BURDEN, MOOD STATES, SOCIAL SUPPORT, AND PROACTIVE COPING IN CAREGIVERS OF ELDERLY ADULTS

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Abstract

The current study sought to further understanding of caregiver burden by investigating the associations among caregiver burden, proactive coping, social support, and mood states. The central hypothesis was that proactive coping and social support would be associated with less burden and less negative affect. This study also evaluated levels of burden experienced by spousal caregivers versus non-spousal caregiver counterparts and the burden reported by caregivers of elderly people with cognitive confusion versus the caregivers of more lucid elderly people. The nature of the caregiver stress experience was also explored. The participants were 154 female family caregivers from Sunnybrook Health Sciences Centre. They completed structured self-report measures of caregiver burden (i.e., the Caregiver Burden Inventory), proactive coping (i.e., the Proactive Coping Inventory), multidimensional social support, and mood states (i.e., the Profile of Mood States). Caregiver participants also completed a descriptive survey with open-ended responses regarding their experience of stress. Analyses indicated that higher reported levels of caregiver burden were associated with all negative mood indicators, including subscales tapping anger, confusion, depression, fatigue, and tension. Caregiver burden was also associated negatively with social support. Specifically, the strongest negative associations were found between burden and emotional and practical support. Proactive coping was not associated with caregiver burden, but it was correlated negatively with mood state (i.e., depression-dejection). Additional analyses confirmed that caregivers of people with cognitive confusion experienced considerably greater burden (i.e., time burden, developmental burden, and physical burden) in comparison to those caring for the more lucid elderly, and greater burden was reported by spousal caregivers than their non-spousal counterparts. More fine-grained analyses of the open-ended responses emphasized caregiver stress within the context of physical and/or mental change in their relative, feelings of guilt, the change in relationship with their loved one, and the pressure of having to respond to caregiving demands. Collectively, the results illuminate the challenges inherent in the caregiver role and provide insights into which caregivers are more likely to experience burden and the nature of this burden. The implications of these findings and future research directions are discussed.

Dedication

This dissertation is dedicated to my mother Bonnie; my late father Ronnie; and to my children Zachary, Justin and Ashley, whose love and support have been my greatest motivation.

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TABLE OF CONTENTS

LIST OF TABLES

Burden, Mood States, Social Support, and Coping in Caregivers of the Elderly

This study explores the vital role of caregivers, highlighting both the invaluable nature of their contributions and the considerable demands and stresses these caregivers endure. As life expectancy continues to rise, the number of individuals assuming caregiving responsibilities is expected to rise steadily. This demographic trend signals a growing reliance on informal caregivers to tend to the needs of their elderly loved ones. It is for this reason that caregiving warrants focused research attention to deepen our understanding of the caregiving experience and its impact, as well as to identify effective strategies for supporting these essential caregivers.

Caregiving for the elderly is a pervasive global phenomenon (see Cheng & Haley, 2020). There has been a striking growth of interest in caregiving research for several reasons. One consideration is the changing demographic landscape of contemporary society: people live longer; the longer they live, the more at risk they are for chronic ailments that impair their ability to care for themselves (Khan, 2019). Furthermore, because of medical advances, people survive for longer periods of time despite their health problems (Chappell, 2011; Jull, 2010), requiring more caregiving by others. Given that these kinds of changes have made informal caregiving a more common experience, it is understandable that its economic, social, and psychological impacts would become areas of concern (for a discussion, see Pearlin et al., 1990). One of the most salient themes in the literature is the burden and stress of being a caregiver. Jull (2010) stated that the health and well-being of caregivers is an emerging public health issue of paramount concern. More recently, Schulz et al. (2020) reiterated that because of the psychological and physical health effects of caregiving, caregivers are at risk for adverse outcomes. For these reasons, caregiver burden and stresses have received global attention from various researchers and investigators.

Several issues have yet to be investigated when it comes to understanding caregiver burden. The current study sought to explore three interconnected issues in a sample of 154 female family caregivers caring for institutionalized relatives. First, the current study examined the extent to which levels of caregiver burden were associated with self-reported levels of coping, social support, and mood states. While the focus was on correlates of caregiver burden, the possible associations among all of these variables were examined. A unique element of this study was that coping was assessed in terms of a measure of proactive coping. Unlike other forms of coping, proactive coping perceives upcoming events as challenges that are potentially self-promoting (Schwarzer & Taubert, 2002; Straud & McNaughton-Cassill, 2019). When people are engaged in proactive coping, they set goals that reflect current and anticipated challenges and create opportunities for growth (see Straud & McNaughton-Cassill, 2019). Proactive coping is described in more detail below along with a discussion of why it was included.

Second, this study investigated whether levels of caregiver burden differed significantly as a function of the nature of the caregiver-receiver relationship (i.e., spouses versus non-spouses). Third, this study examined whether levels of reported caregiver burden differed between caregivers of people who did or did not have dementia (i.e., always confused versus lucid).

In addition to the abovementioned three key relationships, this study also evaluated whether the potential correlates of burden (i.e., coping, social support, and mood states) have predictive utility after accounting for the nature of the caregiver-receiver relationship and the cognitive status of the receiver. Furthermore, this study was conducted to gain a better understanding of what it means to be a caregiver by examining different sources of stress as described qualitatively by various caregiver participants.

The introductory section below begins with a discussion outlining the concepts of burden and stress followed by a general description of the role of caregivers. Subsequently, an overview of caregivers of the institutionalized elderly is provided. The section continues with an examination of why caregiving is often experienced as stressful and burdensome, outlining the types of caregiving tasks involved and identifying who typically provides care. This is followed by discussion of burden levels of spousal caregivers versus nonspousal caregivers and lucidity of care-receiver and burden level of caregiver. Next, key background literature related to caregiver burden and the associated constructs of proactive coping, social support, and mood states is summarized. This section concludes with an overview of the main hypotheses guiding this research and the rationales put forward for the anticipated results.

The Concepts of Burden and Stress

There is currently a lack of standardization in the literature when describing the concept of caregiver burden, interchangeably using terms such as *stress*, *distress*, *tension*, and *burnout* (see Bastawrous, 2013; Grandon et al., 2008; McCarthy & Fitzpatrick, 2016). Stress is the most common term used to represent caregiver burden (Liu et al., 2020). Steven Zarit (Zarit & Edwards, 2008), the developer of the Burden Inventory, has referred to caregiver stress as an overarching concept when discussing burden and distress among caregivers. When seeking to understand burden and distress, Zarit focused primarily on a stress model proposed by Pearlin and colleagues (1990). This model suggests that caregiver stress is the result of a process that includes characteristics of the caregiver and care-receiver, primary stressors (e.g., caregiving hours, care-receiver's behaviour and health) and secondary stressors (e.g., difficulties arising from the caregiving related situation) (Pearlin et al., 1990).

There are commonalities and overlaps among the terms burden and stress within the literature on caregiving (Hoffman & Mitchell, 1998). For example, both terms imply that some sort of imbalance exists between physical and mental resources for the recipient and those available within the family unit or community (Hoffman & Mitchell, 1998). Furthermore, research that uses the concept of caregiver burden is inherently focused on the stress posed by the caregiving role (Kramer, 1997). Lazarus and Folkman (1984) also discuss the relationship between these two terms by stating that the subjective evaluation of the care situation (stressor) by the caregiver is critical for the development and maintenance of subjective burden. Even though these terms are often used interchangeably within the literature, it is important to recognize that viewing them as equivalent is criticized by some researchers, and will be addressed as a limitation of this study later on.

Interpreting research in this field and comparing results across studies of caregiver burden has been challenging because of the lack of consistency and precision in defining the concept caregiver burden. To date, to my knowledge, there is no singular or uniform conceptualization or definition of the term *caregiver burden* (Bastawrous, 2013; Chou et al., 2003; Liu et al., 2020). According to Braithwaite (1992), this is because the concept of caregiver burden is so multi-faceted. Zarit et al. (1986) proposed a useful definition reflecting this multifaceted aspect of burden. These researchers described burden as the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning. This definition emphasizes the multidimensional toll caregiving may have on care providers and also that caregiving is a highly individualized experience (Gillick, 2013).

A more detailed definition of both caregiver burden as well as stress will be provided below. To maintain consistency, the term burden will be used when reporting findings throughout this dissertation, with the exception of qualitative findings, which are participants own descriptions of their caregiver stresses.

Burden

What is caregiver burden? Research defining caregiver burden began in the 1960s. Grad and Sainsbury (1963) described caregiver burden as any cost to the family. Hoenig and Hamilton (1966) and Platt and Hirsch (1981) modified this concept by stressing the importance of separating activities (such as feeding, bathing and moving) from emotions. Montgomery et al. (1985) further expanded the definition by distinguishing the difference between objective (activities) from subjective (emotions) burden, where objective burden was related to the type of caregiver task performed while subjective burden was related to the characteristic of the caregiver, such as emotional disturbances experienced by the caregiver (Provencher & Mueser, 1997; Reinhard et al., 1994; Schene et al., 1994). More specifically, objective burden includes events and activities associated with a negative caregiving experience, something which is often a consequence of physical and behavioural changes of the care receiver. Subjective burden involves emotional reactions of the caregiver, such as worry, anxiety, frustration and fatigue (Montgomery et al., 1985).

Studies that focus on caregiver burden often evaluate multiple domains of burden. George and Gwyther (1986) found that physical, psychological or emotional, social, and financial problems all related to caregiver burden. They believed caregiver burden and caregiver well-being were opposite sides of a coin.

Research on family burden has been increasingly focused on identifying relationships between the physical, psychological, and emotional health of caregivers (e.g., Gutierrez-Maldonado et al., 2005), and care-receivers' symptoms (e.g., Lauber et al., 2003; Provencher & Mueser, 1997). Care-receiver predictors of burden are typically related to clinical characteristics (e.g., behavioural disturbances, negative symptoms, rehospitalization rates, compliance with medication, duration of illness, unawareness, psychosocial functioning and diagnostic subtype) (Dyck et al., 1999; Koukia & Madianos, 2005; McDonell et al., 2003; Provencher & Mueser, 1997; Wolthaus et al., 2002). Caregiver predictors of burden have been found to be related to sociodemographic variables (e.g., family resources, social support, educational background, social life, co-residence status with the affected, leisure activities, marital relationships, unemployment, living conditions, size of family network) as well as with personality variables such as coping strategies and sense of mastery in care activities (Dyck et al., 1999; Karanci, 1995; Laidlaw et al., 2002; Lauber et al., 2003; Ohaeri, 2001; Reine et al., 2003). Essentially, burden results from a combination of clinical characteristics of the patient, plus personality characteristics of caregivers and social supports (Grandon et al., 2008).

Grabel and Adabbo (2011) defined caregiver burden as the high level of stress that some caregivers may feel in response to the situation. These researchers assert that caring for a chronically ill older relative constitutes a significant demand known as a stressor. This stressor may be perceived as either positive or negative by the persons affected. These ratings apply to all aspects of providing care, for example, rating the relationship with the care receiver, rating the changes in the social environment, or rating one's own efforts with respect to caregiving. These researchers proclaim that the sum of all these ratings in a negative direction is termed perceived burden. These rating processes are subjective in nature (Grabel & Adabbo, 2011).

