants were primary caregivers providing care to someone diagnosed with dementia who attended the RRMC for a one-year follow-up assessment within the last two academic years (i.e., September 1, 2015 to August 31, 2017): 26 eligible caregivers were identified. I was successful in contacting 19 out of the 26 caregivers. Of those, seven agreed to participate in the study. Those who declined to participate commonly reported that they did not see themselves as being caregivers or primary caregivers (e.g., the care recipient was still living independently with a diagnosis of dementia), while others indicated that they did not wish to participate. Three of the seven caregivers were spouses and three were adult children. Two caregivers were men and four were women. Quantitative data from the research database was missing for two of the caregivers. All data pertained to the most recent visit/assessment at the memory clinic.

Ethics. Ethical approval was obtained by the Research Board of Ethics at the University of Saskatchewan (May 2018; REB # 18-103). The study adhered to the guidelines set out by the REB regarding informed consent, oral consent, audio recording, transcript review, and release.

Participants did not report distress, but the clinically trained interviewer would be able to detect and manage distress appropriately.

Measures

I used archival data collected from clinics to elaborate on the participant caregiving context. Archival data used in this study were type of dementia, dementia severity, mood/behavioural symptomatology, and caregiver burden.

Clinical Dementia Rating scale (CDR). The CDR is a common measure of dementia severity used for both clinical and research purposes (O’Byrne et al., 2008). The CDR provides a global scale score and individual scale scores and all have demonstrated adequate reliability and validity (Morris et al., 1997; Berg, 1988). The CDR is based on care recipient/caregiver subjective reports of the care recipient’s cognitive functioning in the domains of memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care (Morris, 1997). Each domain is rated on a 0-3 scale indicating level of severity, with scoring method results in a 0-3 range wherein higher scores indicate greater dementia severity (O’Byrne et al., 2008).

The Neuropsychiatric Inventory (NPI). The NPI assesses 10 domains of behavioural disturbance and is based on informant (e.g., caregiver) reporting (Cummings et al., 1994). The domains include: delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, and aberrant motor behavior. Each domain is scored from 1 to 12 with higher scores indicating increased severity. Content validity, concurrent validity, inter-rater reliability, and test-retest reliability have been shown for the NPI (Connor, Sabbagh, & Cummings, 2008).

Zarit Burden Inventory (ZBI). Caregiver burden was assessed using the ZBI short-form (12-item), which has demonstrated similar psychometric properties to the long-form (O’Rourke & Tuokko, 2003). Factor analyses indicated that the ZBI measures two facets of caregiver burden, theorized to represent role strain and personal strain (Branger et al., 2014) and is commonly used in research on caregiver burden. The 12-item ZBI has been shown to have good reliability and construct validity (Hébert, Bravo, & Prévaille, 2000).

Brief Symptom Inventory (BSI). The BSI is a self-report instrument that evaluates psychological distress and psychiatric disorders in people. The BSI includes 53-items with responses on a 5 point Likert scale (Derogatis & Spencer, 1993). The BSI has been shown to

have good internal consistency, good convergent and content validity, and good test-retest reliability (Derogatis & Melisartos, 1983; Derogatis & Spencer, 1993).

Interview Data Collection

Participants were invited to participate in the study via telephone, and an interview date was agreed upon. The participants were interviewed via telephone using a semi-structure interview format (see Appendix C). The length of the interview ranged from 30 to 60 minutes, dependent upon the participant. The interviews were recorded and the recordings were transcribed by a professional service offered by the University of Saskatchewan. Each participant had the opportunity to receive the written transcript and each participant was invited to contact the research after receiving the transcript, should they wish to clarify, correct the document, or if they had any concerns. One participant requested the interview transcript. No participants contacted the researcher post interview.

Analysis

Interview data was analysed using thematic analysis (Boyatzis, 1998; Braun & Clarke, 2006). Thematic analysis can be used with differing (but not all) epistemological perspectives, and allows for various levels of interpretation (Boyatzis, 1998; Braun & Clarke, 2006; Braun & Clarke, 2014). Thematic analysis is appropriate for the post-positivist epistemology and appropriate for the current study that endeavoured to explore and describe caregivers' perspectives and experiences of the positive aspects of providing care (Boyatzis, 1998; Braun & Clarke, 2006; Vaismoradi, Turenen, & Bondas, 2013). Data analysis was theory driven in that particular questions and points of interest based on a previous study (Branger & O'Connell, 2019a, 2019b, submitted) guided the development of the interview format and the readings of the interview data. The analysis included numerous readings of and immersion in the data. For instance, each participant's interview data was read in entirety and notes and potential codes were identified. The interview data were read pertaining to each question and notes and potential codes were identified. This process of reading interview data from each participant, and then for each question, continued until no new themes were identified. Both semantic and latent level themes were identified (Braun & Clarke, 2006). Overarching themes that spanned participant responses and specific questions were identified. Using the topics covered by the semi-structured interview to broadly frame the findings, I reported universal themes, as well as less common themes that served to capture individual variations in the caregiving experience. I aimed to

capture the variation in caregivers' reported experiences given the exploratory and descriptive nature of the current endeavour. Throughout the analysis process, I kept notes about emerging codes and themes, as well as my thought about these, how I was defining each, and what was influencing the identification of codes, themes, and definitions. Repeatedly, I considered my own biases and the potential influence of my lens of the interpretation of the data. After my analysis, a second coder analysed the interview data, using my themes and definitions. Initial agreement was approximately 80% and discrepancies related to coding of similar themes. After discussion, 100% agreement was met.

3.3 Results

Based on the available participant data in the research database (see Table 3.1), the average age of the caregivers in this sample was 57.2 years (range 41-81 years). The average duration of providing care was 4.5 years (range, one to nine years). All caregivers identified as being primary caregivers. Dementia severity scores (CDR) ranged from 0-3, with two scores in the moderate to severe dementia severity range. The care recipients' scores on a measure of dementia related problem behaviours and symptoms (NPI) ranged from 3-17 (no cut off is used for this scale). Data on the five caregivers indicated that all caregivers scored below cut-off on a measure of depressed mood (BSI; range 0-8). The ZBI scores ranged from five to 33 and two caregivers scored above cut-off, indicating significant caregiver burden.

Consideration of these quantitative data in relation to qualitative data provided some support to our predictions. For instance, high caregiver burden scores and high dementia severity scores were found in the case of one caregiver who had difficulty reporting positive aspects. However, the highest scores of dementia severity and problem behaviours and symptoms were found in the accounts of caregivers whose overall experience was neutral. Further consideration of the quantitative data in relation to qualitative findings was limited due to missing data and high variation in the small sample size. The following are the findings of the thematic analysis.

Caregiving Experience

Analysis of interview data revealed two categories regarding caregivers' overall experience of providing care to someone living with dementia. There were those caregivers whose accounts indicated a neutral or an overall negative experience, and those that indicated an overall positive experience. Within the category of neutral and negative, the theme of *change from normalcy or what was expected* was identified. Within the category of positive overall

experience, the themes of *process* and *journey* were identified. Further, I identified the theme of *functional changes* within the accounts of spousal caregivers and themes of *reciprocity* and *responsibility* within the accounts of adult children caregivers.

Neutral and negative experience. Caregivers whose accounts indicated an overall neutral or negative experience tended to talk about dementia and caregiving as a *change from 'normal' life*. That is, the diagnosis of dementia and commencement of caregiving was an event that made life 'different', or 'interesting', but certainly a departure from what was expected and 'normal.' These caregivers tended to talk a lot about changes. These changes included changes in daily life, changes in the amount of time they had for themselves, changes in mood and personality of the care recipient, and changes in the care recipient's functioning. Those who shared the difficult or challenging aspects of caregiving tended to talk about the changes in the care recipient's abilities and some of the frustrations that they (the caregiver) experienced in response.

The whole experience is a disruption of life as it might be, it doesn't seem to matter what aspect of it you're thinking about everything seems to be negative. Pt01

Caregivers' whose accounts represented a rather neutral tone in their experience of caregiving reported that not much had changed yet because the disease was in the early stages and the care recipient remained largely independent.

Again it's different... it's just not what I was expecting whatsoever that I would have to be doing at this time, but it's taken a little bit to get adapted to everything and change that kinda stuff yeah. Pt02

Positive experience. Two caregivers described their caregiving experience in positive terms. One (Pt03) began by stating that she found it "really quite rewarding". These caregivers both talked about caregiving as a *journey* and/or a *process*, rather than a change or disruption of normalcy. These caregivers' accounts communicated a certain flexibility and acceptance on their part as a caregiver, wherein the focus was not on the implications of the disease on their lives, but rather on living with the disease and adapting. The following quote from one of the participants captures the notion of caregiving and living with dementia as a journey:

Dealing with a parent that has this is definitely a challenge but it's also an amazing journey if you look at it the right way. And for somebody that's gonna be a caregiver or

is a caregiver you have to look for the light in every situation. I mean you know going in that their memory is failing so, you can't focus on those things though. Pt07

Spousal Caregivers. Spousal caregivers tended to report on *functional changes* and difficulties in the care recipient. For instance, one (Pt01) tended to talk about frustration that comes with repeated questioning. Another reported on the change in the activities they used to do together and the friendships they used to have (Pt01).

It has effects on how you associate with friends for example, we used to have bridge partners that we would play with quite often but since not being able to play bridge anymore because of the memory problems that relationship has disappeared. There would be other things along the same lines, relationships have kind of shifted that way. And it's harder to have common interests [with the care recipient] as well. Pt01

Adult Children Caregivers. Commonly, adult children caregivers talked about *reciprocity*. One caregiver, who reported having a positive experience of caregiving, talked about how happy she was to have the opportunity to reciprocate (Pt03).

I feel like I'm giving back. She cared for us while we were all growing up and it's nice to be able to give back because she really did exhibit unconditional love to all of us and it's nice to be able to give that back. Pt03

The importance of reciprocity and the quality of the pre-caregiving relationship was highlighted by one caregiver who found it difficult to report experiencing positive aspects. This caregiver described a challenging history with the care recipient and relayed that, because their parent did not 'parent them', there was no sense of reciprocity. Somewhat related was one caregiver's (Pt07) report of a sense of *responsibility* to the care recipient where they reported in a matter-of-fact manner that it is "what you have to do because they're your parents".

Experiences and Perspectives on Positive Aspects

Outcomes of positive aspects. Analysis of responses to questions pertaining to learning about self or experiencing personal growth in caregiving revealed two themes: *new insights* and *enhanced personal characteristics and virtues*. Only some caregivers reported learning something new about themselves, others stated that caregiving brought characteristics of their personalities to the forefront. For instance, one caregiver reported learning that they had more internal or psychological strength than they previously thought (Pt06). Commonly, caregivers reported increased patience or becoming more aware of their patience as a personal virtue.

Another stated how their compassionate nature had become more apparent to them since becoming a caregiver (Pt05). Although some caregivers seemed to struggle to report on things they had learned about themselves since becoming caregivers, their responses to a follow-up question pertaining to their thoughts on, and experience of, positive aspects commonly revealed self-discovery and personal growth. This is consistent with themes of new insights and enhanced characteristics. Needing the challenging aspects of caregiving in order to experience positive aspects was found in one caregiver's account.

With it still being quite young yet, I haven't been able really to notice that much out of things [positive aspects] but once maybe we get into it a little bit more and she starts digressing a little bit more, things might pop up a little bit more that I notice....I know from being how my mother-in-law dealt with my father-in-law and seeing how she grew with the changes and stuff... (Pt02)

One caregiver reported that the relationship with their daughter had improved since becoming a caregiver. The caregiver's account indicated that the relationship with their daughter grew as the two became partners with a shared goal of caring for the care recipient and as they shared the experience of the disease together. Another caregiver reported that the quality of their relationship with the care recipient (mother) had improved since becoming a caregiver, noting that they "...have gotten really close...my relationship with [her] got way better." (Pt07).

Emergence of positive aspects. Three questions were posed to ascertain the nature of positive aspects. I asked caregivers about their perceptions on how positive aspects emerge and what allows them to experience positive aspects in response to caregiving demands and challenges. I categorized the sub-themes identified in the caregivers' responses to these questions under the larger theme of *facilitating factors of positive aspects*.

Facilitating factors of positive aspects. In response to what allows the caregiver to experience positive aspects, one caregiver reported that *communication* with the care recipient was important, including establishing a *partnership* with the care recipient as they were "in this together" (Pt02). Another caregiver reported that knowing they were doing a good job of caregiving and feeling *competent and capable*, allowed them to feel the positive aspects of the role.

Well for the responsibility of looking after somebody all by yourself...if everything's going okay and if you're keeping them happy and getting them clean, I think that I did a

darn good job... I got a little bit of pleasure in how well I was doing it, I didn't get any pleasure from doing it as such because I knew where the end was (Pt04).

Two caregivers relayed *adaptation and acceptance* as important (Pt03; Pt07). Their responses indicated that being flexible, resilient, and staying present in the day-to-day was important to the experience of positive aspects.

There's lots of stuff we don't control and I had absolutely no control over what was going on with Mom so it was just a day to day thing. Some days were good, some days were bad and you take the bad with the good and keep going (Pt07).

One caregiver, who had difficulty reporting positive aspects, stated that taking on the role of caregiver reinforced her *altruistic values* and this was satisfying even if providing care was not (Pt05). Another caregiver reported that her *faith* in God was central to the experience of positive aspects. This caregiver noted that her faith gave her patience and the sense that she was supposed to fulfill this role... "And he [God] has given me strength and it continues to work." (Pt03).

Knowledge was identified in many caregivers' reports as important in facilitating experiences of positive aspects in the caregiving experience. In this case, having knowledge about the disease, such as the disease progression and what to expect, allowed caregivers to prepare and to understand the care recipient's behaviour. Knowing what to expect, how to prepare for it, and being able to attribute certain behaviours and symptoms to the disease as opposed to the care recipient was important in the caregivers' experience of providing care and in their experience of positive aspects.

One caregiver reported that the *support* she received from family members was integral to her positive experience of providing care. She stated that knowing that her work as a caregiver was *appreciated* by other family members was important (Pt03). In addition, this caregiver often relayed how appreciative the care recipient was of the care she provided. The caregiver's account indicated that the appreciation the care recipient showed not only facilitated the experience of positive aspects but was a positive outcome in and of itself. Presumably because the expression of appreciation from the care recipient communicated that the care recipient understood the meaning and the worth of the caregiver's efforts.

