PERCEPTION OF CHOICE AND PSYCHOLOGICAL ADJUSTMENT IN INFORMAL CANADIAN CAREGIVERS: TESTING A MODIFIED FRAMEWORK OF STRESS AND COPING

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A DISSERTATION SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

GRADUATE PROGRAM IN PSYCHOLOGY
YORK UNIVERSITY
TORONTO, ONTARIO

August 2026

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Abstract

Introduction: With adults (65 years+) continuing to outnumber youth under 15-years, and the prevalence of chronic illness increasing with age, older individuals have increasing needs for caregiving assistance but no access to supports. Caregiving provided by family and friends has been linked to negative psychological, physical, and financial outcomes. While lack of choice has been identified amongst predictors (including illness type, caregiving burden, and relationship quality) of poor psychological adjustment of caregivers, few caregiving frameworks include choice in their models or use similar but conceptually different variables. This study tested a modified model of caregiver stress in a population of Canadian caregivers that includes choice and its relationship to psychological adjustment as a primary focus. Positive psychological outcomes of caregiving despite caregivers' lack of choice were also examined given the literature which shows wellbeing in caregivers despite caregiving burden.

Methods and Analyses: Based modified frameworks (Caregiver Stress Model, the Revised Stress and Coping Model, and Self-Determination Theory), a secondary analysis of the General Social Survey Caregiving and Care Receiving questionnaire was used to test the fit of a proposed caregiving choice and psychological adjustment model. Path analysis measured the relationships between sociodemographic predictors of caregiving choice, caregiving burden, coping, and psychological outcomes.

Results and Discussion: The fit of the model was good, and weighted beta coefficients were generated. In total, 59.14% of caregivers reported that they did not perceive having a choice in caregiving. All caregiver demographic characteristics significantly predicted choice in caregiving and subjective burden (*ps*<0.01). Choice was associated with lower burden (*b*=-1.36, *p*<0.01), anxiety (*OR*=1.74, 95% CI [1.71, 1.76]) and reported psychological symptoms (*b*=-

0.16, $p<0.001$), as well as greater positive aspects of caregiving ($b=0.31$, $p<0.05$) and life satisfaction ($b=0.16$, $p<0.001$). The addition of choice to the caregiving model is an important focus of study given that caregivers report not having caregiving choice. The use of a weighted estimate increases the generalizability of these results to caregivers in Canada, which is a study strength. Clinical considerations include prioritizing mental health evaluations of caregivers who report no caregiving choice given the potential impact on caregivers as well as care recipients.

Dedication

This work is dedicated to my grandfather, GOM, who often quoted the following verse, which accurately reflects the persistence all graduate students demonstrate as they complete their dissertation:

"The heights by great men reached and kept were not attained by sudden flight, but they while their companions slept, were toiling upward in the night."

~Henry Wadsworth Longfellow, The Ladder of Saint Augustine' (1850)

Acknowledgements

I would like to take the opportunity to thank the people involved in supporting my personal and academic growth. Your presence in my life has buoyed me throughout graduate school.

Dr. Mary Desrocher. Thank you for your steadfast and ongoing support. Your presence as a mentor has been invaluable. From project conception to completion, you have been involved in every aspect of this dissertation. I deeply appreciate your compassionate stance, your patience, and when necessary, your assertive approach that has helped me to cross the graduate school finish line. Thank you for believing in me.

Dr. Robert Cribbie. Your support through the statistical planning and execution of this project have been vital. I appreciate your accessibility and your knowledge in relation to this work.

Dr. Karen Fergus. Thank you for your participation on this project. Your perspective has greatly contributed to the quality of this work, and I thank you for your attentiveness and time.

Dr. Hugh McCague. Thank you for agreeing to be a Co-Investigator of this work. Your direct contribution of many side-by-side hours of statistical work has broadened my knowledge of statistics and made this the completion of this work possible. Thank you for time, wisdom, and patience.

Dr. Kristina Kokorelias and Dr. Matthias Hoben. Thank you for your participation as committee members for my defence. Your interest in my work, thoughtful questions, and attention to detail is appreciated.

Dr. Joel Katz. Thank you for chairing the defense committee and for your thoughtful questions and comments.

Dr. Jane Irvine. My journey with Clinical Psychology began with you. Thank you for your guidance, kindness and encouragement.

To my parents. Your unconditional support has been vital. You have expressed your pride in my accomplishments no matter the size, and for that I will always be grateful. I love you both very much.

To the York University Graduate Psychology administrative staff: Lori, Freda, Barb, and Alice. No matter the issue presented to you, you took on these tasks with diligence, perseverance, and creativity. There has never been a problem that you haven't been able to solve, and I express to you all my heartfelt gratitude.

Dr. Karima Kinlock-Quamina. The completion of this work is in part due to our biweekly coworking dissertation meetings, which I appreciate from the bottom of my heart. Thank you for your constant encouragement and humour throughout this process.

Dr. Jennifer Lewin and Dr. Serine Warwar. While our focus was not on research, your constant encouragement in crossing the dissertation finish line was appreciated and valued.

And finally, to my dear friends who have heard about this project and cheered me along on the sidelines for years, thank you. Whether it was being available to listen to the challenges I was experiencing or to cheer on my successes, I truly appreciate every aspect of your support. The completion of this work would not have taken place without you.

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Chapter One: Introduction

Prevalence and Impact of the State of Caregiving

For the first time in Canadian history, the aging population (over 65-years old) outnumbered youth under the age of 15-years old with an estimated population count of 31,350 more seniors in Canada as of 2015 (Statistics Canada, 2015). Recent population estimates revealed that the gap is widening with over 1.2 more million seniors (65-years and older) living in Canada in 2022 (7,330,605 seniors versus 6,707,576 children under the age of 15-years old; Statistics Canada, July 1, 2022). Moreover, the population replacement rate defined by the United Nations as the number of total births required in low mortality populations to ensure the replacement of future generations, is projected as of 2050 to be below the suggested global value of 2.1 children born per family (not accounting for population growth related to immigration; United Nations 2022; United Nations 2024), which may result in fewer individuals being available to support the care needs of the aging population. Research on family network structures by Alburez-Gutierrez et al. (2023) has projected smaller caregiver population pools over time. This study also reported that for a 65-year-old woman, the number of family members potentially available globally for caregiving support was projected to decrease by 38% (from 41 to 25 living relatives) when comparing family size projections between the years of 1950 and 2100. Moreover, increases in age differences between generations are also projected over time, leading the authors to suggest that older generations may be less available to serve as supports for their adult children. Instead, they may contribute to additional care burdens of the adult child's generation due to the older generation's increased need for care. The projections for this study are based on family networks which the authors termed "kinship structures" (Alburez-Gutierrez et al., 2023, p. 1) that include first-degree (parents, siblings) and second-degree family

members (grandparents, aunts, uncles, cousins, nieces, nephews) whom these authors highlight as a "crucial source of informal care" (Alburez-Gutierrez et al., 2023, p. 1). These statistics highlight a current problem faced by a growing number of elderly individuals in the population who have connections to fewer younger individuals to care for them at home (Canadian Institute for Health Information [CIHI], 2020). For the first time in several decades, recent increases in birth rate as per the 2021 Health Canada census (Statistics Canada, 2022a) have been reported, which suggests that trends in birth rates and possible associated kinship structures may be changing; however this new population growth does little to impact the current needs of individuals who require informal familial care.

Typically, supports provided by caregivers include help with the household, transportation, personal and emotional care, and/or lifestyle management support (e.g., appointment scheduling, and management of finances; Wilson et al., 2014). Caregiving supports are often provided informally by family and friends (Turner & Findlay, 2012) due to shifts in governmental policy which has placed increasing pressure on the home care of chronically ill individuals (Buhler-Wilkerson, 2007; Fast, Williamson et al., 1999; Keefe et al., 2007). The provision of home care by relatives or friends has been considered one of the pillars of governments' age based health care policies (Wray et al., 2023); however, the availability of family members as a provider of informal caregiving appears to be dwindling with recent research reporting that one in nine Canadians with mild to moderate functional limitations have been institutionalized, when their care could have been supported in the home environment (Canadian Institute for Health Information [CIHI], 2020). Reasons for these choices have been attributed to financial and time barriers (among other barriers) experienced by unpaid caregivers (CIHI, 2020). This is unsurprising, as an accounting of the out-of-pocket unsubsidized costs of

unpaid caregivers in terms of medications, respite care, transportation, and medical supplies and accessories are suggested to cost the caregiver and possibly the care recipient more than the established public costs of institutionalization (hospital, long-term care homes; Marani & Peckham, 2023). In fact, the Canadian government has purported to save an estimated $24 to $31 billion dollars annually due to the unpaid work of family caregivers (Bernier, 2014). More recent estimates based on Statistic Canada's 2018 Caregiving and Care Receiving survey suggests that this value is higher with the value of unpaid work "ranging from $97.1 billion to $112.7 billion" when estimating the cost that it would take for a professional to replace the work of unpaid caregivers in Canada (Fast, Duncan et al., 2024, p. 242). Fast, Duncan et al. (2024) also estimate that women contribute more to the care economy compared to men given that women spend more time engaged in caregiving. These authors suggest that the value of women's contributions to caregiving reflects up to $63.6 billion dollars in unpaid work for women compared $49.1 billion for men (Fast, Duncan et al., 2024). This reliance on familial contributions to our health care system is problematic given that the availability of unpaid caregivers as a resource of support to our aged population is dwindling. Studies show that women who were on average 85-years or older and who found themselves living alone (often widowed), were less likely to have unpaid caregivers available to provide care in comparison to individuals who lived with family members (CIHI, 2020). Approximately 25% of individuals aged 65-years and older have been called upon to provide unpaid care for immediate family members, relatives, or friends/neighbours (Arriagada, 2020). Thus, the foundational people upon which the government relies to share the caregiving load for aging individuals is unavailable or aging themselves, resulting in a growing gap in the provision of support needs for the population's elderly.

Both age and the degree of illness are among the many factors that have contributed to the increased need for informal caregiving. As individuals age, they are at greater risk of developing and living with disease (Ferri et al., 2005), and chronic illness has been shown to increase with age (Mittelmark et al., 1993; Prince et al., 2013; Siegel et al., 2013). Illnesses such as cancer, cardiac disease, and dementia (amongst other chronic conditions in individuals of advanced ages) are often accompanied by functional limitations (Stewart et al., 1989; Fong, 2019) resulting in an increased need for caregiving within older populations. A study examining the impact of first time cardiovascular and myocardial events on functional ability showed that, post-hospitalization, older adults experienced decreased functional abilities and increased disability over the decade after experiencing a myocardial infarction (MI) or stroke event (Levine et al., 2014). Controlling for their baseline level of disability, Levine and colleagues (2014) found that for individuals without baseline functional impairments, following a myocardial infarction, patients were found to have a mean of 0.4 functional impairments. For individuals experiencing a stroke (without baseline functional impairments), they were found to have a mean of 2.07 functional impairments (Levine et al., 2014). Functional impairments in cancer survivors via the development of chemotherapy-induced peripheral neuropathy has also been documented, contributing to increased needs for caregiving. In a group of older individuals (mean age 60-years), 27% of the sample reported some type of challenge with activities of daily living (ADLs). Further, logistic regression analysis predicted that functional impairment (measured as difficulty performing increasing numbers of ADLs) was 1.26 times more likely in those with greater degrees of neuropathy (Gewandter et al., 2013). Functional impairments remained significant in their analyses when non-walking ADL tasks were substituted as the predictor in the regression analysis (Gewandter et al., 2013). In a longitudinal study following a

sample of south-east Asian older adults, the need for support in the engagement of activities or instrumental activities of daily living (IADLs) were more than two times higher in those with three or more chronic illnesses (2.15 and 2.89 for ADLs and IADLs, respectively for women and men; Sharma, et al., 2021). In a 20-year follow-up of middle-aged individuals (50-64 years), 50% of individuals who experienced functional impairment in ADLs (measured 2-years after onset of their original decline) had persistent impairment, and 9% experienced further ADL decline (Brown et al., 2017). Overall, the research suggests that aging and/or illness is associated with increased functional decline, and therefore increased caregiving assistance. Moreover, the average age of seniors has continued to increase, with the recent Canadian life expectancy from birth (as 2023) being 79.6 years in males and 84.1 years in females (Statistics Canada, 2026). This is likely due in part to the contribution of technological approaches designed to improve the quality and efficiency of providing health care, in addition to greater individual focus on sustaining healthy lifestyle changes (Organisation for Economic Co-operation and Development [OECD], 2025). Social determinants of health (SDH) also impact life expectancies. SDH reflect the conditions in which people are born, raised and are aging (WHO, Overview, para 1), and social inequities experienced by individuals have been shown to have a negative impact on health (Abdi et al., 2025). Lifelong exposures to physical (e.g., nutritional) and social environments (e.g., social connection) have been found to positively predict healthy aging (Hernandez et al., 2025). The health of aging individuals and caregivers matters, as older caregivers' physical health has been associated with their mental health (Savela et al., 2022). As individuals within the baby boomer generation reach senior status, the combination of increased lifespans, efficient medical treatment, and lower birth rates/family networks suggests that fewer

individuals will be available to care for care recipients just as their needs for informal care are likely to increase.

Defining Caregiving and Caregiving Burden

What is Caregiving?

Caregiving is viewed as a multi-factorial construct which includes the promotion and support of a recipient's sense of physical and emotional well-being, as well as their social and professional (e.g., doctor) communications (Burridge et al., 2007). Caregiving can be categorized as provided by paid professionals or unpaid individuals who are providing support for institutionalized or non-institutionalized care recipients. The distinction of the unpaid caregiver lies in their motivation to care, which is driven by their relationship to the care recipient (Canadian Centre for Caregiving Excellence, 2026). The focus of this literature review and the research presented in this dissertation is centered on the experience of unpaid caregivers of adults. In Canada, 7.8 million individuals (aged 15 years and older) provided 20 hours per week of unpaid caregiving (Canadian Centre for Caregiving Excellence, 2026). Further, 1.8 million Canadians have reported being members of the sandwich generation, in which they are caring for both their children as well as older individuals (such as their parents; Statistics Canada, 2024). In general, unpaid caregivers of aged adults, adults with emotional or physical disabilities, or adults with chronic illnesses have been characterized as typically female (Canadian Centre for Caregiving Excellence, 2026; Schulz & Thomkins, 2010, Characteristics of Informal Caregivers, para 2; Statistics Canada, 2022) younger, caring for family members, having a lower income, providing care for individuals in old age (Redican et al., 2025), performing on average up to 35.7 hours of care per week (Canadian Centre for Caregiving Excellence, 2026), juggling work or other family commitments (Schulz & Thomkins, 2010, Characteristics of Informal Caregivers,

para 2; Stanfors et al., 2019), and engaged in long-term care lasting on average five or more years (Schulz & Thomkins, 2010, Characteristics of Informal Caregivers, para 3). For individuals providing help to older care recipients, caregivers providing a significant amount of help (defined as providing 20-plus hours of non-paid help) have been profiled as having greater emotional, financial and social difficulties compared to their non-caregiver counterparts (Wolff et al., 2016). Compared with non-carers, caregivers have also been identified as having poorer self-reported mental health (anxiety, depression) and physical health outcomes (cardiovascular, diabetes, arthritis; Stacey et al., 2019). It is important to note that caregiving from an illness context refers to care that is administered at a level beyond the support typically provided between marital partners or by a parent caring for their child (Revenson et al., 2016). The Canadian Centre for Caregiving Excellence also highlights that while the relationship motivates unpaid care, caregiving in the medical sense "does not include parents or guardians caring for a child without a disability, medical condition or illness" (2026, p. 4). Given this definition, parental support of adult children with chronic illness or those experiencing non-typical development who require support would be considered caregiving. Revenson and colleagues (2016) highlight activities that they consider to be the difference between caregiving and social support which include the following: engagement in caregiving during an extended and consistent period of time, providing care that is "unidirectional," and a relationship which includes a sense of obligation to provide that care (pp. 6–7). Moreover, when caregivers and care recipients are related or living in the same household, it can become difficult to identify the exact transition into the caregiving role (which differs from marriage for example, which has a clear transitional point), particularly when caregiving has increased gradually over time. Stefánsdóttir et al. (2022) detailed the caregiving transition period in a study examining the experience of

males becoming caregivers for spouses with dementia. Their theme of the "denial phase", captured how one participant had not identified changes in their spouse, recognizing the impact of his wife's illness after the fact (Stefánsdóttir et al., 2022, p. 745).

Taken together, an individual's role as an unpaid caregiver can include many physical and emotional challenges. Reduced opportunities for maintaining full time work (Stommel et al., 1994) or quitting work altogether (Lilly et al., 2010) due to the varying needs of the care recipient for at home care or supervision can also contribute to caregiver stress. Further, individuals engaged in greater caregiving hours are more likely to retire early due to challenges balancing care needs with work responsibilities (Koreshi & Alpass, 2026) potentially creating financial pressure for caregivers due to lost retirement income. Governmental subsidies in the form of Employment Insurance Caregiving Benefits are available in Canada for unpaid caregivers; however, the target group for this support are individuals providing care for a care recipient with an acute illness or someone projected to experience imminent death (within 6-months), and the subsidy does not cover the needs of those providing support to individuals with chronic or long-term conditions (Government of Canada, 2025).

How is Caregiving Measured?

Caregiving measurement reflects the behaviours that the caregiver engages in on behalf of another individual (the care recipient). The care recipient, as reflected in studies of adult caregivers lived experiences, exhibit difficulties with functional abilities in areas of personal care and/or cognitive functioning. Further illness type, and the degree to which care recipients experience functional limitations varies (Centers for Disease Control and Prevention [CDC], 2007). Caregiving behaviours are commonly grouped into two overarching types of caregiving which can be differentiated as activities needed for independent functional living, versus

activities that are not necessary but contribute to increased quality of life (Guo & Sapra, 2022). The former labeled 'Activities of Daily Living' (ADLs), often include mostly physical tasks such as "ambulating, feeding, dressing, personal hygiene, continence, and toileting" (Edemekong et al., 2025; Basic Activities of Daily Living, para 1). Tasks that may require greater use of an individual's executive functioning are grouped into the 'Instrumental Activities of Daily Living' (IADLs) category. These tasks include: "cooking, cleaning, transportation, laundry and managing finances" (Guo & Sapra, 2022, Definition, para 1), medication management, and organization and communication related to medical care (e.g., scheduling a doctor's visit; Edemekong et al., 2025).

Kent et al. (2016) have highlighted that that research rarely agrees on a singular construct of caregiving. The operationalization of this behaviour differs across studies by the type and number of tasks, whether tasks provided are heavily focused on ADLs versus IADLs, and the amount of time spent caregiving. Variations in how caregiving is measured can exclude certain types of caregivers from the research (e.g., low-time caregivers), thus potentially ignoring the specifics of their needs.

Caregiving Burden

Caregiving burden reflects a term that captures the negative impacts of caregiving as experienced by the caregiver. Measures of caregiving burden reflect mostly subjective impacts, although the impact of objective caregiving burden has also been studied and has been identified as conceptually different from subjective burden with unique psychosocial correlates associated with both of these concepts (Montgomery et al., 1985). Hoenig and Hamilton (1967, as cited in Montgomery et al., 1985) were identified as the first researchers to dichotomize burden in an effort to extricate subjective perceptions from objective caregiving events. As such, objective

caregiving focuses on the observable impacts that accompany caregiving, such as frequency of activities, and the number of hours engaged in activities or instrumental activities of daily living. Subjective caregiving includes attribution of emotions, attitudes, and feelings associated with the activity of caregiving (Hoenig & Hamilton, 1967; as cited Montgomery et al., 1985). An often-expressed complaint of caregiving burden research is the lack of operationalization and consistent measurement of the construct (Bastawrous, 2013), leading to a heterogenicity of outcome measurement. These differences can challenge attempts to compare and draw conclusions about outcomes of caregiving burden across studies. Further, weak correlations between objective and subjective burden have been reported (Fekete, 2017). The theoretical framework employed in the present study views caregiving burden via an appraisal lens (see Theoretical Framework Chapter Two), and subjective caregiving burden was examined as primary focus in the present work.

Examining the Impacts of the Caregiving Role

As of 2012, eight million individuals were acting as informal caregivers for seniors in Canada (Sinha, 2012). It is well documented that caregiving has been linked to negative psychological (anxiety, depression, stress, quality of life; Buyck et al., 2011) and physical health outcomes (Litzelman et al., 2014; Vitaliano et al., 2004), as well as lost caregiver earnings and employment (Stone & Short, 1990; Whetten-Goldstein et al., 1997) contributing to financial strain (Sawatzky & Fowler-Kerry, 2003). Several factors including illness type (Kim & Schulz, 2008), lifestyle interference and caregiving burden (Cameron et al., 2002), lack of social support (Grant et al., 2000), and relationship quality (Williamson & Shaffer, 2001), have been identified as predictors of negative outcomes in caregivers. Caregivers also report challenges navigating the health care system (Willemse et al., 2016), experience barriers accessing caregiver training

and information, and caregiver supports such as respite care and psychological supports (Bowen, 2001; Law et al., 2021; Willemse et al., 2016) further contributing to caregiver distress (Cruz et al., 2024).

The COVID-19 pandemic placed a spotlight on caregiving-related factors impacting the psychological adjustment of caregivers which were reportedly worsened during the pandemic as supports for caregiving became less accessible due to the need for social distancing. Studies have shown that the pandemic contributed to the disruption of respite care which further contributed to caregiver stress and burden. For example, a qualitive study highlighted caregivers' experience of professional support changes, noting that time allotted for home care was reduced, and as such at home caregivers felt they were doing more caregiving typically taken on by home-care professionals (Parmar et al., 2021). Respondents also reported that the pandemic added to the challenge of navigating the health care system due to rapidly growing amount of caregiving information being provided online which they had to sort through, as well as the challenges in accessing professional help due to health care providers working from home (Parmar et al., 2021). The interruption of respite services during the pandemic resulted in increased stress, worry and emotional difficulty experienced by caregivers due to more time spent with care recipients and increased physical care responsibilities (Ultz et al., 2025). Caregivers also reported decreases in psychological adjustment (i.e., respondent reports of anxiety, depression, and feeling despondent) due to the isolation and the solo shouldering of caregiving responsibilities (Ultz et al., 2025). Caregivers noted that their experiences of isolation also impacted opportunities for brief respite, as well as the loss of physical support from family and friends who, prior to the pandemic tended to offer help without the caregiver making specific requests for aid (Ultz et al., 2025). Also mentioned by caregivers was how the pandemic

emphasised the precariousness of relying on formal respite services due to “lengthy waitlists”, and “staff shortages” (Ultz et al., 2025, p. 5).

Choice in Caregiving and Psychological Outcomes

Given the impact of caregiving on caregivers’ psychological adjustment, research continues to explore relationships between the caregiving role and psychological wellbeing. A lesser explored predictor of psychological adjustment in this population includes perceived choice in engaging in caregiving (Schulz et al., 2012), despite the fact that many caregivers report feeling that they had little choice in becoming a caregiver. Caregiving choice is defined as the “psychological state in which the caregiver feels [they] could choose to stop being a caregiver” (Zegwaard et al., 2013, p. 3). This definition yields two types of caregivers, those who voluntarily choose to engage in caregiving behaviour, and those who feel obligated to remain in a caregiving state and cannot engage in self-deterministic movements to extricate themselves from the caregiving role. Research supports the existence of the latter group with 47% to 82% of surveyed caregivers reporting that they felt they had no choice in engaging in their caregiving responsibilities (Pertl et al., 2019; Sawatzky & Fowler-Kerry, 2003; Schulz et al., 2012; Ward & Carney, 1994).

Lack of choice in becoming a caregiver is an important construct to study due to its association with self-reported emotional distress and strain in caregivers (Berg-Weger, 1995; Li et al., 2024; Longacre et al., 2014; Schulz et al., 2012), and negative association with indices of wellbeing (Al-Janabi et al., 2018; Li & Lee, 2020). Ancillary evidence of the impact of choice on caregiving psychological adjustment is also evident in research on filial obligation. Filial obligation reflects one’s moral or social obligation to care for one’s parent. In many cultures, filial piety reflects the belief that the older adult is respected as the head of the family, thus their

needs as they age become the responsibility of their adult children (Ikels, 2004). While research regarding one's sense of obligation to care and the impact on psychological wellbeing (e.g., caregiving burden) has been mixed, a meta-analysis on the topic has shown that adult children who felt they had a stronger need to engage in filial obligation exhibited greater depression symptoms even when accounting for cultural differences (Pan et al., 2023). Research on East Asian immigrant families has shown that individuals who are acculturated to Western standards of living experience greater reported caregiving burden (Guo et al., 2019). Examining an individual's perception of choice (either as an obligation or as a social choice based on beliefs and ideals related to contributing to one's family) is therefore important, as these outcomes show cultural norms of filial piety may not always buffer the subjective and psychological experiences that arise from caregiving in those contexts (e.g., caregiver burden and distress).

Taken together, the inclusion of choice as a factor in caregiving outcomes research remains important, as individuals who perceive they have no choice in becoming caregivers are more likely to become reluctant caregivers who report less willingness to perform their assigned caregiving role (Burridge et al., 2007). Identification of individuals likely to become reluctant caregivers (due to lack of choice) is important, as it is associated with negative outcomes in caregivers (i.e., stress, decreased quality of life; Berg-Weger, 1995), as well as poor outcomes in care receivers which include care recipient institutionalization (Burridge et al., 2007), or physical/emotional negligence (Schiamberg & Gans, 1999). Ongoing research of factors contributing to one's appraisal of the caregiving experience (specifically factors contributing to caregiver's perception of choice) are therefore needed to precisely identify at risk groups and provide direction for caregiver psychosocial inventions. Research has shown that increased perception of choice for an informal caregiver has been found to predict a 12% decrease in long-

term care use (at 1-year follow-up) for medical populations with progressive illness trajectories such as individuals with Alzheimer's, Parkinson's, or other primary non-specific dementia (Pertl et al., 2019). Taken together, this evidence further highlights the importance of studying the choice construct.

The State of the Literature: Caregiver Stress Frameworks

Despite the empirical evidence that points towards choice as an important predictor of psychological outcomes in caregivers, few caregiving frameworks include perceived choice in caregiving as a factor in their models (Berg-Weger, 1995; Lu et al., 2017; Weitzner et al., 2000). Constructs adjacent to choice such as locus of control have been included in models of caregiving (Pearlin et al., 1990; Raina et al., 2004; Wallander et al., 1989; Wallander & Venters, 1995); however, locus of control (LOC) is conceptually different from perceived choice. Locus of control refers to one's general orientation with respect to one's sense of personal control over one's environment (Rotter, 1966). Thus, individuals with an external LOC might view their outcomes being due to chance, versus those with an internal LOC perceiving instead that they have personal control over their situation. As Funk and Kobayashi (2009) have highlighted, situational events in caregiving (e.g., lack of finances, diminishing systematic resources related to care) often yield caregiving situations that are constrained despite one's desire (or lack thereof) to contribute to a caregiving situation. Funk and Kobayashi's (2009) argument of expanding on societal contributions to one's perception of choice in caregiving (e.g., the contribution of gender and social class that motivates one to engage in caregiving) calls for a level of study complexity regarding caregiving that has been attempted in the present work. Exploring variables that have an impact on choice will be a key goal of this study, with Chapter Three (Specification) outlining these variables. The use of SEM to understand the

interrelationships of these variables is key to quantifying this complexity and is an important starting place to explore the multifactorial nature of caregiving choice.

Structural equation models (SEMs) designed to examine caregiver characteristics and caregiver burden (Tough et al., 2024; Qi et al., 2026), as well as models of caregiver burden and psychological adjustment (Morlett Paredes et al., 2017; Wen et al., 2021) have been tested in various care recipient illness samples (both homogenous and heterogenous medical conditions); however, at the time this study was conceptualized no known SEM had included caregivers' perception of choice as the primary variable of interest as a predictor for both subjective caregiver burden and psychological adjustment. Canadian population level studies examining the relationships between caregiver choice and psychological adjustment are limited, with only two known studies having been published in the last five years (Li, & Lee, 2020; Li, et al., 2024). Both aforementioned studies employed the General Social Survey, Caregiving and Care Receiving datasets in their analyses. Li and Lee (2020) examined the moderating impact of caregiver choice on the relationship between the caregiver/care recipient relationship-type (e.g., spousal, relative, non-kin) and caregiver distress (where distress was measured by the endorsement of up to 10 possible psychological symptoms; Li & Lee, 2020). They based their construction of psychological wellbeing on the Brief Symptom Inventory (an amalgam of somatic and psychological symptoms), and as such Li and Lee's (2020) computed psychological symptoms variable combines questionnaire items of caregiver anxiety and depression as a single outcome. This choice therefore precludes analysis or conclusions on the distinct impact of choice on psychological symptoms versus anxiety in caregivers despite the prevalence of caregiving anxiety being assessed at 35.5% in a meta-analytic study of caregivers (Soh et al., 2025). Li et al. (2024) tested the fit of an SEM examining the impact of caregiver and care recipient factors on

caregiver distress employing a six-factor measurement model of caregiver characteristics. These factors included subjective and objective burden, availability of social support, disruption of social life, emotional experience of caregiving, and caregiving history. Caregiver and care recipient demographics were also included as covariates in this model. While choice in caregiving contributed to the measurement of the caregiver's (positive) emotional experience, its contribution to the latent variable precluded a description of the direct effects of the caregivers' perceived choice on caregiver burden and psychological distress. The present study addresses these limitations by examining caregiver choice and caregiver psychological adjustment using path analysis, allowing for the reporting of relationships between caregiver characteristics and caregiver choice and burden, and caregivers' perception of choice and psychological adjustment as measured by positive adjustment (life satisfaction) and caregiver distress variables (psychological symptoms and anxiety).