Stress

The term *stress* has been used in the English language for centuries to describe human experience. Some definitions use stress to refer to *hardships*, *straits*, *adversity*, or *affliction* (Onions, 1933), while others borrow from physics and engineering to give a physical perspective (Hinkle, 1974), using terms like *distress*, *strain*, and *load*.

Early definitions of stress emanate from Claude Bernard's notion (as cited in Goldstein & Kopin, 2007, p. 109) that the maintenance of life is critically dependent on keeping our internal milieu constant in the face of a changing environment. Cannon (1929) referred to this as "homeostasis." Selye (1956) introduced the term "stress" to represent the effects of anything that seriously threatens such homeostasis. Selye observed that severe, prolonged stress responses might lead to tissue damage and disease.

Stress can be considered from at least two perspectives. First, stress can be viewed as a trigger for a response. It may be thought of in this sense as a cause (Pearlin et. al., 1990) or an actual or perceived threat to an organism (Selye, 1956). When stress is used in this way, it is commonly referred to as a stressor (Pearlin et al., 1990; Selye, 1956). Second, stress can be thought of as an effect (Pearlin et al., 1990), or the response to the stressor (Selye, 1956), in which case it is called a stress response (Pearlin et al., 1990). The stress response is made up of a set of psychological and biological patterns. In reality, neither the stressors nor the stress response exists in isolation. Rather, both feedback on each other to produce the stress experience (Pearlin et al., 1990). Throughout this study, the term *stress* will be used as a means of describing a stressor, i.e., the act of caregiving as a cause of caregiver stress.

Countless events create stress. Some are major environmental changes affecting large numbers of people at once, such as war, nuclear accidents, terrorism and earthquakes (Schwarzer & Luszczynska, 2012). Others are major changes in the personal life of individuals, such as suffering a serious illness, losing a job, getting divorced or the change in health of a family member. While these latter events may also be experienced by a large number of people, they are experienced individually rather than collectively or simultaneously (Holmes & Rahe, 1967). Events that are perceived as stressful usually fall into one or more of the following categories: traumatic events, uncontrollable events, unpredictable events, events that challenge the limits of one's capabilities, and internal conflicts. Stressors also vary in terms of whether they are chronic and long-lasting versus limited in duration.

Uchino et al. (1992) introduced a useful perspective for interpreting the stress of caregivers. In their study on family caregivers of people with Alzheimer's disease, they focused specifically on physiological reactions of people exposed to chronic stress. Their results showed that social support was a key factor and those caregivers in this chronic stress life situation with low social support had poorer cardiovascular health. Their work prompted research on the physiological toll of caregiving and led to the concept of "psychobiological burden" (see Allen et al., 2017). This research by Uchino et al. (1992) also illustrated the need to consider key resources when people are faced with chronic stress.

Accordingly, two resource factors (i.e., social support and proactive coping) were incorporated into the current research. The current work also compares people who are taking care of elderly adults with varying levels of cognitive confusion; it seems likely that caregivers with a more chronic stressful situation should be especially prone to the experience of burden.

People's responses to stress are complex and multidimensional. There is much individual variability in which specific events will elicit a stress response. Moreover, stressors have the potential to produce different reactions among individuals due to the subjective experience of the stressor (Lazarus & Folkman 1984). One cannot assume that exposure to the same stimulus will always result in a stress response in every, or even the same individual (Lazarus & Folkman, 1984). When an individual encounters a situation there is an initial appraisal of how demanding the situation is, the individual's resources for coping with the demand (i.e., one's skillset and knowledgebase as well as knowing others are available to help), and the consequences likely to result from the situation (Lazarus & Folkman, 1984; Spriddle, 2004). If this appraisal leaves one confident that he/she can handle the situation to his/her satisfaction and that there is a balance between the demand and resources for coping, his/her stress level will typically be quite low (Spriddle, 2004). However, if the appraisal leaves the individual believing he/she is unable to handle the situation as well as he/she would like, and if unpleasant consequences are likely to result, his/her stress levels will typically be quite high (Hiebert, 2002). The intensity of the stressful reaction will be based on the degree of imbalance between the demand and the resources for coping, in addition to the perceived severity of the consequences (Hiebert, 2000).

Caregivers and Caregiving: An Overview

The role of caregivers and their experiences are now considered. A persistent and pervasive myth is that most disabled elderly spend their final years living in nursing homes where their care is handled solely by professionals (see Sloan, 1998). Regardless of whether individuals reside within facilities or remain within their own homes, spouses, adult children or other family members alike have to step in and take charge of their care (Beatie, 2021; Mei et al., 2013). They provide assistance to those who have limitations in their physical, mental and/or cognitive functioning (Schulz et al., 2020). This can be a highly stressful experience for the caregiver (Doyle, 2018; Petch & Laupacis, 2012; Sloan, 1998; Toseland et al., 1990).

Caregivers of the Institutionalized Elderly

The majority of studies conducted thus far tend to focus on caregiver stressors and burdens of individuals who care for relatives within the home setting, and little is known about family caregivers providing care for institutionalized relatives. The current study sought to examine the burdens and stresses of family caregivers looking after relatives who reside within a long-term care facility (i.e., two chronic care units at Sunnybrook Hospital) to evaluate the impact of institutionalization on caregiver stressors and burdens. Although some may assume that when an individual is placed in a long-term care facility that this person's caregiver no longer has burden and stresses related to their caregiving role, longitudinal analyses of dementia caregiving make it clear that caregiving does not end with the institutionalization of a cognitively impaired elderly relative (Gaugler et al., 2010). Some studies have found that various measures of caregiving burden and/or stress or depressive symptoms remain stable, or in some cases, increase with nursing home admission (Gaugler et al., 2007; Zarit & Whitlatch, 1992). These caregivers often experience caregiving stress from their dissatisfaction with the care provided at the facility, the exhaustion (both mentally and physically) associated with the caregiving tasks themselves, and lastly, the constant traveling to and from the facility (Majerovitz, 2007). Schulz et al. (2004) conducted research to assess the impact of placing a relative with dementia in a long-term care facility on caregivers' health and well-being. Out of a sample of 1222 caregiver-patient dyads recruited from 6 American cities, a total of 180 patients were placed in a long-term care facility during the 18-month follow-up period. Data collected before and after placement were analyzed to identify factors associated with placement, the nature of contact between caregivers and their institutionalized relatives after placement, and the relation of both of these factors to health outcomes among dementia caregivers. Results indicated that caregivers who institutionalized their relative reported depressive symptoms and anxiety to be as high as they were while the care-receiver was being cared for at home (Schulz et al., 2004). Overall depression scores did not change from before to after placement. Overall anxiety scores also did not change significantly from before versus after placement. These effects were most pronounced among spousal caregivers, those who visited more frequently, and for those who were more dissatisfied with the help they received from others.

Family members remain engaged in the lives of institutionalized relatives. While the provision of hands-on personal care such as ambulation and transferring, bathing, dressing and toileting are often assumed by point-of-care staff in the facility (see Dempsey & Pruchno, 1993; Natan, 2009), family involvement continues and ranges from regular visits to ongoing provision of more instrumental forms of direct care such as transportation and financial management, to interaction with staff to ensure proper care is delivered (see Gaugler et al., 2010). Although families hold staff accountable for the actual performance of most care-oriented tasks, they hold themselves responsible for monitoring and evaluating the thoroughness and quality of the care provided (Cohen et al., 2014). This translates into families teaching staff how to provide care in accordance with personal preferences and standards, filling in when staff fail to meet these standards, and providing care themselves (Bowers, 1988). According to Gaugler (2005), once placement occurs, caregivers essentially renegotiate their role within the context of the institutional setting.

It has been found that spousal caregivers appear more likely to report greater burden, depressive symptoms, and dissatisfaction after nursing home admission in comparison to an adult child or other caregivers (Gaugler et al., 2010). Wives in particular, tend to invest greater emotional resources in their role as caregivers and thus may be less willing to give up day-to-day care responsibility to a nursing home and are more involved in care delivery and supervision compared to other types of caregivers (Gaugler et al., 2010). For this reason, among others, burden may not lessen with nursing home admission for female caregivers who are heavily engaged in the emotional and direct, day to day care challenges associated with assisting a relative with dementia. Caregivers who indicated more frequent behaviour problems in their relatives, provided more hands-on care, reported unmet needs of the care recipients or had physical or emotional challenges during at home care, were also more likely to experience burden following nursing home placement (Gaugler et al., 2010). Although less explored, psychological processes such as guilt, resentment, unresolved problems between the caregiver and recipient, the worry regarding the cost of the long-term care facility, and conflict with family and friends over the placement decision, may also contribute to the caregiver's post-institutionalization burden (Gaugler, et al., 2007).

Why is Caregiving a Burdensome Responsibility?

A vast amount of literature exists that clearly emphasizes the stresses and burdens associated with providing care for the elderly, especially if the patient's illness is severe and prolonged (Doyle, 2018) and if the care receiver suffers from cognitive decline such as Alzheimer's disease or dementia (AARP Family Caregiving, 2020; Chiao et al., 2015; Ingber, 2018; Sung et al., 2021). The constant demands of caring for a person can strongly impact a caregiver's long-term health and wellness (Ingber, 2018). Caregivers often experience negative psychological, behavioural, and physiological effects on their daily lives and health (Bevans & Sternberg, 2012; Inger, 2018; Keefe et al., 2005; Sinha 2013).

Doyle (2018) highlighted how caregiving has tremendous effects on family caregivers, affecting their social activities, finances, emotions, and general health. According to Purk and Richardson (1994), common sources of caregiver burden include role overload, psychological stress, physical fatigue, and health problems. Ingber (2018) discussed how many caregivers suffer from depression, anxiety, anger and irritability. The author further states that chronic caregiver stress can lead to high blood pressure, diabetes and a compromised immune system.

Caregiver burdens and stresses may manifest themselves in various ways, including: feelings of depression, anxiety and/or irritability, trouble concentrating, disturbed sleep, feeling exhausted despite adequate rest, a weakened immune system, loss of interest in personal needs, desires, and pastimes, increased feeling of resentment towards the care recipient and/or family/friends, loss in satisfaction of being a caregiver, and feelings of helplessness, hopelessness and isolation (Doyle, 2018; Ingber, 2018).

Types of Caregiving Tasks

Because of reduced staffing levels and increased workloads facing today's hospital workers, family members are forced to engage in various caregiving tasks that were previously carried out by paid professionals. Such caregiving responsibilities to the elderly may consist of many different types of help, depending on the specific needs of the person. Examples include housekeeping and organizing of the care-receiver's living space, daily supervision, shopping, transportation, lifting, bathing, dressing, feeding, laundering, personal hygiene such as toileting and incontinence care, financial and legal management and advice, supervision of medication, arranging of health care, telephone reassurance, listening and talking, and the provision of emotional support (AARP Family Caregiving, 2020; Hollander et al., 2009; Jull, 2010; Schultz et al., 2020; Smith, 2002). Fengler and Goodrich (1979) characterized the spouses of the disabled elderly as hidden patients because of the laborious nature of many caregiving tasks. These researchers essentially warned the gerontological community that the responsibilities of providing care for an impaired older adult can place the caregiver at risk for physical, psychological, and social burden. Parenthetically, social burden is the strain placed on other social relationships in the caregiver's life (see Novak & Guest, 1989). The causes and effects of such caregiver burden are discussed below in more detail. First, however, it is necessary to establish who the caregivers are.