Another caregiver frequently reported a *choice in attitude* as central to the emergence of positive aspects in caregiving. Here, the caregiver noted that choosing a positive attitude, not

dwelling on the diagnosis and what has been lost (in terms of functioning and personality), and staying in the moment was important in caregiving (Pt07). The caregiver's account indicated frequent use of *humour* as an important means of staying present, and at times they used dark humour pertaining to the realities of the disease. The caregiver noted that use of humour, by both herself and the care recipient, helped to alleviate the seriousness of the situation for both herself and the care recipient.

In response to the question regarding what supports the caregiver in their role, the importance of *time for self*, respite, and instrumental support was identified again in caregivers' responses. Indeed, time for self was identified in a few caregivers' interviews as either something they had lost and missed since becoming a caregiver, or something they saw as integral to improving the caregiving experience. *Social support* was reported by all caregivers as being central in supporting them in their caregiving role. Support came by way of family members and friends. Sometimes, it was about having someone to vent to. Others reported that the support from other caregivers, who understood their experience, was important.

Hindering factors. Caregivers often reported that the losses they experienced as a result of caregiving made the experience of positive aspects difficult. Presumably because the experience of loss was predominant; either obscuring positive experiences or prolonging the emergence of positive aspects until the meaning of the loss was made. *Loss* pertained to loss in relation to their previous life, loss of the pre-caregiving relationship, and loss of the care recipient's former self. Closely related to this was changes in the connection between caregiver and care recipient, as one spousal caregiver reported that "...it's harder to have common interests..." (Pt01) with the care recipient. Another caregiver reported that the care recipient's difficult personality made the caregiving experience challenging (Pt05). Others reported a lack of time for themselves, which made it difficult to experience positive aspects. In addition, one caregiver reported that having poor sleep since becoming a caregiver, a result of being vigilant, made the experience of positive aspects difficult (Pt06).

The responses seemed to reflect the notion that sleep and time for self may serve to replenish the psychological and emotional resources that caregivers draw on in their caregiving role. This was a notion well captured by the following caregiver report:

I take care of myself because if I were to work too hard at something and try and do too much, I get run down and then my mood isn't the best and unfortunately [care recipient]

gets the worst of it then; if I am going to snap at somebody it is usually him. And that's not fair... (Pt03).

Concerning, age, relationship, and caregiving duration. Building upon findings of the systematic review and meta-integration of quantitative and qualitative data (Branger & O'Connell, 2019a, 2019b, submitted), I asked the caregivers how, if at all, they imagined age, years spent caregiving, and the caregiver/care recipient relationship might impact the caregiver experience.

Age. Some caregivers reported that they felt that older age might impact their physical health and functioning (e.g., driving), making caregiving more difficult. Largely, caregivers reported that they felt that their age had afforded them the life experience and skills to be able to adapt to and meet the demands of caregiving. One caregiver had a unique perspective where, in addition to providing care to her mother, she was still caring for her children at home. This caregiver reported that, if she was older, she would have had time between caring for her children and for her parent:

Maybe if I was a bit older and had a few years where I could've just done what I wanted to do, it might have been easier. (Pt05).

Years spent caregiving. Many caregivers reported that they did not feel that the number of years they spent caregiving would impact the experience of providing care because of the progressive nature of the disease. Many acknowledged that what would impact the experience as the years went on was how the disease progressed and the nature of the related changes and demands. One caregiver, however, reported that "experience is always such a teacher..." (Pt03) and went on to state that she had acquired skills and problem-solving techniques from her experience caregiving that she continues to use in the role.

Caregiver/care recipient relationship. When asked how being a spouse or a child caregiver might impact their experience providing care, the majority of the caregivers reported that providing care for a spouse would be easier. For many, they saw caring for a spouse as a natural extension of the care shared and exchanged over the course of the relationship. In addition, many reported having an intimate and nuanced knowledge of their spouse. They reported that such knowledge would be beneficial in noticing changes in the care recipient and in being able to meet the needs of the care recipient (as they [the caregiver] know exactly what the care recipient likes, and how they like things done). One caregiver reported that it might be

easier to care for a spouse because there does not need to be a switch in the caregiving roles, whereas for some adult children caregivers they become the parent and the care recipient becomes the child.

Overarching Themes of Gratitude and Being Other Focused

Two overarching themes were identified across caregivers' accounts. *Gratitude* was reported by a number of caregivers. For instance, gratitude for the opportunity and the ability to provide care to the care recipient. Two caregivers reported being thankful for being in the right place at the right time, when discussing taking on the caregiving role. One caregiver reported being grateful for the moments she had with the care recipient that only occurred because she was providing care, and stated that she felt sorry for family members who would not get those experiences (Pt07). Another caregiver reported being grateful that she got to tuck her mother in every night (Pt03).

The most common finding in the caregivers' reports was the theme of *other focused*. Other focused was identified in those caregivers' who reported feeling that they were in the early stages of caregiving and had yet to experience much of the caregiving role. Being other focused emerged in the accounts of caregivers who struggled to report positive aspects and those who reported having a difficult and strained relationship with the care recipient. Being other focused also emerged in the accounts of caregivers who reported experiencing many positive aspects and having an overall positive experience of caregiving. Across many of the interview questions, all the caregivers' accounts were indications of a propensity toward putting the care recipient's needs, feelings, and well-being first. Satisfaction in knowing that the care recipient was comfortable, could remain in home longer, would remain active, and could enjoy moments of happiness created by the caregiver (e.g., baking cookies for the care recipient) are examples of these caregivers' *other focused-ness*. This was perhaps best captured by one caregiver's account:

You've gotta focus on the things that make them smile and the things that they enjoy...you have to make this journey the best journey it can be. (Pt07).

3.4 Discussion

The purpose of the study was to investigate positive aspects of caregiving in a sample of caregivers of persons living with dementia. This study was informed by a previous study,, which was a meta-integration of the positive aspects literature (Branger et al., 2018; Branger & O'Connell, 2019a, 2019b, submitted). This previous study found that being an older caregiver, a

spouse caregiver, a man caregiver, and a non-Caucasian caregiver were factors associated with higher scores on quantitative measures of positive aspects. Higher scores on positive aspects of caregiving were associated with social support, faith/spirituality, feelings of competency, and subjective health (Branger & O'Connell, 2019a, 2019b, submitted). Factors that underlie positive aspects, including caregiver characteristics and tendencies (e.g., tendency towards practice of gratitude, acceptance, and choice in attitude), were identified. Motivations in caregiving (e.g., altruism, reciprocity) and factors that facilitate (e.g., feeling appreciated, and having social support) or hinder (e.g., feelings of loss and isolation) the experience of positive aspects in caregiving were also identified. The findings from this study support and expand on the findings from the meta-integration.

These findings revealed factors that facilitate the experience of positive aspects of caregiving including feelings of competency within the role, feeling appreciated by care recipient and other family members, knowledge about the disease, support (both social and instrumental), and time for self (or self-care). Altruistic values, faith, responsibility, and reciprocity emerged in these data as motivating factors for some caregivers. Choice in attitude, acceptance, and practising gratitude were identified in the data from caregivers reporting positive experiences of caregiving. Such findings are consistent with the meta-integration findings regarding caregiver tendencies, characteristics, as well as motivators that underlie positive aspects (Branger & O'Connell, 2019a, 2019b, submitted). These findings are also in keeping with the literature pertaining to factors important in the experience of providing care, such as: factors of competency (Quinn et al., 2009; Yu et al., 2018), feeling appreciated (Cheng et al., 2016; Yu et al., 2018), knowledge about dementia (Cho, Ory, & Stevens, 2016; Kramer, 1997), self-care (Sanders, 2005), gratitude (e.g., Albinsson & Strang, 2003; Farran et al., 1991; Yu et al., 2018), and faith/spirituality (e.g., Sander, 2005; Shim et al., 2013; Yu et al., 2018). Positive outcomes of learning about self (personal growth), improved relationships with other family members, and improved quality of relationship with the care recipient were identified in these data and are consistent with the literature on positive outcomes of caregiving (e.g., Cheng et al., 2016; Murphy, 2005; Peacock et al., 2010; Yu et al., 2018).

The factors of loss, isolation, and a poor caregiver/care recipient relationship (relationship dynamic) were identified in these data as hindering the experience of positive aspects. Some caregivers reported that the support of other caregivers who understood their

experience was important to them. This is in keeping with the previous findings of existential isolation, wherein caregivers feel alone in their experience of providing care (Albinsson & Strange, 2003; Branger & O'Connell, 2019a, 2019b, submitted), and the importance of social support in the caregiving experience (Donovan & Corcoran, 2010; Murphy, 2005; Peacock et al., 2010). The findings from the current study expand and extend the findings of the recent meta-integration (Branger & O'Connell, 2019a, 2019b, submitted) in important ways. Caregivers of this study noted the importance of their own physical health in the experience of caregiving. For instance, one caregiver reported that age might impact the experience of caregiving as age-related deterioration of one's physical health might affect their ability to provide care. Another reported the negative impact of poor sleep on the caregiving experience. This is consistent with literature on caregivers' quality of sleep and care recipient and caregiver well-being (e.g., Leggett et al., 2018; Simpson & Carter, 2013). Further, theory suggests that lack of sleep and poor health can affect caregivers' appraisal of caregiving stressors experienced in the future, wherein caregivers feel less able (or less competent) to cope with the challenges presented to them (Chwalisz, 1996).

These data revealed a view of 'partnership' between the caregiver and care recipient as important in the caregiving experience. The notion of partnership reinforces the importance of communication and connectivity in the caregiver/care recipient relationship and perhaps lends further insight into the importance of feeling appreciated by the care recipient as it speaks to the caregiver's contribution to the partnership.

The caregivers of this study, whose accounts indicated an overall positive experience of caregiving, tended to talk about caregiving and living with dementia as a journey rather than a change or departure from 'normalcy' or what was expected. Inherent in this view is a willingness to move, to be flexible, and to adapt as being on a journey requires movement and indicates an unknowable future. Conversely, the idea of a change or departure from normalcy evokes notions of resistance and a desire to return to a 'normal' or previous state. Participants in this study that relayed a neutral or negative overall caregiving experience talked about the diagnosis of dementia and life thereafter as a change or departure from 'normal' life. Although change was invariably an aspect of the journey in caregivers' reporting positive aspects of caregiving, they described change in relation to positive changes and growth. In other words, caregivers' whose

accounts of the caregiver experience were overall positive described change that served to add or enhance, rather than subtract or detract, from life as expected and life experienced.

Literature on resilience indicates that flexibility and optimistic thinking have been linked to psychological resilience (Fredrickson, 1998; Fredrickson, 2001) and have been found to be important in assisting persons in coping with stressful events and situations (Dias et al., 2015; Tugade & Fredrickson, 2004). Facilitating caregivers' abilities to re-frame their view of caregiving, to find acceptance, and to practise gratitude/positive thinking may be important additions to caregiver intervention programs. These data indicated that interventions should continue to incorporate psychoeducational components and caregiver-to-caregiver support, as the caregivers in this study reported that knowledge and support from those who understand their situation were important to improving the caregiving experience. Finally, these data suggest that, for some caregivers, instrumental support and respite care are important to allow the caregiver time for self-care. Self-care has been identified as important to the experience of positive aspects of caregiving in both the current study and the previous meta-integration study (Branger & O'Connell, 2019a, 2019b, submitted).

Limitations. One important limitation of this study is the caregiving sample. The participants of this study represent persons living in rural and remote areas of Saskatchewan, thus limiting the generalizability of these data to caregivers living outside of rural Central Canada (e.g., those living in urban centres). The current sample lacks cultural diversity, with the sample being predominantly Caucasian Canadians. The sample was small, thus variability in the participants' interview data meant that fewer universal themes were identified across the caregivers' accounts. Further, the heterogeneity of the small sample size limited group-based comparisons on quantitative data. Thus, the relationship between factors that impact negative aspects and the relationship between negative and positive aspects were not addressed. Future research should consider such mixed-method investigations with a larger, more culturally diverse sample of caregivers of persons living with dementia.

3.5 Conclusion

Positive aspects are an important part of the caregiving experience. These data revealed that positive aspects were present in the accounts of caregivers who reported a neutral overall experience, negative overall experience, and positive overall experience of caregiving. Importantly, these data revealed the co-occurrence of negative and positive aspects of caregiving.

More specifically, the data showed that positive outcomes of caregiving appear to require the negative or challenging experiences of caregiving in order to emerge. The point where positive aspects emerge from the experience of something negative or challenging reveals an important point for intervention. The data indicated that some factors that hinder the emergence of positive aspects in caregiving may not be amenable to change, such as poor caregiver physical health and a poor pre-caregiving relationship with the care recipient. Nevertheless, these data denoted that the experience of positive aspects can be facilitated by cognitive reframing (of one's perception of the disease, the role of caregiving, and competency in the role), practicing gratitude, and acceptance. The data reiterated the importance of psychoeducation for caregivers, social support (including caregiver-to-caregiver support), respite care (to encourage caregivers to take time for self), and the important ways in which caregiver characteristics (such as age) and caregiver/care recipient relationships might change caregiver needs. Taken together, these findings can be used to inform intervention programs that not only aim to reduce caregiver burden and distress, but to facilitate positive experiences in caregiving.

3.6 Study Two References

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Table 3.1

Caregiver Participant number	PT01	PT02	PT03	PT04	PT05	PT06	Pt07
Qualitative data overall experience	Neutral	Neutral	Positive	Neutral	Negative	Neutral	Positive
CG Age	-	41	51	81	48	65	-
CG Gender	Male	Male	Female	Female	Female	Female	Female
CG/CR Relationship	Spouse	Spouse	Adult Child	Adult Child	Adult Child	Spouse	Adult Child
Dementia Diagnosis	AD	FTD	AD	AD	AD	AD	MCI
NPI	-	17	3	12	10	11	-
ZBI	-	5	13	22*	33*	17	-
BSI	-	4	7	8	0	2	-
CDR	1	0	1	3	2	1	.5

Summary of participant demographics and measurement data

Descriptive summary of caregiver (CG) participants and care recipient (CR) data. The measures included above are, Neuropsychiatric Inventory (NPI), the 12-item Zarit Burden Interview (ZBI), Brief Symptom Inventory, Clinical Dementia Rating Scale (CDR). Items denoted with asterisk indicate the score is above cut-off. Dashes indicate missing data.