Positive Psychological Outcomes Associated with Caregiving

In addition to examining negative psychological outcomes associated with lack of choice and caregiver burden, research in post-traumatic growth has demonstrated the emergence of positive psychological outcomes associated with caregivers' experience of stress within chronic illness contexts. Post-traumatic growth has been conceptualized as personal growth or positive changes that take place after the experience of struggling with a traumatic event (Linley & Joseph, 2004). Tennen and Affleck (2005) refer to growth after trauma as benefits that were gained after a chronically stressful experience. The first known conceptualization of this construct was presented by Tedeschi and Calhoun (1996) who identified three areas of growth that have been identified including a change in interpersonal relationships or desire for connection, change in personal characteristics (e.g., finding self as more resilient), and shift in their beliefs regarding

themselves and the world (e.g., changing what is perceived as meaningful). Within the caregiving context, the concept of post-traumatic growth has been captured by the construct of positive aspect of caregiving (PAC). PAC is an outcome of caregiving, such that positive growth in areas such as relational closeness, and experiences of caregiving satisfaction occurs in the face of a challenging caregiving experience. In a study of Canadian caregivers (of care recipients over the age of 65 years), 95% of the respondents (N= 30,865) reported that the outcome of their caregiving experience was positive which included their sense of personal satisfaction and their sense of closeness to the care recipient (Turner & Findlay, 2012). Further research has shown that PAC is associated with lower depression scores, subjective burden and self-reported physiological health ratings in caregivers (Abdollahpour et al., 2017; Cohen et al., 2002).

Evidence of positive caregiver adjustment (e.g., happiness, life satisfaction) despite experiencing limitations in one's caregiving choice (Al-Janabi et al., 2018), in addition to evidence which has identified chronic stress in caregivers as a co-occurring predictor of negative and positive affect (Pratesi, 2011), suggests the need to account for positive adjustment within caregiving models examining caregiver psychological adjustment. While research centers on negative psychological and health effects associated with lack of choice (Schulz & Sherwood, 2008), factors such as 'marital reciprocity' appear to dampen the negative impact when caregivers perceive a lack of choice regarding their role (Boeiji et al., 2003) suggesting that not all people who perceive little choice in their caregiver role will exhibit negative psychological adjustment. From a policy point of view, while studying the negative outcomes associated with caregiving variables can highlight factors that might identify 'at-risk' individuals, studies focused on fostering positive outcomes are also important. O'Rourke and colleagues (2010) have argued that examining resilience in caregivers can also be used as a means of assessing

vulnerabilities in certain individuals by identifying those who are least resilient. In those who experience positive outcomes it also identifies the existence of potentially modifiable targets for intervention that can facilitate positive adjustment and growth.

Psychological Wellbeing and Physical Health

The focus of this research is not on health outcomes; however, the study of wellbeing is relevant to physical health and wellness research, and there is a great deal of empirical support regarding the positive relationships between psychological wellbeing and physical health. Typically, individual psychological wellbeing is linked to health (Trudel-Fitzgerald et al., 2019), with negative psychological states being associated with disease development (e.g., stress-related cardiomyopathy; Compare et al., 2014), and all-cause mortality (Russ et al., 2012). The mechanisms of illness are posited to be through the experience of stress which has shown to impact behavioural (e.g., engaging in less health promoting behaviours; Sisk, 2000), pathophysiological (Tsigos et al., 2020), and immune (Gialluisi et al., 2020) responses.

Taken together, this brief review supports the development of additional empirical work examining the predictors and psychological impacts of perceived choice in caregiving for unpaid caregivers, which is the focus of the present work. Specifically, the purpose of this study is to examine caregiver characteristics as predictors of their perception of choice in caregiving, as well as to examine how choice impacts psychological adjustment in unpaid caregivers, namely subjective caregiver burden, and caregiver psychological adjustment. This model differs from other SEMs as this study includes both positive (life satisfaction) as well negative (psychological symptoms and caregiver anxiety) psychological measures of adjustment as the outcome variables. Further, this SEM also includes predictors of positive adjustment (via the inclusion of the PAC variable), accounting for the experience of positive outcomes in caregivers even when

caregiving situations are challenging. This model is based on two frameworks of stress and coping and the Self-Determination Theory that are detailed in the Theoretical Framework that follows. Specification of the direct relationships between predictors and outcomes of caregiver choice, adjusting for the contribution of relevant caregiver covariates is presented in a later chapter (Chapter Three).

Chapter Two: Theoretical Frameworks

Given the aforementioned gaps in the literature, the objective of this study is to test a modified model of caregiving and adjustment based on the Conceptual Model of Alzheimer's Caregivers' Stress (Pearlin et al., 1990), and the Revised Stress and Coping Model (Folkman, 2008) in order to examine the relationships between perceived choice in caregiving and psychological adjustment. The inclusion of the choice variable within the relationship between caregiving and psychological outcomes is supported by Self-Determination Theory (Ryan & Deci, 2000), which provides a useful context to explain how choice (or lack thereof) in caregiving can impact one's wellbeing. Specifically, the importance of choice draws from the concept of autonomy which Ryan and Deci (2000) consider an essential psychological need for the development of individuals' wellbeing. The caregiving literature highlights negative outcomes associated with lack of choice in caregiving for both the care recipient (Burridge et al., 2007) and the caregiver (Berg-Weger, 1995; Longacre et al., 2014; Schulz et al., 2012), resulting in a need for choice to be a specific focus in caregiving research. These frameworks are further detailed in the present chapter.

Conceptual Model of Alzheimer's Caregivers' Stress

Pearlin and colleagues' (1990) Conceptual Model of Alzheimer's Caregivers' Stress is often cited as the groundwork for research examining the stress process in caregiving populations (e.g., Anthony et al., 2017; Kavanaugh et al., 2015; Kim et al., 2014; Mickens et al., 2018).

Their model is described as an attempt to unify the caregiving literature and conditions that lead to the development of stress within the domain of caregiving. It was constructed using empirical research which examined the lived experiences of caregiver spouses and children of

care recipients with Alzheimer's disease. It also integrated the combined authors' clinical experience with the dementia caregiver population. Pearlin and colleagues (1990) conceptualized that the caregiver stress process is composed of four domains each of which include multiple sub-components. The domains include the background and context of the caregiving stress process, the stressors (primary stressors, secondary role strains, secondary intrapsychic strains), variables that mediate stressors (specifically social support and coping), and psychological and physical health outcomes. As such the model is constructed such that there is a relationship from the background to the psychological outcomes as detailed by the following: Background>Primary Stressor>Secondary Role Strain > Secondary Intrapsychic Strains>Outcomes. In this model, the background (e.g., the personal and economic caregiver characteristics such as age and socioeconomic status; SES) directly predicts each of the domains following it, such that there is a relationship between the background and all other domains listed in the model. Further, Pearlin et al. (1990) highlights that the coping and social support variables in their model mediate the relationships between and within each domain (that is the five domains listed, as well as mediating the relationships between each sub-category of the stress domain). Pearlin and colleagues' (1990) view of the stress process highlights how social inequity impacts both the "risk of exposure" to stressors as well as the resources needed to modify these stressors (Pearlin, 1999, p. 401). As such, Pearlin (1989) views the social structure in which the stress experience is originated and embedded as an important part of the stress experience, rather than a set of factors to be held constant in one's analyses. Primary stressors (e.g., subjective or objective 'threats' as per the care recipient's illness symptoms, or the caregiver's experience of caring), secondary role strains (e.g., conflicts with family related to perception of caregiving, or the severity of the care recipient's illness, and caregiver social, occupational or economic

pressures), secondary intrapsychic strains (e.g., role captivity, negative impact to self-concept such as self-esteem or mastery, or caregiving related growth), as well as the outcomes (e.g., depression, anxiety) are therefore all directly predicted by background factors. Primary stressors also directly predict each of the domains that follow it in the same manner listed above, and this pattern continues as one moves down the chain. Relationships between domains are all mediated by coping and/or social support resources. As per the authors' suggestion to use this model as a research guide, various caregiving populations (cancer, cardiac, traumatic brain injury, and dementia caregivers) have been included in SEM models of caregiving stress and burden based on Pearlin and colleague's (1990) work (Chronister & Chan, 2006; Gaugler et al., 2009; Kahana et al., 1993), across multiple cultural contexts (e.g., Lee et al., 2006; Meecharoen et al., 2013; Montoro-Rodriguez & Gallagher-Thompson, 2009).

Pearlin and colleagues' (1990) model attempts to capture the positive impacts of caregiving via the measurement of secondary intrapsychic strains (e.g., caregiver self-perceived growth); however, the psychological outcomes domain of this model is solely focused on distress. Thus, it does not directly capture what has been coined in the literature as 'uplifts' (as an outcome) associated with caregiving. The concept of uplifts is further described later in this chapter but in short, they refer to the rewards experienced from providing care and have been hypothesized to protect individuals from the challenges of caregiving (Kinney & Stephens, 1989). Empirically, research on caregivers have shown positive psychological (Yu et al., 2025) outcomes even in individuals who report high subjective caregiving burden. Given Pearlin and colleagues' description of caregiving relationships as being "transformed from the ordinary exchange of assistance … to an extraordinary and unequally distributed burden" (1990, p. 583), it is not surprising that the model tends to hold a more deficit-based outcome view of the

caregiving stress process. The outcomes of anxiety, depression, and irascibility (derived from the Hopkin's Checklist; Parloff et al., 1954) either report the absence or presence of symptoms with items that cover low mood ('feeling blue, feeling lonely'), anger ('feeling tense or keyed up'), anxiety ('feeling nervous' or 'fearful'), or other psycho-physical changes including a failure to maintain health practices, and the seemingly ultimate outcome of "yielding" of one's role (described by Pearlin and colleagues as no longer being a caregiver either abruptly or chronically based on the context; 1990, p. 590). Typically, a deficit-based approach does not capture the well accepted definition of health advocated by the World Health Organization as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (World Health Organization, WHOa, n.d., Constitution, para 1). Similarly, the WHO defines mental health as "more than the absence…of mental disorders" (World Health Organization, WHOb, n.d., para 1); instead, mental health is a phenomenon that exists on a "complex continuum, with experiences ranging from an optimal state of well-being to debilitating states of great suffering and emotional pain" (World Health Organization, WHO, 2022, p. xiv). The present study aims to take the definition of mental health into account by including both distress and growth measures (such as the caregiver's ratings of overall life satisfaction and positive aspects of caregiving) in the model being tested in the present work.

Transactional Model of Stress and Coping

The Transactional Model of Stress and Coping (Folkman, 1984; Lazarus & Folkman, 1987) has previously been employed in studies of psychological adaptation in caregivers (Gilhooly et al., 2016; Lee et al., 2013; Lu et al., 2017; Turner-Cobb & Barnett, 2018). Moreover, this model has been referenced as a theoretical guide for the specification of structural

equation models focused on describing the relationship between caregiving burden and psychological and physical outcomes (Palmor Haspel et al., 2020; Yuan et al., 2024).

Lazarus and Folkman (1987) described the stress process as a system of appraisals (threat and resource appraisals) and coping behaviours that mediate the relationships between the environmental-personal stimuli (antecedents), and positive/negative emotions (outcomes) in relation to the onset of a specific stressor. Their framework details the stressors as an intersection of environment (such as "demands, constraints and resources, ambiguity, and imminence"; Lazarus & Folkman, 1987, p. 143) and person ("goal hierarchies and belief systems", mastery and perception of control; Lazarus & Folkman, 1987, p. 143) related variables such that they are appraised cognitively to establish both the presence of threat from stimuli (stressors) and the appraisals of available coping resources, in order to determine the coping behaviours necessary to address the established threat. The appraisal stage is comprised of a primary appraisal which determines whether there is a personal stake in a specific event, which is then viewed as threatening versus challenging. A secondary appraisal determines the availability of coping resources in relation to the appraisal of threat. Thus, one of the goals of coping as described by this model, is to achieve a transformative response on a threat appraisal via problem focused coping (finding a solution to the threat), or emotion focused coping (emotion regulation strategies aimed towards situations that are unchangeable). Lazarus and Folkman (1987) argue that the function of coping in relation to the stressor and appraisals of said stressor (e.g., situational controllability versus one that needs to be accepted), rather than its efficacy (e.g., positive adaptation of the individual), is the goal of coping within the stress process. It is for this reason that these researchers argue for repeated assessment of coping behaviours within the same stress situation given that the outcome of the stress process may create changes in one's

reappraisal of a stressor (e.g., the stressor may no longer be a threat), this may require different coping strategies, or no further coping behaviours and ultimately the reappraisal leads to varied adaptational outcomes. Outcomes of the stress process are split into short-term and long-term outcomes. These include immediate emotions that are positive or negative, or physiological changes that are more proximate to the appraisal-coping process. Short-term emotional outcomes such as distress or relief are generated (categorized as positive or negative) which contribute to the development of long-term psychological and physical health impacts. The transactional portion of this theory refers to both the interrelationship between person and environmental variables, as well as the feedback loop from the short-term emotional outcomes that contribute to the re-appraisal of potentially altered person-environment stressors. Lazarus & Folkman (1987) posited that if a stress event was resolved, positive emotions would emerge, and if the event was not resolved, negative emotions would be fed back into the appraisal process leading to the experience of chronic stress (Folkman, 2008).

While most caregiving research is focused on negative emotional outcomes associated with caregiving stress and burden, another area of research that attempts to explain caregiver growth is known in the literature as caregiving uplifts. Uplifts are often included amongst measures of PAC and are typically operationalized as the satisfaction experienced as a result of caregiving (Kramer, 1997). It has been defined as a positive appraisal that works to counteract the stressful aspects of caregiving (Kenny & Stephens, 1989). Kenny and Stephens (1989) used a hassles and uplift scale in their research which was designed to test predictors of caregiving hassles/uplifts, and how they impacted psychosocial wellbeing in caregivers of individuals with dementia. They listed the most frequent uplifts (according to their developed scale) reported by their sample of caregivers which included: the care recipient being responsive, cooperative, and

smiling, and the caregiver perceiving their family and friends as showing understanding about their caregiving, as well as family being in the presence of their care recipients. Caregiver characteristics such as being younger and spending more time with the care recipient predicted greater caregiving uplifts. Moreover, their composite scale of net hassles and uplifts (such that a positive score was achieved when caregivers reported more uplifts than hassles) was predictive of fewer interruptions in caregivers' interpersonal relationships due to their caregiving. Further, the caregiving literature has identified caregiving uplifts being present in the face of caregivers' experience of high caregiving burden (Silva et al., 2015). Thus, the model in the present study has included a measure of caregiving uplifts (i.e., positive aspects of caregiving). The inclusion of the uplift variable was guided by the Revised Stress and Coping Model (Folkman, 2008) who theorized the importance of accounting for positive emotions that arise in the presence of "intensely stressful" situations (p. 3). Folkman (2008) postulated that positive emotions could be generated by finding positive meaning in stressful situations. Specifically, Folkman's adapted model describes the negative outcomes of stressful events (as could be the case when caregiving responsibilities increase within the context of worsening or lengthened chronic illness) that still lead to psychological wellbeing via the implementation of meaning-focused coping. Meaning-focused coping draws on an individual's beliefs, values, and goals to motivate coping during times of stress (Folkman, 2008). Benefit-finding was highlighted as one type of meaning-focused coping that reflects a sense of growth or change which involves the active participation of an individual to engaged in meaning-based work (Folkman, 2008). Ongoing stress and how stress is managed is relevant to caregiving research given caregivers' experience of burden, particularly in individuals providing care to recipients with progressive chronic illnesses. For example, serious cardiovascular illness such as heart failure has been shown to involve progressive

declines in health accompanied by moments of acute deterioration (hospital stays) and episodes of recovery until death (Murray et al., 2005) leading to chronic and repetitive stressful episodes for a caregiver. The role of positive appraisals via meaning-based coping, and how they may buffer the impact of a stressful caregiving experience is thus an important aspect to study in caregiving research.

Self-Determination Theory

Self-Determination Theory (SDT) is a framework designed to understand the environmental needs (both psychological and social) of humans that result in fully functioning and thriving people. It aims to delineate between and within person-differences in human functioning and personality development by examining the factors that facilitate or hinder "vitality, motivation, social integration, and wellbeing" (Ryan & Deci, 2017, p. 4). Within SDT, motivation is grounded in an organismic perspective that humans (and other primates) have evolved to be curious and social beings, and that infants' inherent tendencies to seek out novel experiences, explore, and gain mastery in the world is driven by intrinsic motivational forces (Ryan, 1995; Ryan & Deci, 2000). However, these intrinsic motivational forces are not maintained as one develops, therefore SDT is focused on how to maintain or promote intrinsic motivation via the satisfaction of three important basic psychological needs, namely autonomy, competence, and relatedness.

Psychological needs are defined as "nutriments or conditions that are essential to an entity's growth and integrity" (Ryan, 1994, p. 410). Rules that allow other constructs into the SDT as new psychological needs are strict focusing only on needs that are essential for growth (Vansteenkiste et al., 2020). The three psychological needs currently included in SDT are relatedness, competence, and autonomy. Relatedness consists of feeling a sense of belonging and

connection with others. For this need to be satisfied, individuals need to feel personally affirmed and acknowledged by others, or to feel significant, important, connected, or accepted (Ryan & Deci, 1997, p. 96; Ryan & Deci, 2000). Competence refers to a feeling of efficacy or mastery over activities undertaken or planned and includes one's sense of having an impact over their environment (Ryan & Deci 1997, p. 95). Thus, feelings of satisfaction that arise due to a job well done fulfil the need for competence to be experienced. Finally, autonomy refers to concepts such as volition and willingness, such that choices that are made connect with a sense of internal coherence (Ryan, 1995), and do not involve any type of external coercion that influences behaviour (Ryan & Deci, 2017, p. 97). Thoughts, behaviours, and emotions must be congruent, and the full involvement of ones "resources, interests, and capacities" must take place for full satisfaction of autonomy to be experienced (Ryan & Deci, 1997, p. 97). As a need, autonomy is unique in that its presence is posited to be needed for the other psychological needs to be satisfied.

The Basic Psychological Needs Theory

The Basic Psychological Needs Theory (BPNT) is a mini theory of SDT that is focused on the development and maintenance of individuals' psychological and physical wellbeing. The BPNT describes the impact of each of the psychological needs on wellness and posits that satisfaction of all three needs are required to achieve optimal wellbeing. The association between needs satisfaction and wellbeing has been shown to be equivalent across countries (Benita et al., 2020). These psychological needs are said to be universally applied to all individuals through the operationalization of psychological needs. For example, autonomy is defined as willingness rather than one who has an individualistic societal worldview (that is they define autonomy as

individuating oneself from the group). Using this definition, Eastern societies can therefore meet criteria for autonomy, while still maintaining collectivistic traditions and orientations.

An important aspect of the Basic Psychological Needs Theory relates to how wellbeing is operationalized within the theory. It is not merely the presence or absence of what is termed hedonistic pleasure (operationalized as subjective wellbeing), it represents a fuller experience of wellbeing more in line with the concept of fulfillment or thriving. While the Basic Psychological Needs Theory references how fulfilling all three psychological needs contribute to wellbeing, of interest in the present study is how satisfaction of autonomy often correlates positively with individual satisfaction and wellbeing measures across multiple domains. Specifically, autonomy has often been identified as predictive of wellbeing in various domains including the wellbeing of nursing home residents (Kaiser & Ryan, 1999), and individuals in their workplaces (Baard et al., 2004). Within-person variations of these needs have also shown improvement in wellbeing when measured moment-to-moment compared to one's typical baseline state. Research outcomes included improvement in "mood, vitality, physical symptoms, and self-esteem" (Ryan & Deci, 2000, p. 76) when autonomy and competence needs were satisfied. As it relates to the present study and focus on caregiving, the SDT literature has reviewed the impact of meaningful versus coercive choice, and found that the former supports wellbeing, and the latter stifles it. This aspect of the SDT framework therefore supports the inclusion of a choice variable in the model as important to predicting caregivers' psychological wellbeing (or lack thereof).

In conclusion, the three aforementioned frameworks have guided the development of the path analysis being tested in the present research. Pearlin et al.'s (1990) work on caregiver psychological distress has guided the inclusion of contextual factors as predictors of the variables of interest in this study (perception of caregiving choice and the experience of subjective burden

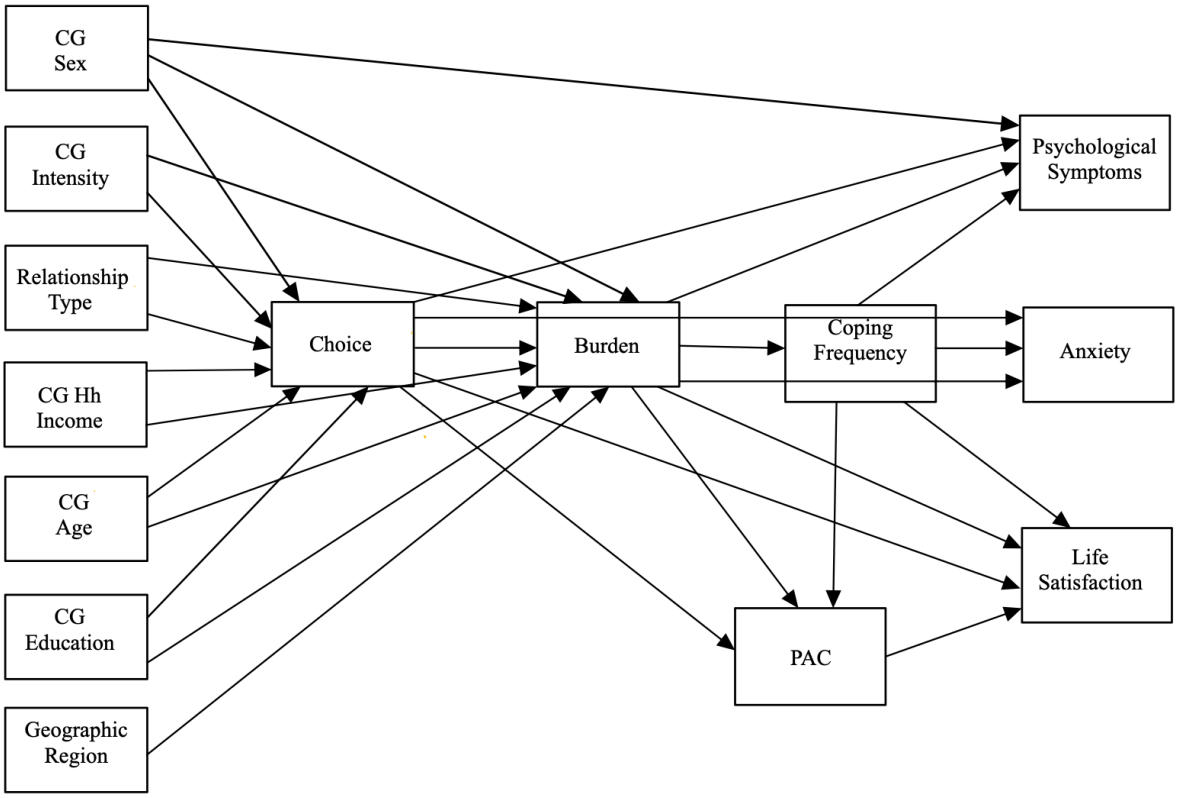
in caregivers). The revised stress and coping model (Folkman, 2008) highlighted the importance of separately examining distress and wellbeing as part of the stress process, noting benefit finding as an important mediating variable of positive adjustment. The caregiving literature has operationalized a potential outcome of benefit finding as positive aspects of caregiving, which was therefore included in the present work. Finally, SDT supports the inclusion and study of caregiving choice in models of caregivers' psychological adjustment. As the caregiving literature has demonstrated positive psychological adjustment amongst the experience of stressful caregiving situations, the SDT theory highlights the importance of accounting for autonomy (which in the case of the present work is represented by choice) in the evaluation of individuals' sense of wellbeing.

Chapter Three: Model Specification

The goal of this model was to examine the overall relationships between antecedents of caregiving choice, caregiving burden, coping, and caregivers' long-term indicators of psychological adjustment and wellbeing. Model specification was guided primarily by two stress-process theories: Pearlin et al.'s (1990) Conceptual Model of Alzheimer's Caregivers' Stress, and the Revised Stress and Coping Model (adapted from Folkman, 1997) as presented by Folkman (2008). The model presented in this work (see Figure 1) is thus an adaptation of previously established stress process models. It is comprised of four sections: context, stressors, appraisals, and psychological adjustment (See Figure 1). The Conceptual Model of Alzheimer's Caregivers' Stress (Pearlin et al., 1990) has guided the exogenous relationships illustrated in the present model, and the Revised Stress and Coping Model (Folkman, 2008) has guided variable selection in terms of the stressors, appraisals, and outcomes. Moreover, the predicted direction of the relationships detailed in this model were drawn from both frameworks. Pearlin and colleagues' (1990) model highlights the interrelationships that influence the caregiver stress process, and the inclusion of positive aspects of caregiving as a coping appraisal was drawn from Folkman's (2008) Revised Stress and Coping Model (referred to by Folkman as benefit finding; 2008). Folkman (2008) acknowledged the distinction between benefit finding as a coping strategy versus an outcome of caregiving, which has guided the use of an outcome-based measure of meaning making (that is positive aspects of caregiving) in the current work.

Figure 1

Modified Model of Caregiver Stress and Psychological Adjustment Featuring the Role of Caregivers' Perception of Choice, Adapted from Pearlin et al. (1990) and Folkman (2008)



CG=Caregiver; Choice=Caregiver choice; Education=Highest education level achieved by the caregiver; Hh=Household Income; Intensity=Intensity of caregiving provided; Psychological Symptoms=Number of psychological symptoms reported; Anxiety=Caregiver anxiety; Life Satisfaction=Caregiver life satisfaction, Relationship Type=Relation of the care recipient to the caregiver; PAC=Positive aspects of caregiving; Geographic Region=Urban versus rural residence of the caregiver.

The inclusion of choice in the model was guided by the Self-Determination Theory (Ryan & Deci, 2000; as detailed in the Theoretical Frameworks section, Chapter Two). The decision to place the caregiving choice variable before the subjective burden variable in the present model was based on their hypothesized temporal relationship, such that the choice (whether free or coerced, known or unknown) of entering into the caregiving role would have to take place before caregiving burden could be initially experienced. Both Pearlin et al. (1990) and Folkman's (2008) models suggest the presence of a feedback loop highlighting the transactional

relationships between stress variables, as well as the generation and maintenance of long-term mood/chronic stress outcomes; however the inclusion of a feedback loop in the present model was not possible due to the limited number of subjective variables available from Statistic Canada's Caregiving and Care Receiving dataset, and the cross-sectional nature of the data utilized for this study, which only includes a single retrospective assessment.

The goal of this specification is to highlight key model variables and their inter-relationships; however, it will not include a comprehensive literature review for each variable. The presented work highlights empirical findings that support the rationale for the inclusion of specific relationships in the present model as derived by the theoretical frameworks previously presented. As such, studies included in this specification include heterogenous samples of caregiver/care recipient dyads. This was considered acceptable due to the participant inclusion criteria used in the present study which is intentionally broad in terms of including caregivers of varied care recipient illness types (e.g., cancer, cardiovascular disease, neurological illnesses) as well as a focus on caregivers of aging care recipients. In some instances, cross-sectional studies highlighted relationships between a determinant and outcome in the opposite direction to the paths that have been specified in the present study. The hypothesized directions presented in Figure 1 are based on theory, and as highlighted further in the limitations section of this work, cross-sectional studies cannot speak to causality.

Studies cited in this specification refer to informal caregivers, which is defined as individuals (generally family or friends) who are not paid caregivers, nor are they providing caregiving services as part of their professional role. Exceptions to this are noted when discussing individual studies. Finally, this model was tested via secondary analysis using data collected by Statistics Canada, therefore tailoring the model exactly to the theoretical

frameworks and empirical literature was not always possible. As described in Chapter Four (Methodology), this study employed pre-selected questions that mapped onto constructs of interest in the current study.