Who Provides Care?

Most of us will be a family caregiver at some point in our lives. Such family caregivers are daughters, wives, husbands, sons, grandchildren, nieces, nephews, partners and friends. While some people receive care from paid caregivers, most rely on unpaid assistance from family, friends and neighbours (Family Caregiver Alliance, 2009). A family (i.e., informal) caregiver is defined as any relative, partner, friend or neighbour who has a significant personal relationship with, and provides a broad range of assistance, for a person with a chronic or disabling condition (Family Caregiver Alliance, 2009). These individuals may be primary or secondary caregivers and can live with or separately from the person receiving care (Family Caregiver Alliance, 2009). Such caregivers provide ongoing care and assistance, without pay, in order for the care recipients to maintain an optimal level of functioning. This includes one who is ill, incapacitated, disabled, or very young (Reinhard et al., 2008).

Canadian data were collected in 2018 from the General Social Survey-Caregiving and Care Receiving to determine exactly who the caregivers are (Statistics Canada, 2020). The analysis covered the population aged 15 years and older and living in a private household (20,258 respondents representing almost 31 million Canadians). Data were obtained from 7,664 respondents who reported providing care in the 12 months preceding the survey. It was found that approximately one in four Canadians aged 15 and older (7.8 million people) provided care to a family member or friend with a long-term health condition, physical or mental disability, or problems related to aging. According to Statistics Canada (2020), 54% of caregivers were female versus 46% male. While most caregivers (64%) spent less than 10 hours a week on caregiving responsibilities, 15% spent 10 to 19 hours, and 21% spent 20 hours or more (Statistics Canada, 2020). Almost half of the caregivers (47%) reported caring primarily for their parents or parents-in-law (Statistics Canada, 2020). Caring for parents was the most common form of caregiving reported in Canada, and it was particularly common among caregivers aged 45 to 64 (61%). Approximately 13% of caregivers reported that they provided care to their spouse or partner (Statistics Canada, 2020). These caregivers were more likely to be older than those who cared for a parent or parent-in-law, and they spent about 14 hours a week on caregiving activities. According to Statistics Canada (2020), 8% of caregivers were providing care for their child, 13% provided care to a close friend, colleague or neighbour, 10% to an extended family member and 9% to a grandparent. Caregivers in these categories typically spent fewer hours on caregiving activities.

As noted in the study above, most family caregivers are spouses or children of the care-receiver and many caregivers of older people are elderly themselves. Avison and associates (2018) reported that the majority of caregivers are between the ages of 55 and 74 years old. In their study, the mean age was 66 years, and 55 percent were aged 65 or older. Older caregivers often spend the greatest number of hours providing care (Avison et al., 2018), and the amount of time spent caring increases substantially as cognitive impairment of the care-receiver worsens (Langa et al., 2001).

Using data from the 2018 General Social Survey on Caregiving and Care Receiving, Arriagada (2020) examined the experience of caregivers aged 65 and older, who reported that, in the previous 12 months, they had either (a) cared for or helped someone who had a long-term health condition or a physical or mental disability, or (b) cared for or helped someone who had problems related to aging. Results from this study revealed that almost one-quarter of seniors aged 65 and older (about 1.5 million people) provided care or help to family members or friends with a long-term condition, a physical or mental disability, or problems related to aging. One-third (34%) of all caregivers aged 65 and older provided care for a spouse or partner. This proportion increased to 47% when focusing on seniors aged 75 and older, and to 50% for those aged 85 and older. Almost one-third (31%) of senior caregivers who were caring for a spouse spent 30 hours or more a week providing care or help, with senior women spending more hours (20 hours) compared to senior men (14 hours).

In Canada, senior caregivers (aged 65 and older) are most likely to provide care and support for a spouse or partner (34%), followed by caring for a friend, colleague or neighbour (20%), a parent (17%), another family member (14%), a child (9%) and a parent-in-law (6%) (Arriagada, 2020). As people aged, they were less and less likely to care primarily for a parent and more and more likely to care for a spouse. For example, more than half (53%) of caregivers aged 45 to 54 provided care to a parent, with an additional 11% caring for a parent-in-law. At the same time, 8% of caregivers in this age group provided care for a spouse. In comparison, over one-quarter (28%) of seniors aged 65 to 75 cared for a spouse, as did almost half (47%) of seniors aged 75 and older. While older caregivers are similar to caregivers in other age groups, they also have unique needs given their age. For example, many seniors will experience their own health-and-age related challenges, resulting in some of them becoming caregivers and care-receivers at the same time.

Now that it has been established who the caregivers are, the types of caregiving tasks they perform, and why caregiving is such a burdensome/stressful responsibility, an overview of burden and spousal versus non-spousal caregivers as well as burden experienced by caregivers to lucid family members versus confused family members, will now be provided. Following, a discussion on proactive coping, social support, and mood states and how they relate to burden will take place.

Burden Levels of Spousal Caregivers versus Non-Spousal Caregivers

In American families, spouses are often the first in line to assume caregiving responsibilities (Brody, 1981). If a spouse is unavailable or is unable to care for the frail elderly, adult children often take on the caregiver role (Pinquart & Sorensen, 2011). Scholars have noted that in many instances, being a caregiver means providing complex, unpaid work in an undervalued role when family members are receiving long-term care (see Barken et al., 2016). While most scholars focus on more contemporary times, the history of caregiving goes back over 100 years, as noted by York University scholar Pat Armstrong (Armstrong & Kits, 2001).

Research on family caregivers has provided a picture of the heterogeneity that exists among caregivers (Raschick & Ingersoll-Dayton, 2004). It is of interest to compare the experiences of subgroups, such as spousal caregivers and adult children caregivers, as it demonstrates how the processes and consequences of caregiving may be experienced differently depending on whether the caregiver is a spouse or an adult child (Raschick & Ingersoll-Dayton, 2004). Although some research has found that adult child caregivers are more burdened than spousal caregivers (Young & Kahana, 1989), several other studies have concluded that spousal caregivers experience greater distress than do adult children (George & Gwyther, 1986; Neal et al., Starrels, 1997; Schulz et al., 1995). Specific negative impacts of being a spousal caregiver (in comparison to non-spousal caregivers) include increased levels of depression, anxiety, poor perceived physical health, increased health care utilization, and conflict between caregivers and other family members (Strawbridge et al., 1997). Reasons for this difference in burden levels between spousal caregivers and non-spousal caregivers include the lack of choice in taking on a caregiver role (Sunmin et al., 2003), the likelihood that a spouse will receive less support from family and friends, the tendency of spouses to spend more hours providing care (Pinquart & Sorensen, 2011; Turcotte, 2013), spouses do more “hands-on” caregiving tasks (Pinquart & Sorensen, 2011), the fatigue linked with the caregiving role for older caregivers, and spouses are often faced with the financial burden of extra medical expenses (Sunmin et al., 2003). Furthermore, in comparison to non-spousal caregivers, spouses likely, in most instances, feel a deeper sense of sadness and loss over changes in their loved one as a result of illness. For example, one of the most common behavioural complications of neurodegenerative disorders such as Alzheimer’s disease and Parkinson’s disease is diminished emotional responsivity and flattened affect. The consequences of these changes in a loved one and the impending loss of the person as they once were, is carer burden and distress (Leroi et al., 2012), which is likely more severe for spouses than non-spousal caregivers.

Although various empirical studies have found higher levels of distress among spouse caregivers than among children or children-in-law, these results are inconsistent. For example, Hong and Kim (2008) found that spouses had higher total burden scores than adult children, although there were no differences in financial burden. However, no differences in strain between spouses and adult children were found in the 1999 Long-term Care Survey (Kang, 2006), and other studies observed even higher caregiver burden in adult children than in spouses (e.g., Young & Kahana, 1989). Results are also inconsistent as to whether or not spouses experience more depression symptoms (e.g., Lawton et al., 1992; Yajima, et al., 2007).

Pinquart and Sorensen (2011) conducted a meta-analytic comparison using 168 empirical studies on differences between caregiving spouses, adult children, and children-in-law. These researchers expected spouses to report higher levels of burden and depression as well as lower levels of positive psychological well-being than adult children and children-in-law because of the greater closeness of their relationship with the care recipient. Results from this meta-analysis indicated that no differences between spouse and adult children were found with regard to overall level of burden. However, more fine-grained analyses found that spouse caregivers reported higher levels of physical burden (d = .39), financial burden (d = .32) and relationship strain (d = .18) than did adult child caregivers but no difference in emotional burden, social strain and job strain. In addition, spouses reported more physical strain (d = .47), financial strain (d =.48), relationship strain (d = .50), and social strain (d = .32) than children-in-law. Spouses also had higher levels of depressive symptoms than adult children (d =.25) and children-in-law (d =.39). Spouses reported lower levels of positive psychological well-being than adult children (d = -.15) and children-in-law (d = -.26) but these differences were very small or small.

Overall, this meta-analysis revealed considerable differences between spousal caregivers and adult children/children-in-law. Spouses use less informal support, perceive their physical health to be worse, provide more care and experience more depressive symptoms than do children and children-in-law. High levels of psychological distress among spouse caregivers are partially explained by the fact that they provide more care. Implications of this research is that spouses, and children/children-in-law caregivers have different needs and may struggle with different issues.

Lucidity of Care-Receiver and Burden Level of Caregiver

A pressing public health crisis is the rising number of people with dementia, doubling every 20 years due to global aging (Cheng, 2017). According to the World Health Organization (2017; 2021), the number of persons with dementia is likely to triple by 2050 affecting up to 139 million people worldwide. Alzheimer's Disease (AD) and dementia related illnesses involve considerable challenge for the patient and family. These primary caregivers are at an increased risk of developing mental health disorders such as depression and anxiety compared with their counterparts who are nonprimary caregivers or those who are caring for loved ones with different types of illnesses (Sallim et al., 2015). The amount of care devoted to the care-recipient increases as dementia progresses (Terry & Salmon, 1993; Sallim et al., 2015). This potentially increases caregiver psychological burden, which can place excessive stress on the mental health of caregivers (Sallim et al., 2015).

According to Reese et al. (1994), demands of caregiving for AD patients have been reported to affect the psychological and immunological health of caregivers. These researchers conducted a study using 25 caregivers of AD patients, 25 caregivers of stroke patients and 25 non-caregiving individuals. Comparisons of all participants made on several psychologic and immunologic indices indicated that the AD caregiving group was more psychologically distressed than the stroke group and both of these groups were more psychologically distressed than a control group (Reese et al., 1994).