4. GENERAL DISCUSSION

The health and well-being of informal caregivers of persons with dementia is of increasing importance in the context of the growing aging population and the rising incidence of dementia, both in Canada (Alzheimer Society of Canada, 2010) and worldwide (World Health Organization [WHO], 2017). Understanding the caregiver experience is important for continued caregiver research and for the development of interventions and support programs for caregivers of persons living with dementia. A review of the caregiver literature reveals a predominant focus on the negative aspects of caregiving, that is, the burden and distress that can emerge from fulfilling the caregiving role. Less commonly investigated, is the positive aspects of providing care to someone living with dementia. A review of the literature on positive aspects of caregiving shows variations in the labels, conceptualizations, and measurement of the positive aspects of caregiving. The purpose of the two studies presented in this document was to gain a holistic understanding of the phenomenon of positive aspects of caregiving by conducting a thorough systematic search, synthesis, and integration of studies on the positive aspects of caregiving and then building upon those findings through qualitative investigation with a sample of caregivers of persons living with dementia. Study one comprised a meta-integration of quantitative and qualitative studies pertaining to the positive aspects of caregiving for someone living with dementia. Study two was designed to expand on the findings of study one through qualitative investigation of caregivers' perceptions and experiences of the positive aspects of caregiving.

The current general discussion is comprised of a summary of each study's objectives, findings, and conclusions, followed by the implications of the current findings including considerations for models of caregiving and caregiver intervention programs. The current discussion will culminate with information pertaining to limitations of this work as well as future directions for research.

4.1 Study Findings, Implications, and Considerations

Providing care as an informal (unpaid and untrained) caregiver has been shown to be challenging on financial, social, physical, and psychological fronts (Brodaty, 2007; Pinquart & Sörenson, 2003), yet research indicates that there are positive aspects associated with caregiving. Largely, the positive aspects of caregiving can be understood as beneficial outcomes (e.g., positive experiences, growth, and feelings) unique to the experience of providing care. Research into the positive aspects of caregiving is growing, but review of the literature reveals that

positive aspects of caregiving research is fraught with variations in labels, definitions, conceptualizations, and measurement. In study one, I aimed to ascertain the common conceptualizations and definitions of positive aspects of caregiving, the labels used to refer to positive aspects, and the measures of positive aspects in dementia caregiver research. A *meta-integration* (Branger & O’Connell 2019a, 2019b) was conducted that included systematic reviews and syntheses of quantitative studies, qualitative studies, and mixed-methods studies, as well as an integration of the findings to provide a full account of what is known of positive aspects in dementia caregiver research. In study two, through the use of semi-structured interview and thematic analysis, general and specific themes were identified in the accounts of caregivers of persons living with dementia regarding the nature of positive aspects of caregiving. The qualitative findings were elaborated on by including quantitative data pertaining to caregiver and care recipient factors found to have significant associations with caregiver outcomes.

My epistemological perspective is post-positivist and it is through this lens that the current research endeavour was conducted. Consequently, the current work was conducted under the philosophical assumption that true reality exists but access to true reality is prohibited by an imperfect apparatus (i.e., human’s ability to know true reality is inhibited by limitations of our perceptual apparatus). The post-positivist epistemological lens holds that, in order to understand a psychological phenomenon, researchers must approximate it through use of varying measures and methods of research (Crotty, 1998). Based on the post-positivist lens, and concerning quantitative data, the primary researcher assumed and accepted that the quantitative measures approximated whatever real facet of the caregiving experience they were designed to measure or represent. The primary researcher assumed that statistical analysis of one measure in relation to another measure revealed something about the ‘true-ness’ of a relationship, or the absence of a relationship, between the two measured constructs. Concerning qualitative data, the primary researcher assumed that commonalities (or themes), and the frequency of the occurrence of these themes across caregivers’ accounts of their experience and across the primary study’s findings, were suggestive of some ‘true’ aspect of the phenomenon under study. By addressing and investigating the phenomenon from the differing approaches of quantitative and qualitative designs, and bringing the findings or knowledge created by the two lines of inquiry together in a coherent whole, I believe that a well-rounded understanding of the phenomenon of positive aspects of caregiving would be attained.

Study One Findings

Study one findings: science and research. An important finding of the meta-integration was that only three of the 80 studies reported the epistemological perspective under which the research was conducted. Three qualitative studies stated that the research was undertaken with a constructivist lens. Based on the methodology and analysis, the primary researcher deduced that 12 of the remaining 16 studies were conducted using a post-positivist epistemological lens, and four used a constructivist lens. None of the 59 quantitative or mixed-methods studies stated an epistemology. It was deduced that all 59 quantitative and mixed-methods studies were working from a post-positivist lens.

The ontology and epistemology underlying any research endeavor should be stated. The epistemology, in particular, should not be omitted as it provides the context in which a study's findings are situated. The goal of research is to share and develop new knowledge and build upon knowledge. Much care and effort should be given to communicate the findings of research in accurate and understandable ways. However, it would seem that the assumption is commonly made that researchers and readers are working within the same philosophy and that the readers understand the findings within the inherent (but not stated) boundaries and assumptions of the researchers' epistemology. In the realm of quantitative research, the assumption of epistemology is perhaps less problematic because quantitative methodologies are most consistent with epistemologies that privilege knowledge born from observation, quantification of observation, and statistical analysis (i.e., objectivist, positivist, post-positivist). For qualitative investigations, however, stating epistemology is essential. Qualitative methods lend well to a number of philosophies regarding what is reality (ontology) and how we can come to know it (epistemology; Crotty, 1998; Frost, 2011). Thus, assumptions of epistemology in qualitative work is problematic. Readers of qualitative work must know whether findings of the study pertain to one unique reality, or a shared reality, as the difference dictates how the findings can be used to inform future research.

Another finding of the meta-integration was that there is inconsistency in labels used to describe qualitative analyses and methodologies. Further, an unclear description of the analysis was a common finding in the qualitative synthesis analysis. Future research should investigate, through meta-design, types of qualitative analysis, labels used to describe the different methods of qualitative analysis, methods of qualitative analysis, and (if available) the epistemologies used

with particular analyses. Such research would provide a good overview of qualitative practices from which conclusions regarding labels, types of analysis, related methods, and epistemologies may be drawn.

Study one findings: definitions and outcomes of positive aspects of caregiving. The majority of the studies included in the meta-integration labeled the positive aspects of caregiving most commonly as positive aspects, followed by positive outcomes, gains, and satisfactions. The majority of the studies described positive aspects of caregiving as factors, or perceptions, of the caregiving experience that could benefit caregivers' experience of self or experience of life. Other definitions describe positive aspects as diminishing negative aspects. Fewer studies described positive aspects and the experience of caregiving as overall satisfying, and others indicated that positive aspects were a means of meaning making and coping within caregiving.

I forward that the term 'positive aspects' be used as an umbrella term under which positive outcomes are situated. Examples of positive outcomes include, but would not be limited to, personal growth (of which there are numerous possibilities, for instance increased patience or personal internal strength), satisfactions (e.g., feelings of purpose, accomplishment), improved relationships, and so on. In sum, positive outcomes may describe any perceived benefit on the part of the caregiver believed to have emerged as a result of providing care and assumed not possible without fulfilling the role.

Study one findings: inter-method integration outcome. From the quantitative data set synthesis analysis, I identified common significant relationships between positive aspects and caregiving factors. The importance of relationships was highlighted in the qualitative data set syntheses as well. Through the inter-method integration process, I was able to elaborate on the relationship between caregiver/ care recipient type and positive aspects measures, gender and positive aspects measures, and how hindering factors impact relationships between positive aspects and important caregiving factors. In sum, I identified conditions for positive aspects in caregiving. These conditions related to both internal factors (i.e., pertaining to the caregiver) and external factors (i.e. pertaining to the caregiver/care recipient relationship and caregiving environment). The data revealed that internal factors that helped create the conditions for the experience of positive aspects in caregiving were 1) caregiver disposition and tendency toward optimistic thinking, practicing acceptance, gratitude, and cognitive-framing, 2) caregiver religiosity and spirituality, 3) values and morals that serve to motivate and sustain caregivers, 4)

feelings of competency, self-efficacy, and mastery, and 5) adaptive coping styles. External factors that helped create the conditions for the experience of positive aspects were, 1) a good pre-caring relationship dynamic with the care recipient, 2) communication and connectedness with the care recipient, 3) feeling appreciated by the care recipient and others, 4) support (i.e., social support and, to a lesser degree, instrumental support), 5) time for self and self-care, and 6) knowledge, preparation, and routine. Conditions for positive aspects faltered when caregivers experienced loss and isolation within the caregiver role. Loss and isolation undermined feelings of connectedness and communication with the care recipient, and support from others.

Study Two Findings

The findings from study two support study one's findings of caregiver characteristics that facilitate experiences of positive aspects of caregiving such as acceptance, practicing gratitude, and choice in attitude. Study two findings revealed a difference in perspective between those caregivers who reported an overall positive experience of caregiving and those whose overall account was neutral or negative. Caregivers reporting positive experiences talked about the dementia diagnosis and caregiving as a journey and process, rather than a disruption of life and a change or departure from normalcy.

Regardless of overall experience (i.e., neutral, negative, or positive), all caregivers were able to report positive outcomes of caregiving. The importance of having experienced challenges or negative aspects of caregiving in the emergence of positive aspects of caregiving was identified in the data. Concerning the caregiver/care recipient relationship type, the findings indicated that most caregivers perceived being a spousal caregiver as a natural extension of the spousal relationship, and some reported that the intimate and nuanced knowledge of the care recipient would be beneficial to caregiving as a spouse. Concerning age, findings indicated that age-related changes to physical health might make caregiving more difficult. Some caregivers' accounts indicated that caregiving at an older age would seem more developmentally appropriate and expected (e.g., in the case of young onset dementia, or for adult caregivers who still care for children in the home). In sum, the findings from study two served to support and expand on findings from study one, and the findings were consistent with extant literature on positive aspects of caregiving. I concluded that the data indicated that the experience of positive aspects could be facilitated by cognitive reframing (of one's perception of the disease, the role of

caregiving, and competency in the role), practicing gratitude, practicing acceptance, psychoeducation for caregivers, and social and instrumental support.

Study One and Two Summary

Qualitative synthesis analysis from study one and findings from study two revealed that positive outcomes of caregiving broadly reflect changes and improvements. More specifically, positive outcomes of caregiving reflect changes in philosophies of life and values, improvements in relationships, personal growth, and self-awareness. These findings are in keeping with that of a recent integrative review conducted by Yu and colleagues (2018), who identified domains of positive aspects that reflect personal growth, change in life philosophy, improved relationships, the importance of reciprocity, and the feeling of personal accomplishment and gratification in the caregiving role. I suggest the current findings expanded on Yu and colleagues' (2018) work in important ways. Study one findings revealed that factors that underlie positive aspects include factors related to caregivers' internal characteristics and tendencies, as well as internal motivating factors. The findings from study one and two indicated that caregivers who reported positive aspects had a tendency toward optimistic thinking and a propensity toward practicing gratitude. In interpreting the data I discovered that caregivers who reported positive aspects in caregiving often reported that attitude was a choice and that they worked to find appreciation and positive aspects in life. Analysis of study two data revealed that the caregivers demonstrated an 'otherfocused-ness' wherein their consideration and concern was often directed at the well-being of the care recipients, regardless of whether the caregivers reported their overall experience of caregiving as positive, negative, or neutral.

The findings from this work revealed that some of the factors that facilitate the emergence of positive aspects are actions, behaviours, and tendencies on the part of the caregiver. It is possible that these actions, behaviours, and tendencies may come naturally to some, but for others these may be effortful. Practicing choice in attitude, acceptance, gratitude, and being present might be particularly difficult for persons in difficult caregiving environments. Differences in perspectives were identified in the caregiver sample of study two, wherein some caregivers saw caregiving and dementia diagnosis as a change or departure from normalcy, while the others saw these as a journey. The latter described an overall positive experience of caregiving and their accounts relayed the importance of optimism, gratitude, and focusing on the positive.

The findings from study one and two revealed circumstances that made the caregiving environment difficult. The findings indicated that difficult caregiving environments included, for example, problematic behaviours and symptoms in the care recipient, challenging mood and personality presentation in the care recipient, and a poor pre-caring relationship dynamic with the care recipient. Caregivers who experienced notable loss and isolation in the caregiving role, particularly those who lacked social and instrumental support, might struggle to engage in practices that underlie positive aspects (i.e., gratitude, acceptance, cognitive-reframing). Expanding on these findings, I forwarded that difficult caregiving environments (e.g., financial stress, poor pre-caregiving relationship, limited supports), and predominant feelings of loss and isolation in the caregiver, tax the psychological and emotional resources required for caregivers to engage in cognitive efforts that underlie positive aspects. This notion is supported by findings from study two, wherein caregivers reported the importance of having time for self and indicated the negative impact of psychological and emotional strain on their ability to provide good care.

4.2 Considerations for Caregiving Models

For a clearer understanding of the link between emotional and psychological resources and caregiver outcomes, I considered the model of caregiver burden forwarded by Chwalisz's model (1996), as well as Lazarus and Folkman's transactional theory of emotions and coping (1987). Chwalisz's model (1996) differentiates objective burden from subjective burden and highlights the importance of caregiver appraisal in caregiver outcomes. This model is in line with Lazarus and Folkman's (1987) transactional theory of emotions and coping, which centers on the importance of appraisal and coping in psychological and emotional responses to stressors (Lazarus & Folkman, 1987). Together, the tenets of both the model and theory would suggest that when caregivers appraise their ability to meet the objective demands of caregiving (which occur within the context of the caregivers' internal and external environment) as sufficient, they do not experience stress and subjective burden does not increase (Chwalisz, 1996; Lazarus & Folkman, 1987). Objective burden increases when the caregiving environment is difficult (e.g., marked problematic behaviours and symptoms), which affects caregivers' appraisal of their ability to meet the demands and may lead to increased subjective burden.