Perceived Choice and Caregiving Burden

Choice in caregiving in this study reflects one's perception of freedom in the provision of caregiving for family or friends. Studies measuring free choice in the caregiving context are limited, and therefore empirical evidence reported on similar constructs such as role captivity, motivation to care, choice with constraint, or willingness or reluctance to care were drawn upon for the purpose of specifying this model. The theoretical construct of willingness to care defines one's attitude regarding provision of support, focusing on the actual act of behavioural caregiving tasks (Zarzycki & Morrison, 2021). Berg-Weger and Rubio (1995) tested a structural equation model of perceived choice in caregiving, willingness to care, and caregiver strain (operationalized as a subjective perception of a caregiver's physical, emotional, family, and work strains), and found that individuals who perceive that there is no alternative to care (and thus a lack of choice) experience less willingness (or more reluctance) to care. This suggests that examining the literature on willingness to care could contribute helpful empirical information related to the lack of choice construct being studied in the present research.

The present study also includes caregiving burden in the model presented. Unless otherwise stated, caregiver burden refers to the subjective experience of caregiver burden. Subjective caregiver burden has been previously defined in Chapter One in the present work, but in brief it refers to emotions, attitudes, and feelings experienced due to caregiving (Hoenig & Hamilton, 1967 as cited in Montgomery et al., 1985). Montgomery et al. (1985) showed a distinct difference in the correlates of objective versus subjective caregiving burden in a sample

of caregivers for elderly relatives. They reported that while time engaged in activities and availabilities of supports to help in establishing caregiving behaviours were significantly related to objective caregiving burden, characteristics of the caregiver were significant correlates of subjective burden. This distinction further highlights the importance of including and studying the causal impact of socio-contextual variables on choice in caregiving and subjective caregiving burden in this model. Thus, the model presented includes direct relationships between seven background variables, and two mediating variables (perceived choice in caregiving, and caregiver burden), and the subsequent impact on three outcome variables (anxiety, depression, and life satisfaction). Two additional mediating variables between choice, burden, and psychological adjustment include coping (as per the previously highlighted stress models), and a PAC variable which derives from the post-traumatic growth research and reflects the positive outcomes that emerge from stressful situations. The section that follows presents the available empirical evidence supporting the inclusion of each of these variables in the present model.

Caregiver Sex

While studies aim to examine gender differences in caregiving, some studies have used biological sex (female/male) as a proxy for their gender variable. For studies conducting secondary analyses, individuals were not asked to disclose their gender, instead their sex was recorded as male or female (Al-Janabi et al., 2018; Swinkels et al., 2019; Pertl et al., 2019). Similarly, data collected as a part of a national community survey (Winter et al., 2010) collected respondent sex as a demographic variable.

In studies examining sex differences in caregiving, females report greater caregiving (Liao et al., 2026; López-Martínez et al., 2024) and non-caregiving (Oksuzyan et al., 2010) related burden and psychological distress (e.g., severe depression for female caregivers

compared to males; Gallicchio et al., 2002). Results are mixed with some studies showing fewer sex effects in terms of caregiver strain (Miller, 1990). Further, informal female caregivers have been shown to report poorer health satisfaction with Kim and Woo (2022) reporting a one standard deviation decrease in perceived health satisfaction as compared to non-caregiving females. While gender and sex are not the same construct, the study of sex differences on caregiver psychological outcomes (e.g., burden, depression, anxiety) contribute important information regarding the unique experiences of caregivers across both sex and gender.

Gender has commonly been studied in caregiving research. This is not surprising given that women engage in the majority of unpaid caregiving (Hirst, 2005), with a 2022 survey reporting that 8.4 million women in Canada (52%) have engaged in this role (Statistics Canada, 2022b). Gender has been flagged as a determinant of psychological wellbeing in certain cases where women have served as caregivers due to increased comfort for certain type of sensitive caregiving with like-gendered care recipients (Pillemer & Suitor, 2006). It has also been hypothesized as being due to existing societal pressures for women to care based on social roles (Miller, 1990) and expectations among many societies (Esplen, 2009 as cited in Revenson et al., 2016). Pearlin et al. (1989) posited that differences in women's experiences of stress and lack of financial resources likely explains known differences in gender when it comes to psychological outcomes.

Friedemann and Buckwalter (2014) highlighted how gender roles, values and societal pressure to care contributes to womens' sense of obligation towards caregiving. Lack of choice in caregiving is one of the many inequities caregivers may face that Pearlin (1989) posits as contributing to a caregiver's experience of stress. No known studies have examined the relationship between caregiver choice (measured as a Yes or No construct) and the gender of the

caregiver, however, qualitative studies provide some evidence of the presence of this relationship. In a study examining reports of a 'felt-obligation' sub-scale of caregiving (which represents one's expectations within a personal relationship), women reported greater perception of obligation compared to men (in related samples of young and middle-aged adults; Stein et al., 1998). Further qualitative studies have yielded additional evidence regarding the role of gender as an important contributor to one's perception of choice. A meta-synthesis of qualitative studies aimed at understanding caregiver motivation and willingness to care highlighted social roles as contributing to women respondent reports of a lack of perceived choice in caregiving. Further this study highlighted a belief carried by men and women that caregiving was considered 'women's work' (Zarzycki et al., 2023, Gender-Specific Roles, para 2). Williams et al.'s (2017) research on the impact of women's experiences in palliative caregiving argued that gendered caregiving exists beyond cultural norms that contribute to expectations of caregiving behaviours. They cite the norms of Western women who are expected to be compassionate and sensitive to others' needs above their own, and their research demonstrates how gender norms influence older women's views about their roles in providing end-of-life care for family members. The intersection between gender and choice in caregiving was evident within two identified themes which included *women's duty to provide care*, as well as the *expectations* that women (that is, spouses, daughters) would provide care to family members in need. While this research did not focus on choice in caregiving specifically, these themes reflected women's beliefs about lack of choice when it comes to caregiving, such that women who detailed the challenges of having a dual role (working and caregiving) were not shown empathy from other women in the study who cited caregiving as an expectation of marriage. Interestingly, while women were not required to have provided end-of-life caregiving to be included in William et al.'s (2017) study, all women

in the study noted that they had previously provided some form of caregiving to family members. Moreover, these individuals expressed feelings of guilt in situations where they could not provide care (e.g., due to their own ill health), further reinforcing this idea of gendered expectations, and ultimately women's perceived lack of choice when it comes to the decision of entering into the caregiving role. Boeije and van Doorne-Huiskes' (2003) highlights the likely presence of a relationship between gender and caregiver distress. In their qualitative study on spousal caregiving for partners diagnosed with multiple sclerosis, Boeije and van Doorne-Huiskes (2003) reported increased guilt and distress identified within a theme around women's lack of choice in entering into the caregiving role. This lack of choice contributed to the women's self-reported experiences of distress and burden. In comparison, men (who reported greater flexibility in choosing not to provide care) reported fewer emotional consequences (e.g., fewer feelings of guilt). One study identified gender as a moderator of the relationship between choice in caregiving and depression (the relationship between choice and depression/perceived stress was significant in husbands), despite not finding a significant difference in the perceived choice across gender overall (Robinson-Whelen & Kiecolt-Glaser, 1997). Robinson-Whelen and Kiecolt-Glaser's (1997) study was limited to spousal caregivers which likely impacted the respondents' perception of choice in caregiving as they rated themselves as highly willing to provide care for their spouse. This willingness may have been driven by many factors, including one's spousal vow in marriage. These studies support the inclusion of both a gender-choice and gender-distress path within the present model.

Quantitative studies examining caregiving choice have operationalized the choice construct in different ways. This includes a dichotomous 'Yes' or 'No' variable (Longacre et al., 2014; Schulz et al., 2012; Winter et al., 2010), a measure of constrained choice (meaning that

caregivers perceived they had a choice in caregiving but were limited by at least one constraint such as a sense of duty or lack of financial resources; Al-Janabi et al., 2018), and a continuous variable reflecting the degree to which caregiving was perceived as voluntary (Pertl, 2019). These studies examined the relationship between sex and choice in caregiving, however no significant association between sex and perceived choice in caregiving was reported (Al-Janabi et al., 2018; Longacre et al., 2014; Pertl et al., 2019; Schulz et al., 2012; Winter et al., 2010). Studies of caregiver willingness suggest that the sex-choice relationship exists. For example, in a study examining caregivers' willingness to perform caregiving tasks for family receiving mechanical ventilation, females demonstrated a significantly higher mean level of willingness to engage in family caregiving tasks compared to males (Wilk & Petrinec, 2024).

Both sex and gender as a predictor of caregiver burden has been studied in greater detail, though mixed outcomes are attributed to methodological differences across studies (Xiong et al., 2020). Higher caregiving burden scores in women have been reported across studies of various illness populations including those taking care of care recipients living with advanced cancer (Schrank et al., 2016), cardiovascular disease (Palacios-Galvez et al., 2025), dementia (Campbell et al., 2008; Kim et al., 2012) and older adult populations (del-Pino-Casado et al., 2012). A meta-analysis focused on gendered caregiving which pooled results across 229 studies found that while the effect sizes were small, women's experiences of burden were greater than men's reports, and that variances of caregiver burden explained by gender alone were of practical significance (Pinquart & Sorensen, 2006).

Taken together, the presented literature supports the inclusion of the following paths in the present model: Sex as a determinant of caregiver's perceived choice and burden (respectively), as well as sex as a determinant of caregiver psychological symptoms.

Caregiver Age

Empirical evidence is mixed regarding the role of the caregiver's age as a determinant of perceived choice in caregiving. Some studies suggest no differences exist between older and younger caregivers, and their perceived choices in taking up the caregiver role (Al-Janabi, et al., 2018; Longacre et al., 2014; Pertl et al., 2019; Winter et al., 2010); however, Schulz and colleagues (2012) reported a statistically significant proportion of older caregivers felt they had no choice regarding the provision of caregiving in comparison to younger caregivers (65-year old plus versus the 18-49 year old reference group). This relationship remained significant in subsequent logistic regression analyses when caregiver and care recipient characteristics, and caregiver burden were held constant. Studies of choice-adjacent constructs such as role captivity also provides support for the inclusion of age as a determinant of perceived caregiving choice in the present model. Role captivity highlights the experience of feeling trapped into a caregiving role, which Pearlin and colleagues (1990) describe as an "involuntary" role (p. 589). Narayan et al. (2001) found caregivers' age to be significantly and negatively correlated to role captivity with younger caregivers reporting greater role captivity. This study identified participants who experienced caregiving in a manner that was contrary to their personal wants and desires, thus suggesting that role captivity is a proximal construct to one's experience of lacking caregiving choice. Evidence regarding the impact of age on perceived choice in caregiving is thus limited, suggesting a good rationale for its inclusion as a predictor of choice in the present model.

This model also includes a direct relationship between age and caregiving burden, a subject on which there is a greater degree of empirical evidence. The literature regarding age and burden has yielded more consistent results that younger age is associated with increased caregiving burden (Cain & Wicks, 2000; Montgomery, et al., 1985; Unson et al., 2016). Risks of

greater caregiver strain in younger individuals (in comparison to their older counterparts) have been reported across multiple care recipient illness types such as Parkinson's disease (Carter et al., 2010), Muscular Dystrophy (Boyer et al., 2006), Alzheimer's disease (Haro et al., 2014) and cancer (Hsu et al, 2014: at the bivariate level of analysis only). When stratified across the type of relationship to the caregiver (child, adult, or other), younger non-kin (42-60 years) experienced more isolation and higher emotional involvement (e.g., feeling angry with the care recipient; an item included as a sub-scale of burden) as compared to older caregivers (62-82 years; Andrén & Elmståhl, 2007). In cases where older caregivers were found to experience more burden compared to their younger counterparts, Andrén and Elmståhl (2007) conjectured that the relationship type between the caregiver and care recipient likely contributed to increased burden due to older caregivers typically being the spouse. As detailed later in this chapter, spousal caregivers have been found to experience burden to a greater degree as compared to other relationships (e.g., adult child, second degree relatives), and thus the relationship of the caregiver to the care recipient is also included in the presented model as an exogenous predictor of caregiving burden.

Caregiver Income

Research highlights the high direct and indirect costs of being a caregiver, which include some of the following expenses: hiring respite, transportation costs, paying for caregiving tools (e.g., wheelchair lifts) and medications, as well as loss in personal earnings due to a need to divert time towards caregiving activities (Fast, Williamson et al., 1999; Rice et al., 1993). While few studies focus primarily on the relationship between income and choice in caregiving, having minimal resources would logically curtail one's ability to make choices when it comes to the costs of caregiving (either in time or money). Moreover, most studies employ convenience samples with

medium to high SES groups as respondents (e.g., Schulz et al., 2012, identified that 60% of their sample had an income over $50,000), resulting in limited empirical evidence regarding the relationship between income and a caregiver's perception of choice. Further, studies that measure caregiver income tend to report income as a demographic variable, refer to income as a constant in their analyses, and/or do not report relational tests between a caregiver's income and perceived choice in caregiving as part of their presented results. Of those studies that have reported the bivariate relationships between caregiver choice and income, no significant differences in income as a determinant of choice have been reported (Longacre et al., 2014; Winter et al., 2010). Given the dearth of research regarding the association between income and choice in caregiving, the decision to include income as a predictor of choice in the present model is driven by the rationale of Ward and Carney (1994) who stated that low-income individuals are "unable to purchase institutionally based services...[which may lead them to] turn to kin[ship] care from lack of options rather than choice" (p. 45). Ward and Carney's (1994) qualitative study highlighted the primary experience of low-income women who were relegated into an obligation or duty of care in which caregiving decisions from women were summed up as "inevitable", due to their relational bond or due to lack of options available for supported or paid caregiving. Further, Ward and Carney (1994) highlighted that the experiences of caregiving for these individuals took place under circumstances that were not chosen, for example caring for an abusive but now disabled spouse. Income and its relationship to lack of caregiver choice was also described in other qualitative studies, for example, a lack of financial independence contributed to respondents' status as caregivers (Guberman et al., 1992). Williams et al. (2003) reported that a significantly greater proportion of low-income caregivers reported a sense of powerlessness, and a lack of control over their caregiving as compared to a high-income group (53.3% and

43.8% versus 19.0% and 71.4%, respectively). A qualitative study of Nova Scotia caregivers' experience of high intensity caregiving receiving a Caregiver Benefit (a monthly allowance to support their caregiving efforts), showed that some of the respondents' identities shifted due to their caregiving efforts such that they felt "tied" to the caregiving experience (Matthew et al., 2026, p. 5). Further, reports were mixed regarding the perceived sufficiency of the benefit, particularly given the inability of some respondents to participate in the work force (Matthew et al., 2026). This highlights the presence of a relationship between caregiving choice and income. Canadian reports of lost earnings and reduced working hours due to competing caregiving responsibilities (Canadian Centre for Caregiving Excellence, 2026) suggests that Canadians' choices are limited when it comes to caring for relatives and friends. Fast, Duncan et al. (2024) report that individuals with higher incomes engage in fewer hours of care compared to those with lower incomes. They posited that individuals with higher incomes have choice in terms of having purchasing power to attain caregiving services. This suggests that that lower income Canadians may perceive less choice regarding their caregiving responsibilities, particularly when opportunities to maintain full-time employment is limited, and overall income is low.

The literature has reported some findings on the relationship between income and caregiving burden, however studies that focus on income (as a variable of primary interest and its relationship to caregiver burden) is less researched. Generally, lower income is associated with greater caregiver burden (Andrén & Elmståhl, 2007; Walke et al., 2018). Further, in models adjusted for caregiver age and self-reported caregiver health, caregiver income is significantly negatively associated with caregiver burden and caregiver strain (a sub-scale of the burden measures employed; Andrén & Elmståhl, 2007). In a study measuring objective burden in a Japanese nationwide sample of caregivers, lower income was associated with greater objective

burden (measured in caregiving hours), and individuals who were lower income were up to 1.95 and 2.68 times more likely to provide over 36 and 72 hours (respectively) of care (Saito et al., 2018). Mixed findings have also been reported. Montgomery et al. (1985) and Schwartz et al. (2021) both reported caregiver income as being positively related to caregiver burden (the latter in an African American sample of caregivers of care recipients who survived cancer diagnoses). In these studies, 45% and 56% (respectively) of the caregivers were employed full-time. Montgomery et al. (1985) suggested that their income variable may have captured participants' experience of balancing working load with their caregiving responsibilities, which may explain the presence of mixed findings. Taken together, the inclusion of income as a background factor is warranted for the present study.

Caregiver Education

Similar to income, fewer studies have focused on the relationship between caregiver level of education and perceived choice in caregiving. A study by Schulz et al. (2012) suggests that completing more years of education is associated with perception of less choice in caregiving in a multivariate logistic regression model which held constant caregiver and care recipient characteristics. Other studies have shown no relationship between education and choice (Longacre et al., 2014; Winter et al., 2010). A potential explanation for these mixed findings may be due to how education was measured across these studies with the latter studies utilizing a categorical measurement of education in their analyses, versus Schulz et al. (2012) who measured their education in terms of the number of years of education completed.

The relationship between education and caregiver burden appears to be positively related. Among the studies that have reported on this relationship, completing more levels of education is correlated with increased burden (mental burden, Schnitzer et al., 2017; Schwartz et

al., 2021). It is unclear if, similar to the income variable, the education variable in these studies is capturing caregiver type (e.g., an adult child of a care recipient) and/or the workloads of caregivers. One author hypothesized that the positive relationship between education level and mental caregiving burden was attributed to possible fears related to the caregiver's loss of autonomy (Schnitzer et al., 2017). In a study by Schwartz et al. (2021), more than half of the caregivers were reportedly engaged in some type of full-time or part-time work, or reported a higher household income, thus education may be representing challenges related to balancing work and caregiving responsibilities. Given these findings, the inclusion of education as a predictor variable might aid in teasing apart the impact of education on both choice and burden.

Intensity of Caregiver Engagement in the Care Recipient's Needs

Illness characteristics of the care recipient and their impact on choice or willingness to engage in caregiving remains an understudied area of caregiving research (Zarzycki & Morrison, 2021). Activities of daily living (ADLs) represent the basic human functions that individuals must experience to live (e.g., eating, bathing, toileting). In studies of caregiver choice, greater caregiver-intensity scores were associated with a lack of perceived caregiver choice (Schulz, 2012). These intensity scores computed by Schulz et al. (2012) were based on the National Alliance of Caregiving (NAC) Level of Care Index (Caregiving in the U.S., AARP, 2025, Original Level of Care Index, p. 116) which is a score that represents a calculation of the number of ADLs/IADLs performed by a caregiver and the time engaged in caregiving. The Level of Care Index is described as a tool that reflects the impact of a care recipients' disability on the caregiver (Caregiving in the U.S., AARP, 2025). A similar finding was reported in other research (Winter et al., 2010; in a general caregiving sample); however, this relationship was only identified when examining the two highest levels of caregiving intensity (according to their use

of the NAC measure). Al-Janabi et al. (2018) included a binary questionnaire item (Yes/No) about the caregiver's involvement in the personal care of the recipient and reported a significant bivariate relationship, such that involvement in personal care was associated with a perception of less choice in caregiving. In a study employing a discrete choice experiment methodology which examined willingness to provide care supports and caregiving intensity, the authors reported that increased caregiving hours (that is intensity) was associated with less willingness to provide care in a German sample of non-caregiving adults (de Jong et al., 2023). Interestingly, in a study of care recipients' perceptions of their caregivers' willingness to care, care recipients reported significantly lower ratings of caregiver willingness in relation to their degree of ADL limitations (Sun & Meng, 2023). Care recipients in the moderate functional ADL group had 37% lower odds of perceiving that their caregiver exhibited a moderate willingness to care (compared to the severe ADL functional reference group). This suggests that both caregivers (as per de Jong et al., 2023) and care recipients (as per Sun & Meng, 2023), consider caregiving intensity to be a driving factor of whether individuals choose to provide care. Findings related to caregiving intensity as a predictor of choice is however mixed, with two studies (Longacre et al., 2014; Winter et al., 2010) reporting no differences in the proportion of care recipient ADL tasks that were manageable as a function of caregiver choice.

Studies have demonstrated a relationship between symptom severity of the care recipient's health and caregiver burden, and these relationships substantiate the inclusion of a path between the intensity of care provided by the caregiver and caregivers' experience of subjective burden. Increased symptoms severity is generally associated with increased caregiver burden. For example, care recipients' more frequent engagement in challenging behaviours is associated with greater caregiver reported burden (Clyburn et al., 2000; Sheehan et al., 2021).

Studies examining the differences between caregivers of individuals with and without dementia have shown that the higher appraisals of burden found in the dementia group were attenuated when behavioural problems of the care recipient were adjusted for in multivariate regression models (Sheehan et al., 2021). In a sample of patients who had experienced a stroke, greater severity of symptoms (measured via level of disability post-stroke in the care recipient) was associated with increased caregiver's subjective burden rating at the both the three and 12-month post-stoke burden measurements (at the binary level of analysis; McCullagh et al., 2005). In adjusted analyses, caregiving intensity (measured as increased need for ADLs supports or greater symptom severity) was also associated with increased caregiver burden across various care recipient populations including older individuals (with heterogenous illness; Wahab et al., 2014), care recipients with cancer (Hsu et al., 2014; Schwartz et al., 2021), dementia (Kang et al., 2014), ALS (de Wit et al., 2018), and psychiatric illness (schizophrenia; Talwar & Ganji, 2025). For caregivers of older individuals diagnosed with dementia, higher engagement in caregiver instrumental activities of daily living (IADLs) was associated with increased caregiving burden in models that were both unadjusted and adjusted for neuropsychiatric symptoms (dementia severity) as measured by various neuropsychiatric inventories (e.g., Mini Mental Status Exam; Neuropsychiatric Inventory Questionnaire; Tsai et al., 2021).

Relationship Type

Aneshensel et al. (1993) labelled the relationship shift between the caregiver and care recipient as the "most salient milestone" (p. 58) in a caregiver's journey of care. This shift appears more noticeable in spousal or adult-children caregivers (that is, adults providing care to their aging parent) where the direction and expectations of care within these relationships have changed. This change results in what Pearlin et al. (1990) describe as a shift towards a

unidirectional experience care. As such, examining contextual contributions such as the relationship type to a caregiver's perception of choice is an important focus for research. Both type and quality of caregiver-care recipient relationships have been found to contribute to caregiver psychological wellbeing. More proximally related caregivers (e.g., spousal versus others) have been found to experience greater distress as compared to both non-caregivers and caregivers of differing relationship types (e.g., neighbour or non-kin; Hirst, 2005). Higher degree of relational closeness (e.g., feelings of appreciation, perceived closeness of the relationships, and shared values) has been found to predict improved caregiver wellbeing (Fauth et al., 2012) and worsened depressive symptoms (Lum et al., 2014). That said, the impact of relational closeness/relationship type on wellbeing is complex as a longitudinal analysis of this relationship demonstrated that increased relational closeness among caregivers and care recipients was associated with reduced psychological wellbeing over time (Fauth et al., 2012). With respect to choice in caregiving, few studies have examined the impacts of relationship type, however bivariate relationships between relationship type between the caregiver and care recipient and perceived choice in caregiving have been reported. Spousal and adult-child caregivers (Li & Lee, 2020; Schulz et al., 2012; Winter et al., 2010) reported less choice in becoming caregivers as compared to other family-types (e.g., relatives) and non-related (e.g., friend or neighbour) caregivers. Longacre et al. (2014) reported no association between relationship type and perceived choice in their sample; however, their sample was comprised of a majority parent/grandparent caregivers with fewer spousal caregivers for comparison. Higher degrees of relationship closeness have also been identified as a significant predictor of increased willingness to care in adjusted regression models and path analyses (Li et al., 2023; in a sample of dependent older adults) and have also been explored in qualitative caregiver research (Williams et al.,

2014). That said, among the quantitative studies examining caregiver choice, a study of spousal primary caregivers reported the highest proportion of caregivers who did not perceive they had a choice when it came to caregiving (i.e., 82% of the sample reported that they had no choice), despite reporting a moderate to high willingness to care for their spouse (Pertl et al., 2019).

Generally, research findings have reported that relationship type is associated with subjective caregiver burden, such that closer familial ties such as spousal relationships are related to higher caregiving burden when compared to sibling caregivers (Walke et al., 2018), or non-family caregivers (Bei et al., 2022). Studies comparing burden between spousal versus adult caregivers of older adult care recipients, found that spouses reported higher levels of burden (financial and physical burden, Pinquart & Sörensen, 2011; subjective burden, Oldenkamp et al., 2016). Research is mixed however with studies also showing that adult-child caregivers experience greater social and emotional burden compared to spouses (Fenton et al., 2022). A longitudinal analysis of a U.S. national health survey study of unpaid caregivers (supporting the ADLs of related or unrelated care recipients) found that individuals categorized as other relationships (not adult-child or spouse) had lower odds of experiencing negative emotional burden compared to spousal caregivers when adjusting for demographic factors of the caregiver and dementia status of the care recipient (Kin et al., 2024). As trends in caregiving highlight differences in the amount of caregiving provided by relational type (with spouses providing more caregiving compared to adult-children; Fenton, et al., 2022; Pinquart & Sorensen, 2011), the examination of caregivers' perceived choice and experience of burden as a function of caregiver relationship types is an important area to study and thus has been included in the present research.

Caregiver Geographic Location

The literature suggests that living in different geographical regions is associated with variations in the caregiver experience. Studies of caregivers yielded differences in health reports among urban versus rural caregivers (Crouch et al., 2017). Findings have shown that rural caregivers are more likely to rate themselves as having poorer general health compared to urban dwellers, however, rural caregivers also reported better physical health and fewer limitations as a result of their physical health compared to urban caregivers (Cohen et al., 2021). Rural caregivers also reported greater caregiver support compared to urban caregivers (Cohen et al., 2021), and rural U.S. residents were found to provide more family care (non-paid caregiving) compared to urban caregivers (Cohen et al., 2021; Sterling, et al., 2022), with rural caregivers being more likely to provide 20 or more hours of caregiving per week on average (Cohen et al., 2021). Multivariate analyses also found that rural caregivers provided more family caregiving compared to urban caregivers when covariates such as race, education, birth status (U.S. born versus not) and census region (e.g., Western, Northeastern etc.) were accounted for in Poisson regression analyses; Sterling et al., 2022). Crouch et al. (2017) and Sterling et al. (2022) suggested the influence of cultural norms for rural caregivers (e.g., greater focus on caring for family) as a potential explanation for reported differences among urban versus rural caregivers.

Caregiver burden has also been associated with differences in geographic residence; however, findings have been mixed. Some studies reported no relationship between geographical location of the caregiver and objective caregiver burden (Crouch et al., 2017), whereas other studies have reported greater financial burden among rural caregivers (Bouldin et al., 2018; Cohen et al., 2024). One study reported that rural caregivers were just over two times more likely to experience subjective burden compared to urban caregivers during the COVID pandemic

(Cohen et al., 2021). Caregivers in rural residences have reported difficulty accessing care services (Crosato & Leipert, 2006; L'Heureux et al., 2022). Taken together, rural caregivers' engagement in higher caregiving time, exertion of additional time and effort to facilitate access to health care for their care recipients (either acute or rehabilitation care), and higher financial burden are likely to increase caregivers' experience of subjective burden for individuals living in rural areas.

Mediators

Choice As a Determinant of Caregiving Burden

Both bivariate and multivariate relationships between choice and objective caregiving burden have been reported in the literature. Pertl et al. (2019) examined the relationship between subjective caregiving burden and choice, reporting that only the bivariate relationship was significant, whereas the adjusted multivariate model did not show a significant relationship between subjective burden and caregiving choice. Similarly, Palacios-Galvez et al. (2025) reported that caregivers of care recipients who experienced a stroke reported greater subjective burden mean scores (as per the Zarit Burden Inventory) when caregiving was not considered voluntary compared to those who reported being a voluntary caregiver. Studies of the construct of willingness to care have yielded negative relationships between caregiver's perceived choice and subjective burden. In studies examining spouses' expectation of caregiving burden, the anticipation of high future caregiver burden was associated with low willingness to care (Feeney & Hohaus, 2001; Wells & Over, 1994). Further, increased role captivity (that is, less choice) reported by caregivers of care recipients living with dementia, was positively associated with caregiver burden (in adjusted models; Campbell et al., 2008) and was labeled the strongest predictor of caregiver burden amongst the determinants of burden that were tested. Winter et al.

(2010), Schulz et al. (2012), and Longacre et al. (2014) also tested the relationship between choice and a one-item question on perceived emotional stress in caregivers, and similarly reported significant bivariate and multivariate (adjusted) relationships between their stress variable and perceived choice, such that perceiving less choice in caregiving was significantly associated greater subjective perceptions of caregiving stress. Finally, Cicirelli (1993) conducted a path analysis that examined factors explaining a daughter's motivation to engage in caregiving. They found that feelings of obligation were associated with increased subjective burden. Overall, these results suggest the presence of an association between perceived choice in caregiving and subjective burden.