Karlin and Bromley (1996) conducted a study of great relevance to the current work. They investigated differences in caregivers of nonlucid and lucid chronically ill family members.

This study explored relationships among social support, mood states, and burden in 63 caregivers of chronically ill family members. Caregivers were categorized as providing care for either chronically ill, confused or lucid family members. Findings revealed that caregivers of confused family members differed from caregivers of lucid chronically ill family members in the level of expressed emotional burden and amount of revealed fatigue/inertia, with caregivers of dementia patients reporting higher levels. However, differences between these caregivers were not evident in terms of levels of time, social, developmental or physical burden as measured by the Caregiver Burden Inventory (CBI). Similarly, differences were not evident on dimensions of tension-anxiety, depression-dejection, anger-hostility, vigour-activity, or confusion-bewilderment as measured by Profile of Mood States (POMS). Elevated levels of weariness, inertia and low energy were expressed by caregivers of dementia family members. Fatigue was not evident with the comparison group. The results of this study indicate that there are clear differences and similarities between caregiving responses and needs. More specifically, it was found that dementing illnesses had a more burdensome emotional impact on the caregiver than caring for lucid loved ones (Karlin & Bromley, 1996).

Leinonen et al. (2001) compared the levels of burden reported between two groups (i.e., spouses caring for depressive loved ones versus spouses caring for confused loved ones). Findings revealed that spouses of the confused patients as a group were psychologically more stressed than spouses of depressive patients. Confused patients were further divided into two groups, those admitted mainly for noncognitive symptoms related to dementia (e.g., psychosis, mood disturbances, personality changes, delusions, accusatory behaviour, agitation, aggression, wandering and changed sleep patterns) and those admitted for memory assessment and diagnostic purposes. Analyses of scores on the Zarit Burden Interview (ZBI) revealed that the burden of the spouse in the former group (those admitted for noncognitive symptoms related to dementia) was higher than that of the group of depressive patients' spouses (Leinonen et al., 2001). No difference was found between the latter group of confused patient spouses (i.e., those admitted for memory assessment and diagnostic purposes) and depressive patients' spouses. Caregiving spouses of confused patients with noncognitive psychiatric symptoms were the most burdened group (Leinonen et al., 2001).

Papastavrou et al. (2012) conducted a study in Greece to assess and compare the burden and psychiatric morbidity (in the form of depression) experienced by family members caring for a relative with one of the following: cancer, schizophrenia and AD. A total of 410 caregivers were recruited from the community. Greek translation versions of the Burden Interview and the Center of Epidemiological Studies-Depression scale were used. Results indicated significant differences between the three caregiving groups were detected in terms of burden, with the highest reported for AD caregivers. One-way analysis of variance showed significant differences between the three caregiving groups in terms of depression, with the highest depression levels being for cancer caregivers (Papastavrou et al., 2012).

Other research attests to the need to distinguish between caregivers in general versus caregivers of people with dementia (Badana et al., 2019; Ory et al., 1999: Riffin et al., 2017; Wolff et al., 2016). When it comes to more recent times and contemporary research, the volume of research is still quite limited, but two recent studies point to the need to distinguish caregivers of people with dementia from other caregivers. Sheehan and associates (2021) compared 117 people who were caring for a person with dementia and people who were caregivers for people without dementia. As expected, dementia caregivers had comparatively higher levels of depression, stress, and burden but they did not have significantly higher levels of mental and physical health quality of life. Overall, given projected population trends, Sheehan and colleagues (2021) concluded that there is a growing need for supportive interventions developed specifically for dementia caregivers.

Beatie (2021) conducted another highly relevant study that compared mild cognitive impairment (MCI) caregivers with dementia caregivers on levels of burden, anxiety and depression. This study was part of dissertation research at the University of Manitoba. MCI caregivers (n = 53) and dementia caregivers (n = 84) recruited from a memory clinic were asked to complete self-reported measures of their mental health (caregiver burden, anxiety, and depression) and distress arising from care-recipient symptoms (memory deficits, behavioural disruptions, and depression). MANOVA results revealed significant mean differences for depression, anxiety, and burden in MCI caregivers versus dementia caregivers (Beatie, 2021). Chi-square tests revealed significant differences in anxiety and caregiver burden. Although the chi-square test indicated no clinically significant difference in depression, more dementia caregivers had depression symptoms in comparison to MCI caregivers. The study clearly demonstrated that dementia caregivers had greater levels of anxiety, depression and burden in comparison to their MCI caregiver counterparts. This researcher attributed poorer mental health of dementia caregivers (in comparison to MCI caregivers) to caregiver distress reactions to care-recipients' behavioural disturbances and depression, but not memory deficits (Beatie, 2021). These data suggest the clear need to distinguish between caregivers of different types of recipients. Beatie et al. (2021) also provided some useful context in qualitative research with caregivers of those with mild impairment and how such caregivers struggled with role ambivalence and the change in the relationship with their loved ones.

An earlier meta-analysis provided by Pinquart and Sorensen (2003) integrated findings from 228 studies on the association of six caregiving-related stressors and caregiving uplifts with burden and depressed mood. These researchers set out to investigate whether the associations with caregiver burden and depression would vary by the types of illnesses of the care receiver. They compared dementia caregivers to lucid older adults who were physically impaired (e.g., patients with cancer, hip replacement, pulmonary disease and fractures) to mixed samples of caregivers. The association between caregiver burden and depression was stronger among dementia caregivers than among mixed caregivers and among caregivers for lucid adults (Pinquart & Sorensen, 2003). Caregiver burden and depression accounted for 27% of variance in dementia caregivers but only 22.1% of variance in mixed caregivers and 14.4% of variance in caregivers for lucid older adults (Pinquart & Sorenson, 2003).

Salim et al. (2015) reported a meta-analysis to investigate the overall prevalence of mental health disorders among caregivers of patients with Alzheimer's disease. A total of 17 studies were eligible for systematic review and meta-analysis. It was found that caregivers of patients with Alzheimer's have a higher prevalence of mental health disorders, particularly depression and anxiety, as compared with the general population and with their counterparts caring for patients with other illnesses (Salim et al., 2015).

Another meta-analysis by Rodriguez-Gonzalez and Rodriguez-Miguez (2020) sought to determine whether the ZBI scores differed by care-receiver pathology. Results from 125 studies showed that caregivers of individuals with a physical disability have a ZBI score that is significantly lower than caregivers of persons with dementia or cognitive impairment, mental illness or Alzheimer's (Rodriguez-Gonzalez & Rodriguez-Miguez, 2020). Their analysis of Alzheimer's revealed differences among cases of mildly, moderately, and severely afflicted care recipients. For this study, these researchers classified the studies based on the care receiver's pathology: (1) Alzheimer's; (2) mental illness (e.g., schizophrenia, depression, adult psychiatric care); (3) dementia or cognitive impairment (but not confirmed Alzheimer's); (4) elderly/dependent persons with no specifically identified illness; and (5) physically impaired (e.g., Parkinson's, multiple sclerosis, heart failure, stroke). Only studies that used the ZBI were included in this meta-analysis. Findings revealed that scores for those who care for physically disabled persons are significantly lower than the scores of those who care for persons with dementia/impairment, mental illness or Alzheimer's. Caregivers of persons with dementia had a mean ZBI score that was significantly higher than scores of the Alzheimer's caregivers. Regarding caregivers of persons with Alzheimer's, those caring for people with severe Alzheimer's had a mean ZBI score that was significantly higher than caregivers of patients with only moderate severity, who in turn have a ZBI score that is significantly higher than those caring for patients whose symptomology is just mildly severe. This meta-analysis confirms that those who are most burdened are the caregivers of dependent persons suffering from some kind of mental disease; caregivers of dementia/impairment patients have mean ZBI scores in excess of 34 points, which is 26% higher than for caregivers of the physically disabled. Studies of Alzheimer's patients show that caregivers' burden varies greatly depending on severity of the disease. Whereas the mean ZBI score of caring for mild cases of Alzheimer's is 26, caregiver burden increased by 38% (to 36) in moderate cases and by 66% (to 43) in severe cases. This metal-analysis supports the finding that caregivers are more burdened when the care receiver has mental rather than physical disabilities.

After considering the information discussed above, it is clear that there are some basic issues which require further exploration, two of which were examined here. These include: the burden levels of spousal caregivers versus nonspousal caregivers and the lucidity of care-receivers and burden levels of caregivers.

Coping and Its Relevance

This study has a unique emphasis on the potentially positive role of proactive coping. An introduction to the coping literature and the summary of relevant, representative research is now provided.

Coping Styles

Coping is difficult to define because of the broad usage of the concept (Krohne, 1986). Nevertheless, Folkman and Lazarus (1980) define coping as the thoughts and behaviours used to manage the internal and external demands of situations that are appraised as stressful. This model of coping was viewed as an adaptive reaction to stressful experiences and was regarded as reactive, a strategy to be used once stress had been experienced (Straud & McNaughton-Cassilll, 2019).

Folkman and Lazarus (1980) distinguished between two forms of coping: *problem-focused coping* where efforts are aimed at altering the person-environment transaction or altering or managing the source of stress (i.e., addressing the problem causing distress); and *emotion-focused coping*, which is aimed at regulating emotional responses elicited by the situation (i.e., ameliorating the negative emotions associated with the problem).

The current study has incorporated a particular focus on a form of problem-focused coping by studying proactive coping. This emphasis on proactive coping was due to multiple considerations, as discussed below. Most notably, it fits with evidence from research on burden among caregivers for people in the early stages of Alzheimer’s Disease indicating that their predominant coping orientation was characterized by a problem-solving orientation marked by positivity rather than negativity (Zucchella et al., 2012). The nature of proactive coping in general is now considered.

The Concept of Proactive Coping

Most research on coping focuses on how people cope with events that have occurred in the past or that are occurring in the present (Somerfield & McCrae, 2000). One key development in coping has to do with the ways people cope in advance to prevent the impact of events that are potential stressors (Somerfield & McCrae, 2000). Aspinwall and Taylor (1997) refer to these responses to potential stressors as "Proactive coping." Unlike other forms of coping, proactive coping is not preceded by negative appraisals such as harm, loss or threat, which is the case with reactive coping (harm or loss experienced in the past), anticipatory coping (an imminent threat in the near future) and preventative coping (uncertain threat potential in the distant future) (Schwarzer & Taubert, 2002). In contrast, proactive coping perceives upcoming events as challenges that are potentially self-promoting (Schwarzer & Taubert, 2002; Straud & McNaughton-Cassill, 2019). It initiates a constructive path of action where challengeable goals are set and opportunities for growth are created (Straud & McNaughton-Cassill, 2019).

Proactive coping differs from traditional conceptions of coping in three main ways: firstly, traditional forms of coping tend to be reactive (Schwarzer, 2000; Straud & McNaughton-Cassill, 2019). More specifically, they deal with stressful events that have already occurred and their purpose is to compensate for past harm or loss while proactive coping is more future-oriented.

Second, reactive coping is regarded as risk management whereas proactive coping is regarded as goal management (Schwarzer, 2000). When engaged in proactive coping, people seek risks, demands and opportunities in the future but they do not appraise these as threats.