The findings from study one and study two indicate that negative aspects and positive aspects co-occur, largely because one cannot exist without the contrast of the other. In this way, it may be that notion of positive and negative aspects reflects a false dichotomy in the caregiver

experience. Rather, there is a process, that may begin with the onset of caregiving and the experience of difficulties/challenges and demands, and through learning, adaptation to the role, and making meaning, positive aspects emerge. Positive and negative aspects continue to rise and fall, sometimes in an inverse fashion, other times they may rise and fall simultaneously, as the process and cycle ‘restarts,’ or, never ends, as the caregiving experience progresses, and the caregiver grows, and the caregiving environment changes. What directs the rise and fall of negative and positive aspects is the caregiver’s appraisal. The factors that influence caregivers’ appraisal of objective challenges and demands include their feelings of competency, mastery, and self-efficacy in the role, as well as faith and spirituality. In addition, I considered resilience literature and the importance of psychological flexibility and adaptation in response to difficult situations and stressors. Resilience literature indicates that caregivers with high resilience show low subjective burden under high objective burden conditions (Gaugler, Kane, & Newcomer, 2007). A conceptual model of resilience in caregiving, forwarded by Gaugler and colleagues, posits that intrapsychic (emotional and psychological) resources contribute to caregiver resilience (2007). Taken into consideration with the current findings, I forward that resilience impacts psychological and emotional resources by affecting how ‘much’ of these are lost to a difficult caregiving environment or the cycle of caregiver burden. Having ‘adequate’ psychological and emotional resources might improve the caregiving experience by supporting resilience (in a cyclical fashion, resilience improves experience thereby supporting psychological and emotional resources) and by allowing caregivers to engage in the cognitive efforts that underlie positive aspects (i.e., cognitive-reframing, gratitude, and acceptance). Conversely, the presence of subjective burden and distress might tax emotional and psychological resources, thereby negatively impacting psychological resilience and making practices that support the emergence of positive aspects more difficult (creating a cycle supporting the experience of negative aspects in caregiving). In this way, the appraisal process explains the co-occurrence of negative and positive aspects of caregiving. The appraisal of the caregiving challenges and demands determines a positive or a negative outcome.

Some motivating factors may serve to support emotional resources in caregivers. The findings of the two studies indicate that love, feelings of responsibility and commitment, sense of purpose, and altruistic values were motivating factors that underlie positive aspects. The findings indicate that these motivating factors led to the experience of intrinsic rewards when caregivers

fulfilled the caregiving role. Thus, the absence of such motivators might contribute to a difficult caregiving environment, or at least fail to contribute to emotional resources. I suggest that factors identified as facilitating the experience of positive aspects (identified in study one and supported by findings in study two) serve to support emotional and psychological resources (i.e., resilience) in caregivers. For instance, communication and connection with care recipient, humour, and feeling appreciated by care recipients and the family members. In addition, I forward that facilitating factors that support psychological resources are social support and self-care (see Figure 4 for visual representation of the theorized interplay between positive aspects, the appraisal process, and caregiver burden).

4.3 General Implications

The findings of these studies support and elaborate on the Lazarus and Folkman's transactional theory of emotions and coping (1987). These findings add depth to the person variables and environmental variables of the theory by providing insight into the relationships and complex processes between caregiving variables. The transactional model is not value laden in that it is not a model of stress or burden, nor one of positive outcomes. Rather, it describes a process of emotion and coping that allows for either positive or negative outcomes and for the complexity of the caregiving experience. Previous research and the current findings indicate that positive aspects are outcomes, mediators, and methods of coping (e.g., Pearlin et al., 1990; Branger et al., 2014). Thus, a model that can account for the influence and the outcome of positive aspects, as well as the many contributing caregiving factors, is preferred, such as the transactional model of emotions and coping.

Caregiving in general.

The findings of this research elaborated on the model and theory described above and, while some factors are particular to caregivers of persons with the dementia, some factors are arguably applicable to caregivers in general. For instance, a difficult caregiving environment would theoretically impact caregivers' appraisal of objective demands, and their psychological and emotional resources, regardless of the 'type' of caregiving (i.e., caring for someone living with cancer, caring for a chronically ill child). Some motivating factors may not be applicable, or may be less relevant, for some caregiving types (i.e., reciprocity may not be a motivating factor for parents caring for chronically ill children [at least not reciprocity as it is described by caregivers of persons with dementia]). Nevertheless, motivating factors in general are present for

all caregivers, and the current findings indicate that living in line with personal values that motivate providing care creates intrinsic rewards that help sustain caregivers in their role. The facilitating factors of appreciation for the care recipient and other family members may not be relevant for some caregiver types (e.g., parent caring for child), but could be relevant for other non-dementia caregiver types (e.g., spouse caregiving for chronically ill spouse). Loss as a hindering factor may not be as pronounced in some caregiving situations wherein the illness or condition of the care recipient does not lead to progressive and varied loss (such as is the case in dementia), but loss of life as expected or imagined could be present in all caregiving types. In addition, lack of support would likely apply to caregivers in general. Thus, the specific motivating factors, facilitating factors, hindering factors, and factors that underlie positive aspects of caregiving are considered to vary according to caregiver type, but the presence of such factors and how they ‘fit’ into the model and theory described in this work holds for caregivers in general. Concerning culture and caregiving, research indicates that cultural differences in caregivers are present in intrapersonal and interpersonal caregiving environments, in the psychosocial health of caregivers, in caregiving appraisals, in caregiver spirituality, in coping, and in caregiver self-efficacy (Napoles et al., 2010). Thus, conceptualization of the caregiving experiences discussed here may be limited in applicability across cultures.

Intervention for caregivers of persons living with dementia. In consideration of interventions for caregivers of persons living with dementia, I forward a multi-component, group-based intervention program based on the principles, theories, and tools of cognitive behavioural therapy (CBT) and including elements of acceptance and commitment therapy (ACT). CBT is a therapeutic approach that is amendable to persons of varying intellectual capacity and levels of insight (Hatton, 2002). CBT is adaptable to group-based therapeutic settings and the tools and practices are easily individualized and used outside of the therapeutic setting (Dobson & Dobson, 2009). The principles and practices of ACT are complimentary to the findings of this research, which emphasizes the importance of acceptance and being present (Hayes, Strosahl, & Wilson, 2012) in improving the caregiver experience.

Finally, CBT and ACT are complementary therapeutic approaches, with both working to improve personal insight and affecting cognitive responses to improve outcomes (Hofmann & Asmundson, 2008). The findings of this research indicate that knowledge and preparation, choice in attitude, acceptance, social support, and self-care, are central to improving the caregiver

experience. I propose a group intervention program adapted from a CBT individual intervention program for caregiver of persons living with dementia, by Losada and colleagues (2015), which includes modules on cognitive restructuring, assertiveness skills and asking for help, relaxation, and increasing pleasant activities that has been shown to be successful in reducing caregiver distress. I propose a three-module group intervention program based on (a) psychoeducation and support, (b) mindfulness, acceptance, cognitive re-framing, and (c) acknowledging and engaging in self-care. Multi-component interventions have been shown to be most efficacious in improving outcomes for caregivers (van Dam et al., 2016). Ideally, the intervention would be group-based to allow caregivers to share their experiences and challenges, as well as the knowledge, skills, and tools they have acquired from caregiving.

Module one: Psychoeducation. In theory, the psychoeducation module would serve to 1) allow caregivers to accurately ascribe problematic behaviours and symptoms to the disease, rather than the care recipient, 2) gain skills and tools to address caregiving demands and challenges, and 3) share their own knowledge and skills with others. In theory, this module would address some of the factors found to facilitate positive aspects of caregiving, such as knowledge and preparation, feelings of competency in caregiving, and the motivating factors of passing on knowledge. In addition, this module is theorized to combat hindering factors of physical and existential isolation. Further, by attributing difficult behaviours and symptoms to the disease, rather than the care recipient, this knowledge and support based module may serve to improve caregiver/care recipient relationships, which has been found to be a positive outcome of caregiving.

Module two: Mindfulness and cognitive re-framing. The second module would focus on mindfulness, acceptance, and cognitive reframing. In theory, this module would serve to 1) allow caregivers to become mindful of negative and positive experiences and emotions, 2) identify, challenge, and re-frame unhelpful cognitions, 3) improve cognitive appraisal of caregiving demands and challenges, and 4) facilitate gratitude, acceptance, and being present through practices of mindfulness. Mindfulness practices (of which there are many) are often incorporated into CBT (Singh et al., 2008), but are also a central component of ACT (Hayes, Strosahl, & Wilson, 2012). Here, mindfulness practices that aim to bring one's attention to the present moment (through practices as, body scanning, mindful walking/eating, and mindful detachment) would be used to help caregivers identify those moments where they are feeling stressed,

overwhelmed, hopeless, happy, grateful, content and so on. Practicing being present should facilitate caregivers in ‘catching’ those moments where they experience a negative emotion (e.g., “I suddenly feel stressed”) will allow them to identify their internal dialogue (e.g., “I can’t do this”) and then challenge the veracity of that inner dialogue and engage in cognitive re-framing (e.g., “I am feeling this way because this is a new and difficult challenge. I have always managed to find a way. I will find a way to meet this new demand.”). Modifying dysfunctional or maladaptive thoughts about caregiving in caregivers of persons with dementia has been found to reduce depressive symptomology and dysfunctional thoughts about caregiving, as well as modify caregiver appraisal of care recipient’s problem behaviours (Marquez-Gonzalez et al., 2007). ACT theory holds that life is naturally challenging and negative emotions are an inescapable part of the human experience (Hayes, Strosahl, & Wilson, 2012). Thus, the focus is placed on accepting the reality of the difficulties in life and caregiving and focusing on adjustment and reactions to the difficulties. In this module, acceptance would be practiced in relation to caregiving demands and challenges, as well as the negative emotions that arise in response to caregiving experiences. When cognitive re-framing practices follow acceptance, the two play an integral role in impacting the appraisal process of caregiving. Thus, this module is theorized to be important in diminishing negative aspects and facilitating positive aspects of caregiving through affecting caregivers’ appraisal of caregiving demands and challenges. Using mindfulness to facilitate caregivers in ‘catching’ moments where they are experiencing positive emotions supports identification of positive emotions and positive experiences in caregiving, which is theorized to facilitate gratification and being present. Mindfulness, gratification, and acceptance are related to improved psychological well-being (Ciarrochi & Kashdan, 2013). Together, this module would aim to diminish negative aspects of caregiving and encourage positive aspects through affecting the appraisal process in caregiving. Further, it is theorized that the positive aspects of caregiving are facilitated through mindfulness practices that support gratitude and acceptance and, thus, psychological well-being.

Module three: Self-care. The third module would focus on identification and commitment to personal values, and practices of gratitude and self-care. The aim of this module would be to 1) shift caregivers’ perspectives of caregiving to strength-based perspectives, 2) enhance caregivers’ acknowledgement of and engagement in self-care practices, and 3) improve practice of gratitude. An important aspect of ACT is acknowledging one’s personal values and living in

line with them (Hayes et al., 2012). The current findings indicated that many of the motivating factors underlying positive aspects represented personal values, for instance, altruism, responsibility, reciprocity, faith, and spirituality. The findings indicated that caregivers experienced intrinsic rewards when they lived in line with these values by fulfilling the caregiving role. In this way, the commitment component of the proposed intervention would focus on supporting caregivers in identifying the personal values that motivate them to assume and maintain the caregiving role. Understanding the part that one's personal values play in assuming and maintaining the caregiving role provides opportunity for a shift in perspective. Rather than being the subject upon which the trying times (caregiving) are imposed, focus would be placed on the strength of the caregiver to live in line with their values in context of the trying times.

In addition, practices in self-care and gratitude would be an important component to the final module. I have been involved in co-facilitating caregiver support groups, interviewing caregivers at a memory clinic, and visiting and learning from caregivers through varying venues and events. A common report I have encountered from caregivers is that there is no time for self-care and that it is frustrating when they are told by friends, family, and health care personnel to engage in self-care. Thus, this module would focus on small acts of self-care, and on identifying moments when one might naturally engage in self-care without realizing it.

Self-care can be a small act, such as doing something that is pleasurable to the senses (i.e., applying a favorite perfume, or cologne, or savoring a piece of chocolate). The tools and skills of mindfulness and being present would support caregivers in identifying small and spontaneous acts of self-care. By acknowledging these acts, the positive effects of self-care should be enhanced, and awareness should encourage more small acts of self-care in the future. The module would also address larger acts of self-care, in part by addressing how to find time for self, to engage respite care services, or to learn to ask for help. The findings from these two studies indicate that some caregivers struggle with asking for help from others, and some struggle with feelings of guilt in relation to using respite services or other forms of instrumental support. Thus, the self-care component of this module would provide an opportunity for caregivers to practice cognitive framing in a new aspect of the caregiving experience. Finally, gratitude has been found to be positively related to well-being and decreased levels of stress (Emmons & McCullough, 2003; Wood, Froh, & Geraghty, 2010). Thus, this module would

provide caregivers with practices that support gratification in daily life, such as, daily listings of gratitude, grateful contemplation, and behavioural expressions of gratitude (Wood, Froh, & Geraghty, 2010).

In sum, this intervention program would work to provide caregivers with the knowledge, skills, and support to help them address caregiving challenges and demands, as well as improve feelings of competency in caregiving. Through practices of mindfulness, acceptance, and cognitive re-framing, this intervention would work to improve caregivers' appraisal of the caregiving demands and challenges, as well as their willingness and ability to engage in self-care. Together, the intervention supports practices of gratitude and being present, which these findings revealed to be factors that underlie the experience of positive aspects of caregiving. Thus, the modules outlined here present a method of intervention that, based on literature and the findings of this dissertation research, should serve to reduce negative aspects and facilitate caregivers' experiences of positive aspects of caregiving by influencing caregivers' perspectives and affecting the appraisal process of caregiving.