Choice and Positive Aspect of Caregiving

The inclusion of positive aspects of caregiving (PAC) in the present model was derived from the literature which shows that caregiving while difficult, also results in positive appraisals of the caregiving experience (Cohen et al., 2002; Zarit, 2012). There is emerging evidence of an association between choice and PAC. Pertl et al. (2019) found that their degree of choice variable (measured as degree of voluntariness of caregiving ranging from 1 to 9, reflecting no choice to completely voluntary) positively and significantly predicted PAC in multivariate models which measured feelings of appreciation and meaningfulness associated with spousal caregiving. A study examining predictors of PAC reported that choosing to be a caregiver (described as a "free and personal option", p. 90) was associated with increased PAC in caregivers of elderly care recipients (López et al., 2005). This relationship between choosing to be a caregiver and PAC remained statistically significant when controlling for coping strategies (use of venting), the pre-caregiving relationship, caregivers' working status, and leisure time experienced by the caregiver (López et al., 2005). More recent research by Zimami et al. (2025)

suggests that having a choice (Yes/No) to engage in caregiving has been associated with a greater likelihood of having a positive caregiving experience, when controlling for factors such as caregiver stress, depression and caregiving factors such as isolation or caregiver confidence. Further, perceiving choice in caregiving reduced the likelihood of caregivers reporting a negative experience by 36% (also adjusted for the same covariates as the positive caregiving experience outcome; Zimami et al., 2025). Finally, significant first degree intercorrelations have been reported that further support the choice-PAC relationship. Quinn et al. (2012) reported a negative correlation between the role captivity experience by a caregiver and the degree to which caregivers found meaning in their role. Yu et al. (2026) also reported a significant positive association between intrinsic motivation to care (that is having a reduced sense of caregiving obligation), and their measure of meaning focused coping. Given the importance of examining predictors of both positive and negative outcomes of caregiving, as well as the emerging evidence in this area of research, the path between choice and PAC was included in the present model.

Subjective Burden

The goal of this section was to highlight the current evidence regarding the relationship between caregivers' subjective burden and the outcomes specified by the endogenous paths illustrated in Figure 1, namely coping and positive aspects of caregiving.

Subjective Caregiver Burden and Coping

As per Lawton et al. (1991) caregiver burden was operationalized in the present model as a caregiving appraisal strategy that is employed as part of the experience of caregiver stress and distress. In line with previous stress process models (Folkman, 2008; Lazarus & Folkman, 1987), coping behaviours are initially applied after an appraisal of a stressful situation takes place.

Coping has been categorized in various ways (e.g., approach versus avoidance, problem-focused versus emotion-focused); however, it is theorized that coping behaviours that increase one's orientation to a problem that is controllable or increase one's emotional management of uncontrollable situations generally result in positive psychological outcomes (Lazarus & Folkman, 1987). Further, coping strategies considered madaptive may be functional in situations where problem-solving is not possible. In a study examining individuals' choices of coping strategies, emotion focused strategies were found to predict lower depressive mood when matched with stress contexts that had a low level of control (Leslie-Miller et al., 2025). A qualitative study of caregivers' coping responses (in a sample of dementia and stroke care recipients) found that caregivers adapt different coping techniques to a variety of contexts (that is acceptance and avoidance when situations were uncontrollable and planning when attempting to gain control of a situation; Williams et al., 2014), which fits with the tendency to view coping behaviours as functional or non-functional rather than labelling certain coping behaviours (such as distracting oneself) as maladaptive. This view is supported by the results of a meta-analysis focused on the coping strategies of caregivers of frail older people which found that the overall emotion-focused coping score was not significantly associated with caregiver burden (controlling for confounding variables such as objective burden and care recipient characteristics); however, specific sub-groups of coping (e.g., positive appraisals, religious coping, seeking emotional support) were associated with lower subjective caregiver burden (Muñoz-Cruz et al., 2024a). Further, a higher order functional coping category operationalized by Munoz-Cruz et al. (2024b) as a mix of both problem and emotion focused coping was significantly associated with lower subjective caregiver burden overall. In a study of caregivers attending to care recipients undergoing at-home mechanical ventilation, they found that increased use of coping strategies

(such as acceptance) reduced ratings on several subscales of subjective burden (strain, isolation, emotional involvement; Płaszewska-Żywko et al., 2024). A study exploring patterns of coping using a latent class analysis identified a 'high coping group' of caregivers consisting of participants who reported the use of more coping strategies such as active coping, self-distraction, and emotion-focused coping (Yuan et al., 2021). Using a multinomial logistic regression strategy, these authors reported that caregivers reporting higher burden scores were more likely to be classified in the 'low coping group' (Yuan et al., 2021), suggesting that a higher frequency of coping was associated with greater adaptation (or lower burden) in this group of caregivers.

Opposite findings in cross-sectional studies examining the relationship between the frequency of coping strategies and burden in caregivers of people with dementia (PwD) have been reported. Huang et al. (2015) found that adjusting for care recipient characteristics (e.g., disruptive behaviour of the care recipient), greater frequency of avoidance coping was found to be positively associated with caregiver burden. It is possible that coping in this case was a response to a stressor, which reflects the direction of the relationship between subjective burden and coping in the present study.

Subjective Burden and Positive Aspects of Caregiving

One of the more common efforts within caregiving research is the expansion towards examining positive outcomes associated with caregiving in the face of caregiver burden. These studies have contributed to our understanding of reports of positive psychological adjustment for caregivers reporting high degrees of caregiving burden (Pristavec, 2019). Positive aspects of caregiving is defined as perceived individual gains originating from the experience of caregiving which include feeling they are doing meaningful work, felt satisfied or rewarded by the

caregiving experience, or developed an emotional closeness with the care recipient (American Psychological Association, 2011, para 2). Miltiades and Pruchno (2002) summarized previously theorized conceptualizations of PAC, namely PAC as an appraisal of benefit from caregiving (an *ongoing process*), and/or PAC as a positive affect *outcome* as a result of engaging in caregiving such as experiencing a rewarding feeling from caregiving. The latter definition suggests that PAC is an outcome of one's appraisal of the caregiving situation. This differs from benefit finding as described by Folkman as a meaning making process (Folkman 2008). PAC as a positive affectual outcome is the focus of the present study, therefore empirical evidence regarding its relationship with caregiving burden are presented here. A stepwise regression analysis controlling for demographic and stressor variables in a group of Canadian caregivers (of seniors) found that positive experiences in caregiving were predictive of lower caregiver burden (Cohen et al., 2002). A study examining the role of PAC as a mediator between caregiver life satisfaction and caregiver subjective burden (as the outcome variable) reported a significant direct negative effect between PAC and burden (Fauziana, et al., 2018). Finally, part of a meta-analysis focused on examining predictors of burden and depression found that caregiver uplifts (that is, measures of caregiving satisfaction, growth, gains, and enjoyed aspects of caregiving) is associated with caregiver burden (Pinquart & Sorensen, 2003). In Pinquart & Sorensen's (2003) study, a small but significant negative relationship was found between positive caregiver uplifts and subjective burden at the bivariate level, and the relationship remained significant at the multivariate level after controlling for sociodemographic caregiver/care recipient factors. When PAC is examined as the outcome variable, negative relationships between caregiver burden and PAC continue to be reported, although the interpretation reported is opposite to previously cited studies. For example, studies have found that subjective burden was negatively related to ratings

of caregiver satisfaction (López et al., 2005) and meaningfulness (Palacios-Galvez et al., 2025) at the bivariate level (*ps*<0.01), suggesting that high burden is associated with low PAC. Additionally, a cross-sectional analysis examining predictors of PAC in caregivers of individuals with breast cancer-related lymphedema reported that caregiver burden was predictive of PAC in their multivariate model (Tang et al., 2025) such that higher burden was associated with lower PAC. Overall, these studies highlight inter-relationships between burden and PAC, however as acknowledged by Pinquart and Sorensen (2003), the cross-sectional nature of these analyses might support alternate interpretations of these results.

Coping and Positive Aspects of Caregiving

Both problem-focused and emotion focused strategies have reportedly been associated with caregiver PAC. Ekwall and Hallberg (2007) asked caregivers of elderly care recipients (75 years and above) to complete the Caregiver's Satisfaction Measure (which included PAC related items such as having fulfilling relationships with the care recipient and experiencing personal growth) and examined the relationship between caregivers' satisfaction to the coping strategies they employed. Their analysis yielded two cluster groups of caregivers, those satisfied with caregiving, and those who were not satisfied. In examining cluster differences in coping, they found that the satisfied caregiving group engaged in more problem-solving, and greater "self-empowerment and control" (Ekwall & Hallberg, 2007, p. 836) as measured by the CAMI, which describes self-empowerment and control as an active management strategy to cope with caregiving stressors (Nolan et al.,1995). Studies examining emotion focused coping strategies such as religious coping have reported that increased religious coping positively predicts PAC (Heo, 2014), as well as adjacent variables such as meaningfulness, closeness to the care recipient and caregiving satisfaction across various care recipient illnesses (Miltiades & Pruchno, 2002).

Heo (2014) tested a structural equation model examining the contribution of positive religious coping to caregiver psychological outcomes and reported a positive significant relationship for the path between religious coping and positive appraisals of the caregiving experience. Interestingly, an additional path between an increased negative religious coping variable and PAC was not significantly associated with PAC, suggesting the presence of functional coping strategies as a potential mechanism through which positive or meaningful emotions from caregiving are generated. Studies also point to the absence of dysfunctional coping as a predictor of PAC. López et al.'s (2005) study reported that less engagement in venting and self-blame coping strategies were associated with increased PAC in related caregivers of elderly care recipients. That said, increased frequency of coping strategies considered to be dysfunctional (such as avoidance) have been reportedly associated with increased PAC among dementia caregivers (Grover et al., 2017). These mixed findings might be better explained by Parveen and Marrison (2012), whose longitudinal study found that PAC gains were attained via active coping, instrumental coping and humour at the 3-month follow-up, but that increased PAC gains were predicted by self-distraction and denial at the 9-month follow-up (in their heterogenous illness sample of care recipients). They suggested that there may be different needs for different phases of the caregiving journey, which explains the mixed findings regarding predictors of PAC in the literature. Taken together, this literature supports a path from the coping variable to the PAC variable which has been included in the present model.

Psychological Adjustment in Caregivers

Meta-analytic/systematic reviews report greater stress, depression, and lower subjective wellbeing (Pinquart & Sörensen, 2003; Janson et al., 2022) as well as higher mortality rates (Janson et al., 2022) in caregivers compared to non-caregivers. A population level multi-

European study also reported poor self-perceived health in caregivers versus non-caregivers, although they acknowledged the magnitude of the relationship was small (Maguire et al., 2019). A longitudinal study provided some insight into the development of anxiety and depression in unpaid caregivers which shows ongoing experiencing of psychological symptoms that remain high throughout their caregiving journey (e.g., depression did not change in cancer caregivers of various cancer diagnoses over a six and 12-month period; Lambert et al., 2013). The following section highlights evidence for paths included in the present model, all of which are hypothesized to impact the psychological wellbeing of caregivers.

Choice in Caregiving and Psychological Adjustment

Life satisfaction is often researched in studies on caregiver wellbeing. As it relates to the relationship between choice and psychological adjustment, while all studies have not reported significant relationships between choice and life satisfaction (Pertl et al., 2019), the literature has reported evidence of significant relationships between choice and wellbeing. For example, perceived choice was associated with higher self-reported life satisfaction and happiness compared to individuals who perceived no choice in caregiving in a heterogenous community caregiving sample (Al-Janabi et al., 2018). Of those who reported a lack of choice, their overall life satisfaction and happiness were lower on average compared to non-caregivers (Al-Janabi et al., 2018). Similar findings have been reported in a study of caregivers of people with dementia (PwD) and their experience of role captivity. High role captivity was associated with lower satisfaction with life and lower wellbeing in models adjusted for caregiver and care recipient demographic factors (e.g., gender, age, relationship, dementia diagnosis; Quinn et al., 2012). In a study that included a general appraisal of autonomy in their measure (“I am free to decide how to live my life”, Maguire et al., 2019, p. 2138), self-reported caregiver wellbeing (e.g., feeling

cheerful, in good spirits, and well rested) was found to be higher in a multivariate regression analysis adjusted for sociodemographic, caregiver characteristics, and caregiver appraisals. This suggests overall that caregiver choice leads to improved caregiver wellbeing and overall life satisfaction.

Choice in Caregiving and Anxiety and Depression

Studies examining caregivers' perceived stress as their caregiving adjustment outcome reported that lack of perceived choice in caregiving was associated with increased self-reports of emotional stress in caregivers in both bivariate (Robinson-Whelen & Kiecolt-Glaser, 1997) and multivariate analyses (Longacre et al., 2014; Winter et al., 2010; adjusting for caregiver and care recipient variables). Pertl and colleagues (2019) examined caregivers' perceived choice in caregiving using both a bivariate caregiving choice variable (Yes/No), and a score of perceived voluntariness of caregiving (with a score of 10 indicating that care was provided completely voluntarily). They had unexpected findings such that both dichotomous choice and degree of voluntariness of caregiving were not significantly associated with any of their psychological adjustment outcome variables (that is, depression or anxiety). Pertl et al. (2019) attributed this finding to the longitudinal and homogeneous (particularly in terms of the relationship type, and voluntariness of care) nature of their study. This differed to a similar study (methodologically speaking) but using a smaller sample of spousal caregivers where the focus was centred on gender differences between spousal caregivers (Robinson-Whelen & Kiecolt-Glaser, 1997). Robinson-Whelen and Kiecolt-Glaser (1997) reported baseline relationships in choice and distress (perceived stress and depression) only among men, and a significant interaction (gender x choice) in their multivariate analyses.

Studies examining caregiving motivation have also provided support for the relationship between choice and anxiety and depression. In Self-Determination Theory (SDT), autonomy refers to the perception that one's actions are based on one's own choices (Dombestein et al., 2020). Dombestein et al. (2020) conducted a narrative analysis of studies examining perceived autonomy (from the SDT theory) in caregiving and psychological outcomes. They found that caregivers who felt obligated to care (that is, externally motivated) was predictive of depressive symptoms. Barry et al. (2021) also reported a negative relationship in their study examining needs satisfaction (a measure of autonomy, competence and relatedness) and depressive symptoms in a sample of heterogeneous illness-type caregivers. Research regarding the relationship between choice in caregiving and anxiety is limited, however one study suggests possible evidence of a relationship between caregiving choice and caregiver anxiety. Romero-Moreno et al. (2011) studied the role of cultural motivations on the impact of caregiver psychological outcomes and used a cultural caregiving measure (The Cultural Justifications for Caregiving Scale Revised) which tapped into intrinsic versus extrinsic motivations for providing care. When factor analyzed, the scale yielded two factors: intrinsic and extrinsic motivations. The latter group reflected questionnaire items reflecting a lack of choice in provision of caregiving due to cultural obligations (e.g., "I have no alternative", "It's my duty to provide care", "My family expects me to provide care", p. 4). This study reported that extrinsic motives were positively and significantly related to the tension-anxiety subscale of the Profile of Mood States questionnaire in caregivers. Further, motivation profiles (groups) with a mixture of high versus low intrinsic and extrinsic factors (e.g., High Intrinsic, Low Extrinsic; Low Intrinsic, High Extrinsic) were generated, and post-hoc group differences showed the following: the 'low intrinsic, high extrinsic' group demonstrated significantly higher scores of anxiety, depression,

and anger compared to the other three groups, with anxiety and depression yielding medium effect sizes. These results suggest an established relationship between social obligation to engage in caregiving (that is a lack of choice to care) and anxiety (and depression) in caregivers. Taken together, these data support the addition of paths between caregiver choice and anxiety and depression outcomes in the present study.

Choice in Caregiving and Life Satisfaction

Studies examining caregivers' perceived choice to care and its relationship with life satisfaction are limited, and empirical evidence regarding this relationship is mixed. Pertl et al. (2019) sought to examine caregiving choice as a predictor of indices of wellbeing in a longitudinal study but surprisingly found approximately zero relationships (at either the bivariate or multivariate levels) between perceived choice in caregiving and life-satisfaction. This was also the case for their degree of choice variable, whose association with life satisfaction was non-significant. As highlighted in their discussion, their sample demonstrated high willingness to care such that the median and mode rating of degree of choice was nine, which was the highest rating possible. Pertl et al. (2019) also pointed out the high degree of sample homogeneity (e.g., spousal caregivers of people living with dementia, PwD, living at the same address), which possibly contributed to difficulties in identifying the presence of a relationship between choice and caregiver wellbeing, particularly if the effect sizes were small. Al-Janabi et al. (2018) also examined choice in caregiving and its relationship to caregiver wellbeing but utilized a categorical choice response which included a completely free choice, choice with constraint (meaning that some outside factor motivated the decision for the caregiver to take on the role), and a no choice response. Compared to caregivers with no choice in caregiving, Al-Janabi and colleagues (2018) found that individuals with free choice in caregiving reported 57% lower odds

of reporting unhappiness related to caregiving. Further, free choice and constrained choice were both associated with higher mean ratings of caregiver life satisfaction. Li and Lee (2020) examined the relationships between caregiver-care recipient relationship types, caregiver choice and psychological wellbeing (measured via a Likert-style measurement of life satisfaction which was rated 0-10). Controlling for family relationship type, socio-demographics of the caregiver and care recipient, degree of caregiving provided, use of coping strategies and availability of social support, having perceived choice in caregiving was associated with greater reports of caregiver life satisfaction. One study grounded in SDT and autonomy also showed that caregivers experience of motivational autonomy is associated with positive wellbeing (Dombestein et al., 2020). This further supports the included path between choice and life satisfaction in the present model.

Caregiver Burden and Negative Psychological Adjustment

This section presents a brief summary of the literature examining the relationships between subjective caregiver burden and psychological adjustment (anxiety, depression, and life satisfaction). The impact of caregiving burden has been identified across caregivers of various care recipient illness groups including cancer (Unsar et al., 2021; Wen et al., 2022), spinal injury (Secinti, Yavuz & Selcuk, 2017), dementia (Cooper et al., 2008), and care needed for age related issues (Brandão et al., 2017). These studies reported positive relationships between caregiver subjective burden, anxiety, and depression. Two separate meta-analyses reported large effect sizes regarding the relationship between subjective caregiver burden and anxiety (del-Pino-Casado et al., 2021) and depression (del-Pino-Casado et al., 2019) with both studies reporting similar effect sizes (r=0.51 and r=0.514, respectively) and minimal heterogeneity of findings across cross-sectional and longitudinal studies. A structural equation model specified to test a

model of care recipient neuropsychiatric status, caregiver burden and depression (predicted in that order) of recently discharged hospital patients (of multiple disease-types) was found to fit the data well and supports the authors' initial hypotheses regarding the causal direction of their variables of interest (Sherwood et al., 2005). Sherwood et al. (1999) stated that "[c]aregiver burden is an initial reaction to demands for care that will in turn affect depressive symptoms" (p. 129). Sherwood et al. (1999) further tested the direction of this relationship by fitting a path where depression predicted caregiver burden, noting that this model did not produce acceptable fit indices, and suggested that these results serve as evidence that the inverse relationship is more appropriate.

In adjusted models identifying determinants of caregiver quality of life (of dependent elderly relatives), caregiver burden was negatively associated with two quality-of-life sub-scales (i.e., physical capacity of the caregiver, and perceived social support; Rodríguez-Pérez et al., 2017). In studies of caregivers of PwD, reports of a strong negative correlation between well-being and burden (McConaghy & Caltabiano, 2005) were reported, and subjective burden was negatively associated with indices of life-satisfaction (Chappell & Reid, 2002). Similar results regarding caregiving burden and life satisfaction have been reported in studies of caregivers of individuals with Parkinson's disease such that the path between burden and life satisfaction in their structural equation model examining caregiver/care recipient sleep, caregiver burden, and life satisfaction was significant (Perez et al., 2022).

Coping and Psychological Adjustment (Anxiety and Depression)

Cooper et al. (2008) have reported that caregivers tend to use a variety of psychological coping strategies (emotion-focused, problem-focused, and dysfunctional types of coping) regardless of their psychological effectiveness. A study examining the relationship between

coping frequency and psychological adjustment in caregivers of PwD, reported that the use of more frequent engagement and disengagement coping strategies negatively and positively predicted caregiver anxiety and depression scores, respectively (García-Alberca et al., 2012). In a study that used approach and avoidance dimensions to measure coping in caregivers, results suggest that increases in avoidance strategies (such as distraction, denial, self-blame) were associated with increased anxiety and depression at the 6-month and 12-month follow-ups compared to baseline measures (Lambert et al., 2013). The measurement of coping strategies at the level of problem-focused versus emotion-focused coping in caregivers have at times yielded similar results to studies of engagement and disengagement coping, such that negative relationships between coping and anxiety were reported. In a longitudinal study by Cooper et al. (2008) emotion-focused coping was negatively associated with anxiety (measured one-year post initial data collection) but was not a significant predictor of time two depression in caregivers. Cooper et al. (2008) also reported that increased problem-focused strategies were predictive of worsened anxiety scores at their time two measurement of psychological distress. Similarly, López-Martinez et al. (2024) reported a negative association between emotion-focused coping (namely positive reframing and acceptance) and anxiety in caregivers of older adults. In a mediation model examining how types of coping mediated the relationship between caregiver strain and depression (in caregivers of individuals with frontotemporal dementia), emotion-focused coping was significantly and negatively associated with depression (Roche et al., 2015). Muñoz-Cruz et al. (2023) however reported a weak negative relationship between use of emotion focused coping in caregivers (of dependent adults) and depression symptoms when controlling for confounding variables. More specifically, positive appraisal and acceptance coping were both associated with lower depression symptoms (Muñoz-Cruz et al., 2023). Further, studies of

clinically depressed caregivers of individuals with cancer engaged in more maladaptive strategies (e.g., confronting and avoidance strategies) and fewer emotion-focused strategies (e.g., seeking support, and positive approach strategies) compared to non-depressed caregivers (Papastavrou et al., 2012). In contrast to studies generally reporting a negative relationship between emotion-focused caregiving and psychological adjustment, a longitudinal study of amyotrophic lateral sclerosis (ALS) caregivers (i.e., newly diagnosed care recipients with ALS) found that emotion-oriented coping was positively associated with anxiety and depression (de Wit et al., 2019). These mixed findings may be explained by the care recipients' different needs, as Muñoz-Cruz et al. (2023) reported that caregiver anxiety differs according to coping type, noting problem-focused coping serving caregivers of the elderly (who usually address care recipients' physical problems), but not caregivers of individuals with dementia (citing that caregivers of PwD are focused on addressing cognitive or behavioural declines in care recipients). Interesting, the study by Lopez-Martinez et al. (2024) also reported positive associations between problem focused type coping (e.g., proactive coping) and anxiety in their study that consisted mostly of frail elders as the main condition experience by the care recipients.

Coping and Life Satisfaction

Coping style has also been found to be associated with psychological wellbeing. In related caregivers of dependent elderly care recipients, researchers found that (in sociodemographic adjusted models), avoidance coping style (passive disengagement) was negatively associated with measures of positive affect, whereas increased engagement in emotion-focused coping (active reinterpretation and humour) was positively associated with measures of positive affect (as measured by a quality-of-life sub-scale; Rodríguez-Pérez et al., 2017). McConaghy and Caltabiano (2005) computed a category that they labeled 'practical

coping', which consisted of emotion and problem-focused coping that oriented the caregiver towards specific caregiving issues (e.g., planning for an issue, engaging in growth and acceptance). They found that carers who used of more practical forms of coping reported higher levels of life satisfaction.

Positive Aspects of Caregiving and Life Satisfaction

A call for a more balanced view of caregiving has been made (Brown & Brown, 2014), such that positive psychological outcomes in caregivers have been reported and is now a common area of focus within caregiving research. Positive appraisals such as the identification of meaning or perceived benefits from the caregiving experience has been identified as a potential buffer for challenging and often unchanging/uncontrollable experiences of caregiving, particularly in situations where the care recipient's health is declining, or terminal, and has been found to be associated with greater life satisfaction in caregivers of individuals with terminal illness (Haley et al., 2003) in hierarchical regressions controlling for demographics of the caregiver/care recipient, stressors, and social support. Maguire et al. (2019) found that various positive psychological appraisals such as 'I generally feel that what I do in life is worthwhile' (p. 2138) were significant predictors of increased caregiver wellbeing in 4171 European caregivers of ill or infirmed care recipients. Further, compared to higher PAC scores, lower PAC was associated with reduced reports of general wellbeing and life satisfaction (Quinn et al., 2019). In a study examining benefit finding in caregivers of cancer survivors (Kim et al., 2007), a subdomain reflecting appreciation or how the caregiving experience influenced their emotional or spiritual growth (increased benefit finding) was found to predict better life satisfaction (controlling for psychosocial covariates including perceived stress, psychological and physical functioning of care recipient and other socio-demographic factors). Benefit finding (which has

been found to consist of domains such as “acceptance, empathy, appreciation, family, positive self-view, and reprioritization”; Lum et al., 2014, p. 307) was also found to be negatively associated psychological distress in a heterogenous sample of cancer caregivers (Cassidy, 2013).

Summary and Rationale of the Present Study

Many of the studies cited in the specification (Chapter Three) have yielded mixed results regarding the relationships between contextual factors, choice, burden, and psychological adjustment in caregivers. Different findings across studies may be attributed to sample size, analysis type (bivariate versus multivariate analyses), or a failure to control for confounds within these relationships (Rodríguez-Pérez et al., 2017). The use of structural equation modelling in the present study addresses the confound issues by accounting for various demographic determinants that have been found to be associated with caregiver choice and burden. The examination of choice in caregiving as a primary focus in this model adds to researchers’ emerging interest in caregivers’ sense of autonomy and its impact on caregivers’ psychological experiences namely subjective burden, anxiety, psychological symptoms and life satisfaction. The inclusion of a PAC variable in this model also helps to provide a more robust understanding of the overall caregiving experience given that not all outcomes of caregiving are negative. Studies examining adjacent constructs which have yielded outcomes indicative of a positive relationship between choice-like variables and psychological adjustment further support the significance of the present study. Overall, the value of this research lies in the continued reports of mental and physical health outcomes reported to be worse in caregivers compared to non-caregiver groups, as well as the known negative health and mental health outcomes in caregivers and care recipients of individuals who feel obligated to provide care.

Research Objectives

1. To test the fit of the proposed caregiver choice and psychological adjustment model (outlined in Chapter Three, Figure 1), to data from a Canadian caregiver sample as collected in the 'General Social Survey - Caregiving and Care Receiving' survey.
2. To examine the relationship between perceived choice and (a) predictors of caregiver choice, and (b) measures of psychological adjustment and wellbeing.

Hypotheses

H1: The structural model will fit the data well

Based on the previously summarized literature, the following hypotheses are proposed[1]:

H2a: Females caregivers will report no perceived choice in caregiving compared to male caregivers

H2b: Female caregivers will report greater subjective burden compared to male caregivers

H2c: Female caregivers will report more psychological symptoms compared to male caregivers

H3a: Older caregivers will report no perceived choice in caregiving compared to younger caregivers

H3b: Caregiver age will be negatively associated with caregiving burden

H4a: Caregivers reporting lower household incomes will report no perceived choice compared to caregivers reporting higher household incomes

[1] The findings that address these hypotheses are considered within the context of the findings of the SEM.

H4b: Caregivers reporting lower household incomes will report greater subjective burden compared to caregivers reporting higher household incomes

H5a: Caregivers reporting higher levels of educational achievement will report no perceived choice compared to caregivers reporting lower levels of educational achievement

H5b: Caregivers reporting higher levels of educational achievement will report greater subjective burden in caregiving compared to caregivers reporting lower levels of educational achievement

H6a: Caregivers engaging in higher intensity caregiving will report no perceived choice compared to caregivers engaging in lower intensity caregiving

H6b: Caregivers engaging in higher intensity caregiving will report greater subjective burden compared to caregivers engaging in lower intensity caregiving

H7a: Caregivers who are spousal caregivers will report no perceived choice compared to caregivers of other relationship types

H7b: Caregivers who are spousal caregivers will report greater subjective burden compared to caregivers of other relationship types

H8: Rural caregivers will report greater subjective burden compared to urban caregivers

H9a: Caregivers with no perceived choice will report greater subjective burden compared to caregivers with perceived choice

H10a: Caregivers with no perceived choice will report higher odds of anxiety compared to caregivers with perceived choice

H10b: Caregivers with no perceived choice will report more psychological symptoms compared to caregivers with perceived choice

H10c: Caregivers with no perceived choice will report lower positive aspects of caregiving outcomes compared to caregivers with perceived choice

H10d: Caregivers with no perceived choice will report lower life satisfaction compared to caregivers with perceived choice

H11a: Caregiver subjective burden will be positively associated with the number of coping strategies reported by caregivers[2]

H11b: Caregiver subjective burden will be positively associated with the number of psychological symptoms report by caregivers

H11c: Caregivers reporting greater subjective burden will report a higher odds of caregiver anxiety

H11d: Caregiver subjective burden will be negatively associated with positive aspects of caregiving

H11e: Caregiver subjective burden will be negatively associated with life satisfaction

H12a: Number of coping strategies reported by caregivers will be negatively associated with the number of psychological symptoms reported by caregivers

H12b: A greater number of coping strategies reported by caregivers will be associated with lower odds of caregiver anxiety

H12c: Number of coping strategies reported by caregivers will be positively associated positive aspects of caregiving

H12d: Number of coping strategies reported by caregivers will be positively associated with life satisfaction

H13: Positive aspects of caregiving will be positively associated with life satisfaction

[2] The results of this hypothesis will not be presented as this estimate was not released by the Statistics Canada Research Data Centre in line with their confidentiality rules, see Statistics Canada Privacy Notice from: https://www.statcan.gc.ca/en/about/transparency/privacy

Chapter Four: Methodology

Original Survey Purpose and Design

The questionnaire upon which the present secondary analysis is based represents an ongoing study of caregivers and care receivers that is adapted each time a new version is released in an attempt to improve data collection. The original General Social Survey, Caregiving and Care Receiving (GSS CGCR, Statistics Canada, 2013a) survey began in 1996 and has been modified and released in 5-year increments, referred to as cycles (Statistics Canada, 2017). The full-length questionnaire is composed of several measures created and reviewed by the Statistics Canada Questionnaire Design Resource Centre. Each iteration of the survey was designed as an observational, cross-sectional self-report study. The development of the 2012 (Cycle 26) GSS CGCR survey took place via a pilot study consisting of 2000 interviews with caregivers in 2011 conducted across British Columbia, Alberta and Quebec. Qualitative testing by Statistics Canada's Questionnaire Design Resource Center took place to assess questionnaire clarity. Where possible, observations from the tests and qualitative responses from the test respondents were filtered back into the survey in order to improve questionnaire quality (Statistics Canada, 2013a).