Instead, they perceive difficult situations as challenges so proactive coping becomes goal management instead of risk management (Straud &McNaughton-Cassill, 2019).

Finally, the motivation for proactive coping is more positive (Schwarzer, 2000; Straud & McNaughton-Cassill, 2019). Situations are perceived as challenging whereas reactive coping emanates from risk appraisal, where environmental demands are appraised as threats.

This project focused on proactive coping due to these characteristics and the task-oriented focus that is often needed in the role of a loved one receiving institutional care. It was also believed that this emphasis on proactive coping, as opposed to more reactive forms of coping, can better address the fact that some caregivers with extreme burden may not be coping very much at all due to the circumstances. The issue for these people is not how they cope but whether they are engaged in active coping efforts.

According to Greenglass et al. (1999), the proactive perspective asserts that one can do something before burden occurs. Individuals have the potential to envision success, to plan to work towards their goals, and to believe they can achieve goals (Schwarzer, 1999). Proactive coping is seen as a way of coping with challenges in the environment that focus on success rather than failure. Going beyond self-confidence, the proactive coper actually has several plans for dealing with challenges and burdens in the environment. In doing so, proactive copers utilize proactive emotional coping for self-regulatory goal attainment, and they identify social resources and incorporate them into active coping processes (Greenglass et al., 1999).

Aspinwall and Taylor (1997) divided proactive coping into five stages. Proactive coping starts with *resource accumulation* involving the mustering of money, time, planning and organizational skills, social support, and the management of the chronic burden so that when stressors are detected one is prepared as much as possible to manage them. Proactive coping also involves the *recognition of potential stressors*. Recognition refers to the ability to see a potential stressful/burdensome event coming. After a potential burden has been detected, *initial appraisal* occurs which consists of preliminary assessments of the current and potential status of the potential stressor as well as related assessments. These appraisals may promote increased attention to the potential burden and may also give rise to *initial coping efforts*. Initial coping efforts are activities undertaken that are deemed likely to prevent or minimize a potential burden. The *elicitation and use of feedback* is the final step in the proactive coping process. It centers around the acquisition of feedback about the development of the stressful event itself, the effects one's preliminary efforts have had so far on the stressful/burdensome event, and whether the event requires additional coping efforts. This feedback may be used to revise one's appraisals of the potential or emerging stressor/burdensome event and to modify one's strategies for offsetting it.

Proactive Coping and Coping with Burden

How can proactive coping relate to less burden? When proactive coping is deployed during burdensome transitions, it can elicit many benefits by helping to minimize the overall impact of burden and offset the weight of long-term burdens (Rogalla, 2020). Aspinwall and Taylor (1997) observed that in comparison to other coping strategies that are implemented following a burdensome encounter, proactive coping has not received extensive attention in the stress/burden and coping literature. Most researchers focus instead on stress and coping reactivity following identifiable events such as an illness, financial strain, interpersonal discord or academic failure.

The overall paucity of research is unfortunate given research evidence that attests to the protective role of proactive coping. For example, Schwarzer and Taubert (2002) reported a study examining the relationship between proactive coping and stress/burnout in German teachers. These researchers hypothesized that proactive coping would be associated with lower levels of burnout. A total of 316 German teachers were surveyed and job burnout was defined three-dimensionally in terms of emotional exhaustion, depersonalization and lack of personal accomplishment. To identify the relationship between proactive coping and burnout, the sample was subdivided into low, medium and high proactive teachers who were plotted against the three dimensions of burnout. Results showed a significant pattern of decreasing burnout with increasing levels of proactive coping. High proactive teachers reported less emotional exhaustion, less depersonalization and more personal accomplishment than low proactive teachers (Schwarzer & Taubert, 2002). The study also examined dimensions of challenge, threat and loss. It was expected that high proactive coping would be associated with higher challenge appraisals, whereas low proactive coping would be linked to higher threat and higher loss appraisals. The data confirmed this hypothesis. Essentially proactive teachers perceived their stress as more challenging and less threatening and loss-based than their less proactive counterparts. To summarize, proactive teachers in this study experienced less job burnout, perceived more challenges and less threat and loss and displayed more professional engagement than their reactive counterparts (Schwarzer & Taubert, 2002).

Greenglass (2005) described a study examining work stress and burnout in relation to proactive coping using a sample of 178 respondents who were employed in a variety of mainly white-collar occupations in a large Canadian city. Individuals filled out an anonymous self-report questionnaire consisting of various psychological measures. Burnout was measured using the MBI-General Survey (Schaufeli et al., 1996) which yields measures on three burnout components-emotional exhaustion, cynicism, and reduced professional efficacy (see Schaufeli et al., 1996). Proactive coping was assessed using the 14-item proactive subscale of the Proactive Coping Inventory (PCI; Greenglass et al., 1999). The relationship between proactive coping and burnout was examined using structural equation modeling. The theoretical model put forth hypothesized that proactive coping would lead to higher levels of professional efficacy and to lower levels of emotional exhaustion and cynicism. Findings revealed that proactive coping had a negative impact on emotional exhaustion and cynicism and it directly increased the level of professional efficacy. It was also found that proactive coping had an indirect effect on cynicism through emotional exhaustion. As expected, proactive coping contributed positively to professional efficacy. People who employed proactive coping strategies were less likely to experience emotional exhaustion and cynicism, likely owing to their perception that they possessed greater resources to cope with stress, including the ability to plan, reflect and utilize social resources.

Chang and Chan (2013) assessed optimism and proactive coping in relation to burnout among 314 staff nurses in hospitals in Taiwan. Findings suggested that higher levels of proactive coping behaviours and optimism were associated with lower levels of burden (Chang & Chan, 2013). Similarly, Gillespie and Gates (2013) assessed the use of proactive coping as a way to manage the burden levels of trauma patient care in nurses. Results revealed that proactive coping strategies that focus on the planning and preparation to provide care for traumatically injured patients may be effective at preventing traumatic burden.

Straud and McNaughton-Cassill (2019) investigated proactive coping as a mediating variable between self-blame and stress/burden in a sample of undergraduate college students. Findings indicated the relationship between self-blame and stress was mediated by proactive coping. Those with higher levels of self-blame were predictive of higher levels of stress and lower levels of proactive coping. Additionally, higher levels of proactive coping were predicated by lower levels of self-blame and predictive of lower levels of stress. These findings support previous research demonstrating the negative relationship between proactive coping and self-blame and stress.

Relationship Between Caregiver Burden/Stress and Proactive Coping. Given the demographics and aging patterns of our current population, the study of caregiving and coping has been a popular area of study. According to Baharudin et al. (2019), research indicates that many coping strategies mediate caregiver burden, especially when caring for someone with dementia. However, to my knowledge, research focusing specifically on proactive coping and caregivers does not exist. Thus, this emphasis on proactive coping is a unique element of this study. After examining the specifics of proactive coping and how it is connected to stress, one would likely assume that a caregiver utilizing proactive coping tactics would experience less burden, in part, because such an individual would typically plan ahead, access information, and effectively strategize. Proactive coping also enables a caregiver to be vigilant and effectively advocate for her family member in an institution by foreseeing the specific needs of her loved one. Furthermore, proactive coping allows a caregiver to have some feeling of control over her situation even though she does not have control over the condition of her relative. In using these tactics, it is assumed that one would be well equipped to address burden/stress related to her caregiver role, thus resulting in less caregiver stress/ burden. Likewise, it is expected that caregivers who are proactive in their caregiving approach would experience more positive affect and less negative affect, and those caregivers who have more social support would likely be better copers and in turn, those who are better copers will have more social support.

The Concept of Social Support

Some people are obviously able to withstand the ravages of burden better than others. As noted earlier, the potential importance of social support was documented by Uchino et al. (1992). A number of mediating variables can reduce the impact of burden on physical and mental health (Pearlin et al., 1990). Research continues to attest to the benefits of social support as a key mediating variable, especially for caregivers (see Kalaitzaki et al., 2021). Social support serves as a protective buffer for people during times of high burden, reducing their negative impact on burdensome events. As a mediating variable, social support would indirectly be limiting deleterious outcomes (Pearlin et al., 1990).

Social support is a multifaceted concept that has been defined in several different ways. To date, a universally accepted definition of social support does not exist. Consequently, many discrepancies exist within the literature regarding the nature, meaning, and measurement of social support. Furthermore, definitions vary in their degree of specificity, breadth of transactions encompassed, and the importance attributed to the stability of interpersonal relationships (Wolchick et al.,1989). Nevertheless, in order to obtain a general understanding of the concept social support, it is necessary to review some of the definitions that have been discussed within the literature.

House (1981) provided an integrated view of social support. This researcher distinguishes between four types of supportive acts or behaviours: emotional (the provision of trust, empathy, and love), instrumental (helping behaviours such as loaning money or giving one’s time and skill), informational support (advice), and appraisal support (evaluative feedback).

As an alternative to House’s categories discussed above, social support can also be divided into primary, secondary, and tertiary levels on the basis of the intimacy of social relationships (Cassel, 1976). The primary level support structure includes one’s own family and closest friends. The secondary level includes friends, relatives, workmates, and neighbours, and finally the tertiary level includes the authorities and other distant support structures. Social support may be given by professionals or non-professionals. The primary and secondary levels include mainly non-professionals, and tertiary includes professionals, such as social and health care personnel (Cassel, 1976).

The most important aspect of social support is perceived social support, or the belief that help would be available if needed (Sarason et al., 1990). Health and wellbeing are dependent on what the person sees and believes, be it accurate or not. On the other hand, it has been questioned whether measures of perceived social support truly reflect the actual availability of support (Huurre, 2000). However, there is evidence that self-reports of the validity of the perceived social support measures are rather accurate (Schwarzer & Leppin, 1991).

Relationship Between Burden/Stress and Social Support

Since the 1970s, following the notable works of Caplan (1974), Cassel (1976) and Cobb (1976), there has been an increase of interest in the concept of social support as it affects health and wellbeing. Two different processes through which social support has a beneficial effect on wellbeing have been presented.

One model, the main-effect model, proposes that social resources have a beneficial effect irrespective of whether persons are under stress. A generalized beneficial effect of social support could occur because large social networks provide persons with regular positive experiences and a set of stable, socially rewarded roles in the community (Cohen & Wills, 1985). This kind of support could be related to overall wellbeing because it provides positive affect and a recognition of self-worth (Cohen & Wills, 1985). Integration in a social network may also help one to avoid negative experiences. This view of support has been conceptualized from a sociological perspective as “regularized social integration” or “embeddedness” in social roles and from a psychological perspective as social interaction, social integration, relational reward, or status support (Cohen & Wills, 1985).