4.4 General Limitations

Potential Bias. Having two or more researchers conducting the work would have improved rigour. Research suggests that having a second researcher conduct data extraction and data coding leads to a reduction in error, thereby improving reliability and rigour of a systematic review (Buscemi et al., 2006). Screening, coding, and amalgamation of the primary studies, as well as theme identification and integration of findings from study one, were highly involved and time-consuming processes. It was not feasible to have a second researcher for the entirety of the work. For study one, I created a data extraction and coding manual and 15% of the references were screened and coded by a second researcher, to assess for potential bias and none was found. Furthermore, the protocol for the meta-integration was submitted for peer review and accepted for publication. The peer review process served as a 'peer checking' procedure and supports the validity of the coding process of a study (Creswell, 2012), and in this case, of the screening and data extraction process as well. Concerning study two, I used a method of inter-coder agreement to assess rigour (Mayring, 2014). Study two was conducted by myself, and while single independent coding did not occur simultaneously, the interview data were coded by a second researcher with use of defined and described codes. Discrepancies between the two coders were

minimal, agreement was met with ease, and themes were then discussed and agreed upon with a third researcher.

Quality appraisal. The quality of primary studies was assessed in study one using the Mixed-Methods Appraisal Tool (MMAT); however, these scores were not used to weight the value of the studies differently. In this way, findings from poor study designs (e.g., MMAT score < 50) were considered with equal attention to those with strong study designs whose findings were more trustworthy. Still, the aim of this work was to get a sense of how positive aspects of caregiving were being investigated, and the strength of the research designs were not important in answering that question. If meta-analysis would have been conducted, I would have considered weighting the studies differently by giving more ‘weight’ in the statistical analyses to high quality studies, as measured by MMAT.

The MMAT is a 27-item appraisal tool that covers the domains, of qualitative design (five items), quantitative randomized controlled trial (five items), quantitative non-randomized design (five items), quantitative descriptive (five items), mixed methods (five items), and two initial screening questionings. Responses options are ‘yes,’ ‘no,’ and ‘cannot tell.’ A challenge with the MMAT is the scoring method. The recommended scoring method is a descriptive account of the study quality based on the scoring of each item. An alternative scoring method to improve across study comparison is to sum ‘yes’ responses (1 point), and allot ‘no’ and ‘cannot tell’ responses a score of zero. I chose to also calculate a percentage score (based on the number of ‘yes’ responses out of the items scored), but this numerical representation of the study quality scores was rudimentary.

While the preferred method of ‘scoring’ is descriptive, the tool was meant to facilitate across study comparisons on quality and it was my opinion that a descriptive ‘score’ comparison would prove cumbersome. Further, the scoring of certain items on the MMAT is more subjective than others. This can be problematic for inter-rater reliability, but consistency can be established by the researcher defining what is considered ‘adequate,’ for instance, prior to appraisal. Nevertheless, I found that the MMAT was easy to use, the MMAT did provide a consistent measure of study quality, and the appraisal per study was relatively quick. Studies investigating the reliability and efficacy of the MMAT tool reported good efficacy with an average appraisal per study time ranging from about 11 (Souto et al., 2015) to 14 minutes (Pace et al., 2012), and good reliability with fair to perfect inter-rater reliability depending upon the item (Souto et al.,

2010). It would appear that the MMAT is a tool that is growing in popularity for mixed methods reviews; the MMAT is currently recommended by the National Institute of Excellence in Health Services for mixed method reviews and the MMAT has reportedly been used in approximately 50 published reviews (Souto et al., 2010).

Sample size and heterogeneity. Heterogeneity in the quantitative dataset of study one precluded meta-analysis of the data. Although for some research pursuits it is suitable to combine different measures of the same construct to calculate effect size (i.e., investigating efficacy of intervention and grouping measures of a particular outcome variable), for the current endeavour I did not believe that combining measures would be a defensible practice. A goal of this research was to investigate the different measures of positive aspects of caregiving, and to group them would be to suggest that I believed that any two or more instruments were measuring the same facet(s) of the phenomenon of positive aspects of caregiving. I do not believe this is the case. In line with my epistemological view, I hold that measures of constructs are only approximations of the construct. They are imperfect approximations that may address some, but not all, aspects of the construct/phenomenon under study. It is my opinion that combining different, and imperfect, measures would lead to nonsensical data as the scores on the different measures do not represent the same aspects of the construct. Each score represents some aspect(s) of the phenomenon, but it cannot be known if any two or more measures overlap in the aspects they address or if they overlap to a degree that would make the measures' scores comparable enough to amalgamate in a meaningful way (in the case of this work). Future research should consider meta-analysis for studies using the positive aspects of caregiving (PAC) measure. As this measure appeared most common in literature and thus most promising for such endeavors. In a similar way, the small sample size of study two made for a high degree of variation across caregivers' accounts. While identification of themes was still possible, the heterogeneity in the small sample made comparison based on quantitative data difficult.

4.5 Future Directions

The findings of this research support and expand on models of caregiving that present caregiving as a fluid process with caregiver outcomes rather than fixed models of negative or positive caregiver experiences. These findings reiterate the importance of caregiver appraisal and perception of caregiving demands over the importance of objective caregiving demands, with the exception of problematic behaviours and symptoms (which can challenge caregivers' feelings of

competency and impact appraisal of their caregiving abilities). Thus, intervention programs for caregivers of persons with dementia should focus on appraisal as the point of intervention.

Multi-component interventions have been shown to be particularly effective for caregivers (Laver, Milte, Dyer, & Crotty, 2016) and more effective at reducing caregiver burden than support group, education, psychoeducation, counseling, respite care, alone (Acton & Kang, 2001). The current findings indicate that dementia caregiver interventions should continue to include psychoeducation and caregiver-to-caregiver support. These findings reiterate the importance of support programs that provide caregivers time for self and the opportunity to share with peers that understand the caregiving experience. In addition, research should begin to investigate the utility of incorporating cognitive re-framing practices to help caregivers re-appraise their responses to caregiving demands. Aspects of CBT are included in some dementia caregiver interventions, but with the goal of reducing caregiver depression and anxiety (Pinquart & Sörensen, 2006). Using CBT and ACT techniques to facilitate caregivers' appraisals, and in effect their 'choice in attitude' and acceptance, may serve to bolster positive experiences in dementia caregiving. In a similar way, implementing mindfulness practices into intervention programs may help caregivers be present, and, according to the findings, being present was commonly found to be both a positive outcome of caregiving and something that facilitates the experience of positive aspects.

Finally, interventions that use daily listing of gratitude, grateful contemplation, and behavioural expressions of gratitude show promising outcomes (Wood, Froh, & Geraghty, 2010). Gratitude has been linked to well-being (e.g., Emmons & McCullough, 2003; Wood, Froh, & Geraghty, 2010) and decreasing levels of stress in individuals (Wood et al., 2008). Future research should investigate the utility of incorporating practices to facilitate finding gratitude into caregiver interventions, and examine whether such practices serve to improve the caregiver experience. It is evident that more needs to be done to encourage, foster, and support positive aspects in the caregiving journey with dementia.

4.6 General Discussion References

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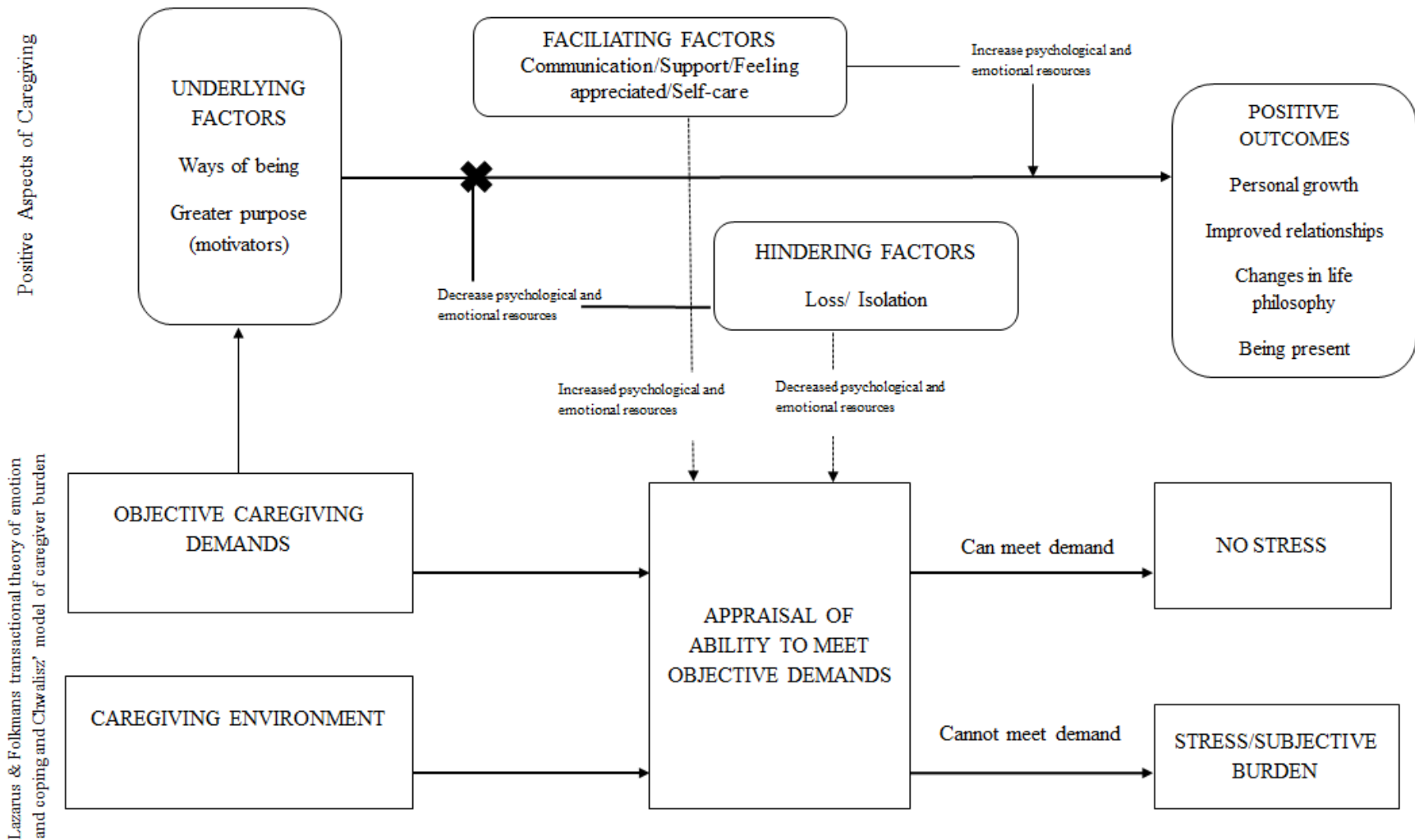


Figure 4. Diagram depicting positive aspects of caregiving situation within extant theory of emotion and coping and a model of caregiver burden.

Appendix A: Published Protocol

Protocol for a Meta-Integration: Investigating Positive Aspects of Caregiving in Dementia.

Branger, C., O'Connell, M., & Peacock, S. (2018). Protocol for a Meta-Integration: Investigating Positive Aspects of Caregiving in Dementia. *BMJ Open*, 8(7). doi:10.1136/bmjopen-2017-021215

Abstract

The current work describes the protocol for a meta-integration investigating the positive aspects of providing care to someone living with dementia. We aim to understand the position of positive aspects in caregivers' experience, as well as identify how positive aspects are commonly conceptualized, investigated, and measured in literature. Meta-integration is a method of investigation that synthesizes findings from meta-analysis or systematic review of quantitative studies and meta-synthesis of qualitative studies, to provide a coherent and holistic account of a phenomenon. As a relatively new method, terminology and methodological approaches are varied. The current work describes the process of conducting an advanced convergent meta-integration, including protocol for systematic search, inclusion/exclusion screening phases, intra-method analysis synthesis, and inter-method synthesis on quantitative, qualitative, and mixed methods research pertaining to the positive aspects of providing care to someone living with dementia. There are no ethics or safety concerns about dissemination, which includes plans for a conference presentation and publication.

Protocol for a Meta-Integration: Investigating Positive Aspects of Caregiving in Dementia.

Advanced aging is associated with an increased risk of developing dementia, a neurodegenerative disease that leads to increasing impairment in independent functioning and activities of daily living (Lezak, Howieson, Bigler & Tranel, 2012). Globally, it is estimated that 35.6 million people were living with dementia in 2010, and the prevalence of dementia is expected to rise as aging populations continue to grow (Prince et al., 2013). Research indicates that care for persons living with dementia is largely provided by informal caregivers (i.e., family members and friends; hereafter referred to as *caregivers*) who are untrained and unpaid for the care that they provide (Prince et al., 2013). Caregiving for a loved one with dementia poses challenges for caregivers financially, socially (e.g., Brodaty, 2007), physically, and psychologically (e.g., Pinquart & Sorensen, 2003). Some research, however, has shown that there are positive aspects associated with caring for a loved one with dementia, including, but not limited to, feelings of personal gain and satisfaction (Farran, 1997; Peacock et al., 2010). Research into the positive aspects of caregiving is growing, but it remains fraught with variations in labels and challenges in measurement and conceptualization. Without a comprehensive understanding of what is currently known of positive aspects and how these aspects are conceptualized and measured, advances in salutogenic caregiver research is limited. Without a thorough understanding of the positive aspects of caregiving, supportive efforts of intervention programs risk working to diminish negative aspects of caregiving while missing the opportunity to bolster positive aspects for caregivers. The researchers of the current work aim to gain a holistic account of the state of research on the positive aspects of caregiving through using a novel method of *meta-integration* which brings together findings from a meta-analysis of the quantitative studies pertaining to positive aspects of caring for a loved one with dementia and findings from a meta-synthesis of qualitative studies on the positive aspects of caregiving. The current work describes the protocol for the meta-integration.

Research Question

The researchers propose that meta-integration would be central to advancing the study of positive aspects of caregiving for persons with dementia. Meta-integration is the chosen method for this objective because this method can determine the current status of positive aspects in quantitative and qualitative research, and by integrating varied approaches to studying positive aspects of caregiving we hope to gain a cohesive understanding of the phenomena. The research

questions for current meta-integration are 1) how are positive aspects of caregiving most commonly conceptualized in research? 2) what are the most common labels used to refer to positive aspects of caregiving? 3) what are the most common methods of measuring positive aspects of caregiving? 4) what do the data indicate about the relationship between positive aspects and other informal caregiving variables?