The GSS CGCR questionnaire was created for the primary purpose of assessing the ongoing needs of caregiver/care receiving Canadians, as well as to collect information designed to influence policy that aids in supporting the needs of these individuals. Families and friends providing unpaid caregiving, or individuals receiving caregiving from unpaid caregivers were sought out as the target population for this survey. Questions in this survey covered the following topics: sociodemographic and health characteristics of caregivers/care receivers, familial relationships requiring or receiving care, palliative caregiving, types, or categories of care

provided or received, hours of care provided or received, paid professional caregiving support received by the care receiver, and the physical, emotional, and economic impact of caregiving. Most questions regarding the above-mentioned topics related to unpaid caregiving, that is caregiving that was not provided by professionals; however, questions covered aspects of caregiving that took place in the caregiver's or care recipient's home, as well as unpaid care taking place within institutions or other types of supportive housing.

Survey Administration

The long version of the questionnaire (which includes all questions in a particular cycle) was administered to individuals 15 years or older, who were caregivers or care receivers living within the 10 provinces of Canada from March 1st to December 31st, 2012. In cases where individuals contacted were not care recipients or caregivers, they were administered the short version of the questionnaire. Only responses from individuals who completed the long version are included in the present study. Original recruitment of participants was achieved using random digit dialling of listed residential phone numbers using Computer Assisted Telephone Interviewing (CATI; Statistics Canada, 2013a). CATI is a data collection method which is designed to direct the flow of the questionnaire based on previous responses and identify values out of range. For example, if a previous question was "off path" because previous responding suggested that the respondent was not in the category being reviewed, the question was coded "Not Asked". Questionnaire administrators were able to override the system and send in data to the Statistics Canada head office for resolution when necessary. The survey respondent was considered to be randomly selected; such that, the first eligible participant who answered the phone was chosen as the respondent for that phone number if they met the above-mentioned inclusion criteria. Prospective participants were informed of the nature of the study, specifically

that the questionnaire "collects data on the situation of Canadians who receive help or care because of a long-term health condition, a disability or problems related to aging, and of those who provide help or care to family members or friends with those conditions…to better understand the needs and challenges faced by these Canadians, and allow policy makers to design programs that meet their needs" (Statistics Canada, 2013a, Description, para 1). They were also informed that all responses would be kept strictly confidential, that responses could be used for secondary analysis, and that the nature of this survey was voluntary. Surveys took approximately 40 to 45 minutes to complete.

Population Sampling Methodology

Geographical regions were stratified into 26 areas across Canada in an attempt to achieve a generalizable sample. Survey weighting (estimation and bootstrap weights) were calculated in order better approximate the population being sampled. Probability sampling was employed such that the respondent was selected randomly for individuals in the household over the age of 15 years old. Proxy respondents (allowing responses from another individual on behalf of the randomly chosen caregiver) were allowed to respond to the GSS CGCR questionnaire due to language barriers, or the possibility that chronic illness on the part of the target respondent prevented them from participating in the study. Given the predicted difficulty of identifying and sampling caregiving populations (care recipients or caregivers), a rejective sampling methodology was employed for the 2012 GSS CGCR survey. The target for the entire GSS sample was set at 25,000 individuals, and in total 23,093 responses were collected for the 2012 GSS CGCR survey. The reported response rate (calculated on two levels, household and individual) was 65.7% (Statistics Canada, 2013a). The original response rate was not broken down by caregivers, care recipients, and non-caregiver/care recipients.

Rejective sampling is a strategy that consists of constructing a proposal distribution (such as a Gaussian distribution usually multiplied by a constant) that includes within it the target population (Martino & Miguez, 2009). Random sampling is conducted from the proposal distribution, and samples are either rejected or accepted based on strict criteria in which the sample contains anything within the target sample until the desired number of samples are achieved. This method leads to an easier-to-sample population as compared to the target distribution being sought. There are limitations to this type of sampling (primarily that the acceptance rate might be low and the cost to implement this strategy might be high); however, this does not seem to be a problem that was faced by the 2012 GSS CGCR survey given that the resulting sample size achieved for the GSS CGCR survey was large (Statistics Canada, 2021, Statistical Activity, para 2). Quality control measures were also implemented throughout the study in training and supervision of the questionnaire administrators, as well as the use of computed response tools which were used to collect the data from each respondent (Statistics Canada, 2013a).

Sampling Adjustments

Weighting factors were created by Statistics Canada at the individual and household level (bootstrap weights) and were provided to address any sampling error that may have arisen from respondent variability. Weights were employed to adjust for respondent age and sex by province.

Methodology of the Secondary Analysis

At the time this study was submitted for ethics evaluation, the most current dataset was the 2012 GSS CGCR questionnaire, which was the dataset utilized in the current study. A secondary analysis was performed with the 2012 data, with the aim of testing a model of caregiver choice and psychological adjustment' (outlined in Chapter 1) in a Canadian caregiver

population. This model was based on previous theoretical and empirical research (as outlined in Chapters two and three), which was used to identify the variables included in this model. As the initial goal of the GSS CGCR survey was descriptive in nature, questionnaire items were developed as categorical questions (Yes/No), as well as Likert based scales to assess degree of impact of the various concepts being studied (e.g., degree of life satisfaction, measured on a 0-10 scale). No validated psychological scales were included in the survey, although it appears that for certain constructs (such as mood), Statistics Canada appears to have sampled several items that together could be used to describe that construct. To address the absence of validated psychological measures in the GSS CGCR, the variables of interest included in the present study were modeled on validated questionnaires measuring those desired constructs, and items from the GSS CGCR questionnaire were identified to compute summed scores to represent those constructs (as detailed in the methodology; see items listed in the following resource: Statistics Canada, 2013b). Both deductive and inductive measurements were used to assess validity of the computed variables. For each computed measure, two researchers reviewed validated questionnaires, and matched items from the GSS CGCR dataset for each scale, until 100% agreement was achieved for these constructed measures to be used in the analyses. Analyses were conducted using STATA Statistical Software, Version 15 (StataCorp, 2017) and R Studio (R Core Team, 2021). The results section specifies the analysis tools employed for the results presented.

Participants/Inclusion Criteria for the Secondary Analysis

Inclusion criteria for the secondary analysis were as follows: Adults (18 years and older), identified as a current caregiver (by indicating that they were still helping a care recipient at the time of the questionnaire administration), and who reported that they were considered by the care

recipient to be their primary caregiver. Individuals must have provided a response for the item asking caregivers if they had a choice to engage in caregiving to be included in the present research. Only respondents who provided care for individuals diagnosed with a long-term health condition (physical or mental) and/or the care recipient experienced a disability related to aging were included in this study. As per previous caregiving research, caregivers included in the present study were included in the study if they endorsed one of the following activities of daily living/instrumental activities of daily living. These included: bathing, dressing or toileting, transportation, meal preparation/housework, outdoor maintenance of residence, providing medical treatment or medication, scheduling medical appointments, and managing finances. In order to reduce questionnaire fatigue, the original administration of the GSS questionnaire included rules for skipping questions such that individuals had to have cared for at least one individual and provided two or more hours of care on average per week in order to be administered the questions related to psychological appraisals of caregiving (e.g., see Statistics Canada, 2013b, p. 156, questionnaire rules). Thus, an inclusion criterion for the present study was that the respondent had to report that they provided a minimum of two hours of caregiving (on average) per week in order to capture as many caregivers as possible. A review of other studies shows a variation in the minimum caregiving time needed to meet inclusion criteria in studies of caregiver psychological adjustment from five hours to 20-hours per week. Proxy interviews were allowed in the original GSS CGCR data collection where another respondent could provide answers to the questionnaire on behalf of the primary caregiver. These proxy interviews were excluded from the present study, as proxy respondents were not asked about appraisal questions (such the caregiver's experience in relation to caregiving) on behalf of the primary caregiver. Thus, the data from proxy individuals was not included in descriptive

characteristics presented in the results chapter (Chapter Five). Finally, as further described in the Analysis section of this chapter, imputation was not possible for individual items; if any case was missing individual items or variables included in the SEM (e.g., caregiver burden, psychological symptoms, and coping behaviours), these cases were excluded from the final analysis. An exception was made for the household income variable, in which missing data from this variable was carried over from the respondent's individual income if that information was provided. Applying these inclusion and exclusion criteria, 2170 individuals remained in the secondary analysis. To develop a model that is generalizable to more caregivers, the care recipients' illness was not limited to a particular illness, or age (thus parents to children of all ages with long-term caregiving needs have also been included in this sample). The population of interest for the present study were unpaid caregivers which was operationalized as respondents who answered 'Yes' to either of the following questions: "During the past 12 months, have you helped or cared for someone who had a long-term health condition or a physical or mental disability?" or "During the past 12 months, have you helped or cared for someone who had problems related to aging?" (Statistics Canada, 2013b, p. 77). Respondents who self-identified solely as care recipients were excluded from the analyses; however, caregivers could also identify as care recipients. Primary caregivers were identified as respondents who answered 'Yes' to the following question "Would you say that other than professional care, this person considered you to be his or her primary caregiver?" (Statistics Canada, 2013b, p.140). Respondents from all 10 provinces were included in the analyses.

Ethics

Permission to use this data was granted by the joint initiative between Statistics Canada, the Social Sciences and Humanities Research Council (SSHRC), and the Canadian Institute of

Health Research (RDC file numbers: 5229 and 10734; extension). Application through the Social Sciences and Humanities Research Council (SSHRC) allows for access to anonymized data that includes patient health information (e.g., date of birth, medical diagnosis), which not available in the Public Use Microdata Files (PUMP) collection (https://statcan.gc.ca/en/microdata). Ethics approval was also granted by the York University Human Participants in Research (HPRC) Certificate #: STU 2017–146.

Path Analysis Modeling Assumptions and Model Identification

The theoretical frameworks and a summary of empirical evidence that guided model specification were detailed in Chapters Two and Three (respectively). Path analysis was used to test the presented model (see Figure 1, Chapter Three), which consisted of 20 observed variables. The strengths in path analysis lie in its ability to test multiple complex causal relationships at the same time. No post-hoc modification of the model was necessary given the obtained fit indices which are presented in Chapter Five. Requirements for model identification, as cited by Kline (2016), were met such that the model degrees of freedom (as assessed by the counting rule) was zero or greater. In the present study, the larger number of variables assures that the parameters freely estimated would be less than the number of unique elements in the variance-covariance matrix. While SEM has the capability of analyzing a non-recursive model given the feedback loops suggested in Folkman's (2008) and Pearlin and colleagues' (1990) frameworks, the use of this method of analysis requires the presence of an independent exogenous indicator variable to be causally connected to one of the variables in the loop. There were no sufficient indicator variables present in the GSS dataset which is necessary for a non-recursive model to be estimated. Thus, a linear causal model was tested.

A combination of computed versus one-item measures were used in the present model.

The computation of the variables used in the present study are detailed in the 'Measures' section. The use of computed versus one-item measures improves upon previous research which used single item measures for the constructs of "mental health" and "stress" (Grant, 2014). The following SEM assumptions were evaluated: normality, linearity, multicollinearity, use of specification to create the model. The present study used the General Structural Equation Model (GSEM) syntax to generate the model estimates in STATA. As normality of the observed exogenous variables are not assumed with GSEM, violations of the normality assumptions were not addressed. Further the use of the GSEM syntax allows for appropriate estimators to be used with mixed dependent variables in the path analysis. For example, Bernoulli Logit estimators were used when the dependent variable (DV) was dichotomous (such as for the choice as the DV), and Gaussian estimators (Maximum Likelihood) were used when the DV was continuous. Individual/Household probability weights (p-weights) and bootstrap estimates were also used to estimate the model to generate population level estimates that are presented in Chapter Five.

GSEM in STATA allows for complex models with both continuous and categorical outcomes to be estimated, while allowing for the use of probability weights and bootstrapping of the data. At the time this research was conceptualized and analyzed, computation in R did not allow for the inclusion of the weights, however it was determined that having fit indices was important to report, therefore R was used to generate fit indices for the estimates.

Measures

The items from the GSS survey used for the following measures are listed in Appendix A. Most of the measures available in the GSS CGCR dataset included categorical responses which were coded as 'Not Asked', 'Not Known', 'No Response' and 'Not Sure' as possible options that were stated by the respondent. Unless specifically stated, no imputation for

individual items were made, and cases which bore these responses were treated as missing variables and excluded from the present analyses.

Demographic Variables

While not included in the SEM model tested in the present study, the following items were measured and reported in the weighted demographics table (See Chapter Five, Results, Tables 2 and 3) for the purpose of describing the caregivers and care recipients included in the present sample. The question "What is/was the main health condition or problem for which the care receiver received help?" (Statistics Canada, 2013b, p. 96) listed 20 illness types (coded as Yes/No) and were re-categorized into five domains reflecting the care recipient's functional and physiological status as reviewed by two coders who discussed these categories until 100% agreement on the categories was reached. These categories were recoded as follows: diseases/disorders with roots in early development, acquired diseases of episodic onset, aging and associated conditions, and auto-immune diseases. A study also employing the GSS Caregiver/Care Receiver dataset (2012) also recoded this variable into five similar categories (Li & Lee, 2020). Additional demographics included: the employment status of caregiver which was dichotomized from ten options to three categories (employed, student/other, retired), marital status which was also dichotomized from six categories to four (married/common law, separated/divorced, widowed, single), and presence of children in the home (Yes/No). Variables included for the purpose of demographic description (that is, not in the model) were not screened for missingness, thus the weighted population N may differ among these variables in comparison to variables included in the model. Caregiver ethnicity was not specified as the GSS CGCR survey contains a single item asking respondents to state the ethnic or origins of their ancestors. The item detailed ancestral nationalities (e.g. English, French, Scottish etc.) rather than provided

specifics regarding the cultural influence of caregivers. Additional demographics regarding the caregiver or care recipient (e.g., length of caregiving) was not available for release at the time of publication.

Observed Variables

Choice

The main variable of interest for this study was the respondent's perceived choice in engaging in caregiving. In the present study, choice was measured using the Emotional Health/Stress (ICS) measure via a single item question: "Do you feel you had a choice in taking on your caregiving responsibilities during the past 12 months?" (Statistics Canada, 2013b, p. 156). In the GSS CGCR survey, choice was presented as categorical with three possible responses ('Yes', 'No', 'No Answer'). 'Yes' items were recoded as 1, and 'No' items were recoded as 0, and non-answer items were recoded as missing. No attempt was made to impute the response of those who did not provide a 'Yes' or 'No' answer to the question. Previous studies have used a one-item 'Yes' or 'No' response in their measurement of a perceived choice in caregiving construct (Longacre et al., 2014; Pertl et al., 2019; Winter et al., 2010). For example, caregiving choice has been previously measured in other studies using similar prompts as follows: "Do you feel you had a choice in taking on this responsibility of caring for him/her [the care recipient]?" (Longacre et al., 2014; Winter et al., 2010); "Do you feel you had a choice in taking on the responsibility of caring for your spouse?" (Pertl et al., 2019).

Predictors of Choice

Predictors of choice included in this model included characteristics of the primary caregiver (age, gender, education, income, geographic region, relationship to the care receiver), and the care receiver (intensity of caregiving provided).

Caregiver Age

The variable age was included in the present research as originally measured (in years). Respondents were asked to report their age at the time of questionnaire completion. An age variable was computed in the GSS CGCR dataset, and this variable was used in the present analyses. Given the inclusion criteria, this variable represents the age of adult, primary caregivers, who provided two hours or more of caregiving, and were still providing care at the time they completed the GSS CGCR questionnaire.

Caregiver Sex

Caregiver sex was recorded by the survey administrator at the beginning of the interview with the respondent. The respondents were allowed a dichotomous choice of male or female when recording sex. Caregiver sex was listed among the variables in the GSS CGCR dataset.

Caregiver Household Income

The household income variable was originally measured as a continuous variable using the following questionnaire item: "What is your best estimate of your total household income, received by all household members, from all sources, before taxes and deductions, during the year ending December 31, [year]?" (Statistics Canada, 2013b, p. 246). The continuous income variable was found to be non-normal and not responsive to log or square root transformation attempts. The item was therefore dichotomized according to the median income of the sample ($69,000.50 Canadian Dollars) and coded as 0 (below the household income median) and 1 (at or above the household income median).

Caregiver Education

The respondent's highest level of reported education was assessed via the following questionnaire item: "What is the highest level of education that you have completed?" (Statistics

Canada, 2013b, p. 168). This item originally had seven categories and was recoded into four categories as follows: less than high school, high school or equivalent, trade school and college diploma, undergraduate degree or higher (e.g., graduate degrees).

Relationship Type

The type of relationship to the caregiver was measured using the question "What is/was the relationship of the care recipient to you?" (Statistics Canada, 2013b, p. 94) and recoded into five categories that represent familial distance to the care receiver (in line with the work of Longacre et al., 2014). They include caregiver's spouse or ex-spouse, caregiver's child or grandchild, caregiver's parents or grandparents, caregiver's relatives (aunts, uncles, nieces, nephews), and non-kin (neighbours, friends). Similar categorizations are reported in previous research (e.g., Logan et al., 2012). Findings that kinship explains the motivation of individuals to engage in informal caregiving activities (Manderson & Block, 2016), and that caregiver burden differs based on relationship type between the caregiver and the care recipient (e.g., spousal versus adult child relationship; Bei et al., 2022; Oldenkamp et al., 2016) have guided the coding of the relationship-type variable.

Intensity of Caregiving

The National Alliance for Caregiving (NAC) and AARP study (Caregiving in the U.S.; AARP, 2020) established the Level of Care Index, which is a computed score representing the intensity of caregiving provided by caregivers. Points are assigned to reflect increasing number of care activities completed by caregivers (i.e., the number of ADLs/IADLs engaged in), and the hours of caregiving engaged in per week. The points are summed to represents five levels of care, where level one and two represents low intensity caregiving, level three represents medium intensity caregiving, and level four and five represents high intensity caregiving (See Appendix

H of the AARP report; Caregiving in the U.S.; AARP, 2020, p. 116). In the present study, items from the 'Types of Help Provided by Respondent' section of the GSS CGCR questionnaire were used to compute the Intensity of Caregiving score. This scale listed six IADL questions (reflecting help with tasks such as transportation, meal preparation, house maintenance, medical treatments, banking support, and scheduling tasks and appointments), and one ADL question (referring to dressing, bathing, toileting, and care of hair and nails as a single question). For each IADL/ADL question, respondents were asked to indicate the type of help they provided to a care recipient using a 'Yes' or 'No' format. In the present study, when caregivers reported that they did not perform specific ADLs/IADLs, they were coded as two, and when individuals indicated that they participated in a specific caregiving activity, they were coded as one. 'Yes' items were recoded as 1, and 'No' items were recoded as 0, and non-answer items were recoded as missing. The time engaged in caregiving was measured using the item: "In an average week, how many hours of care or help did you provide with these activities?" (Statistics Canada, 2013b, p. 82). Using these items the Intensity of Caregiving Score was computed using a similar method as the NAC Level of Care Index score (See Appendix H of the AARP report; Caregiving in the U.S.; AARP, 2020, p. 116).

While limited research exists regarding caregiving intensity and caregivers' perceived choice, Longacre et al. (2014) reported a non-significant relationship between the NAC caregiver intensity score in their sample and perceived choice. Longacre et al.'s (2014) study was based on 104 cancer caregivers (a subset from a national U.S. survey on caregiving). The specification presented in Chapter Three highlights the rationale for inclusion of the Intensity of Caregiving Score as a predictor of choice in the present model.

Caregiver Geographic Location

The geographic region of the caregivers was drawn from a variable that listed urban and rural geographic regions coded by Statistics Canada based on the respondent's address (which was not included in the dataset viewed by researchers). These levels were recoded into two groups, 0 for Rural and 1 for Urban for the present analyses.

Caregiving Appraisals and Coping

Subjective Caregiver Burden

Caregiver burden was operationalized in the present model as a caregiving appraisal strategy that is employed as part of the experience of caregiver stress and distress (as per Lawton, 1991). Subjective caregiving burden was measured in the present study by approximating a validated short-form version of the of the Zarit Burden Interview (Zarit et al., 1980, a long-form caregiving measure) created by Bédard et al. (2001). Bédard and colleagues' (2001) measure has been validated in a caregiver sample of heterogenous illness care recipients (Cronbach's alpha=0.88, as per Bédard et al., 2001). Bédard et al.'s (2001) measure consisted of 12-items (nine personal strain, and three role strain variables). Personal strain represents the impact of caregiving on one's life, and role strain reflects a mastery concept which attempts to measure the caregiver's sense that they are providing adequate care. Each questionnaire item is rated on a 5-point Likert scale where 0=Never, 1=Rarely, 2=Sometimes, 3=Quite Frequently, 4=Nearly Always, and the total score of the scale is calculated by summing every item with scores ranging from 0–16 points. The subjective burden variable in the present study was computed by creating a composite burden score that was modelled on Bédard and colleagues (2001) short-version scale using categorical items (Yes/No) based on the personal strain factor only as it was determined that there were no items available in the GSS CGCR survey that

adequately represented role strain. Items from the GSS CGCR 'Caregiving Responsibilities and the Respondent's Health' and 'Emotional Health/Stress' measures reflecting face valid questions consistent with the Bédard Scale (2001) were reviewed by two researchers (see Appendix B for the specific items employed). Each of these items were recoded by assigning a score of 1 for 'Yes', and 0 for 'No' for seven included items, and total scores were computed by summing the 'Yes' responses from the included items yielding a caregiver burden score ranging from zero to seven. The correlations between each item and the total score ranged from 0.60 to 0.71 (See Appendix C). The KR-20 (reliability coefficient) was calculated for the computed scale of caregiving burden and was found to be 0.81 for the included items.

Coping Frequency

The coping frequency variable was computed using an item from the 'Find it Stressful' measure. The questionnaire asked respondents to identify whether they used "specific coping methods to help [them] deal with [their] caregiving responsibilities" (Statistics Canada, 2013b, p. 160) over a twelve-month period. Of those individuals who responded 'Yes', caregivers were asked to endorse all employed coping strategies from a list of provided coping behaviours using a 'Yes' or 'No' response format. Coping options included: exercising, use of professional therapeutic services, social support (speaking to other caregivers or friends), religious/spiritual practices, meditation, distraction via television, reading or music, use of prescription medication, and eating, drinking and smoking. Of these eight options, six adaptive coping strategies (all aforementioned strategies minus prescription medication, and 'eating, drinking and smoking') were identified via discussion by two researchers. Strategies that represented an approach coping strategy (such that individuals turn towards their stressor rather than away from it; Holahan et al., 2007) were used to compute the coping frequency variable. Eating and prescription medication

have been identified as escape/avoidant types of maladaptive coping (Vitaliano et al., 1985) which is correlated with poor psychological adjustment (e.g., depression, anxiety and poor quality of life) in caregivers (Rodríguez-Pérez et al., 2017). A lack of clarity on the adaptiveness of certain coping behaviours within the present sample (e.g., one can use medication to aide in shifting thoughts away from engaging in negative attributions, and subsequently negative coping styles), resulted in the decision to engage in a conservative measurement of coping by excluding possible maladaptive coping strategies from the coping frequency variable. The inclusion of television and reading or music as an adaptive coping strategy is supported by empirical evidence that this type of coping may represent a type of adaptive coping called Palliative Leisure Coping (PLC). Research suggests that PLC allows for temporary breaks from chronic stressful situations which leads to opportunities for self-renewal prior to re-entering a stressful event (Iwasaki et al., 2005). Evidence also suggests that when controlling for behavioural or cognitive disengagement strategies, positive distraction (such as behavioural or cognitive strategies that redirect attention to positive tasks or thoughts) positively predicts emotional wellbeing and positive emotions, and negatively predicts depressive symptoms (Waugh et al., 2020), as well as stress (Waugh et al., 2021) in samples of individuals undergoing chronic stressors (the latter group being adult caregivers of children with chronic illness).

A frequency count of the coping strategies was generated by summing the number of coping behaviours coded as 'Yes' by respondents (score ranges from zero to five). A zero was coded for individuals who endorse 'No' to the first question regarding their use of any caregiving coping strategies over the previous year (Yes/No). A frequency-based approach to coping measurement has been shown to capture the relationship between positive coping strategies and psychological adjustment, as well as identify distinct relationships between positive coping and

adjustment as compared to established coping subscales (Heffer & Willoughby, 2017), the latter of which is the typical approach to measuring coping (e.g., Carver, 1997). Moreover, use of a frequency count allows for direct use of the available data with no transformation needed. A longitudinal study showed that caregivers use multiple and simultaneous coping strategies over a year's follow-up, and that their use of coping strategies (problem focused, emotion focused and social support) decrease over that time (Chappell & Dujela, 2009). Further, Folkman and Lazarus (1980) highlighted both the expectation and study finding that respondents engaged both types of coping processes (problem and emotion focused) across multiple measurements of daily stressful incidents in middle-aged individuals (non-caregivers). This single factor measurement of coping is supported by the approach/avoidant factor structure of coping as conceptualized by Tobin, et al. (1989). They determined that the factor structure of coping was organized from lower-order primary groups (such as the eight factors identified in Carver's Ways of Coping questionnaire; Carver et al., 1989) to a single higher order factor of coping (in a sample of college students reflecting on a recent general stressor).

Positive Aspects of Caregiving

The positive aspects of caregiving (PAC) variable is hypothesized to reflect an outcome of benefit finding that arises from a meaning-based coping strategy engaged in by caregivers (Folkman, 2008). A longitudinal study of dementia caregivers by Yu et al. (2026) supports the decision of the present study to use PAC as a proxy of benefit-finding. Their study showed PAC to be an outcome of meaning generation, and their model of PAC highlighted the predictive function of meaning making on PAC. They also reported a significant positive relationship between meaning making and PAC both at the bivariate and multivariate levels (holding constant baseline levels of caregiver PAC; Yu et al., 2026). PAC was measured via a single item from the

'Emotional Health/Stress' scale which examined the degree to which caregivers viewed their caregiving as a rewarding experience (i.e., "How rewarding has your caregiving experiences been during the past 12 months?"). In the GSS CGCR survey, participants rated this question on a four-point scale with 1 representing very rewarding, and 4 representing not at all rewarding. This item was reverse scored so that a higher score represented greater perception of caregiving reward. The use of a single-item scale to measure positive outcomes that emerge from stressful situations is consistent with reported studies. Tomich and Helgeson (2002) employed a single-item measure of benefit-finding rated on a five-point scale from 1 (none) to a 5 (a lot) to assess the meaning of life attained by cancer survivors using the following question "How much good has come out of [the stressful event]?" (Tomich & Helgeson, 2002, p. 159). Tomich et al. (2005) also compared a single-item question (7-point scale) measuring the overall effect of a reported stressful event of being diagnosed with breast cancer to a 14-item benefit-finding scale created by the same authors (Helgeson et al., 2004; Tomich et al., 2005) with both items yielded similar outcomes as it relates to respondents' perception of benefit. Specific to the caregiving literature, the use of a single-item measure of PAC in the present study is further supported by Cohen et al. (1994) who reported significant test-re-test reliability of a single open-ended question regarding the enjoyable aspects of the caregiving, noting that the correlation between the baseline PAC responses of the caregivers was highest at the 12-month re-test of PAC.

Outcome Variables

Three outcome variables measuring caregiver psychological adjustment have been included in this model. These include *psychological symptoms*, *anxiety*, *life satisfac*tio*n*.