The alternative model, which was incorporated in the current study, proposes that support is related to wellbeing only (or primarily) for persons who are burdened. This is termed the buffering model because it posits that support buffers (protects) persons against the potentially pathogenic influence of stressful/burdensome events (Cohen & Wills, 1985). Kalaitzaki et al. (2021) further emphasize the importance of social support by stating that meaningful relationships with family and friends enables caregivers to develop resiliency towards potential caregiver stressors. Support may play a role at two different points in the causal chain linking stress/burden to illness (Cohen & Wills, 1985). First, support may intervene between a burdensome event and a burden reaction by attenuating or preventing a burden appraisal response. Second, adequate support may intervene between the experience of burden and the onset of the pathological outcome by reducing or eliminating the burden reaction or by directly influencing physiological processes (Cohen & Wills, 1985).

del Pino-Casado et al. (2018) conducted a meta-analysis to assess the relationship of perceived and received social support with subjective burden among informal caregivers of an adult or older adult. Fifty-six studies were included in the meta-analysis, which provided 46 independent comparisons for perceived support and 16 for received support. Most studies were cross-sectional. There was a moderate negative association of perceived social support on subjective burden and a very small negative association of received support on subjective burden (del Pino-Casado et al., 2018). It was found that the relationships between social support and burden depend on whether the social support is measured as perceived or received, where the relationship of perceived social support with burden has a bigger effect size than that of received social support. The association between received support and subjective burden was found to be clinically irrelevant (del Pino-Casado et al., 2018).

Burden/Stress and Mood/Emotional States

When people are under stress, they typically react emotionally. While it has been suggested that some stress is positive, stress tends to mostly elicit unpleasant emotions rather than pleasurable ones (Lazarus, 1993). The link between burden and emotion was apparent in a study of 96 women who filled out daily diaries about the burdens and moods that they experienced over a 28-day period (Caspi et al., 1987). The investigators found that daily fluctuations in burden correlated with daily fluctuations in mood. As burden increased, mood tended to become more negative. Other studies on burden and mood have established links between them (e.g., Affleck et al., 1994; van Eck et al., 1998).

No simple one-to-one connection has been found between specific types of burdensome events and particular emotions. However, researchers have begun to uncover some strong links between specific cognitive reactions to burden (appraisals) and specific emotions (Smith & Lazarus, 1993). Although many emotions can be evoked by burdensome events, some are certainly more likely than others. Common emotional responses to burden include: annoyance, anger and rage, apprehension, anxiety and fear, dejection, sadness and grief (Lazarus, 1993; Woolfolk & Richardson, 1978). Richard Lazarus (1991) identifies five other emotions that are common reactions to stress: guilt, shame, envy, jealousy, and disgust.

Hypotheses Tested in the Current Study

The background literature provided above was designed to provide the context for the specific hypotheses evaluated in this research investigation. The main issues guiding this research were outlined above. To summarize, using this unique caregiver population of the institutionalized elderly, the current study focused on burden and its association to proactive coping, social support, and mood states of caregivers. The burden levels of spousal caregivers versus non-spousal caregivers were investigated as well as the lucidity of the care-receiver and how that impacted the burden level of the caregiver. Given the research questions stated above, the key hypotheses were as follows:

1) Individuals with higher burden levels (as measured by the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989) would have lower proactive coping scores as measured by the Proactive Coping Subscale (Greenglass et al., 1999), in accordance with past research findings (e.g., Chang & Chan, 2013; Gillespie & Gates, 2013; Greenglass, 2005; Schwarzer & Taubert, 2002; Straud & McNaughton-Cassill, 2019). Individuals experiencing more burden would also have lower levels of social support, as measured by a variation of Caplan et al. (1975) Social Support measure. This notion is supported by previous research (see for example, Lai, & Thomson, 2018; Rodakowski et al., 2012; Tosun & Temel, 2017). Lastly, those with higher burden scores would have more negative mood states (as measured using a shortened version of the Profile of Mood States (SV-POMS; Shacham, 1983). Correlational analyses were used to test the hypotheses stated above.
2) It was expected that caregivers who are proactive in their caregiving approach would experience more positive affect such as vigour-activity and less negative affect,

namely anger-hostility, tension-anxiety, depression-dejection, fatigue-inertia and confusion-bewilderment. The reason for this anticipated outcome is because by predicting the needs of his/her relative in advance and thus implementing what is necessary to fulfill these needs accordingly, a proactive caregiver can help minimize the amount of burden resulting from the caregiver role, which in turn will likely result in a more positive caregiving experience. It was anticipated that caregivers who have more social support would likely be better copers and in turn, those who are better copers will have more social support (see for example Greenglass & Fiksenbaum, 2009; Greenglass et al., 2006; Vaculikova & Soukup, 2019). Correlational analyses were used to test these hypotheses.

3) Spousal caregivers would have greater burden levels than non-spousal caregivers (i.e., daughter, sister, daughter-in-law, niece, neighbour, friend, granddaughter). Reasons for this include: spouses spend more hours providing care than other relatives (Turcotte, 2013), they carry out more caregiving tasks (Turcotte, 2013), and they are often faced with the financial burden of extra medical expenses (Sunmin et al., 2003). Furthermore, the intensity of commitment involved in caring for a spouse compared to caring for other relatives is greater for spouses (Sunmin et al., 2003). Caregiving for a spouse is often inescapable, while caring for other relatives tends to be more voluntary or shared between siblings and others (Sunmin et al., 2003; Turcotte, 2013). These hypotheses were tested using correlational analyses.
4) Previous research suggests that caregivers of family members suffering from AD or dementia experience greater levels of emotional burden than caregivers of lucid chronically ill family members (Karlin & Bromley, 1996).

However, differences between these caregivers were not evident for time, social, developmental or physical burden as measured by the CBI (Karlin & Bromley, 1996). For this reason, it was expected that these two groups would only differ in their level of emotional burden, with caregivers of the confused elderly to display higher emotional burden levels. In order to test for these hypotheses correlational analyses were used.

5) It was anticipated that in regression analyses, burden as an outcome measure would be predicted significantly by whether a care receiver was lucid and whether a caregiver was a spouse; specifically burden was expected to be higher for spousal caregivers with a non-lucid care receiver. It was further expected that social support, less negative affect and greater proactive coping would be associated uniquely with burden. As noted above, regression analyses were used to test these hypotheses.
6) It was predicted that level of confusion and relationship of caregiver would predict mood in regression analyses. It was also anticipated that social support and proactive coping would predict a significant proportion of unique variance in POMS scores.

No explicit prediction accompanies the open-ended component. This element was intended to be exploratory and stemmed from an interest in illuminating the factors that are seen by the participants as contributing to their degree of burden.

Method

Respondents

One-hundred and fifty-four family caregivers from Sunnybrook Health Sciences Centre were asked to complete a questionnaire on an anonymous basis. It should be noted that some potential participants declined the offer to participate in the study. Unfortunately, the number of refusals was not documented by the hospital personnel. Parenthetically, the sample size sought reflected Green's (1991) criteria to determine sample sizes for regression analyses. Established in 1943, Sunnybrook originated as Canada's largest Veterans hospital (Sunnybrook Health Science Centre, 2021). It has developed into a fully affiliated teaching hospital of the University of Toronto. Today, Sunnybrook has established itself across three campuses and is home to Canada's largest trauma center. The main campus, where this research was conducted, is located at 2075 Bayview Avenue in Toronto, Ontario. Sunnybrook provides care from premature newborns to those requiring critical care, specialized trauma, musculoskeletal, oncology, mental health, dementia, cardiac or stroke care, to elderly war veterans living at Sunnybrook (Sunnybrook Health Sciences Centre, 2021).

Participants (i.e., family members or friends/neighbours of patients) were recruited from the Kilgour Wing (K-wing) as well as the George Hees Wing (L-wing). Both units are long-term care facilities for community residents (75%) as well as Veterans (25%) who suffer from physical as well as cognitive impairments. Only female participants (primarily spouses of the patients) were used for this study, since over 90% of the family caregivers were female and no male caregivers participated. To the best of my knowledge, none of the participants suffered from any cognitive impairments.

The average age of the participants in the sample was 67.25 years (*SD* =15.1), with ages ranging from 18-96 years. Approximately half (51.9%) of the respondents were spousal caregivers. Over fifty percent of the participants had been providing care between two and five years. Thirty caregivers looked after individuals who were confused all of the time (19.5%), 36 of the care-receivers were moderately confused (23.4%), 68 caregivers tended to individuals who were sometimes confused (44.2%), and 18 caregivers looked after lucid individuals (11.7%). Table 1 provides a detailed description of the demographic characteristics of the sample.

Procedure

After having done an internship at Sunnybrook Hospital, I came to view Sunnybrook as the ideal facility to conduct this research. Learning includes all phases of the research project. As the student conducting this research, the author completed all the required steps in order to be granted permission to conduct research at this hospital. An extensive research proposal was submitted that outlined the purpose of the project, the participants to be recruited, as well as details highlighting the data collection process. This proposal was reviewed and approved by both a research committee as well as an ethics board, ultimately allowing this study to be conducted with this population of caregivers. Care and attention were given to issues such as the appropriateness of scale content and the length of questionnaires in accordance with the recommendations from the hospital research committee.

Data collection was scheduled to take place in October 2004, but this had to be abruptly postponed because of the outbreak of SARS. Research resumed in 2005 and continued until June 2006. It is worth noting that the data collected were not affected by the SARS outbreak, as collection took place over a year and a half later in 2005 when all visiting hours and activities resumed back to how they were prior to the SARS outbreak. Data were collected using self-report questionnaires (see Appendix A). All questionnaires protected the anonymity of respondents and confidentiality of answers.

Hospital staff associated with each of the designated units distributed the questionnaires. Each participant was given a research packet containing a cover letter explaining the nature and

Table 1

Demographic Characteristics of Individuals Sampled (N=154)

Measure	*N*	%
Relation to Care-Receiver		
Wife	80	51.9
Daughter	44	28.6
Daughter-in-law	7	4.5
Sister	2	1.3
Niece	7	4.5
Grand-daughter	3	1.9
Neighbour	2	1.3
Friend	9	5.8
Length of Caregiving		
One month or less	3	1.9
2-6 months	11	7.1
7 months to 1 year	14	9.1
2-5 years	81	52.6
6-10 years	27	17.5
11 or more years	18	11.7
Sole Caregiver		
Sole caregiver	63	40.9
Others available	90	58.4
Age of Caregiver		
18-23	3	
24-29	1	
30-35	1	
36-41	1	
42-47	7	
48-53	17	
54-59	18	
60-65	20	
66-71	11	
72-77	22	
78-83	37	
84-89	13	
90-95	1	

Measure	*N*	%
Age of Caregiver		
96	1	
Number of Weekly Visits		
Less than once a week	7	4.5
1-2 days a week	43	27.9
3-4 days a week	39	25.3
5-6 days a week	35	22.7
7 days a week	30	19.5
Length of Visits		
Less than 1 hour	10	6.5
1-3 hours	91	59.1
4-6 hours	44	28.6
7-9 hours	6	3.9
10-12 hours	1	.6
More than 12 hours	2	1.3
Is Care-Receiver Confused		
Never	18	11.7
Sometimes	68	44.2
Moderately	36	23.4
All the time	30	19.5
Smoker		
Non-smoker	136	88.3
Smoker	18	11.7
Who Provides Help		
Spouses/partner	50	32.5
Children	102	66.2
Friends or neighbours	75	48.7
Others	36	23.4
No one	8	5.2