Method

Meta-integration, or mixed-meta-synthesis, is a novel form of research synthesis that integrates quantitative meta-analysis and qualitative meta-synthesis. Differences in ontological and epistemological perspectives historically divided quantitative and qualitative research (Sandelowski, Voils, & Barroso, 2006). Each approach, however, has strengths. Meta-analysis is the classic method for aggregating related empirical findings and can generate new knowledge and has proved useful in the development of theory (Cooper, 2009; Schulze, 2004). Meta-analysis consists of two main parts: a systematic review of literature of a particular field of study/research question (e.g., caregiver satisfaction and caregiver well-being) and high order statistical analysis of these literature findings (Cooper, 2009; Schulze, 2004). For qualitative data, meta-synthesis can reveal powerful explanations, provide greater generalizability, and increased levels of abstraction (Sherwood, 1999) which allows researchers to revise, or refute, extant theories and understanding of human phenomenon (Hannes & Lockwood, 2011). Meta-synthesis methods can be aggregative or interpretive. Aggregative meta-synthesis methods use the findings from systematically reviewing the qualitative literature to identify themes or similar descriptors in order to produce a general description of the phenomenon under study (Hannes & Lockwood, 2011). Aggregative synthesis methods (e.g., meta-summary, thematic analysis, content analysis, case survey, qualitative comparative analysis, and Bayesian meta-analysis) do not consider the context under which individual study findings occur (Hannes & Lockwood, 2011). In contrast to interpretive meta-synthesis methods that involve a high degree of circular iteration for analysis, aggregative models are marked by low or absent iteration, and, instead, adopt a highly structured manner of selecting, organizing, and reporting individual study findings (Hannes & Lockwood, 2011).

Meta-integration methods can be categorized as segregated or integrated (Sandelowski, Voils, & Barroso, 2006). Segregated, or convergent, designs assume that quantitative and qualitative studies, and related findings are different entities that must be treated separately.

Thus, a segregated method is suitable when the synthesis outcome is intended to be a configuration, not assimilation of the research findings (Sandelowski, Voils, & Barroso, 2006). Integrated designs, conversely, do not view quantitative and qualitative research approaches as fundamentally different, but rather as producing findings that are easily transformed from quantitative to qualitative and vice versa (Sandelowski, Voils, & Barroso, 2006; Onwuegbuzie & Teddlie, 2003). Thus, integrated designs are suitable when synthesis is intended to produce assimilated research findings (Sandelowski, Voils, & Barroso, 2006). The current research endeavor is exploratory, consequently we concluded that a configuration of the findings (i.e., segregated [Cooper, 2009], or, convergent [Frantzen & Fetters, 2016]) would be more appropriate than assimilation (Sandelowski, Voils, & Barroso, 2006; Onwuegbuzie & Teddlie, 2003).

To design the current protocol, we relied on the models of meta-integration described by Frantzen and Fetters (2016). Frantzen and Fetters (2016) compared published methods of synthesizing work from quantitative, qualitative, and mixed-method studies. Models of meta-integration are differentiated by the inclusion or exclusion of mixed-methods studies (inclusion of mixed-methods require *advanced* model designs, rather than *basic* models designs), and use of data transformation (wherein, for example, a researcher might choose to transform quantitative data into qualitative data and conduct a convergent qualitative meta-integration). We chose an advanced model over the basic model due to the inclusion of mixed-method studies. Further, given the exploratory nature of this research, we determined that models of integration that included data transforming (transforming quantitative data into qualitative data and vice versa for synthesis purposes) would be inappropriate, as we did not want to privilege any one line of inquiry (i.e., quantitative or qualitative). In the chosen model of meta-integration, the mixed methods studies are fractionated, that is, quantitative data and qualitative data are extracted and added to quantitative and qualitative datasets, respectively. After this step, we integrate the findings using inter-method synthesis.

The following outlines the protocol for conducting the advanced convergent meta-integration, including the process of determining the research question(s), conducting the systematic search, inclusion and exclusion screening process, intra-method synthesis-analysis, inter-method synthesis, and finally, organization of results, assessment of fit, and conclusions.

Advanced Meta-Integration Protocol

1. Identify literature (see systematic literature search protocol below)
2. Categorize studies
 - a. Divide studies into quantitative, qualitative, and mixed method categories.
 - b. Fractionate mixed methods studies
 - i. Extract quantitative data from mixed method studies and add to quantitative dataset, extract qualitative data from mixed methods studies and add to qualitative data set.
 - c. Coding and data extraction
 - i. Develop coding manual and develop coding summary sheet
 - ii. 10-15% of final references coded by second coder to assess consistency and potential bias. If evidence for bias exists, a second coder will have to be used consistently and consensus in coding will be required.
 - iii. Extract data and document on code summary sheet
 - iv. Create database of coded reference material.
3. Conduct intra-method analysis-synthesis and comparison.
 - a. Intra-method analysis of quantitative dataset
 - b. Intra-method analysis of qualitative dataset
4. Conduct inter-method integration
5. Organize results and assess fit
6. Draw final conclusions.

Step 1: Systematic Literature Search

The following steps outline the approach used to obtain the sample of references to be used in the proposed meta-integration:

1. Identify relevant databases
2. Identify search terms
 - a. Develop concept charts for each database
3. Conduct search of each database
 - a. Export each database search results into reference manager program
4. Screening criteria
 - a. Develop protocol to determine eligibility for inclusion in study

- i. Based on protocol most appropriate for research endeavor (e.g., PICO, SPICE, SPIDER, etc.)
5. Phase one screening
 - a. Screen titles and abstract for relevance
6. Phase two screening
 - a. Screen methods and measures for relevance.
7. Final screening phase
 - a. Screen body of reference for relevance
 - b. Organize retained references by scientific approach (i.e., quantitative studies, qualitative studies, mixed-method studies).
 - c. Document inclusion and exclusion.

Search Strategy: Step 1

A systematic literature search for relevant studies will be conducted using the databases: PsychINFO, MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Sociological Abstract, SocINDEX, AgeLine, Anthropology plus, and Embase. Databases were chosen in consultation with a librarian employed at the University of Saskatchewan who specializes in psychology and selection was based largely on relevance (i.e., disciplines likely to have interest/investigation in the topic of caregiving and dementia). The method of selection is in line with Crumley and Blackhall's (2003) guide on search strategies for systematic reviews.

Concept Chart Development: Step 2

The researchers chose 'caregiver,' 'dementia,' and 'positive aspects' to be the search concepts used for the systematic search (these concepts were chosen based on the researchers knowledge of the most common labels used to describe these constructs, being active researchers in the area). Synonyms for each of these search terms will be identified for each database and included in the search. To assist this aim, a "concept chart" will be created for each database. Disciplines differ in the terms they use to describe concepts, thus synonyms for the search term had to be identified in each database. For example, we will enter search term 'caregiver' in the database PsychINFO (Ovid platform). We will search the *key word* and *subject heading* sections of the first 100 or more references of 23,012 returned (the decision to stop will be somewhat arbitrary and based on repetition of the identified synonyms and marked decrease in identification of new synonyms). Next, a search of PsychINFO 'caregiver' AND 'dementia'

(‘exploded’ to include ‘dementia’ derivatives) will be entered to ensure that any additional synonyms for caregivers in the context of dementia may be captured. The first 100 or more of the 3,296 articles returned will be searched and new synonyms added. A new search for synonyms for the construct ‘dementia’ will be completed and 100 or more articles of the 28,466 returned will be searched for dementia synonyms.

The process will be repeated for the search term ‘positive aspects.’ Having experience in this research area, the researchers understand that many terms have been used to describe positive aspects, thus identification of all possible synonyms is particularly important in identifying relevant articles. Positive aspects in the context of caregiving will be searched [positive aspects (as keyword) AND caregiving (‘exploded to include derivatives of the term)]. All articles will be searched and synonyms for ‘positive aspects’ identified. Please see Table 1 for concept chart exemplar. The researchers will conduct the search and examine the identified references to assess whether the articles returned are relevant to the current research endeavor. The researchers will be able to identify ‘synonyms’ that result in references that are not appropriate for the current research study. For instance, a positive aspects synonym, ‘psychological endurance’ may be found to pertain to negative aspects of caregiving, rather than positive. Similarly, another synonym, ‘quality of care’ may be found to be too vague and related to professional caregivers. The synonyms identified as not appropriate for the search will be indicated on the concept chart with notation regarding reason for omission (Table 1).

The PsychINFO concept chart will be comprehensive and will be used as a general concept chart to be adapted to all other databases. More specifically, we will repeat the process of identifying synonyms for each concept in each database, and those unique to the particular database will be added to the general concept chart (synonyms unique to the database will be indicated on concept chart by italicized font).

Database Search: Step 3

Once concept charts for each database are completed, the systematic search will commence. No limit in terms of year of publication will be placed on the search. While the stated goal is to understand the current conceptualization and measurement of positive aspects, the researchers understand that this is a relatively new area of research and identified studies are unlikely to be outdated to the point where they are not of use. In addition, gaining a sense of the history and evolution of the concept and its measurement should prove to elucidate the current

state of the concept. In each database the term ‘caregiver’ and all identified synonyms will be entered, using OR action (e.g., ‘caregiv*’ OR ‘care partner’ OR. etc.). Then the term ‘dementia’ and all identified synonyms will be entered, using OR action. The term ‘positive aspect*’ and all identified synonyms will be entered using OR action. In addition, each term’s ‘exploded’ derivatives will be considered for inclusion. The three compiled search terms (i.e., including all synonyms) will be searched together using AND action. References from each database will be exported into their respective folders in *Zotero* reference manager.

Screening criteria: Step 4

The PICO and SPIDER guides will be used. The search tools, PICO and SPIDER, have been shown to have good sensitivity and specificity, respectively, in identifying relevant references (Methley, et al., 2014). As noted, the researchers used a liberal search approach, thus we rely on the guidance of PICO and SPIDER later in the screening phase (i.e., eligibility phase), rather than reference identification phase. Given its applicability to quantitative research design (Methley, et al., 2014), PICO will be used to inform criteria pertaining to quantitative studies. SPIDER protocol is suitable for reviews with an exploratory nature and will guide the majority of the eligibility criteria as it is applicable to quantitative, qualitative, and mixed method studies (Cooke, Smith & Booth, 2012).

Screening for Inclusion: Step 5 & 6

Screening phase one. In the first screening phase, titles, and abstracts will be screened to determine whether the manuscript pertains to positive aspects and informal caregivers of persons diagnosed with dementia or mild cognitive impairment (MCI; although it is meant to describe a condition with no functional impairment, the researchers understand that the term MCI is used inconsistently and may be applied to those who do require some assistance, thus, the researchers chose to err on the side of caution and ‘cast a wide net’ by including MCI). If unclear based on title, abstracts will be screened to ensure that the study relates to informal caregiver and experience/caregiver outcomes, and/or, positive aspects/synonyms. If the abstract does not include ‘positive aspects’ or a synonym, but does address caregiver non-negative outcomes/experience the article will be kept. If it is unclear, the article will be kept for further screening.

Screening phase two. In the second screening phase, the methods and measures sections of manuscripts will be examined. For inclusion, the study must report positive aspects/synonyms

or clearly report on non-negative caregiver experience (i.e., not exclusive to caregiver: burden, burnout, distress, strain, negative health effects). The positive aspect has to be measured and described. The inclusion criterion was purposefully broad because labels and definition of positive aspects is currently inconsistent in the burgeoning field of positive aspects in caregiving for someone with dementia.

Final screening phase. After phase one and two screening, the full body texts of remaining references will be screened for eligibility using the eligibility criteria. References excluded in this phase will be documented, including reason for exclusion. The references will be divided into quantitative, qualitative, and mixed-methods categories before data extraction and coding phase.

Categorize Studies: Step 7

Development of the coding manual will first be based on theory and will be amended during data extraction phase. Due to the exploratory nature of the research endeavor, the researcher may find predetermined variables are not applicable (i.e., not investigated/reported in primary studies), and new variables of interest might emerge (i.e., primary studies might present novel constructs related to positive aspects, or new facets of positive aspects). The Mixed Methods Appraisal Tool (MMAT) was designed for the appraisal stage of systematic literature reviews that include quantitative, qualitative, and mixed-methods studies (Pace et al., 2012). The MMAT will be used to describe the methodological quality of each study, and the MMAT score for each study will be included in the database. The following variables from primary studies will be extracted.

Study variables. Study identification number, publication type (journal article, thesis/dissertation), publication year, care recipient dwelling (e.g., community, institution, etc.), and study country of origin.

Research variables. Purpose of the study, relationships measured (i.e., positive aspects in relation to caregiver age, burden, etc.), caregiver sample size, care recipient characteristics (i.e., persons diagnosed with dementia, dementia due to Alzheimer's disease, etc.), caregiver/care recipient relationship, number of caregiver relationship types (i.e., number of spousal caregivers in sample, number of child caregivers in sample, etc.), mean age of caregivers, number of females in caregiver sample, number of males in caregiver sample, number of caregivers employed, sample mean duration of caregiving in years.

Study design variables. Theoretical approach, stated epistemology, study design.

Construct variables. Labels given to describe positive aspects of caregiving, positive aspects definition, positive aspects measure(s), properties of positive aspects measure(s), evidence of validity and reliability of positive aspects measure(s), sample size, mean, and standard deviation on positive aspects of caregiving measure. Relationship between positive aspects scores and caregiver: sex, age, race, relationship to care recipient, employment, care recipient dementia diagnosis, years spent caregiving, burden, distress, psychological health/well-being, physical health/wellbeing, subjective health, satisfaction with life, coping style, support, level of education, religiosity/spirituality, competence/mastery/self-efficacy, quality of caregiver/care recipient relationship, and severity of care recipient dementia, dementia behaviours and symptoms. After data extraction of a primary study is complete, the reference section will be cross-referenced against the sample of studies for the meta-integration, and new relevant references will be obtained and added to either the quantitative, qualitative, or mixed-methods sample pools.

Conduct Intra-Method Analysis-Synthesis and Comparison: Step 8

The intra-method analysis and synthesis is an iterative process wherein the quantitative dataset is synthesized and analyzed and the qualitative dataset is synthesized and analyzed, ensuring a separate overview is created for each dataset (Frantzen & Fetters, 2016). Synthesis will bring together the main findings from each dataset; combing the results and interpretations to create an integrated and summative account of all the quantitative studies, and then of all the qualitative studies. The iterative synthesis and analytic process will occur simultaneously, as results and interpretations of the data will be deconstructed and reconstructed; separated into their previous state and then recombined. The iterative synthesis-analysis process is what will allow for new perceptions and advancements in knowledge of the phenomenon to occur (Frantzen & Fetters, 2016). The current protocol is elaborated in the following sections, *quantitative dataset synthesis* and *qualitative dataset synthesis*.