Anxiety

The measurement of anxiety consisted of a single item asking respondents whether they felt anxious as a result of their caregiving duties in the past 12-months from the '*Caregiving Responsibilities and the Respondent's Health*' (CRH) scale. All responses within this scale are categorical (recoded to 1=Yes, 0=No). The following item was used to measure anxiety: "During the past 12 months, have your caregiving responsibilities caused you to feel anxious?" (Statistics Canada, 2013b, p. 158). Single-item scales of anxiety have been found to correlate strongly with validated anxiety measures. Davey et al. (2007) reported a strong significant correlation (r=0.78) between the use of the State Trait Anxiety Inventory and a 1-item visual analogue scale measuring anxiety in a female cancer population. Further, evaluation of a general 'Yes/No' anxiety question in a general cancer population also yielded a sensitivity of 0.78 95% CI [0.75-0.81], meaning that there was high accuracy in identifying individuals who are anxious (Shreffler & Huecker, 2023, Issues of Concern, para 2) using the 1-item measure when compared against the Hospital Anxiety and Depression Scale (Turon et al., 2019).

Psychological Symptoms

A computed measure of respondents self-reported psychological symptoms was included in the present model. The psychological symptoms measure was also comprised of items from the '*Caregiving Responsibilities and the Respondent's Health' (CRH)* scale. The psychological symptoms scale in the present study was modelled on the Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) which includes questions regarding the cognitive, emotion and behavioural symptoms of depression. Face valid categorical items in the GSS Caregiving and Care Receiving questionnaire were matched with the CES-D items (see the psychological symptoms measure and associated CES-D items listed in Appendix B). In the

present dataset, when caregivers reported that they did not experience specific psychological symptoms, they were coded as two, and when individuals indicated that they did experience a specific psychological symptom, they were coded as one. 'Yes' items were recoded as 1, and 'No' items were recoded as 0, and non-answer items were recoded as missing. The total number of 'Yes' responses to the following five items were summed: feeling lonely or isolated, feeling short-tempered or irritable, feeling depressed, experiencing disturbed sleep, and experiencing a loss of appetite, resulting in a scale continuous measure ranging from 0 to 5 symptoms endorsed. Higher scores reflected greater number of psychological symptom reports. KR-20 (internal consistency reliability coefficient) was calculated for the computed psychological symptoms scale and was found to be 0.74 for the included items. The correlations between each item and the total psychological symptoms score ranged from 0.60 to 0.75 (See Appendix C). While the GSS questionnaire also included questions about somatic symptoms (feeling tired, loss of appetite), these were intentionally excluded from the present measure of psychological symptoms due to the potential confounding of these items with physical exertion that takes place as result of engagement in caregiving rather than being present due to low mood. The Hospital Anxiety and Depression Scale also exclude somatic symptoms to avoid confounding of chronic illness symptoms with a respondent's experience of anxiety and depression (Beekman & Verhagen, 2018; Johnston et al., 2000).

Life Satisfaction

Life satisfaction has been defined as a "cognitive evaluation" that contributes to defining the construct of subjective wellbeing (Ryan & Deci, 2017). Further it measures a feeling of satisfaction with life, not merely an absence of distress, allowing for the measure of caregiving uplifts that have been found to be important outcomes in caregiver burden research (Cheung &

Lucas, 2014). Life satisfaction was measured in the present study using the Life Satisfaction Respondent Scale (LSRS) which is a 10-point continuous measure based on the question: "How do you feel about your life as a whole right now?" (Statistics Canada, 2013b, p. 216). Respondents are asked to indicate the degree to which they feel satisfied with their life with zero representing 'very dissatisfied', and ten representing 'very satisfied'. Life satisfaction and psychological flourishing have been found to be significantly correlated (Padgett et al., 2026); thus, the decision was made to use of a life satisfaction rating as a proxy for positive caregiver affect in the present work. Studies report strong correlations (r=0.68) between single item measures of life satisfaction and validated measures (e.g., satisfaction with life scale), as well as theoretically relevant variables related to satisfaction (e.g., happiness), demonstrating strong criterion and construct validity when life satisfaction is measured as a single item variable (Atroszko et al., 2017).

Statistical Analyses

Model Assumptions

Model assumptions including normality, homogeneity of variance and linearity were tested using univariate and multivariate methods. Assumptions of linearity were examined via scatterplot (not presented) and all relationships were found to be linear. Univariate normality of the continuous variables was evaluated via the examination of histograms and Shapiro-Wilks tests. Except for the age variable, all the continuous variables were found to be non-normal, with square root and exponent transformations not having an effect on skewness and kurtosis of the continuous variables. That said, the use of a generalized structural equation model does not assume multivariate normality (StataCorp, 2013, p. 43, para 2), and the use of a large sample size makes the analyses robust to departures of normality. The presence of multicollinearity was

assessed by evaluating the variance inflation factors of the continuous variables in the present model, which were all under 2 for this sample suggesting no serious issue with multicollinearity was present.

Structural Equation Modeling

Structural equation modeling (SEM) was used to test the model outlined in Figure 1 (See Chapter Three, Specification). The path analysis estimates were generated using the STATA software package (version 17, StataCorp, 2017). The generalized structural equation model framework was used to generate the estimates in STATA due to the presence of endogenous categorical dependent variables in the model. The default maximum likelihood (ML) method estimator was employed with a link function that was specified for continuous endogenous dependent variables, and a logit function that was specified for paths with categorical endogenous dependent variables. A person-level probability weight (based on age-sex groups by province) was applied to the analysis to improve generalizability of the present study results to the Canadian caregiver population. The advantage of using the GSEM command is that there is no assumption of multivariate normality regarding the distribution of observed exogenous variables (Huber, 2014, slide 64). Fit indices for the model were generated in R Studio (R Core Team, 2021), as STATA does not yield SEM fit indices when the GSEM command is used.

The GSS-CGCR dataset contained 500 bootstrap weights that were available to generate precise confidence intervals, and they were used in the present analysis. At the time of study conceptualization and data analysis, an R package that could account for the bootstrap weights was not in existence. Using the *lavaan* package (Rosseel et al., 2025) the model was estimated and a Weighted Least Squares Mean and Variance adjusted (WLSMV) estimator was employed in R to address the presence of categorical endogenous dependent variables. Fit indices were

drawn from this analysis and presented in the Results section (see Chapter Five, Results). The WLSMV estimator allows for the generation of estimates when both continuous and categorical endogenous dependent variables are present in the model, as well as provides robust fit indices and estimates due to its use of a diagonally weighted least squares approach to calculate the outputs. The DWLS estimator is recommended when path analyses are specified with categorical (nominal and ordinal) endogenous dependent variables as they yield low bias estimates (Liang et al., 2025). Comparison of the model estimates from R and STATA yielded similar outputs, with all but a few noticeable differences between the STATA and R outputs. The choice to present the weighted estimates from STATA allows for generalization of the results to the Canadian population of caregivers.

Model fit was determined using the following fit indices: Tucker-Lewis Index (TLI), Comparative Fit Index (CFI), Root Mean Squared Error of Approximation (RMSEA), and the Standardized Root Mean Squared Residual (SRMR). The cut-off criteria as cited by Hu and Bentler (1999) were used to assess model fit. The chi square was assessed to evaluate the discrepancy between the model-implied covariance matrix and the original covariance matrix. Generally, a non-significant chi-square is desired and indicates a good fitting model, however in analyses involving large sample sizes such as in the present study, the chi-square test is often biased (Peugh & Feldon, 2020). The chi square result is reported, but the fit of the model will focus primarily on the other fit indices.

Missing Data

Addressing missing data is a common issue in self-report research, as many factors contribute to missing data including a lack of engagement in the survey, personal distractions, missing pages of the questionnaire, respondent fatigue/anxiety, or a desire for privacy. As such,

dealing with missing data is an important step in inferring characteristics from a sample about a population of interest. As will be highlighted in the strengths and limitations section of this work, the sample size of this present work (N=2170 respondents), and the data collection methodology and analysis (the use of rejective sampling and bootstrapping) has yielded a generalizable and representative sample, allowing for missing data to be excluded from the analysis while attempting to minimize the risk of bias being introduced into the data.

When addressing missing data, imputing data for cases missing completely at random (MCAR) or missing at random (MAR) are options that are frequently considered. MCAR refers to missing data that has nothing to do with respondent behaviour (for example when the questionnaire is lost in the mail). MAR suggests that the missing data is related to the participant, however missing data can be predicted from other data about the participant, thus imputation is still possible. In the present study, the majority of the data was dichotomous, and Statistics Canada deemed imputation to be inappropriate for the present dataset (Statistics Canada, 2013a); therefore, no imputation was performed. However, as indicated previously in this work, some survey questions were repetitive. Thus, in cases where a previous question could be used to transpose the data (that is, not impute but carry forward information from a previous question), this was performed.

The original GSS Caregiving and Care Receiving dataset originally sampled 23,093 caregivers and care recipient respondents. Not all caregivers were care receivers, and vice-versa. Proxy respondents who completed the questionnaire on behalf of the chosen household caregiver were not administered the subjective questions and therefore were excluded from the present study. Further, when estimating structural equation models the analytic programs (STATA and R) deletes missing cases listwise, meaning that the SEM results only included those will full

data. In order for the demographics and bivariate analyses to remain consistent, only individuals with complete data in terms of the parameters included in the path analysis were included in the present study. After applying all exclusion/inclusion criteria, the total sample was 2170 respondents upon which the analyses reported in Chapter Five (Results) are based.

Chapter Five: Results

Statistical Assumptions

Assumptions of SEM were evaluated. Continuous variables (age, illness severity, subjective burden, coping frequency, positive aspects of caregiving, and psychological symptoms) included in the present path analysis (see Figure 1) met criteria for linearity at the bivariate level, and multicollinearity was not detected as per the variance inflation factor computed for all continuous data (VIF<5 for of all observed variables which is considered acceptable, see Table 1). Evaluation of univariate histograms (not presented), skewness and kurtosis, and the Shapiro-Wilk test (See Table 1) suggested that the assumption of normality was not met for each of the continuous variables, however the present study utilized a generalized structural equation model estimation command in STATA which does not assume normality (Huber, 2014, p. 64).

Table 1

Caregiver Normality Characteristics (Unweighted, Unstandardized)

Variable	Skewness	Kurtosis	Shapiro-Wilk Test for Normality (W)[a]	VIF	1/VIF
Age	-0.31	2.96	0.56	1.20	0.83
Burden Symptoms	0.32	1.91	0.99	1.91	0.52
Coping Strategies	1.85	6.86	0.96	1.17	0.85
Positive Aspects of Caregiving	-0.48	2.22	1.00	1.17	0.85
Psychological Symptoms	0.64	2.22	0.98	1.24	0.81
Life Satisfaction	-0.99	4.55	--[b]	1.32	0.76

[a]all *p*-values<0.01 (significant *p*-values suggest non-normal data)
[b]The Shapiro Wilks estimate for Life Satisfaction was not available at the time of publication
Estimates are rounded to the second decimal

Bivariate Analysis

The inclusion of variables in the present model was predetermined using theoretical evidence, however given that research findings examining the relationship between caregiver

choice and positive aspects of caregiving were limited during initial conceptualization of this research, a bivariate analysis was conducted. An independent samples *t*-test suggested a significant mean difference between the PAC ratings for caregivers with caregiving choice (*M*=1.81, *SD*=0.96) versus those without choice (*M*=2.27, *SD*=0.77), *p*=0.000, *d*=-0.5, 95% CI [-0.60, -0.42][3].

Demographics

The weighted[4] (population level) caregiver and care recipient characteristics are described in Tables 2 and 3.

Table 2

Respondent Characteristics (Categorical Variables, Weighted, Unstandardized)

	Population N (weighted)	Proportion of Population
Caregiver Characteristics		
Sex	1,742,980	
Male		0.38
Female		0.62
Education	1,742,980	
Less than High School		0.12
H.S. or Equivalent		0.30
College or Trade School Diploma[a]		0.36
Bachelor's Degree or Higher		0.22
Marital Status	1,741,943	
Married/Common-Law		0.71
Widowed		0.03
Separated/Divorced		0.08
Single/Never Married		0.18
Caregiver Employment	1,740,335	
Working		0.56
Student or Other		0.23
Retired		0.21
Caregiver with Children in the Household	1,742,501	
Yes		0.76
No		0.24
Household Income	1,742,980	
Below $69,000.50		0.45

[3] T values not reported as the associated degrees of freedom were not released by the Statistics Canada Research Data Centre in line with their confidentiality rules, see Statistics Canada Privacy Notice from: https://www.statcan.gc.ca/en/about/transparency/privacy

[4] Statistics Canada releases only weighted or unweighted demographics based on the researcher's requests.

Above $69,000.50		0.55
Intensity of Caregiving		
Low		0.68
Medium		0.15
High		0.17
Caregiver's Relationship to the Care Recipient	1,742,980	
Spouse or Ex-Partner		0.20
CG's Child or Grandchild		0.12
CG's Parents or Grandparents		0.46
Relative		0.13
Non-Kin		0.09
Did the Caregiver Have a Choice?	1,742,980	
Yes		0.41
No		0.59
Coping Strategies	1,742,980	
Zero Strategies		0.67
One Strategy		0.24
Two Strategies		0.07
Three to Five Strategies		0.03
Anxiety	1,742,980	
Yes		0.66
No		0.34
Frequency of Endorsed Psy Sxs[b]	1,742,980	
Zero Symptoms		0.35
One Symptom		0.20
Two Symptoms		0.17
Three Symptoms		0.13
Four Symptoms		0.10
Five Symptoms		0.06
Care Recipient Illness Type	1,680,594	
Disorders with Roots in Early Development		0.15
Acquired Disease–Chronic		0.26
Acquired Disease–Episodic Onset		0.07
Aging and Associated Conditions		0.40
Autoimmune Diseases		0.11
Geographical Location of Caregiver	1,742,980	
Rural		0.21
Urban		0.80
Care Recipient Characteristics		
Sex of Care Recipient	1,742,980	
Male		0.35
Female		0.65

[a]College, Non-University or Trade Diploma; [b]Psychological Symptoms
CG=Caregiver; H.S.=High School
Estimates are rounded to the second decimal

Table 3

Respondent Descriptives (Continuous Variables, Weighted, Unstandardized)

	Population (Weighted)	Population Mean (Weighted)	Bootstrapped Standard Error	Bootstrapped Normal Based 95% CI (Lower)	(Upper)
Caregiver Characteristics Age (in Years)	1,742,980	49.86	0.10	49.66	50.05
Average Hours of Caregiving Provided Weekly	1,742,980	19.77	0.19	19.40	20.15
Caregiver Burden	1,742,980	2.91	0.01	2.88	2.93
Number of Coping Strategies Reported	1,742,980	0.46	0.004	0.45	0.47
Positive Aspects of Caregiving	1,742,980	2.00	0.01	1.99	2.01
Life Satisfaction	1,742,980	7.53	0.01	7.51	7.55
No. of Psychological Symptoms Endorsed	1,742,980	1.62	0.01	1.60	1.64
Care Recipient Characteristics Mean Age (in Years)	1,742,980	64.11	0.14	63.84	64.38

[a] No=Number
Estimates are rounded to the second decimal

Primary caregivers in this sample were middle aged (weighted mean age 49.86 years, *SE*[5]=0.10), and most of the respondents reported that their care recipients were their parents or grandparents (46.16%) with spousal/ex-spousal care recipients making up the second largest relationship type category (19.48%). The balance of the sample was composed of relatives which included second or third-degree relatives (13.35%), followed by the caregivers' children or grandchildren (12.4%), and non-kin (neighbour or friends; 8.62%) care recipients. In total, 28.67% of the caregiving sample reported they were single, separated or widowed with the balance reporting that they were married (71.33%), and 76.36% of caregivers reported that they

[5] All SEs represents a bootstrapped Standard Errors.

were also caring for children within the household. Caregivers in this sample were mostly female (62.44%), and a large proportion of the sample (40.08%) were caring for individuals due to aging or aging related conditions. This category included individuals who were receiving care due to old age, as well for those whom caregivers reported were diagnosed with dementia or neurological conditions such as Parkinson's disease. The household income level was almost equally split with just over half (55.1%) of the sample reporting an income above $69,000.50 Canadian Dollars (CAD). In terms of working status, 20.68% were reportedly retired, with the balance of respondents working (56.33%) or engaged in other activities 22.98% (e.g., going to school, volunteering). The majority of caregivers reported that their highest level of education attended was high school or college, or trade school (30.46% and 35.64% respectively). The average number of reported care hours per week was 19.77 hours (*SE*=0.19).

Just under 60% of individuals reported that they perceived they had no choice in becoming caregivers (59.14%). The psychological profile of the sample was such that a greater proportion of caregivers reported experiencing anxiety (65.87% of the sample answered 'Yes' on the anxiety item) but reported fewer psychological symptoms on average (mean of 1.62 items on the psychological symptoms scale; *SE*=0.01) with the total number of psychological symptoms ranging from zero to five. The life satisfaction rating of this sample was also high, with a mean rating of 7.53 (*SE*=0.01; scale ranging from 0-10). Over two-thirds of the respondents engaged in zero coping strategies over the previous year of active caregiving (66.54%) with 23.56% reporting the use of a single strategy, and 4.95% reporting the use of between two and five strategies. Low to moderate burden was reported by this sample (mean score of 2.91; *SE*=0.01; scale range of 0 to 7). These caregivers also reported moderate ratings of positive aspects of caregiving, with a mean of 2.00 (*SE*=0.01; on a four-point scale) which represents an overall

sense of feeling somewhat rewarded by their caregiving role.

Path Analysis of the Model

The model consisted of 56 parameter estimates including the direct relationships between the caregiver context variables and choice and burden (respectively), as well as the independent relationships between choice/burden and the coping, PAC, and psychological adjustment outcomes. Model fit indices were as follows: the chi-square goodness of fit statistic was significant ($p<0.001$) suggesting poor model fit; however, chi square is sensitive to both non-normality of the data and the sample size which were both the case in the present analysis. Other fit indices that are robust to sample size suggested good model fit (*CFI*=0.92; *TLI*=0.98; *SRMR*=0.016; and *RMSEA*=0.036) which all met acceptable limits for conventional thresholds of these fit indices (Hu & Bentler, 1991).

Interpretation of Estimates

All significant weighted path coefficients are reported in Tables 4 and 5 and illustrated in Figure 2. The estimate between caregiver burden and number of coping strategies is not reported as the anonymization rules by Statistics Canada did not allow for this estimate to be released.

All relationships were significant and in their expected direction with the exception of the following: relationships between number of coping strategies with anxiety and psychological symptoms, relationships between income with choice and burden, the relationship between education and choice (high school versus no high school reference group only), and the relationship between caregiver sex and psychological symptoms.

Table 4

Path Analysis Estimates (Weighted, Unstandardized)

DV	Independent Variables	Estimate	*SE*[b]	*z*-value	*p*-value	95% confidence Interval Upper	Lower
Choice[a]							
	Caregiver Sex (ref: Male)						
	Female	-0.36	0.03	-12.88	0.00	-0.42	-0.31
	Caregiver Age	-0.02	0.001	-15.57	0.00	-0.02	-0.013
	CG Household Income (ref: Below $69,000.50)						
	Above $69,000.50	-0.25	0.03	-9.19	0.00	-0.30	-0.20
	CG Relationship to CR (ref: CG's Spouse)						
	CG's Child/Grandchild	-0.45	0.05	-8.86	0.00	-0.55	-0.35
	CG's Parent/Grandparent	0.27	0.03	7.70	0.00	0.20	0.33
	Relative	0.83	0.04	20.26	0.00	0.75	0.91
	Non-Kin	1.66	0.06	28.79	0.00	1.55	1.77
	CG Education (ref: Less than HS)						
	High School or Equivalent	0.16	0.04	3.84	0.00	0.08	0.24
	College or Trade School	-0.14	0.04	-3.27	0.001	-0.22	-0.06
	Bachelor's Degree or Higher	-0.38	0.05	-8.22	0.00	-0.47	-0.29
	Intensity of Caregiving (ref: Low Intensity)						
	Medium	-0.32	0.04	-8.64	0.00	-0.39	-0.25
	High	-0.10	0.04	-2.81	0.005	-0.17	-0.03
Burden							
	CG Choice (ref: No)						
	Yes	-1.36	0.03	-54.42	0.00	-1.41	-1.31
	Caregiver Sex (ref: Male)						
	Female	0.77	0.02	32.47	0.00	0.73	0.82
	Caregiver Age	-0.02	0.001	-19.24	0.00	-0.02	-0.01
	Caregiver Household Income (ref: Below $69,000.50)						
	Above $69,000.50	0.21	0.02	8.99	0.00	0.16	0.25
	CG Relationship to CR (ref: CG's Spouse)						
	CG's Child/Grandchild	0.22	0.04	5.24	0.00	0.14	0.30
	CG's Parent/Grandparent	-0.15	0.03	-5.13	0.00	-0.21	-0.09
	Relative	-0.34	0.04	-9.54	0.00	-0.41	-0.27
	Non-Kin	-0.25	0.05	-5.34	0.00	-0.34	-0.16

	CG Education (ref Less than HS)						
	High School or Equivalent	0.39	0.04	10.37	0.00	0.32	0.47
	College or Trade School	0.75	0.04	20.81	0.00	0.68	0.82
	Bachelor's Degree or Higher	0.77	0.04	19.93	0.00	0.70	0.84
	Intensity of Caregiving (ref: Low Intensity)						
	Medium	0.84	0.03	28.05	0.00	0.78	0.89
	High	1.46	0.03	43.57	0.00	1.39	1.54
	CG Geographic Location (ref: Rural)						
	Urban	0.09	0.03	3.48	0.001	0.04	0.15
PAC							
	CG Choice (ref: No)						
	Yes	0.31	0.01	29.42	0.00	0.29	0.33
	CG Burden	-0.09	0.003	-36.54	0.00	-0.10	-0.09
	No. of Coping Strategies	0.05	0.007	8.19	0.00	0.04	0.07
Anxiety[a]							
	CG Choice (ref: No)						
	Yes	-0.54	0.03	-19.08	0.00	-0.60	-0.49
	CG Burden	0.55	0.008	65.43	0.00	0.53	0.57
	No. of Coping Strategies	0.44	0.03	16.94	0.00	0.39	0.49
Psy Sxs							
	Caregiver Sex (ref: Male)						
	Female	-0.10	0.01	-7.89	0.00	-0.13	-0.08
	CG Choice (ref: No)						
	Yes	-0.16	0.01	-11.80	0.00	-0.18	-0.13
	CG Burden	0.49	0.003	161.09	0.00	0.48	0.49
	No. of Coping Strategies	0.22	0.008	26.49	0.00	0.20	0.24
Life Sat							
	CG PAC	0.29	0.01	26.52	0.00	0.27	0.32
	CG Choice (ref: No)						
	Yes	0.16	0.02	8.71	0.00	0.13	0.20
	CG Burden	-0.34	0.005	-66.68	0.00	-0.35	-0.33
	No. of Coping Strategies	0.04	0.01	3.34	0.001	0.02	0.07

[a]Estimates represent the log odds. Odds ratios are presented in Table 5; Estimates are rounded to the second decimal
[b]Bootstrapped standard error reported, 500 bootstrap weights
Abbreviations: CG=Caregiver; CR=Care Recipient; HS=High School Psy Sxs=Psychological Symptoms; PAC=Positive Aspects of Caregiving; Life Sat=Life Satisfaction; DV=Dependent Variable; No.=Number

Table 5

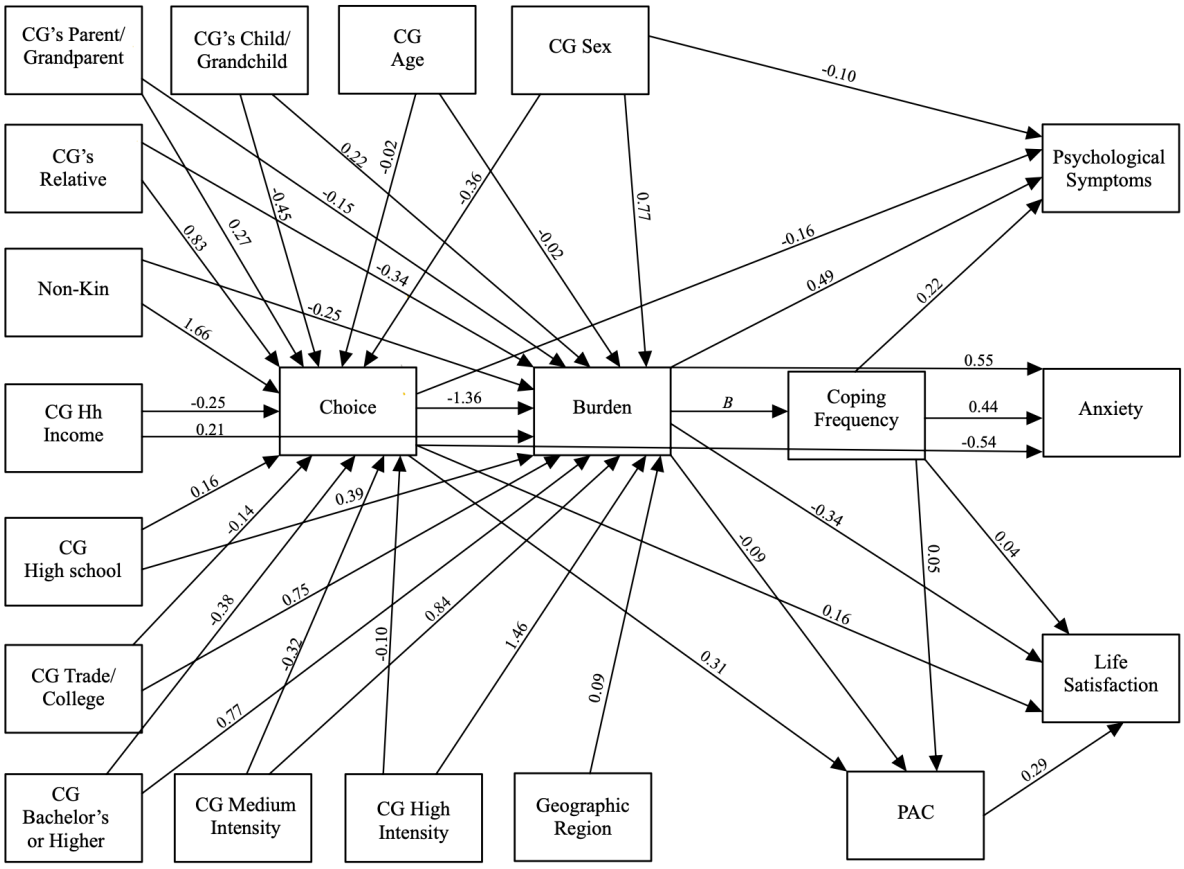
Path Analysis Odds Ratio Estimates and Confidence Intervals (Weighted, Unstandardized)

			95% confidence Interval	
DV	Independent Variables	Odds Ratio	Upper	Lower
Choice				
	Caregiver Sex (ref: Male)	0.70	0.66	0.74
	Caregiver Age	0.99	0.98	0.99
	CG Household Income Above $69,000.50	0.78	0.74	0.82
	Relationship of CG to CR (ref: CG's Spouse)			
	CG's Child/Grandchild	0.64	0.58	0.70
	CG's Parent/Grandparent	1.31	1.22	1.40
	CG's Relative	2.30	2.12	2.50
	Non-Kin	5.27	4.70	5.90
	Caregiver's Education (ref: Less than High School)			
	High school or Equivalent	1.17	1.08	1.27
	College/Trade School	0.87	0.80	0.95
	Bachelor's or Greater	0.68	0.62	0.75
	Intensity of Caregiving (ref: Low Intensity)			
	Medium Intensity	0.73	0.68	0.78
	High Intensity	0.91	0.84	0.97
Anxiety				
	CG Choice (ref: No)			
	Yes	0.58	0.55	0.61
	CG Burden	1.74	1.71	1.76
	CG No. of coping Strategies	1.55	1.47	1.63

Abbreviations: CG=Caregiver; CR=Care Receiver; DV=Dependent Variable
Estimates are rounded to the second decimal

Figure 2

Path Analysis Illustration with Included Estimates (Weighted, Unstandardized)



Note: Paths towards the Choice and Anxiety variables represent the log odds of the estimates
CG=Caregiver; Hh=Household Income; PAC=Positive Aspects of Caregiving

All weighted estimates of caregivers' sex, age, education, income, caregiving intensity, and relationship type were found to be significantly related to one's perception of having a choice to engage in caregiving (*ps*<0.01). Being female was associated with 30% lower odds of perceiving one had a choice in caregiving compared to being male (*OR*=0.70, 95% bootstrapped CI [0.66, 0.74]. Similarly, reporting a higher income (above $69,000.50 CAD) was associated with 22% lower odds of having a perceived choice in caregiving compared to an income below $69,000.50 CAD (*OR*=0.78, 95% bootstrapped CI [0.74, 0.82]. This study also yielded a significant relationship between the age of the caregiver and perceived choice, such that a one

unit increase in caregiver age (in years) was associated with 1% lower odds of perceiving choice in caregiving (*OR*=0.99, 95% bootstrapped CI [0.98, 0.99]. When examining the impact of caregiver age on choice over a decade, the results suggest that for every 10-year increase in caregiver age, the odds of perceiving one had a choice in caregiving decreased to 15[6]%. Relationship-type between the caregiver and care recipient were all significantly related to one's perceived choice in caregiving such that the odds of perceiving choice were greater for most relationship types (i.e., when caring for one's parents, relatives or non-related care recipients) compared to spousal caregivers (the reference variable). Adult caregivers caring for their parents or grandparents had 31% higher odds compared to spousal caregivers of perceiving they had a choice in engaging in caregiving (*OR*=1.31, bootstrapped 95% CI [1.22, 1.40]). Caregivers that were second degree relatives to their care recipients (such as aunts, uncles, cousins or nieces/nephews) had 130% higher odds of perceiving choice in caregiving (*OR*=2.30, bootstrapped 95% CI [2.12, 2.50]. The odds of perceiving that one has a choice in caregiving for non-related care recipients (friends, neighbours) was 427% higher compared to spousal caregivers (*OR*=5.27, 95% bootstrapped CI [4.70, 5.90]). The only relational type that showed lower odds of perceive choice when referenced against a spousal caregiver was the parent or grandparent of a care recipient. Being a parent/grandparent caregiver was associated with 36% lower odds of perceiving that one has a choice to engage in caregiving (compared to the spousal caregiver reference group; *OR*=0.64, 95% bootstrapped CI [0.58, 070]. With respect to caregivers' education, individuals who reported that their highest level of education was high school had 17% higher odds of perceiving they had a choice in caregiving (*OR*=1.17, 95% bootstrapped CI [1.08, 1.27]) as compared to the reference group of caregivers who reported that

[6] Based on the multiplying the choice-age path estimate (*b*=0.015) by ten.

they completed less than high school (as their highest level of education). Those reporting completing education at the college and non-university certificate level, and at a bachelor's degree or above were found to have lower odds of reporting perceived choice in caregiving compared to caregivers whose highest level of education was less than high school (*OR*=0.87, 95% bootstrapped CI [0.80, 0.95]; *OR*=0.68, bootstrapped 95% CI [0.62, 0.75], respectively). Finally, the results suggested lower odds of perceived choice in caregiving for individuals engaged in medium and high intensity caregiving (in comparison to caregivers providing low intensity caregiving; *OR*=0.73, bootstrapped 95% CI [0.68, 0.78]; *OR*=0.91, bootstrapped 95% CI [0.84, 0.97], respectively).