Measure	*N*	%
Types of Unpaid Help		
Visiting relative	81	52.6
Assisting with tasks	31	20.1
Cleaning your home	11	7.1
Shopping	20	13
Preparing meals	24	15.6
Advice/Encouragement	81	52.6
Amount of Unpaid Help Per Day		
0-less than 1 hour	109	70.8
1-5 hours	28	18.2
6-10 hours	2	1.3
11-15 hours	1	.6
16-20 hours	0	.0
21 hours or more	1	.6
Amount of Unpaid Help Per Week		
0-less than once a week	76	49.4
1-2 days a week	38	24.7
3-4 days a week	13	8.4
5-6 days a week	7	4.5
7 days a week	4	2.6

the importance of the study (see Appendix B), assuring that participation is voluntary. Participants were also given a consent form (Appendix C) that was to be completed prior to filling out the questionnaire. Once respondents completed the questionnaires, they were instructed to deposit the self-addressed envelopes into the mailbox. The final sample (*N*=154) represented a response rate of approximately 18%. The response rate reported here is only an approximation because not all of the questionnaires were actually distributed. A total of 850 questionnaires were given to the hospital staff to distribute to the appropriate individuals. Because I was not permitted to personally distribute the questionnaires, I do not know the exact number of questionnaires that were actually handed out. When the outbreak of SARS occurred, my data collection was put on halt for several months. Because of this, many of the questionnaires that I gave to the hospital staff did not get distributed. For this reason, I am certain that far less than 850 were distributed, thus resulting in a possibly much higher response rate than that originally estimated.

Measures

The following variables were included: burden, mood states, proactive coping and social support. Demographic information as well as personal responses were also analyzed. The measures included to assess these variables are described below. Please refer to Table 2 to see a summary of the constructs used.

Caregiver Burden

Burden levels were measured using the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989). This is a 24-item multidimensional instrument that measures the impact of burden on caregivers. The CBI provides a unique set of five subscales designed to measure the burden of caregivers of impaired older people (Novak & Guest, 1992). These include: time dependence

Table 2

Summary of Constructs

Construct	Source	Subscales
Caregiver Burden Inventory (CBI)	Novak and Guest (1989)	1. Time-dependence burden 2. Developmental burden 3. Physical burden 4. Social burden 5. Emotional burden
Proactive Coping Inventory (PCI)	Greenglass et al. (1999)	14-item scale
Social Support Scale	Greenglass et al. (1996); Caplan et al. (1975)	1. Practical support 2. Emotional support 3. Informational support
Profile of Mood States (POMS)	Shacham (1983)	37-item scale

burden, developmental burden, physical burden, social burden, and emotional burden. Each subscale contains different high-loading items. Responses to each item range from 0 (*not at all descriptive*) to 4 (*very descriptive*), yielding maximum subscale scores of 20 for all of the subscales with the exception of the physical burden subscale, which produces a score of 16. Time dependence burden describes the burden due to restrictions in the caregiver's time. Because disabled persons often have trouble carrying out daily tasks independently, caregivers tend to devote considerable amounts of time and energy in assisting with such tasks. This constant responsibility places stress on the caregiver. Items like "my care receiver is dependent on me" or "I don't have a minute's break from my caregiving chores" reflect caregivers' feelings of burden. The internal consistency reliability (coefficient alpha) was .85 (Novak & Guest, 1989). In a study which examined the multidimensional nature of caregiver burden through the use of the CBI, Caserta et al. (1996) obtained a reliability coefficient score of .85.

Novak and Guest (1992) who conducted a study on the stresses of spouse and nonspouse primary caregivers of older people, also obtained an alpha level of .85.

Developmental burden describes caregivers' feelings of being "off-time" in their development with respect to their peers. Caregivers see their peers enjoying their later years as they expected, but they feel continued anxiety and strain. They often ask the existential question "why did this happen to me?" Items like, "I feel like I am missing out on life" and "I expected that things would be different at this point in my life" reflect this feeling of burden. The internal consistency reliability of this subscale (coefficient alpha) was .85 (Novak & Guest, 1989; 1992) and .87 (Caserta et al., 1996).

Physical burden items describe caregivers' feelings of chronic fatigue and damage to physical health. Many studies report that caregivers run a high risk of physical illness due to caregiving. Items like “I’m not getting enough sleep” and “caregiving has made me physically sick” reflect caregivers’ feelings of physical burden. The internal consistency reliability was estimated originally as .85 (Novak & Guest, 1992) and .86 (Caserta et al., 1996; Novak & Guest, 1989).

Social burden items describe caregivers’ feelings of role conflict and strain on social relationships. A caregiver might argue with a spouse or with other family members over how to manage the care receiver’s needs. Caregivers sometimes feel unappreciated and neglected by others. They may also have to limit the time and energy that they invest in relationships or in their jobs. Items like, “I don’t get along with other family members as well as I used to” and “I don’t do as good a job at work as I used to” reflect caregivers’ feelings of social burden. The internal consistency reliability was .69 (Caserta et al., 1996) and .73 (Novak & Guest, 1992).

Lastly, emotional burden items describe caregivers’ negative feelings toward their care receivers (Novak & Guest, 1989). Caregivers may feel guilty about these socially unacceptable feelings. Items like, “I resent my care receiver” and “I feel angry about my interactions with my care receiver” reflect these feelings of emotional burden. The internal consistency reliability was .81 (Caserta et al., 1996) and .77 (Novak & Guest, 1992).

Moderate intercorrelations were obtained for the CBI subscales. The correlation between time dependence burden and developmental burden was 0.38 (Novak & Guest, 1989), and was 0.44 for time dependence burden and physical burden (Novak & Guest, 1989). For time dependence burden and social burden the correlation was 0.06, and for time dependence burden and emotional burden was 0.43. For developmental burden and physical burden, the correlation was 0.62 (Novak & Guest, 1989), and was 0.26 for developmental burden and social burden. The correlation between developmental burden and emotional burden was 0.47. The correlation between physical burden and social burden was 0.18 and was 0.48 for physical burden and emotional burden. Lastly, the correlation between social burden and emotional burden was 0.19.

Because the CBI greatly differs from existing measures of burden and stress, evidence of its concurrent validity was not established using other stress measures. Novak and Guest (1989) explained by stating that other stress measures are unidimensional and thus, produce a total stress score. In contrast, the CBI is multidimensional in that it measures five dimensions of stress, therefore providing a more comprehensive depiction of stress and burden. Yet when examining the correlation between the various subscales of the CBI and depression as measured by the Epidemiological Studies Depression Scale (CES-D), research has demonstrated that these two measures are correlated. For example, Caserta et al. (1996) have found that the correlation between developmental burden and depression is .58, and for physical burden .63. Novak and Guest (1989) also found that high levels of developmental burden highly correlate with depression ($r = .70$ $p < .001$) (Guest & Novak, 1987).

Proactive Coping

Proactive coping was measured by the Proactive Coping Inventory (PCI; Greenglass et al., 1999), which consists of seven scales that assess various aspects of proactive coping in cognitions and behaviour (Greenglass et al., 1999). For this study, the proactive coping subscale was used. It is a 14-item scale, which combines autonomous goal setting with self-regulatory goal attainment cognitions and behaviour (Greenglass et al., 1999). In scoring responses, individuals are asked to indicate whether statements are not at all true, barely true, somewhat true or completely true (by selecting a 1-4 rating respectively). A selection of sample items includes statements such as: “I am a ‘take charge’ person”, “after attaining a goal, I look for another more challenging one”, “I try to pinpoint what I need to succeed”, and lastly “I turn obstacles into positive experiences." This scale has high internal consistency as seen in reliability measures (α) of .85 and .80 in two samples (Greenglass et al., 1999). In addition, the scale shows good item-total correlations and acceptable skewness as an indicator of symmetry around the mean (Greenglass et al., 1999). A principal component analysis confirmed its factorial validity and homogeneity (Greenglass et al., 1999).

The construct validity of the PCI subscales was explored by having participants in the Canadian Student and Polish-Canadian samples complete measures of other coping styles and then examining the relationship between the PCI subscales and these additional measures. The other measures used were Active Coping, Denial, Use of Instrumental Support and Use of Emotional Support, all from the Brief COPE, a coping inventory composed of 14 subscales (Carver, 1997). Coping subscales from the Coping Inventory of Peacock and Wong (1990) were also administered to participants in both samples. These included Internal Control, a measure of the extent to which the individual takes the initiative in coping efforts, and Self-Blame (Greenglass, 2002). Proactive coping scores correlated significantly with active coping and internal control, ranging from .46 to .62 in both samples. Moderately high negative correlations were observed between proactive coping and levels of denial and self-blame.

Social Support

Social support was assessed using a measure used previously by Greenglass et al. (1996), which was an adapted version of the measure devised by Caplan et al. (1975). This measure examines the availability of three types of social support (emotional, informational, and practical) collapsed into one measure. Respondents are provided with a series of scale items that require them to indicate on a 4-point scale, the extent to which individuals provide them with certain kinds of support. Sample items are as follows: "How much can people be relied on to provide you with assistance when you really need it most? (Practical), “How much do people boost your spirit when you feel low?” (Emotional); and “How much useful information do people provide you with when you really need it most” (Informational). The reliability (α) for this measure ranges from 0.89 to 0.95 (Caplan et al., 1975).

Mood/Emotional States

A shortened version of the Profile of Mood States (SV-POMS) (Shacham, 1983) was used to assess individuals’ mood states over the previous week. It is an adjective checklist consisting of 37 items rated on a 5-point scale that ranges from “*not at all*” to “*extremely*.” The SV-POMS contains six subscales: tension-anxiety, depression-dejection, anger-hostility, vigour-activity, fatigue-inertia, and confusion-bewilderment.

Shacham developed this shorter version by first administering the POMS (65 items) to 83 cancer patients with pain complaints. The contribution of each adjective to the internal consistency of its corresponding mood subscale was then examined. Items found to have higher internal consistency and judged to be face-valid were retained in this shorter version of the POMS (SV-POMS). Shacham reported that scores on the six subscales and the Total Mood Disturbance scale of the SV-POMS were highly correlated ($r = .95$ to $.98$) with the scores from the full-length POMS. Comparable levels of internal consistency were also found for the subscales and the Total Mood Disturbance scores (Shacham, 1983).

Demographic Information

Demographic information included: relationship to care receiver, whether or not an individual is the primary caregiver, the age of the caregiver, the type of help one receives with caregiving tasks (including how often and how much), how long one has been a caregiver, and lastly, whether the care-receiver is ever confused.

Personal Responses

In addition to the measures discussed above, participants were given a list of 10 items and were asked to rank them in terms of stress, with “10” being the most stressful and “1” being the least. These 10 items are listed in Table 14. Once caregivers ranked these items they were asked to elaborate and explain in writing why the item they ranked as “10” caused them the most stress in comparison to the other items listed.