Quantitative dataset synthesis. The extracted data from quantitative studies will be closely reviewed to gain a sense of the degree of homogeneity. Specifically, we will look at whether there is enough consistency in the measures used for positive aspects across studies (i.e., it would not be appropriate to group measures of gain with measures of satisfaction) and in the variables in which positive aspects are investigated in relation to (i.e., it would not be appropriate

to group investigation of positive aspects and caregiver burden with positive aspect and caregiver distress), to calculate effect sizes. It is possible that the studies will be too few and perhaps too heterogeneous in methods of measurement and variables investigated for meta-analysis. If the studies do not vary greatly on the factors described above, the variables of interest will be extracted, coded, and findings from the studies will be transformed into a common metric to calculate an overall effect size for the relationship(s) of interest (Whittemore & Knafle, 2005). Should a meta-analysis not be possible, a narrative analysis of the primary studies will be conducted. A narrative analysis will summarize and bring together the findings from primary studies and may employ frequency counts or other quasi-statistical approaches to best describe the meta-data (Cooper, 2009). Both meta-analysis and narrative analysis are appropriate for meta-integration methods (Sandelowski, Voils, & Muers, 2006).

Qualitative dataset synthesis. The qualitative studies will be closely reviewed and the following data will be extracted and included in the dataset: author(s), epistemology, sample size, sample population, aims/topics, method of data collection, data analysis, findings, and notes/caveats. The researchers will use thematic synthesis of the qualitative dataset, as described by Kavanagh and colleagues (2012). Qualitative data to be included in the dataset can be part of the body of text, Kavanagh et al., (2012) suggest the “findings” or “results” sections of primary studies be used as the raw data to be extracted. Should a study’s goals correspond to the current research study, then the conclusions drawn by the primary study may be included in the dataset (Kavanagh et al., 2012). Primary study findings will be summarized in data extraction form and included in the dataset and consideration will be given to the ways in which the methodologies and epistemologies used in the primary study shaped the understandings and findings. Line by line coding of the dataset will be conducted. Each line will receive a code that encapsulates the meaning. *Conceptual translation* is a key characteristic of qualitative synthesis, and it occurs when codes begin to be applied to data from a second primary source (Kavanagh et al., 2012). Either performed simultaneously or after line by line coding, the researcher(s) will generate descriptive codes and organize the emerging codes into descriptive themes. To do so, the researcher will develop an overarching conceptual framework to group codes that are conceptually similar. While the development of the framework will require some interpretation, the purpose is to summarize and organize the dataset rather than draw new/original conclusions.

Importantly, while the two datasets (quantitative and qualitative) are not yet integrated at the intra-method synthesis-analysis stage, it is unrealistic to suggest that the researcher can effectively disentangle pondering the emerging findings from the two separate datasets. The synthesis-analysis of quantitative dataset will be affected by the synthesis-analysis of the qualitative dataset, and vice versa, even if only at the sub-conscious level of the researcher. Thus, the model includes the process of ‘mindful comparison’ during the synthesis-analysis of each dataset.¹³ Mindful comparison describes the conscious and intentional consideration of the findings of each dataset, paying heed to the similarities and differences between the quantitative and qualitative datasets, and, ultimately, how they relate to one another. The mindful comparison process lays the intellectual groundwork for the inter-method synthesis (Frantzen & Fetters, 2016).

Conduct Inter-method integration: Step 9

The inter-method integration will be a gradual iterative transition from intra-method synthesis-analysis to inter-method integration. Although an iterative transition, it will be important to have ‘completed’ the intra-method synthesis-analysis of each database before transitioning into the inter-method integration, as a thorough understanding of each data set (for instance, consistent themes, relationships investigated, main findings) is important before integrating the two (Frantzen & Fetters, 2016). To facilitate inter-method integration, displays of each dataset will be created; these ‘joint displays’ will provide an overview of the complex inter-relational connections within each dataset and facilitate identification of connections across datasets. The ‘joint displays’ may take many forms and will likely go through much iteration, and refinement, as insights about the data emerge. The ‘joint displays’ are thought to support and foster a better understanding of the dissimilar data during the analytic phase, but are also useful in the dissemination of results in final publications and presentations.

Organize and Assess Fit: Step 10

In this phase, organization refers to the final and comprehensive grouping of the data for presentation of the end product (Frantzen & Fetters, 2016). Importantly, the organization process includes backtracking and determining the origins of the data; this is a critical part of the process that allows for full clarity and accountability. In backtracking, the researcher will make a constant effort to keep track of the underpinnings, or statements, that lead to each conclusion.

The final stage of organization will be an assessment of ‘fit.’ ‘Fit’ refers to examining the concordance between the findings of the integrated datasets (Fetters, Curry, & Creswell, 2013). Here, similarities in results and conclusions across the two databases indicates support. If the findings contradict each other, there is discordance. If the findings address different aspects of the phenomenon, there is expansion. The researcher will reflect on the ‘fit’ and make arguments for the ‘fit’ of the integration, which is expected to strengthen the quality of the conclusions. Outcomes from ‘fit’ assessment may also serve to inform future research directions.

Draw Final Conclusions: Step 11

After completing the processes of synthesis-analysis, integration, organization, and ‘fit’ the researcher will draw final conclusions based on all the included sample studies. The conclusions will go beyond reiteration of specific findings to focus on novel information and knowledge based on the findings from the convergent meta-integration findings.

Patient and Public Involvement

This is a review of published material; consequently, for the current project there was no patient or public involvement.

Ethics and Dissemination

There are no ethical or safety concerns associated with the proposed research. No participants will be used in this study. The findings from this research will be published in scholarly journals, the findings will be available through the Alzheimer’s society of Canada, the funding source of the graduate student’s research.

Conclusion

This paper describes protocol for conducting a meta-integration, which is a relatively novel method of investigation of quantitative and qualitative inquiry to provide a coherent and holistic account of a particular phenomenon (Kavanagh et al., 2012). Literature on caregivers of persons living with dementia focuses predominantly on negative aspects of caregiving, but increasingly, the positive aspects of caregiving are being studied. As a new area of inquiry, however, the study of positive aspects of caring for persons with dementia displays variation in labels and definitions of positive aspects. The current work describes the protocol used to conduct a meta-integration on literature pertaining to positive aspect so caregiving with the aim of identifying common labels and conceptualizations, common measures, and relationships between positive aspects and other caregiving related factors.

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Table 1.

Concept chart of search terms and synonyms

Concept A Caregiver (16)	Concept B Dementia (21)	Concept C Positive Aspects (36)
Care partner*	AIDS dementia complex/	Adaptability- too vague
Care provider *	Alzheimer's disease/	Advocacy-too vague
Caregivers/	Cognitive decline	Assertiveness-to vague
Carer*	Cognitive impairment/	Autonomy/
Caring behavior*	Corticobasal degeneration/	Behavioural intention-too vague
Child caregiv*	Creutzfeldt Jakob syndrome/	Caregiving benefit*
Elder care/	Dementia with Lewy bodies/	Caregiving competence
Familial care*	Dementia*/	Caregiving gain*
Family care partner*- redundant	Dysexecutive syndrome- redundant	Contentment/
Family care provider*- redundant	Early onset dementia	Coping behaviour-too broad
Family care*	Frontotemporal dementia	Emotional adjustment- not positive
Informal caregiv*	Frontotemporal lobar degeneration	Empowerment
Informal care*	FTD- acronym, redundant	Enthusiasm-Too broad
Primary caregiv*	Late onset dementia	External reward/
Primary family caregiv*	Memory disorders/	Finding meaning
Quality of care/ - too vague	Neurodegeneration/	Gain*
Sandwich generation caregiver*- redundant	Neurodegenerative diseases/	Independence--Too broad
Spouse caregiver*	Parkinson's dementia Picks disease/	Intention --Too broad Internal reward/

Presenile dementia- not relevant

Semantic dementia/

Senile dementia/

Vascular dementia

Young onset dementia

Intrinsic behavior-not relevant

Intrinsic motivation

Involvement- too vague

Life satisfaction/

Meaning/

Meaningfulness/

Motivation/

Optimism/

Persistence/

Positive aspect*

Positive caregiver experience*

Positive caregiver outcome*

Positive dimension*

Positive emotion*

Positive feeling*

Positive psychology/

Positive value-too vague

Positivism-not relevant

Posttraumatic growth/

Protective factors-too vague

Psychological Endurance – infers negative

Psychological Stress __not positive = omitted

Quality of life-too vague/not relevant

Relationship satisfaction

Resilience/(psychological)
Rewards/
Role satisfaction/
Satisfaction/
Self-affirmation
Self-confidence/
Self-determination/
Self-efficacy/
Self-evaluation/
Self-perception/
Well-being/

Search term synonyms identified in the PsychInfo database. Terms that were searched as subject heading are indicated with '/'. The asterisk notation indicates truncation and the search would include that term with any suffix (e.g., caregiv* includes, caregiver, caregiving). Items in bold formatting were items included in final search, unbolded items were omitted.

Appendix B: Data extraction and Coding Manual for Study One Positive Aspects of the Caregiving Experience: A Meta-Integration

Study Admissibility

In order to be included in the Meta-Integration study (2017/2018) pertaining to positive aspects of providing informal care to someone living with dementia, the study had to meet the following criteria.

The aim of this review is to gather all existing studies (including quantitative, qualitative or mixed method designs) that have investigated positive aspects of informal caregiving in dementia, within the scholarly arena. With the ultimate goals of understanding how positive aspects are commonly, labeled, defined, measured, and investigated (e.g., context, other variables of caregiving, etc.), this review omitted non-scholarly material as well as scholarly articles that were theoretical and investigative. More specifically, studies had to meet the following criteria in order to be considered admissible.

Study Characteristics

- The study must be available in the English language.
- All dates of publication are acceptable.
- All geographical locations of study are acceptable.
- The article must be peer reviewed and/or the study must be a graduate level dissertation or thesis.
 - The study must have some semblance of having been reviewed by researchers in the field (i.e., published in scholarly journals, or work supervised by graduate level supervisors and committee members).

Phenomenon of interest

- The article must address and report on positive (non-negative) experience/outcome, as identified by a positive aspects label and/or definition.
 - The study must include positive aspects or indicate investigation into caregiver (non-negative) experience.

- The study must not pertain solely to negative aspects such as caregiver burden, strain, stresses, distress, etc.
- For quantitative studies, the positive aspects must be measured.
- Positive aspects must pertain to the caregiver experience of caregiving, and not pertain to outcome or experience of intervention, changes in nature of care (e.g., caregiver experiences of respite of care recipient's admission into long-term care).

Population

- The study must pertain to informal caregivers of persons diagnosed with dementia.
 - Should the study not use the terminology of informal caregivers, include if the study populations is family caregivers, family member, and friend caregiver.
 - The study should include a sample of the population of interest and not be a theoretical body of work (e.g., development of theory or framework).
- If the study includes caregiver dyads (caregiver/care recipient) or mixed caregiver groups (i.e., dementia and non-dementia caregivers), the study must analyze and discuss data pertaining to caregivers of persons living with dementia separately.

Design

- All research designs and theoretical frameworks are admissible.

Quality

- All outcomes on study quality assessment will be admissible.
- Quality will be assessed using Mixed Methods Appraisal Tool (MMAT)

<http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/84371689/MMAT%202011%20criteria%20and%20tutorial%202011-06-29updated2014.08.21.pdf>

Study Identification

Each study that was found to be admissible was given a study identification number. The studies were categorized according to method of investigation, that is, quantitative (QT), qualitative (QL), and mixed-methods (M). Study identification numbers indicated method of investigation, with QT, QL, or M, preceding a numerical designation (e.g., QT01, was the first quantitative article accepted for the review).

Study Descriptive Information

A Study Description form was completed for each study. The Study Description form included a brief description of each study with information about key study characteristics. Specifically, the Study Description Form included:

- Whether the study is published or unpublished
 - Published studies include peer reviewed journal articles and book chapters
 - Unpublished include thesis/dissertation, conference presentations
- Year of publication
- The country the study originated from
- The purpose of the study
 - Hypotheses
- Participants
 - Number of participants
 - Gender distribution
 - Age
 - Relationship to care recipient
 - Years spent caregiving
 - Dementia diagnosis for care recipient
- Study design
 - Method (qualitative, quantitative, mixed)
 - Epistemology
- Methodology
 - Tools (e.g., interview)
 - Measures
 - Concepts
 - Concepts
 - Constructs
- Analysis
- Results
- Quality assessment score

Significant Digits

When calculating the effect size d , we included 3 digits after the decimal point.

STUDY DESCRIPTION VARIABLES (S)

SSTUDYID: study identification number. QT# for quantitative studies, QL# for qualitative.

SSCHOLA: if study is from academic journal code '1.'

STHEDISS: if study is a thesis or dissertation, code '1.'

SPUBYR: year the study was published/released/completed.

SLOCNTYPE: care recipient dwelling.

SCOUNTRY: country where study originated.

RESEARCH VARIABLES (R)

RPURPOSE: report the purpose/objective of the study.

RRLNS: report the number of relationships investigated, that will be extracted for Meta-Integration.

RSAMPLN: caregiver sample size. If divided by group, report total caregiving sample.

RSAMPLCHAR: report characteristic of informal caregiver sample (IC), in relation to type of dementia diagnoses.

0 = IC of persons living with dementia

1 = IC of persons living with dementia due to Alzheimer's disease

- 2 = IC of persons living with dementia and AD
- 3 = IC of persons living with frontotemporal dementia
- 4 = IC of persons living with mild cognitive impairment
- 5 = IC of persons living with Huntington's disease

RCGRLSHN: caregiver relationship to care recipient, code '0' (NO), '1' (YES) for each category. If unclear, use other category. Combine caregiver groups if necessary (i.e., extended family member and friend).

RLNSP = spouse:

RLNCH = child or child-in-law:

RLNOT = other relation/friend:

RCG SPOUSE: number of CG sample that is spouse.