All predictors of caregiver burden were found to be statically significant (*ps*<0.01). Perception of caregiver choice was associated with a lower mean burden score by 1.36 units compared to the caregiver group that perceived no choice in caregiving (*b*=-1.36, *p*<0.01, bootstrapped 95% CI [-1.41, -1.31]). The results show that for every one unit increase in caregiver age, the caregiver burden score decreased by 0.016 units (95% bootstrapped CI [-0.02, -0.01]). This suggests that for every extra decade in caregiver age, burden scores decrease by 0.16 points. Female caregivers scored 0.77 burden units higher on average compared to male caregivers. Regarding the caregiver/care recipient relationship type, parents or grandparents of care recipients experienced a higher mean burden score when compared to the spousal reference group. Parent or grandparent caregivers (of a child or grandchild care recipient) scored 0.22 points higher on average in terms of the caregiver burden score compared to spousal caregivers. Adult caregivers of their parents/grandparents, relatives, and non-kin caregivers all scored lower on average (on the burden scale) compared to spousal caregivers (*b*=-0.15, *b*=-0.34, *b* =-0.25, respectively; *ps* <0.01). Across all levels of education, caregivers reported an average burden

score above the reference group of caregivers endorsing less than high school as their highest level of education. Caregivers endorsing having a high school/high school equivalent diploma, CGEP, or attending trade-school, and individuals with a bachelor's degree or higher (master's or doctorate) scored higher on average in terms of burden compared to caregivers who reported having less than high school (b=0.39, b=0.75, b=0.77, respectively, ps<0.001). Caregivers with a higher household income (above $69,000.50 CAD) scored 0.21 points higher on average in terms of burden compared to caregivers whose household income that was at or below $69,000.50 CAD. In terms of caregiving intensity, both medium and high caregiving intensity caregivers scored higher on average in terms of caregiver burden compared to caregivers reporting lower caregiving intensity (b=0.84, b=1.46, respectively, ps<0.001). For geographical location, caregivers living in urban regions scored 0.09 units higher on average in terms of burden compared to caregivers living in rural regions p<0.001).

Results regarding positive aspects of caregiving were found to be in the hypothesized direction. Perceiving one has a choice of engaging in caregiving was associated with a 0.31 unit mean increase in caregivers' ratings of PAC when compared to caregivers who perceived no choice in caregiving (p<0.001). A positive relationship between the frequency of coping strategies employed by caregivers and positive aspects of caregiving was also found in the present study. For every unit increase in the number of coping strategies employed (that is, for every additional coping strategy employed), caregivers experienced a 0.05 unit increase in PAC (p<0.001). The relationship between caregiving burden and PAC was negative, such that a one unit increase in caregiving burden resulted in a 0.09 unit decrease in PAC (p<0.001).

For predictors of psychological symptoms, caregivers that perceived they had a choice scored 0.16 points lower on average in terms of number of psychological symptoms reported

compared to caregivers who did not perceive a choice (b=-0.16, p<0.001). Further greater caregiver burden was positively associated with caregiver reports of psychological symptoms (b=0.49, p<0.001). Contrary to our hypotheses, being female was associated with a significantly lower mean score in terms of number of psychological symptoms reported compared to male caregivers (b=-0.10, p<0.001). Further employing more coping strategies was associated with a higher number of psychological symptom reports (b=0.22, p<0.001).

The results suggest that having a choice in taking on the caregiving role was associated with a 42% reduction in the odds of experiencing anxiety (OR=0.58, bootstrapped 95% CI [0.55,0.61]). Anxiety was negatively associated with caregiver burden, such that for every one unit increase in caregiver burden, the odds of caregivers reporting that they experienced anxiety increased by 74% (OR=1.74, 95% bootstrapped CI [1.71, 1.76]). Similarly for coping frequency, for every unit increase in number of coping strategies used, the odds of caregiver anxiety increased by 55% (OR=1.55, 95% bootstrapped CI [1.46, 1.63]), which was opposite to the hypothesized direction.

For overall ratings of life satisfaction, caregivers who perceived they had a choice to engage in caregiving scored 0.16 points higher on average in terms of reported life satisfaction compared to individuals who did not perceive they had a choice to engage in caregiving (b=0.16, p<0.001). Further PAC was positively associated with life satisfaction such that a one unit increase in PAC was associated with a 0.29 unit increase in life satisfaction ratings (b=0.29, p<0.001). With respect to burden, a one unit increase in burden was associated with a 0.34 unit decrease in life satisfaction (b=-0.34, p<0.001). For coping, a one unit increase in coping frequency resulted in a 0.04 unit increase in life satisfaction (b=0.04, p=0.001).

Chapter Six: Discussion

The primary goal of this study was to test a modified model of caregiving stress that includes perceived choice within a stress and coping framework of caregiver psychological adjustment. The secondary goal was to examine predictors of perceived caregiving choice and the impact of lack of choice on caregivers' psychological adjustment (both distress and wellness). The use of a Canadian sample of caregivers is important as it situates perceived choice and the psychological adjustment of caregivers within the context of the Canadian health care system. This is crucial given the physical and financial stresses that are relieved from the system when support is provided by unpaid family caregivers (Jacobs et al., 2013). The present study adds to the limited empirical evidence on perceived caregiver choice and caregivers' psychological functioning and wellbeing.

The above detailed objectives were examined using the 2012 sample from Statistics Canada's Caregiving and Care Receiving survey. Overall, the observed data was found to fit the model well, suggesting that perceived choice fits well within a stress and coping framework as a significant predictor of caregiver psychological adjustment. Only one other study has conducted an SEM using the Statistics Canada 2012 GSS Caregiving and Care Receiving dataset. They examined factors contributing to caregiver distress; however, perceived choice was not the primary focus of that study (Li, et al., 2024). Li et al. (2024) used perceived caregiver choice as part of a latent variable named *positive emotional experiences*. The present study included perceived choice as an observed variable, and a selection of predictors and outcomes of perceived choice was guided by several psychological frameworks (two stress and coping frameworks, and the Self-Determination Theory). Work by Lawton et al. (1991) theorized the importance of measuring unique outcomes for caregiver distress and adaptation which was

captured in the present research via the use of a life satisfaction outcome (which was not employed in the study by Li and colleagues, 2024). Thus, the present study differs in terms of how the psychological outcomes were presented, and how perceived choice relates to both caregiver distress and wellbeing.

Consistent with other research on perceived choice in caregiving, respondents in the present study were mostly middle-aged adult females (Al-Janabi et al., 2018; Longacre et al., 2014; Li & Lee, 2020; Schulz et al., 2012; Winter et al., 2010), and the care recipients being cared for were adults caring for their parents/grandparents followed by spousal caregivers. The exception to present findings of the caregiver age range was a study by Pertl et al. (2019) who selected for caregivers over the age 50 years old as a methodological consideration. As in other research, most of the caregivers in the present sample were caring for individuals with disabilities related to acquired chronic diseases or old age (Li & Lee, 2020; Schulz et al., 2012). These demographics are also consistent with studies examining caregiver psychological wellbeing (of individuals with heterogenous illness) overall (Scerri et la., 2019). A recent publication of the General Social Survey Caregiving and Care Receiving survey results administered in 2018 (Statistics Canada, 2018) reported that the 2018 sample was mostly middle-aged females caring for their adult parents (Statistics Canada, 2020). This suggests that the profile of caregivers in Canada has remained unchanged between 2012 and 2018. The caregiver profile representing middle aged, female caregivers of parents or grandparents is unsurprising given that care needs increase with age (Ferri et al., 2005), and that society expects women to carry out the caregiving work (Jacobson, et al., 2025).

The results of the present study found that just under 60% of respondents reported no perceived choice in caregiving which is similar to an AARP/United Hospital Fund U.S. national

study on the caregiving of individuals with cognitive and behavioural health issues who reported that exactly 60% of their sample perceived a lack of choice in caregiving (Reinhard et al., 2014). The proportion of individuals reporting a lack of choice in the present study is higher than many comparable studies, as perceived lack of choice in other studies ranges from 31% to 82% (Li et al, 2024; Li & Lee, 2020; Longacre et al., 2014; Schulz et al., 2012; Winter et al., 2010). Methodological considerations may account for these differences. Studies that reported a lack of perceived choice on the lower end of the range included both primary and secondary caregivers (where secondary caregivers are not primarily responsible for the care work) in their samples (Li et al., 2024; Li & Lee, 2020; Longacre et al., 2014; Winter et al., 2010). This suggests that individuals in the present study may represent caregivers who have likely engaged in a greater degree of the care work. Identifying caregivers engaged in greater intensity of care remains important, as research has shown that engagement in 20-hours of care per week or greater is associated with higher levels of general distress (measured longitudinally; Hirst, 2005). Li and Lee (2020) did not report the average care hours of their sample, however Li et al. (2024) indicated that 70.4% of their sample engaged in less than ten care hours on average per week. The exception was reported by Longacre and colleagues (2014) who reported a greater intensity of caregiving; however, caregiving intensity may have been related to their study's focus on caregivers of individuals with cancer. Caregiving of care recipients with cancer has been shown to be burdensome physically, psychologically, and socio-economically (Girgis, et al., 2013; Rezaei et al., 2024). Regarding the higher end of the perceived choice range, Pertl and colleagues (2019) reported that 82% of their sample experienced lack of choice; however, their focus was on older spousal caregivers of people with dementia (PwD). Interestingly, the majority of their sample reported that the provision of care was almost completely voluntary when measured by a

willingness to care variable, likely due to the marital commitment and relational quality present in long-term marriage. Studies suggest that low relational quality between spouses is associated with less spousal presence in care (Swinkels et al., 2022). It is important to note that choice may be "bounded with by linguistic and/or cultural variation" making the decision of saying no to caregiving "difficult or even impossible" (Kietzman et al., 2013; p. 535). Kietzman et al.'s (2013) description of a passive assumption of care highlights the complexity in studying choice in caregiving. In fact, Al-Janabi et al. (2018) showed that while individuals perceived they have choice, their decision to choose at times is constrained due to the need to manage pragmatic circumstances such as a lack of financial or human resources available for individuals to make a true choice regarding their involvement in the provision of care. This points to the nuanced experience of studying perceived choice in caregiving.

With respect to psychological adjustment, the mean caregiver subjective burden score in this sample was mild to moderate (mean of 2.91 of seven total burden items), and the mean number of reported psychological symptoms was low (average score of 1.62 measured from 5 items), however more than half of the individuals in the present study reported feeling anxious as a result of their caregiving over the past 12-months. Life satisfaction of the respondents was reportedly high in this sample. Methodological differences in construct measurement across studies make it difficult to compare levels of life satisfaction and mental health.

Demographic Predictors of Choice

All socio-demographic variables included in the present research were found to significantly predict caregivers' perception of choice. The results suggest that being older, female, having a higher income and education, and engaging in greater intensity caregiving are associated with lower odds of perceiving that one has a choice to engage in caregiving. In the

present study, older individuals were less likely to perceive choice in caregiving. Evidence of this relationship in the literature is mixed with some studies citing no relationship (Al-Janabi et al., 2018; Longacre et al., 2014; Pertl et al., 2019; Winter et al., 2010), and one study supporting the finding that older age is associated with less perceived choice (Pertl et al., 2019). Comparison between the present study and Pertl et al. (2019) remains difficult however as the age range of their reference group was wide (18-49 years). Pertl and colleagues (2019) included young adults and individuals in mid-life in the same reference group which precludes specific comparisons between the experience of caregiving in midlife versus the experience of older caregivers. A survey of older adults suggests that there is a decrease in the availability of paid caregivers (Age Wave & John A. Hartford Foundation, n.d.), and research suggests that the number of unpaid caregivers available to care for older individuals is shrinking (Alburez-Gutierrez, et al., 2023). Further, older care recipients are less likely to receive care from their spouse compared to middle age care recipients (Lima et al., 2008), likely due to competing health issues that occur as their spouse ages. Thus, lack of caregiving choice for older individuals may be due to situational constraints contributing to less perception of choice as one becomes older.

In the present study, being female was associated with lower odds of perceiving one had a choice in caregiving compared to male caregivers. Longacre et al. (2014), Pertl et al. (2019) and Al-Janabi et al. (2018) reported no significant sex differences in caregivers' reports of perceived choice. Given that Pertl et al.'s (2019) study was focused on spousal caregivers, this factor may have been mitigated by spousal expectation to care due to marital commitments. Regarding the study by Al-Janabi and colleagues (2018), it is difficult to compare their results due to their categorization of choice (free choice, constrained choice, no choice) as it relates to how they analyzed differences among groups. Longacre et al. (2014) reported that none of their

demographic variables were associated with perceived choice, however their focus on caregivers of individual with cancer resulted in a smaller number of respondents, with the majority reporting that they felt they had a choice to engage in caregiving. It is possible that these factor in addition to other sample characteristics (suggesting a homogenous sample) may have precluded the detection of a difference in perceived choice among male and female caregivers.

Contrary to the results of this study, a study by Friedemann and Buckwalter (2014) of a multicultural sample of caregivers found that male spouses scored higher on a measure of caregiving obligation compared to female spouses. Their concurrent finding that male spouses in this sample experienced less burden compared to female spouses, led the authors to suggest that this outcome was in line with cultural norms, with them positing that a high degree of voluntariness may have existed in the males of their sample. Qualitative research highlights the societal pressures females experience related to caregiving due to expectations that the work of a female is to provide care for their family members, regardless of any personal cost (Williams et al., 2017). Studies have shown that a care recipient's expectation for who will care for them in the future is often their daughters (Stafford & Kuh, 2018), particularly if the care recipient is female themselves. Daughters-in-law in Japan have long been referred to as the "default caregivers of aging parents" (Tsutsui et al., 2014, p. 799) further highlighting the expectation of women as caregivers to aging members of society. Caregiving studies often report more females in their samples compared to males (Li & Lee, 2020; Pertl et al., 2019), and women are more likely to become caregivers (Statistics Canada, 2023). Given women's cultural expectations to care, further study of the relationship between sex and perceived caregiving choice is warranted.

The reported household income in the present sample was almost evenly split as per the methodology, with just over half of the respondents reporting a higher household income of

$69,000.50 CAD or above. Li and Lee (2020) is the only known Canadian study examining caregiving choice that reported caregiver income as a descriptive characteristic of their sample. Their results also suggest that higher incomes are associated with a lack of choice. Individuals reporting education at the high school level (compared to caregivers reporting less than high school education), had higher odds of perceiving they had a choice to engage in caregiving whereas individuals reporting completion of college/trade school and post-secondary education reported lower odds of perceiving that they had choice in caregiving compared to the 'less than high school' reference group. Few studies have examined the association between caregivers' education and perceived caregiving choice, although the evidence of education as a significant predictor of choice is mixed. Schulz et al. (2012) reported that the proportion of individuals who perceived choice in caregiving decreased with increased years of education, and Li and Lee (2020) reported a significant difference between categorized education levels across caregiver choice versus no choice, however they did not report post hoc findings to specify this outcome further. Other studies reported no differences or associations between education and perceived choice (Longacre et al., 2014; Pertl et al., 2019; Winter et al., 2010). Schulz et al. (2012) suggested that the pattern of higher education being associated with less choice might reflect one's experience of a loss of autonomy. This may be in part due to individuals' participation in professional careers which might offer less flexibility in shifting to a caregiving role. Variables to test this hypothesis are not available within the present study, nor have any other studies provided evidence or insight into this relationship. One study showed that most participants are still engaged in full or part-time work (Li & Lee, 2020). Li and Lee (2020) also reported a greater proportion of individuals who perceived choice in the "other" category reflecting students or individuals who are seeking work. Perhaps flexibility built into those roles might be related to

better perception of choice when a family member or friend needs caregiving support. Regarding the finding on choice and income, demographic descriptions (Schulz et al., 2012) and bivariate associations (Li & Lee, 2020) have been presented but studies have shared no further analysis or discussion regarding this variable. Greater economic strain is reportedly associated with institutionalization of older individuals with Alzheimer's Disease (Aneshensel et al., 1993). While the results of the present study suggest that higher income is associated with less perception of choice, physical caregiving often comes with economic consequences both in terms of missed work (particularly for female caregivers who reporter poorer financial wellbeing compared to males; Lalani et al., 2025) and the costs of caregiving in terms of medical supplies and paid support (Committee on Family Caregiving for Older Adults, 2016; Stommel et al., 1994). Dementia caregiving research by Lee et al. (2015) reported that the type of care offered (physical versus financial support) differed based on caregiver characteristics. Of note, they reported that being older and male were among the caregiver characteristics that predicted the provision of financial care over physical care.

The present study also reported associations in perceived choice across relational types between the caregiver and care recipient. While Longacre et al. (2014) reported no significant difference between relational type and perceived choice, Schulz et al. (2012) reported that compared to non-relational caregivers, spousal and parent caregivers experienced more of a lack of perceived choice. Pertl et al. (2012) reported that caregivers grouped into to the 'relative' category (i.e., not parents or children of care recipients) more frequently reported that they had a choice in caregiving. These results fit with the present study in which compared to spousal caregivers, non-family caregivers, relatives, and adult-children caregivers (that is, caregivers of parents and grandparents) reported greater odds of perceiving they had a choice in caregiving.

The present study also reports the additional finding that parents or grandparents of care recipients reported greater odds of perceiving no choice compared to spousal caregivers.

Research on adults caring for their parents might explain motivation to care as stemming from a sense of obligation, duty or reciprocity towards their parents (Charenkova, 2023; Sharma, et al., 2016; Tavero et al., 2018; Zarzycki & Morrison, 2021). Parent caregivers of children with disabilities perceive that caring for their children is their responsibility (Barratt et al., 2025). This position leaves little room to view their caregiving role as a choice. Li and Lee (2020) reported significant interactions of relational type and perception of caregiving choice in the prediction of caregiver distress and life satisfaction. They reported the finding that non-kin and relatives experience greater life satisfaction and fewer psychological symptoms compared to parent or spousal caregivers. Altogether, this evidence may suggest that identifying the relationship of the primary caregiver to the care receiver might provide information regarding caregivers' risks to their wellbeing while taking on this role.

In the present study, higher caregiver intensity was related to lower odds of perceiving caregiver choice. One study reporting a caregiving intensity score using the National Alliance of Caregiving Index (based on weekly average hours of caregiving and ADLs/IADLs provided) noted engagement in caregiving intensity levels in proportions similar to the present study (Schulz et al., 2012). Longacre et al. (2014) reported greater caregiving intensity; however, their sample consisted of caregivers of individuals with cancer, of whom the majority were providing care for less than a year. Longitudinal research has shown increases in objective burden reports (such as time spent caregiving, number of ADLs performed) over a year's time in caregivers of individuals with terminal cancer (Siminoff et al., 2024). The present study found lower odds of perceiving caregiver choice when caregiving intensity was at the medium or high levels

(compared to low intensity caregiving). Unsurprisingly, a study measuring objective burden (measured using the NAC burden calculation) showed that caregivers with choice reported lower intensities of caregiving, compared to those without a choice (Winter et al., 2010). Despite using the NAC measurement, not all studies reported this finding (Longacre et al., 2014). The provision of high intensity caregiving is likely associated with personal sacrifice (e.g., career, personal time). The presence of this relationship might therefore be explained by other factors such as lack of availability of others family members to provide high intensity care. Alternatively, individuals possessing a greater sense of responsibility to care for older family members (such as those high in beliefs of filial obligation), may be self-selecting into providing high intensity care.

A path between sex and psychological symptoms was included in the present model. This relationship was found to be significant in the present study, however the mean difference between psychological symptoms in males and females was small. This result is consistent with Pinquart and Sorenson (2006) who conducted a meta-analysis examining the impact of gender differences on the psychological outcomes (e.g., burden, depression) of caregivers. They noted in their results that differences in depression related to gender were of "practical importance" (p. 39). Robinson-Whelen and Kiecolt-Glaser (1997) reported no differences in perceived stress or depression between male and female spousal caregivers. Their findings did report a significant choice by gender interaction which positively predicted perceived stress (with a trend in the positive direction). Their longitudinal results yielded a negative association between degree of choice and perceived stress in men but not women. Overall, this suggests that sex effects may be present when examining psychological functioning in caregivers, which should be assessed. Men and women are socialized differently in terms of their responsibility towards caregiving (Paoletti,

2002) which may result in differences in the way that they emotionally experience and adapt to their caregiving role (Zygouri et al., 2021). Thus, while the sex difference in psychological symptoms in the present study was small, further consideration of their shared and varied experiences are warranted.

Choice in Caregiving and Psychological Adjustment

The present study found that caregivers' perceived lack of choice impacted their caregiving experience (subjective burden and positive aspects of caregiving), caregiver distress (anxiety and psychological symptoms), and caregiver wellbeing (life satisfaction) in the a priori hypothesized directions. Lack of caregiver choice was associated with increased caregiver subjective burden, psychological symptoms, and anxiety, as well as with lower PAC and life satisfaction. The reported outcome for life satisfaction is consistent with the SDT framework highlighting the relationship between autonomy and wellbeing. For individuals to thrive in terms of their experience of wellness, they need to satisfy what Ryan and Deci (2000) termed their *basic needs*, one of which centres on the experience of autonomy. When applying this framework to caregivers' perception of choice, the absence of choice may explain the experiential and emotional outcomes reported in the present study, namely that becoming an unwilling caregiver (due to lack of choice) is associated with a poorer caregiving experience. Further, not having caregiving choice can contribute to the caregiver's personal experience of loss. An individual's transition into the caregiving role has contributed to shifts in identity that contributes to a loss of self (Eifert et al., 2015). Qualitative research examining the development of a caregiver's identity yielded two (of four) themes that reflected a lack of caregiving choice and associated distress ('The Prisoner') and the experience of being overwhelmed by the role

('The Crumbling Caregiver'; Cooper, 2021). These identities further emphasize the importance of studying caregiver choice.

Only one known study of choice and psychological adjustment included validated measures of anxiety and depression as their outcome variables (Pertl et al., 2019). The finding of an association between choice and caregiver distress in the present study, namely anxiety and psychological symptoms, is consistent with other studies, where lack of choice was associated with increased symptoms of distress (Longacre et al., 2014; Schulz et al., 2012). Pertl et al. (2019) reported no relationship between baseline perceived caregiving choice, and anxiety and depression measured at one year follow-up. Pertl and colleagues (2019) examined long-term caregiving of PwD where the average number of years of caregiving reported was on average five years. High intensity (20+ hours on average) caregivers experienced distress that reportedly peaks across a caregiver's transition (first) year into the caregiver role (compared to distress experience in prior years when individuals were not identified as caregivers; Hirst, 2005). Hirst (2005) also reported reductions in distress over the following caregiving years, noting that distress returned to baseline distress after four years (for female caregivers). It is possible that the sample from Pertl and colleagues (2019) had already experienced adaptation prior to the year of their assessment which could explain the difference in results compared to the present study. Further, Pertl et al. (2019) reported a high degree of willingness to care which potentially buffered known psychological impacts related to perceiving a lack of caregiving choice.

Consistent with the results of the present study, prior research examining constructs similar to subjective burden (that is, whose conceptualizations overlap with the construct of subjective burden) has reported associations with perceived caregiver choice. Al-Janabi et al., (2018) reported that compared to having no caregiving choice, having constrained choice and

free choice were associated with higher scores on the Caregiving Experiencing Scale, with the magnitude of these associations increasing across the constrained and free choice options. In a content analysis examining the caregiving experiences of older spousal caregivers (namely poor sleep health, lack of finances, lack of family support and caregiver esteem), those who experienced caregiving negatively were more likely to express that they had no choice in engaging in the caregiving role (Aloweni et al., 2019). Pertl and colleagues (2019) also reported a negative bivariate relationship between subjective burden (measured by the Zarit Burden Interview) and degree of caregiving choice, suggesting that greater willingness may buffer unavoidable negative impacts associated with caregiving. Studies of caregiver psychological resiliency supports this buffering hypothesis, as caregiver resilience was found to both moderate and mediate the relationship between subjective burden and depression in a sample of caregivers caring for an individual who had a stroke (Yu & Chen, 2025).

Few studies have independently examined the relationship between perceived choice and caregiver anxiety; however, three studies reported an association between lack of choice and "emotional stress" (measured as a single-item question asking participants to rate their experience of emotional stress in caregiving) adjusting for demographic factors (Longacre et al., 2014; Schulz et al., 2012; Winter et al., 2010). Both studies hint at the impact of uncertainty on one's perception of choice. Longacre et al. (2014) focused on caregivers of individuals diagnosed with cancer, which is reportedly perceived to be uncertain in terms of caregiving course and the future of the care recipient (Weiss et al., 2023).

Only Pertl et al. (2019) measured caregiver depression with a validated scale, and they reported no relationship between choice in caregiving and depression. In the present study, efforts were made to examine the degree to which caregivers reported psychological symptoms

associated with a lack of caregiver choice. Measurement of this construct was purposely strict to allow the psychological symptoms variables to best represent depressive symptoms experienced by caregivers. Li and Lee (2020) reported a greater proportion of reported psychological symptoms between caregivers reporting no choice versus those reporting choice, as well as a negative association between caregiving choice and psychological symptoms (using similar measurements of psychological symptoms as per the present study); however, they included anxiety and an item measuring caregiver overwhelm in their measure, possibly the limiting conclusions that can be drawn between perceived choice and caregiver depression. Overall, a focus on caregiver distress remains important given recent statistics reporting that two out of five Canadian caregivers experience distress (CIHI, 2024). Caregiver mental health and well-being is important to their ability to take care of their own needs while providing support for their care recipients.

Lack of choice in the present study was associated with lower life satisfaction and lower ratings regarding the rewarding nature of the caregiving experience (measured in the present study as PAC). Choice being associated with PAC fits the literature. Zimami et al. (2025) found that having caregiver choice is associated with an increase in PAC. A negative correlation between caregiver meaning and role captivity has previously been reported (Quinn, 2010), such that caregivers who felt more stuck in their role reported less meaning making based on their experience. Pertl et al. (2019) found that degree of baseline choice was positively associated with an increased sense of usefulness and meaningfulness in caregivers at a year follow-up in both bivariate and multivariate models. They did however note a minimal impact of choice, such that their measure of dichotomous choice only accounted for 2% of the variance of PAC one-year post-measurement. PAC was mostly determined by baseline level of PAC, followed by caregiver

demographic variables (Pertl et al., 2019). While the present study suggests positive outcomes in caregiving might be affected when caregivers do not have a choice in their role, Pertl and colleagues' (2019) results suggest that trait like tendencies for personal growth (such as feeling rewarded by the caregiving experience or emotional closeness between the caregiver and care recipient) primarily drive the experience of PAC. Taken together, the literature suggests that assessing level of PAC in caregivers may indicate the presence of a resilience marker that can be fostered (particularly for individuals experiencing complex caregiving situations). Further, clinical focus on the caregiver's choice to enter into the role may impact this resiliency. Further research on the interaction of caregiver choice and PAC is therefore warranted.

With respect to life satisfaction the present research showed that having choice was positively associated with life satisfaction. Al-Janabi et al. (2018) also reported that compared to having no choice, both the constrained choice and the free choice variables were associated with increased life satisfaction. Pertl et al. (2019) found no relationship between choice, degree of choice and quality of life, however quality of life has been conceptualized as a broad assessment of an individual's wellbeing (WHO, 1998), whereas life satisfaction is the general subjective evaluation one's life (Yotsidi et al., 2023). Thus, it's possible that these items were not capturing the same construct. Outside of caregiving research, choice is viewed as having a positive impact on measures of subjective wellbeing such as life satisfaction (Headey et al., 2013). It is therefore not surprising that caregivers addressing complex and unknown care needs, particularly those choosing to undergo life changing experiences (related to caregiving) would exhibit greater happiness when autonomy in making decisions is present.

Caregiver Subjective Burden and Choice

The relationship between subjective burden and choice is under-studied, with limited evidence reporting significant relationships between objective burden and choice. A qualitative study of older caregivers highlighted that caregivers reporting a negative caregiving experience also reported no perceived choice in their caregiving role (Aloweni et al., 2019). Their measurement of negative experience included caregiving impacts on health, finances, and caregiver esteem, which aligns with the concept of subjective burden, and fits with the results of the present study that show increased subjective burden when caregivers perceived that they had a lack of choice. Adjacent choice constructs such as role captivity and caregiving willingness and their relationship with subjective burden show similar relationships. Willingness to care has been found to be negatively associated with burden (Li et al., 2023 although relationships in the opposite direction have been proposed in the present study). A study detailing the experience of caregivers of PwD noted how taking on the role was associated with financial and social strains, and personal stressors regarding a lack of resources and knowledge regarding how to take care of their loved ones (Wilson et al., 1989).

Predictors and Outcomes of Subjective Burden

Unsurprisingly, subjective burden was found to be significantly associated with increased anxiety and psychological symptoms, as well as decreased PAC and life satisfaction, although the associations reported in the present study for PAC and life satisfaction are weak, suggesting that there is little relationship present between subjective burden and these variables. Sezek et al. (2023) reported a strong bivariate correlation between a ‘Satisfaction with Life’ scale and subjective burden, however their study did not account for confounds by using a multivariate analysis, thus comparison is not possible. In the literature, high subjective burden is reportedly

associated with low mental health ratings (Fekete et al., 2017), anxiety (del-Pino-Casado, Priego-Cubero, López-Martínez, & Orgeta, 2021), and depression (del-Pino-Casado et al., 2019) and poor psychological adjustment across varied care recipient conditions (Brandão et al., 2017; Cooper, et al.; 2008; Unsar et al., 2021; Secinti et al., 2017; Wen et al., 2022). Further higher burden is associated with lower PAC (del-Pino-Casado et al., 2015), and life satisfaction (Chappell & Reid, 2002).

All determinants included in the presented model were also significantly associated with subjective burden. Similar findings exist in the literature, namely that experiencing worsening burden is associated with being a younger caregiver (Andrén & Elmståhl, 2007; Cain & Wicks, 2000), being female (Iavarone et al., 2014; although this relationship has also been described as inconsistent; Xiong et al., 2020), having a lower income (Andrén & Elmståhl, 2007; Walke et al., 2018) and higher education levels (Schwartz et al., 2021; Schnitzer et al., 2017, mental burden; Oedekoven et al., 2019), and reporting engagement in more intense caregiving (Alghamdi, 2026). This study found that living in an urban location was associated with greater burden, however this is opposite to what has been reported in the literature (Bouldin et al., 2018; Cohen et al., 2021). In terms of relationship type, only parent/grandparent caregivers in the present study reported greater burden compared to spousal caregivers. Parents manage both daily and future worries about the wellbeing of their chronically ill their children. They also cope with personal changes such as losing one's identity due to the care needs of their children (Rabbani & Nawaz, 2026) which may explain their greater sense of burden compared to other caregiver relationship types. Subjective burden reflects the perceived negative impacts of the caregiving experience in terms of emotions, attitudes, and feelings (Hoenig & Hamilton, 1967, as cited in Montgomery et al., 1985), thus its inclusion in a caregiving model is important. That said, given

that many studies have examined predictors and outcomes related to caregiving burden, these relationships will not be further discussed within the present work.

Coping, Caregiver Distress, and Caregiver Adaptation

Findings suggest that caregivers use of coping strategies vary across their caregiving experience (Baumstarck et al., 2018; Cooper et al., 2008; Williams et al., 2014). A study of caregivers of individuals with acute brain injury reported the use of disengagement strategies (e.g., avoidance) to manage initial painful emotions, and problem-focused strategies (e.g., problem-solving) in later caregiving phases to manage caregiving needs (Hwang et al., 2024). Generally, findings suggest that an individual engaging in adaptive coping strategies is associated with improved psychological adjustment (with adaptive coping serving in one study as a moderator to maladaptive coping; Thompson et al., 2010). Adaptive coping refers to coping strategies that direct an individual's attention towards a stressor. Generally, problem-focused strategies (such as problem-solving) are considered adaptive, but emotion-focused strategies such as seeking social support can also be helpful in achieving specific goals (Carver et al., 1989). The use of emotion focused strategies (e.g., acceptance, perspective taking, meaning making) have reportedly been helpful in situation where control over the caregiving experience is not possible (e.g., caring for some with a progressive disease; Williams et al., 2014). Further, emotion-focused coping has been associated with reduced anxiety in palliative family caregivers of individuals with cancer (Perez-Ordóñez et al., 2016). In the present study, the use of more adaptive caregiver coping strategies was associated with increases in psychological symptoms and higher odds of caregivers experiencing anxiety over the previous 12-months of caregiving. Hirst (2005) showed that caregiving distress decreases after the first two years of caregiving. It is possible that asking respondents to reflect back on their experiences over a single year may not

have been enough time to capture the impact of caregivers' use of coping strategies on caregiver anxiety and psychological symptoms in the present sample. Alternatively, the focus on computing a variable that reflected approach coping might not have been the best fit given the heterogeneous nature of the care recipients included in this sample. Folkman (2008) highlighted research by Tedlie Moskowitz et al. (1996) who cited that different types of coping yielded different relational strengths to positive or negative moods, such that weaker associations would be present when coping style and psychological outcome were not well matched. In the present study the associations were not found to be weak; however, anxiety and psychological symptoms represent negative mood outcomes in caregivers, whereas the coping strategies were coded as adaptive coping approaches (both emotion and problem focused coping strategies). Generally, adaptive coping styles are suggested to involve a forward focus towards challenging issues on the part of the caregiver to mitigate the impact of a stressor. The majority of this sample in the present study reported caring for individuals with aging or aging associated conditions (such as Chronic Obstructive Pulmonary Disease, Parkinson's and Alzheimer's Disease) which may require acceptance as the progression in age related or disease-related factors may be uncertain or unpredictable (Hurt et al., 2017; Hynes et al., 2012; Stone & Jones, 2009), and care related tasks can seem unending (Wilson, 1989). A quarter of the present sample reported that they were caring for individuals with acquired disease (e.g., cancer and cardiac illness), which in the initial stages and/or later management may require practical and active steps in order for caregiver adaptation to occur. Coping strategies measured in the present study would be considered emotion-focused coping strategies (seeking professional support, focus on religion), therefore an alternate explanation may be that the coping style measured did not match with the needs of caregivers.

The present study yielded significant positive relationships between number of coping strategies employed and positive adjustment, namely PAC and life satisfaction. That said, the presented estimates are low suggesting weak relationships for both outcome variables. There is limited empirical evidence regarding the relationship between coping and PAC. Both adaptive (i.e., seeking support; Manalel et al., 2025) and maladaptive (e. avoidance; Grover et al., 2017) coping strategies are reported to be positively related with PAC. Findings are mixed, with PAC being reportedly lower among caregivers of children with rare diseases who engage in maladaptive coping practices (i.e., venting; Manalel et al., 2025). Positive relationships between adaptive coping (religious coping and spirituality) and life satisfaction have also been reported (Darvyri et al., 2014). Coping strategies focus on the actions that individuals undertake (emotionally or physically) to address stressful situations. This allows for individuals to manage periods of stress, which in caregiving can be uncertain and long-term. Roth and Cohen (1986) summarized the approach-avoiding coping dimensions as a behaviour that results in the orientation towards or away from threat. They highlighted that cognitive or emotional activities can allow for changes to be observed and made to threat situations when coping occurs in the approach dimension but can result in a reduction of stress (typically in uncontrollable environments) when avoidant coping strategies are employed. Their research argues for a flexible application of these constructs that are context and interpersonally (e.g., trait-specific) dependent in order to understand how approach versus avoidant coping can be viewed as adaptive or maladaptive. Therefore, what may be considered madaptive coping (e.g., avoidance, venting) may be adaptive for individuals in high stress contexts, when these coping strategies are elicited for short periods of time. The above-mentioned studies focus on parents of children with rare diseases, and caregivers of PwD which is often accompanied by uncertainty of their care

recipient's prognosis and future, and chronic stress for the caregiver. Taking "breaks" in terms of avoidance of difficult emotions (temporarily) may be helpful in managing distress, in order turn their attention to immediate caregiving needs. In the present study, the heterogenous nature of the sample may not have exhibited these high levels of stress, resulting positive associations reported between the use of adaptive coping strategies and the presented measures of wellbeing (that is, life satisfaction and PAC).

Finally, a key objective of this study was to highlight caregiver wellbeing, particularly in the face of stress. The present study found that caregivers who perceive a greater sense of reward from their experience reported greater life satisfaction. The association with positive aspects of caregiving and life satisfaction fits with existing literature which shows positive associations in caregivers (of various illness-types) with self-esteem (Kruithof et al., 2012), caregiver gains (García-Castro et al., 2022), and positive aspects of caregiving (Fauziana et al., 2008). Life satisfaction as reported by this sample was high, despite the majority reporting no choice in caregiving. This could be a reflection of the general sample perceiving low to medium subjective burden in relation to their caregiving, or it could reflect personal traits of the individuals sampled, such as agreeableness which has been shown to moderate the relationship between caregiving onset and life satisfaction in caregivers (Hajek & König, 2018). Positive adaptation in the face of caregiving challenges could also explain these findings. Pertl et al. (2019) showed that baseline presence of caregiver PAC explained the most variability of PAC measured at a year follow-up. This suggests that certain caregivers may possess personal traits that increase their likelihood of creating positive meaning under conditions of stress resulting in greater perceptions of caregiving rewards. Identifying and fostering meaning making in caregivers who

might possess greater resiliency would be a benefit to the both the caregivers and care recipients' wellbeing.

Strengths and Limitations

The major strength of this work lies in how it targets two identified limitations of previous research (as highlighted per Jutras & Veilleux, 1991), namely caregiving research's focus on caregivers of dementia, and the lack of generalizability of most caregiving studies due to data sampling strategies (e.g., snowball, convenience). The present study addresses these issues by employing data that sampled a heterogenous sample of caregivers who are caring for individuals with various medical and age-related issues, using random digit dialing. Further, the data included in this study were sampled across Canada, and sampling weights were used during analysis. This allowed for better specificity of the estimates and increased the generalizability of the present research. Further, the sample size available in the GSS caregiving and care receiving dataset allowed for implementation of complex statistical analyses (e.g., SEM). The frameworks that guided the present research are complex models with multiple indicators and outcomes; thus, the availability of a large sample size allowed for these multiple relationships to be assessed at one time.

Limitations of this work lie in the cross-sectional nature of the dataset employed. Cross-sectional data collection does not allow for causal statements to be made, thus while the paths presented in this model point to a hypothesized direction of these relationships, it is not possible to confirm causality. Further, there were a lack of unique variables on the subjective experience of caregiving, which did not allow for feedback loops to be incorporated and tested in the present model. Caregiving is a dynamic process that changes as the trajectory of illness changes, and results in caregivers transitioning into and out of the caregiving role. The frameworks upon

which the present model is based includes feedback related to the outcomes of stressful situations, which could not be accounted for in the present study. While longitudinal methodology would address these limitations, financial constraints would limit the ability to engage in repeated measurements for a nation-wide study. Statistics Canada does collect data on caregiving and care receiving every five years, however, a strong focus on confidentiality and privacy precludes the linking of this data across data collection years.

A second limitation of the present study is related to the limited imputation conducted in the present work. The methodology was designed to reduce respondent fatigue, thus in some cases participants in this study were not asked specific questions due to their previous responses. Thus, while attempts were made to carry forward certain responses (e.g., individual income for household income), case-wise deletion was employed to manage missing data. Only individuals with full data (that is, a completed variable for each observation in the presented model) were included in the analyses. Thus, with no current assessment of the degree of variable missingness (that is, whether the degree of missingness for all variables is less than 5%) there is a possibility of bias being introduced in the estimates presented.

Finally, this model does not explore the influence of certain variables important to the study of caregiver wellbeing. Firstly, cultural expectations on caregiver choice and wellbeing were not studied in this model. The GSS Caregiving and Care Receiving dataset had a single but limited variable on ‘ethnicity of ancestors’ which precluded the ability to account for respondents’ cultural influences in the present model. Studies of filial obligation suggest that degree of acculturation may act as a protective or risk factor, with a greater degree of acculturation being associated with greater caregiver distress (Guo et al., 2019; Nguyen, 2024). Secondly, caregiver social support was also not included in the present model. Pearlin et al. (1990) highlighted the

impact of caregiver social support as buffering the effects of caregiving or inhibiting the effect of secondary stressors. The GSS CGCR survey specified members of caregivers' support network to accommodate their caregiving duties, but no detailed information on instrumental and emotional support was available. The exception this was an item regarding availability of support from friends to help cope with stress, which was included in the present study as part of a composite coping variable. Overall, the inclusion of ethnicity and support variables would have contributed to a more comprehensive understanding of caregiver psychological adjustment.

Despite these limitations, the noted strengths outweigh the limitations in the present study, as the nation-wide sample and large sample size are not commonly available when engaged in social sciences research. This study is important, as it adds to the limited empirical evidence on caregiver demographics and experiences (such as caregiver choice), and how these factors impact caregiver psychological distress and wellbeing.

Future Research Directions

The present study represents a cross-sectional analysis of predictors and outcomes of choice on caregiver psychological adjustment. Longitudinal studies may better identify the causal relationship between choice in caregiving and intermediate and long-term psychological outcomes such as caregiver burden and positive aspects of caregiving, as well as anxiety and depression. Temporally speaking, one's choice to engage in caregiving (either recognized or unrecognized) takes places before caregiving occurs, however one's perceived choice could be impacted by one's caregiving experience, particularly if caregiving is burdensome. Thus, while Pertl et al. (2019) reported that few individuals in their longitudinal study reported a change in perceived choice at a year follow-up, longitudinal studies would better help solidify the direction of the relationships specified in the present study.

The present study did not focus on the mediational relationships in the present model, however examining specific mediators of the choice and psychological adjustment relationship could assist in the identification of modifiable factors that could contribute to improved caregiver adjustment in the face of lack of caregiver choice. Further, a focus on moderating factors of caregivers' perceived choice (such as gender as identified by Robinson-Whelen and Kiecolt-Glaser, 1997) is warranted. The role of gender socialization has been highlighted as a potential explanatory variable within the choice-caregiving relationships, however its impact to date in relation to perceived choice in caregiving requires additional study.

While not a specific focus of this study, future directions regarding the use of population level databases could focus on the impact of caregiver choice on psychological adjustment among various homogeneous care recipient illness groups, as some models of stress have outlined illness-specific impacts on caregivers (Kahana et al., 1993).

Finally, while gender was considered as a predictor of choice, burden, and psychological symptoms in the present study, given gender differences the psychological adjustment of caregivers across caregiving outcomes such as burden (Bueno & Chase, 2023; Ghosh et al., 2020), depression (for in-home caregivers; Lee, Bierman et al., 2020) and anxiety (Wister et al., 2022; Zwar et al., 2023), as well as gender differences when comparing caregivers to non-caregivers (Bhan et al., 2020), future research should consider stratifying the sample by gender if attempts are made to replicate this analysis.

Clinical Implications

The present study suggests that having a lack of choice impacts both psychological adjustment of caregivers (that is, increased burden, anxiety, and psychological symptoms, and reduced life satisfaction) and is also associated with reduced perception of positive aspects of

caregiving (PAC). Further, several demographic variables (being female, higher education level, higher intensity of caregiving) are shown to be predictive of perceived caregiver choice. While empirical evidence suggests that PAC may act as a buffer or moderate against the stressful nature of caregiving, clinicians should be attuned to sociodemographic factors that may impact one's caregiving experience (e.g., burden) and perception (e.g., PAC) of caregiving, particularly as it relates to perceiving autonomy in choosing to take on the caregiving role. Clinicians should therefore enquire about the nature of the caregiver's engagement and ongoing experiences related to caregiving, in addition to evaluating caregiver burden, anxiety, and depression.

Further, the present study showed that in individuals who reported increased frequency of adaptive coping strategies over their previous caregiving year, anxiety and psychological symptoms were not attenuated. Rather this study showed increased psychological symptoms and higher odds of anxiety in caregivers reporting increased engagement in coping strategies. Thus, caregiver reports of engagement in adaptive coping strategies may not be enough to ensure that caregivers are adapting well to what is considered in some cases to be a challenging and exhausting role. For Psychologists these results suggest the need for comprehensive assessment, as engagement in adaptive coping strategies alone may not be indicative of positive psychological adjustment in caregivers. The use of depression screeners (such as the PHQ-2) or other mental health scales (e.g., Centre for Disease Control – Depression Scale, Hamilton Anxiety Rating Scale; HAM-A) should be considered, particularly when subjective and objective caregiver burden is high.

The present study therefore calls on the use of additional assessment of caregivers who report a lack of caregiving choice. This study also highlights the importance of involving multidisciplinary teams when assessing the psychological health of caregivers, particularly given

informal caregivers' contribution to the support and wellbeing of older individuals in the population.

Conclusion

Perception of choice was found to have a significant impact on many aspects of the caregiving experience, including subjective burden, positive aspects of caregiving, life satisfaction and the psychological adjustment of caregivers (anxiety and depressive symptoms). Further, exogenous predictors of choice (and burden) such as family relationship type, income, education, caregiver sex, and age were found to influence a caregiver's perceived choice in caregiving. Previous studies have argued the importance of examining caregivers' *perception* of choice, as well as their willingness to engage in caregiving over actual caregiving choice in the evaluation of caregiver psychological adjustment. That one's perception might buffer the challenges of caregiving (or shift caregiving experiences via meaning making), suggests that evaluating caregiver choice is an important aspect in the overall assessment of a care recipient and their primary caregiver. This is particularly important given the known negative impacts of lack of choice on caregivers, as well as the impact on care recipient health and psychological wellbeing when care is provided by an unwilling caregiver.

This study highlighted that engaging in adaptive coping strategies alone may not be an adequate clinical indicator of caregiver wellbeing. This study found that more frequent coping was associated with worse psychological adjustment. Thus, meaningful assessment might require additional exploration regarding the context of coping (that is, evaluating the driver of coping frequency such as increased burden, versus increasing coping to adapt to the caregiver's experience). Repeated assessment in studies of caregiver coping and psychological adjustment is warranted.

Research Acknowledgement

This research was conducted at York University, a part of the Canadian Research Data Centre Network (CRDCN). This service is provided through the support of the Canada Foundation for Innovation, the Canadian Institutes of Health Research, the Social Sciences and Humanities Research Council, and Statistics Canada, and through the support of York University. All views expressed in this work is my own.

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Appendix A: GSS Caregiving and Care Receiving Items

Variable Codes and Descriptions from the 2012 GSS Caregiver and Car Receiving Survey

Variable Code	Variable Description
Target Population	
ICG_Q110	During the past 12 months, have you helped or cared for someone who had a long-term health condition or a physical or mental disability?
ICG_Q115	During the past 12 months, have you helped or cared for someone who had problems related to aging?
PRG_Q10	What was the relationship of the primary caregiving recipient to you? Are you a current caregiver?
HAP_Q10	In an average week, how many hours of care or help did you provide with these activities?
PRG_S10	What was the relationship of the primary caregiving recipient to you?
SPR_Q10	Are you still helping the primary care receiver?
Demographics Care Recipient	
PRG_Q20	What the primary care receiver's sex?
PRG_Q20	What the primary care receiver's age?
Demographics Caregiver	
NLC_Q100	How many children do you have? Please include all birth, step and adopted children.
MAR_Q110	During the past 12 months, was your main activity working at a paid job or business, looking for paid work, going to school, caring for children, household work, retired or something else? Options dichotomized into three categories: Working at a paid job or business, looking for paid work, going to school, caring for children, household work, retired, maternity/paternity leave, long-term illness, volunteering, providing care to family or friends for a long term health condition.
EOR_Q04	What is the highest level of education that you have completed?
INR_Q110	What is your best estimate of your total household income, received by all household members, from all sources, before taxes and deductions, during the year ending December 31, 2012?
PRN_Q20	How old is the person you have dedicated the most time/resources to because of a health conditions/disability?
PRP_Q10	What was the main health condition for which this primary person received help?: Select all that apply.

Intensity of Caregiving	
HAP_Q10	In an average week, how many hours of care or help did you provide with these activities?
APR_Q10	During the past 12 months, have you helped someone with: … …transportation to do shopping or errands, or to get to medical appointments, or social events?
APR_Q20	… meal preparation, meal clean-up, house cleaning, laundry or sewing?
APR_Q30	… house maintenance or outdoor work?
APR_Q40	… personal care, such as bathing, dressing, toileting, hair care, or care of nails?
APR_Q50	… medical treatments, such as changing bandages, taking medications or other medical procedures?
APR_Q60	… scheduling or coordinating care-related tasks, such as making appointments or hiring professional help?
APR_Q70	… banking, bill paying or managing their finances?
Caregiver Burden	
ICL_Q150	In the past 12 months, have your caregiving responsibilities caused you to:… spend less time on relaxing or taking care of yourself?
ICP_Q10	During the past 12 months, has your overall health suffered because of your caregiving responsibilities?
CRH_Q50	During the past 12 months have your caregiving responsibilities cause you to feel: …resentful?
ICL_Q210	In the past 12 months, have your caregiving responsibilities caused strain in your relationship with family members or friends?
ICS_Q40	How stressful have your caregiving responsibilities been during the past 12 months? (Dichotmized into 1=High Stress, 0=Low Stress)
ICL_Q140	In the past 12 months, have your caregiving responsibilities caused you to spend less time on social activities or hobbies?
CRH_Q30	During the past 12 months, have your caregiving responsibilities caused you to feel: …overwhelmed?
Caregiving Choice	
ICS_Q10	Do you feel you had a choice in taking on your caregiving in the past 12 months (Y/N)?
Coping Frequency	
CMC_Q10	In the past 12 months, have you used any specific coping methods to help you deal with your caregiving responsibilities (Y/N)?
CMC_Q20	What were these coping methods?
Positive Aspects of Caregiving	
ICS_Q30	How rewarding have your caregiving experiences been during the past 12 months?

Anxiety	
CRH_20	During the past 12 months have your caregiving responsibilities cause you to feel: …anxious?
Psychological Symptoms	During the past 12 months have your caregiving responsibilities cause you to feel:
CRH_10	…tired?
CRH_35	…lonely?
CRH_40	…isolated and short-tempered/irritable?
CRH_50	… resentful?
CRH_60	…depressed?
CRH_70	… loss of appetite?
CRH_80	…disturbed sleep?
Life Satisfaction	
LSR_Q110	Using a scale of 0 to 10, how do you feel about your life as a whole right now?

Items from the 2012 version of the GSS Caregiving and Care Receiving manual (Statistics Canada, 2013b)

Appendix B: Computed Measures

All items were dichotomous variables, and the total score of each computed measure represents the sum of each item endorsed by the participant as yes (coded as 1).

Burden Symptoms

Question Number	Bédard et al. (2001) Item Question	GSS CGCR Question Items
2	Do you feel that that because of the time you spend with your relative that you don't have enough time for yourself?	In the past 12 months, have your caregiving responsibilities caused you to spend less time relaxing or taking care of yourself? 1=Yes, 0=No
5	Do you feel angry when you are around your relative?	During the past 12 months, have your caregiving responsibilities caused you to feel resentful? 1=Yes, 0=No
6	Do you feel that your relative currently affects your relationship with family members or friends in a negative way?	In the past 12 months, have your caregiving responsibilities caused strain in your relationship with family members or friends? 1=Yes, 0=No
9	Do you feel strained when you are around your relative?	How stressful have your caregiving responsibilities been during the past 12 months? Dichotmized (1 = high stress, 0 = low stress)
10	Do you feel that your health has suffered because of your involvement with your relative?	During the past 12 months, has your overall health suffered because of your caregiving responsibilities? 1=Yes, 0=No
12	Do you feel that your social life has suffered because you are caring for your relative?	In the past 12 months, have your caregiving responsibilities caused you to spend less time on social activities or hobbies? 1=Yes, 0=No
17	Do you feel that that you have lost control of your life since your relative's illness?	During the past 12 months, have your caregiving responsibilities caused you to feel overwhelmed? 1=Yes, 0=No

The burden symptoms scale originally included items from the 'Find It Stressful' Scale of the GSS Caregiving and Care Receiving survey. These items were removed due to their low inter-item correlations (below r=0.3). The three FIS items were replaced with a single variable (a

1-item rating of perceived stress in caregiving) which appeared to measure a similar construct. This change was found to improve the inter-item correlations, yielding a correlation matrix with all zero order item correlations being 0.3 or above.

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*(5), 652–657. https://doi.org/10.1093/geront/41.5.652

Appendix B: Computed Measures Continued

Psychological Symptoms

Centre For Epidemiological Studies Depression Scale Questionnaire Items	GSS CGCR Question Items
During the past week: I was bothered by things that usually don't bother me	During the past 12-months, have your caregiving responsibilities caused you to feel ... short-tempered or irritable?
During the past week: I did not feel like eating; my appetite was poor	During the past 12-months, have your caregiving responsibilities caused you to feel ... experience loss of appetite?
During the past week: I felt depressed	During the past 12-months, have your caregiving responsibilities caused you to feel ... depressed?
During the past week: My sleep was restless	During the past 12-months, have your caregiving responsibilities caused you to feel experience disturbed sleep?
During the past week: I felt lonely	During the past 12-months, have your caregiving responsibilities caused you to feel ... lonely or isolated?

Radloff, L. S. (1977). The CES-D scale: A self report depression scale for research in the general population. Applied Psychological Measurements, 1, 385-401.

Appendix C: Correlation Matrices

Correlation Matrix of Caregiver Burden Symptoms

	CG Burden Total Score	Relaxing	Resentful	Family Strain	Health	Hobbies	Overwhelm	Stress (high/low)
CG Burden Total Score	1.0000							
p-value								
Relaxing	0.7117	1.0000						
p-value	*0.0000*							
Resentful	0.6040	0.2825	1.0000					
p-value	*0.0000*	*0.0000*						
Family Strain	0.6382	0.3382	0.3489	1.0000				
p-value	*0.0000*	*0.0000*	*0.0000*					
Health	0.6977	0.4056	0.3269	0.3479	1.0000			
p-value	*0.0000*	*0.0000*	*0.0000*	*0.0000*				
Hobbies	0.6860	*0.5625*	0.2528	0.3046	0.3828	1.0000		
p-value	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*			
Overwhelm	0.7033	0.3914	0.3653	0.3369	0.4028	0.3604	1.0000	
p-value	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*		
Stress (high/low)	0.7181	0.3729	0.3653	0.3762	0.4809	0.3626	0.4626	1.0000
p-value	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	

Appendix C: Correlation Matrices Continued

Correlation Matrix of Anxiety and Psychological symptoms

	Psychological Symptoms	Lonely	Short-tempered	Depressed	Appetite	Disturbed Sleep
Psychological Symptoms	1.0000					
p-value						
Lonely	0.7348	1.0000				
p-value	*0.0000*					
Short-tempered	0.6750	0.3360	1.0000			
p-value	*0.0000*	*0.0000*				
Depressed	0.7289	0.4676	0.3395	1.0000		
p-value	*0.0000*	*0.0000*	*0.0000*			
Appetite	0.6031	0.3657	0.2170	0.3272	1.0000	
p-value	*0.0000*	*0.0000*	*0.0000*	*0.0000*		
Disturbed Sleep	0.7495	0.4094	0.3762	0.4203	0.3609	1.0000
p-value	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	