RCG CHILD: number of CG sample that is children/children in law.

RCG OTHER: number of CG sample that is other family.

RCG FRIEND: number of CG sample that is friend.

RCG AGE: caregiver sample mean age, report standard deviation in parentheses, when given. If reported across CG groups, calculate overall mean.

RCG FEMALE: number of females in sample. If reported in percentage, compute number.

RCG MALE: number of males in sample. If reported in percentage, compute number.

RCG EMPLOY: number of CG in sample that are employed, either full-time or part-time. If reported in percentage, compute number.

RCG YRS: years spent caregiving. If reported in months, transform into years. If reported across CG groups, compute overall mean in years.

STUDY DESIGN VARIABLES (D) ***items bolded below are either specific to QUALITATIVE DATA EXTRACTION FORM, or shared variables with the Quantitative data extraction form. Variables in regular font (not bolded) will only be found in the quantitative data extraction form.

DSTAPPRCH: report the theoretical design based on study design, if not reported explicitly.

DEPISTY: report the epistemology. If not apparent, search document (CNTRL 'F') for 'epistemology,' 'philosophy,' 'objectivist,' 'positivist,' 'post-positivist,' 'constructionist,' 'constructivist.'

0 = not stated

1 = objectivist

2 = positivist

3 = post-positivist

4 = constructivist/social constructivist

DPROBLEPST: for qualitative studies report probable epistemology, based on approach and methods.

1 = objectivist

2 = positivist

3 = post-positivist

4 = constructivist/social constructivist

DSTDESIGNB: report overall (broad) design of study. Most of the studies are exploratory (descriptive/correlational) in nature. Use 'correlational' in a broad sense, that is, pertaining to relationships among variables/constructs, not necessarily the type of statistical analysis used. This should be used to capture more complex correlational analyses such as multiple regression, for instance.

0 = experimental

1 = descriptive

2 = correlational

DSTDESIGNSP: try to identify specific study design. Sometimes the design will be reported, if not consider the study purpose and method of data collection (i.e., survey, sampling procedure) to help guide selection.

0 = RCT

1 = non-RCT

2 = cohort studies

3 = cross-sectional

4 = case study

5 = ecological

6 = survey

7 = evaluation

8 = interview

9 = observational

10 = document analysis

DMETHODOLOGY: describe the methodology of the study, for instance, grounded theory, or phenomenological approach with use of hermeneutics.

DMANALYSIS: describe the method of analysis, and the steps/procedure outlined by the researchers.

DASSUMPT: describe the assumptions inherent in the approach/method of analysis. For instance, the use of language to convey experience, or the implied importance of consistency and frequency in themes as being indicative of some 'real' aspect of the phenomenon (as a positivist, content analysis approach/analysis would imply).

CONSTRUCT VARIABLES (V)

VPALABEL = positive aspects label: report the label most consistently used in the study to refer to positive aspects. If unclear, use the term that researchers tend to use to capture the greater concept of positive aspects, rather than the facet of positive aspects they are investigating. For instance, the researcher may refer to positive aspects of caregiving and indicate this as the phenomenon of interest, but the study may investigate 'satisfaction' as a facet of the positive aspects phenomenon. In this case, you would code '0', for positive aspects.

- 0 = positive aspects
- 1 = positive outcome
- 2 = satisfaction
- 3 = gain

VPADEFN = positive aspects definition: Search in the body of the study for a working definition of positive aspects. This may not be present.

VPAMEASURE = positive aspects measure: Code according to the following for the measure used by the study.

- 0 = Positive aspects of caregiving (PAC)
- 1 = Caregiver Gains
- 2 = Carers' Assessment of Satisfaction Index (CASI)
- 3 = Caregiver Satisfaction Scale
- 4 = Caregiver Reciprocity Scale
- 5 = Caregiver Appraisal Tool
- 6 = Caregiver Satisfaction Scale Revised
- 7 = Family Role Reward Scale (FRRS)
- 110 = Positive Aspects of Caregiving Questionnaire-Iran
- 111 = Study specific

VPAPROPTIES = properties of the positive aspects measure: Describe the properties of the measure, for instance the number of items, the response method, possible range of scores, and meaning of score (higher versus low scores). If a facet of positive aspects is under investigation (e.g., satisfaction) report here that satisfaction is investigated as an indication of positive aspects and describe the measure.

VPAN = positive aspect (PA) sample size: Report the sample size related to the positive aspects data.

VPAMEAN: report the mean score of the sample of the measure PA measure.

VPASD: report the sample standard deviation on PA score.

CATEGORICAL VARIABLES INVESTIGATED IN RELATION TO PA

If PA measured in more than one way, indicate additional analysis by 1, 2, etc. (i.e., VSEXDT1, VSEXDT2) and describe in string variable.

If measure of relationship given, indicate whether 'r' or 'd', by adding this notation onto the end of the variable name (e.g., VSEXCORRGIVENr)

VSEX = sex of Caregiver and PA.

VSEXDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator (<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VSEXDAT = data for 'd': report raw data used to calculate effect size (e.g., Group X (Tx)(Tx = for treatment) mean, standard deviation, group sample size, etc.)

VSEXESCALC = reported the calculated effect size.

VSEXCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VSEXSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VRACE = race and PA: describe the racial groups investigated, and indicate the relationships that were investigated (e.g., African American Caregivers by White caregivers; Hispanic caregivers by White caregiver (2); where 2 indicates the second relationship investigated and include the proper annotation (e.g., VRACECORRGIVEN2d).

VRACEDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator (<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VRACEDAT = data for 'd': report raw data used to calculate effect size (e.g., Group X (Tx)(Tx = for treatment) mean, standard deviation, group sample size, etc.)

VRACEESCALC = reported the calculated effect size.

VRACECORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VRACESIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VRLN = caregiver care recipient relationship and PA

VRLNDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator
(<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VRLNDAT = data for 'd': report raw data used to calculate effect size (e.g., Group X (Tx)(Tx = for treatment) mean, standard deviation, group sample size, etc.)

VRLNESCASC = reported the calculated effect size.

VRLNCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VRLNSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VEMP = caregiver employment and PA.

VEMPDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator
(<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VEMPDAT = data for 'd': report raw data used to calculate effect size (e.g., Group X (Tx)(Tx = for treatment) mean, standard deviation, group sample size, etc.)

VEMPESCASC = reported the calculated effect size.

VEMPCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VEMPSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VDDX = dementia diagnosis and PA.

VDDXDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator

(<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VDDXDAT = data for 'd': report raw data used to calculate effect size (e.g., Group X (Tx)(Tx = for treatment) mean, standard deviation, group sample size, etc.)

VDDXESCALC = reported the calculated effect size.

VDDXCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VDDXSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

CONTINUOUS VARIABLES INVESTIGATED IN RELATION TO PA

If PA or other variables measured in > one way, additional analysis indicate by 1, 2, etc. (i.e., VAGEDT1, VAGEDT2) and describe in string variable.

VAGE = age and PA: Caregiver age by PA scores.

VAGEDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator

(<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VAGEDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VAGEESCALC = reported the calculated effect size.

VAGECORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VAGESIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

*[STRING] **VDURN** = duration of caregiving and PA: years of caregiving by PA.

VDURNDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator

VDURNDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VDURNESCALC = reported the calculated effect size.

VDURNCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VDURNSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VBURDEN = burden and PA: Report burden by PA.

VBURDENLABEL = other variable label: report the label used and or name of measure.

VBURDENMEASURE= other variable measure: describe the measure's properties.

VBURDENDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator

(<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VBURDENDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VBURDENESCALC = reported the calculated effect size.

VBURDENCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VBURDENSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VDISTRESS = distress and PA: report the name of caregiver distress used, by PA. * Note, is more likely the study variable is better categorized a psychological health variable.

VDISTRESSLABEL = other variable label: report the label used and or name of measure.

VDISTRESSMEASURE = other variable measure: describe the measure's properties.

VDISTRESSDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator

(<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VDISTRESSDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VDISTRESSESCALC = reported the calculated effect size.

VDISTRESSCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VDISTRESSSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VPHYS = physical well-being/health and PA: Describe the operational definition and measurement of physical well-being used, by PA.

VPHYSLABEL = other variable label: report the label used and or name of measure.

VPHYSMEASURE = other variable measure: describe the measure's properties.

VPHYSDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator (<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VPHYSDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VPHYSESCALC = reported the calculated effect size.

VPHYSCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VPHYSSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VPSY= psychological health/well-being and PA: described psychological health and well-being, by PA.

VPSYLABEL = other variable label: report the label used and or name of measure.

VPSYMEASURE= other variable measure: describe the measure's properties.

VPSYDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator (<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VPSYDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VPSYESCALC = reported the calculated effect size.

VPSYCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VPSYSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VSUBJ = subjective health/well-being and PA: describe subjective health by PA.

VSUBJLABEL = other variable label: report the label used and or name of measure.

VSUBJMEASURE= other variable measure: describe the measure's properties.

VSUBJDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator

VSUBJDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VSUBJESCALC = reported the calculated effect size.

VSUBJCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VSUBJSIG: report n.s. for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VLSAT = life satisfaction and PA.

VLSATLABEL = other variable label: report the label used and or name of measure.

VLSATMEASURE = other variable measure: describe the measure's properties.

VLSATDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator

(<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VLSATDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VLSATESCALC = reported the calculated effect size.

VLSATCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VLSATSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VDEMSEV = dementia severity and PA.

VDEMSEVLABEL = other variable label: report the label used and or name of measure.

VDEMSEVMEASURE = other variable measure: describe the measure's properties.

VDEMSEVDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator (<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VDEMSEVDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VDEMSEVESCALC = reported the calculated effect size.

VDEMSEVCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VDEMSEVSIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

VDEMBS = dementia symptoms and behaviours and PA.

VDEMBSLABEL = other variable label: report the label used and or name of measure.

VDEMBSMEASURE= other variable measure: describe the measure's properties.

VDEMBSDT = data type: indicate data type used to calculate effect size and use the Campbell Collaboration effect size calculator (<https://www.campbellcollaboration.org/escalc/html/EffectSizeCalculator-SMD9.php>).

VDEMBSDAT = data for statistic calculation: report raw data used to calculate the statistic (e.g., Group X (Tx) (Tx = for treatment) mean, standard deviation, group sample size, etc.).

VDEMBSSESCALC = reported the calculated effect size.

VDEMBSCORRGIVEN = include 'r' or 'd' to indicate statistic has been provided. Report the raw data provided for the measurement of the relationship.

VDEMBS SIG: report **n.s.** for not significant finding or report raw data p-value when provided. Report significance of calculated statistic, Confidence interval at 95% for 'd' calculations.

Additional investigations:

Code '0' (NO) or '1' (YES) for each construct investigated *in relation to PA*, and provide narrative on findings.

SUPRT: code '1' for informal, formal, instrumental, emotional support or satisfaction with support:

COPE: code '1' for CG coping:

EDUC: code '1' for CG education:

RESOUR: code '1' for resourcefulness:

RESIL: code '1' for resilience:

ADDNLF: additional findings/outcomes: write brief description of investigation and finding (including raw statistical data).

SUPRTO:

COPEO:

EDUCO:

RESOURO:

RESILO:

Summary of Findings

FSTDYF: provide summary of the findings (i.e., significant correlations, “take home messages”).

SFINDRESULT: extract the ‘findings’ or ‘results’ section of the article into this space.

SPHILOIMPACT: explain the impact of approach/study design/ epistemology on findings. If nothing notable beyond that captured in the data assumptions variable, leave blank.

SCONCL: report the themes that emerge from the synthesis analysis.

References to Check: report number of reference added to meta-integration, gleaned from the reference section of the article. References listed in the article to be cross referenced with Zotero reference manager, in order to identify new articles.

Appendix C

Semi-Structured Interview: Positive aspects of providing care

The interview begins with a brief introduction to let the participant know what to expect (i.e., there are a set questions the interviewer will pose but these are not ‘yes’ or ‘no’ questions, rather we are interested in your experiences and your perspective).

[PART ONE: Motivation and role captivity]

“How long have you been providing care to [CARE RECIPIENT’S NAME]?”

“How did you decide to become the primary caregiver?”

Here, participants may be able to relay a decision making process, but some may relay that it was not a decision, that they did not have a choice. This will provide information on role captivity, a factor related to both positive and negative caregiver outcomes. If the participant indicates they did not have a choice, follow-up questions surrounding their experiences of the perceived lack of choice will be posed, examples are:

“How has it been for you to take on this role, feeling that you did not have a choice?”

“Do you think your experience providing care would be different, if you had had a choice? How so?”

[PART TWO: Experience]

“Please tell me of your experience providing care to someone living with dementia.”

Here, it is possible that participants will not relay positive experiences. If so, the researcher will validate the participants’ experience. The researcher will then probe for positive experiences, examples are:

“[Validating statement such as: We certainly know that the providing care for someone living with dementia is difficult, particularly when that person is a friend or family member. Of course caregiver research has worked to get a better understanding of the negative aspects of providing care in hopes that in some way we might be able to alleviate that for you.]

Interestingly, some caregiver research has identified positive aspects of providing care. For example, some report personal growth, wherein caregivers learn that they are capable of more than they previously thought. What are your thoughts on positive aspects of providing care?”

“How does it feel to care for your parent/spouse/friend in this way?”

“Have you learned something new about yourself, since becoming a caregiver?”

Should a participant fail to report positive experiences, questions surrounding what would improve their experience of providing care will be posed, for example:

“Do you have a sense of what might improve your experience of providing care?”

[PART THREE: Positive aspects]

Should the participant report positive experiences, probing questions based on literature will be posed, examples are:

“What allows you to feel [the positive experience they reported] in response to the caregiving demands you’ve described?”

“Do you have a sense of how [the positive experience they reported] emerged for you?”

“Do you have a sense of what facilitates these positive experiences?”

“Do you have a sense of what makes it difficult to experience the positive aspects you described?”

[PART FOUR: Relationship]

Toward the end of the interview, if not already established, questions surrounding the quality of relationship between caregiver and care recipient will be posed.

“How would you describe your relationship with [CARE –RECIPIENT NAME] before you began providing care?”

“Has your relationship with [CARE RECIPIENT NAME] changed since you began providing care? How so?”