How were these 10 items generated? In order to produce these items for caregiver ranking, thorough literature searches took place in order to identify caregiver stresses and burdens frequently identified by researchers in the field. Additionally, I consulted staff working with the patients as well as family caregivers themselves, to get a sense of what they perceived as causing the most caregiver burden.

Results

Overview of Analyses

Initially, descriptive statistics were calculated. These statistics included Cronbach (1951) alpha reliabilities, as well as means and standard deviations. Pearson product-moment correlations were computed to describe the association between burden and the variables of proactive coping, social support, and mood states. Pearson product-moment correlations were also computed to determine if a relationship exists between proactive coping and mood states, as well as between proactive coping and social support.

Next, a one-way multivariate analysis of variance (MANOVA) was conducted to evaluate possible differences by type of caregiver (i.e., spouse caregiver versus other) on scores on the CBI. Most notably, a one-way multivariate analysis of variance (MANOVA) was also performed to determine the effect of caring for a confused individual versus a lucid individual on the five CBI sub-scales. The distinction between a caregiver to a lucid elderly person versus those caring for the cognitively impaired was then further explored by examining the correlations found for the respective subsamples.

Z-scores were also computed to compare the strength of correlations between burden, mood states, social support and proactive coping for caregivers of the lucid elderly versus those caring for the cognitively impaired. A paired samples t-test was run to compare two groups of individuals-i.e., those who ranked guilt as their first or second greatest stressor versus those who did not select guilt as their top two stressors.

Two hierarchical regressions were also performed. One was conducted to examine the impact of social support, proactive coping and negative mood in predicting overall burden after controlling for relative confusion and caregiver relationship to relative. A second hierarchical regression was conducted to examine the impact of social support and proactive coping in predicting overall mood after controlling for relative confusion (i.e., confused versus lucid) and caregiver relationship to relative (i.e., spousal caregiver versus others).

Descriptive Statistics

The measures and their respective reliabilities, means, standard deviations and number of items on which they are based are reported in Table 3 for the overall sample. Most of the scales satisfied the assumption of normality with the exception of the following four: social burden (CBI), emotional burden (CBI), anger-hostility (POMS) and depression-dejection (POMS). The square root transformation was used to make these score distributions more normal.

It can be seen that the various measures had acceptable levels of internal consistency. Nunnally (1978) recommends that an alpha coefficient of .70 or greater corresponds to a reasonable degree of internal consistency, especially for relatively new measures. The alphas for the CBI subscales ranged from .84 to .89 with the overall scale having an estimated internal consistency of .90. The PCI had an internal consistency of .81 (see Table 3). The alphas for the POMS subscales ranged from .78 to .93 with most subscales having alphas of .90 or greater.

Regarding the means from the current sample, it seems that the level of burden reported by the current participants was elevated. The mean for the total CBI was 30.78 (*SD* = 15.19) in this sample. In contrast, Novak and Guest (1989) provided a CBI mean of 22.14 (*SD* = 16.30) for 107 caregivers of confused or disoriented older people. Their results were for 28 men caregivers and 79 women caregivers, who were evenly split in terms of whether they were providing care to someone in an institution or still residing in the community. However, another study found much higher scores for 86 caregivers of patients with Alzheimer's disease that involved constant daily contact. The reported mean here for the CBI was 37.05 (*SD* = 16.30) (Iavarone et al., 2014).

Overall, it seems that there was a typical level of proactive coping. The PCI yielded a mean score of 38.41 (*SD* = 6.62). This mean is slightly higher than the mean of 37.56 found in a sample of 224 community-residing older adults (see Greenglass et al., 2006). However, is lower than the mean found for the 228 rehabilitation patients who had received either a knee transplant or a hip replacement. The mean in this sample was 43.76 (*SD* = 5.16) (see Greenglass et al., 2005).

Correlations Between Burden Levels and Proactive Coping, Social Support, and Mood States

Next, a series of correlational analyses was conducted. The associations between burden levels and proactive coping scores were examined. No significant correlations were found between proactive coping and burden facets (see Table 4). Pearson product-moment correlations between burden and social support were computed and a negative correlation was found (refer to

Table 3

Means, Standard Deviations, and Internal Reliabilities of Composite Measures

Measure	Alphas (Cronbach α)	Number of Items	*Mean*	*Standard Deviation*
Caregiver Burden Inventory				
Time-dependence burden	.89	5	10.02	5.62
Developmental burden	.86	5	8.91	4.90
Physical burden	.84	4	6.09	4.07
Social burden	.87	5	3.56	4.35
Social burden[a]	.87	5	1.37	1.30
Emotional burden	.85	5	2.63	3.56
Emotional burden[b]	.85	5	1.16	1.14
Total	.90	24	30.78	15.19
Social Support Measure				
Practical support	.85	3	8.74	2.55
Emotional support	.72	2	5.70	1.67
Informational support	.84	3	7.77	2.31
Total	.91	8	22.08	5.71
Profile of Mood States				
Anger-hostility	.90	7	4.89	5.18
Anger-hostility[c]	.90	7	1.79	1.31
Tension-anxiety	.90	6	6.43	5.16
Depression-dejection	.89	8	7.74	6.43
Depression-dejection[d]	.89	8	2.47	1.29
Vigour-activity	.93	6	7.74	5.70
Fatigue-inertia	.92	5	9.13	5.57
Confusion-bewilderment	.78	5	3.62	3.26
Proactive Coping Inventory	.81	14	38.41	6.62

Note. [a]The square root of social burden. [b]The square root of emotional burden.

[c]The square root of anger-hostility. [d]The square root of depression-dejection. The square root was used for the above variables because they were not normally distributed.

**p* < .05. ***p* < .01. ***p* < .001.

Table 4

Correlations Between Burden and Proactive Coping

	Burden					
	CBI total	TDB	DB	PB	SB[a]	EB[b]
Proactive Coping	.00	.10	-.15	.03	.03	-.02

Note. CBI = Caregiver Burden Inventory; TDB = Time-Dependence Burden; DB = Developmental Burden; PB = Physical Burden; EB = Emotional Burden.

[a]Square root of social burden. [b]Square root of emotional burden. The square root was used for the above variables because they were not normally distributed.

Table 5). More specifically, social burden was negatively correlated with practical, emotional, and informational social support. Thus, the more support one received, the less social burden she experienced. Developmental burden was negatively correlated with emotional support indicating that the more emotional support one received, the less developmental burden she experienced. The strongest links with social support were found with the measure of social burden.

Pearson product-moment correlational analyses were computed to evaluate the association between burden (i.e., CBI) and mood states (i.e., POMS). The pattern of results indicated that almost all CBI subscales were positively related to the POMS with the exception of vigour-activity, which was negatively related (see Table 6). Results suggest burden is associated with a complex array of negative mood states. Vigour- activity was negatively correlated with developmental burden, physical burden, and emotional burden, indicating that the more stressed one was, the less vigour-activity she experienced. Correlation fell short of conventional significance levels for time-dependence burden on all components of the POMS except for a link with fatigue-inertia. As expected, these variables positively correlated. These results revealed the more time-dependence burden one experienced, the more tired she was. Thus, it can be said that (with the exception of vigour-activity), the more burden one experienced, the more negative her mood states were.

Correlations Between Coping, Mood States and Social Support

Pearson product-moment correlations were performed to explore the anticipated associations between proactive coping scores and mood states (see Table 7). Scores on the PCI had a significant positive correlation with vigour-activity (r =.25, p < .01). Additional results focusing on negative mood indicators found that higher PCI scores were associated negatively

Table 5

Correlations Between Burden and Social Support

	Burden					
Social Support	CBI total	TDB	DB	PB	SB[a]	EB[b]
Practical support	-.11	-.01	-.13	-.02	-.32***	.02
Emotional support	-.20*	-.06	-.16*	-.07	-.31***	-.06
Informational support	-.03	-.01	-.02	.06	-.17*	.06
Total	-.13	-.03	-.12	-.01	-.30***	.01

Note. CBI = Caregiver Burden Inventory; TDB = Time-Dependence Burden; DB = Developmental Burden; PB = Physical Burden; SB = Social Burden; EB = Emotional Burden.

[a] Square root of social burden. [b] Square root of emotional burden. The square root was used for the above variables because they were not normally distributed.

*$p < .05$. ***$p < .001$.

Table 6

Correlations Between Burden and Mood States

	Burden					
Mood States	CBI total	TDB	DB	PB	SB[a]	EB[b]
Anger-hostility	.32***	.07	-.22**	.30***	.31***	.27**
Tension-anxiety	.46***	.11	.29***	.46***	.32***	.38***
Depression-dejection[d]	.48***	.15	.40***	.44***	.27**	.32**
Vigour-activity	-.21*	-.14	-.20*	-.19*	-.14	-.30***
Fatigue-inertia	.46***	.18*	.39***	.60***	.18*	.17*
Confusion-bewilderment	.35***	.08	.20	.36***	.32***	.25**
POMS total	.50***	.10	.37***	.52***	.31***	.36**

Note. CBI = Caregiver Burden Inventory; POMS = Profile of Mood States;

TDB = Time-Dependence Burden; DB = Developmental Burden; PB = Physical Burden;

SB = Social Burden; EB = Emotional Burden.

[a]Square root of social burden. [b]Square root of emotional burden. [c]Square root of anger-hostility. [d]Square root of depression-dejection. The square root was used for the above variables because they were not normally distributed.

*$p < .05$. **$p < .01$. ***$p < .001$.

Table 7

Correlations Between Proactive Coping and Mood States

	Proactive Coping Inventory
Mood States	PCI total
AH	-.13
TA	-.14
DD	-.23**
VA	.25**
FI	-.12
CB	-.12
POMS total	-.22*

Note. PCI = Proactive Coping Inventory; POMS = Profile of Mood States;

AH = Anger-Hostility; TA = Tension-Anxiety; DD = Depression-Dejection;

VA = Vigour-Activity; FA = Fatigue-Inertia; CB = Confusion-Bewilderment.

**p* < .05. ***p* < .01. ****p* < .001.

with depression-dejection ($r = -.23, p < .01$) as well as with the POMS total ($r = -.22, p < .01$). Caregivers who implemented proactive coping tactics tended to be more enthusiastic and energetic than their caregiver counterparts who did not. Furthermore, caregivers who used fewer proactive coping skills reported more depression. Surprisingly, findings revealed no significant correlation between social support and proactive coping (see Table 8). Unlike other studies which did report a significant relationship between social support and proactive coping, results show that proactive coping is clearly distinguishable from social support. It is possible caregivers for this study did not have access to a social network and thus did not reap the benefits of having better coping skills. This is something that is described in greater detail later on.

Burden Levels of Spousal Caregivers versus Others

A one-way multivariate analysis of variance (MANOVA) was conducted to determine the effect of the type of caregiver (i.e., spousal caregiver versus other) on the five subscales of the CBI (time-dependence burden, developmental burden, physical burden, social burden and emotional burden). Significant differences were found among the type of caregiver and their burden levels. Wilks's lambda = .78, $F(5, 137) = 7.57, p < .001$. The multivariate eta-squared was medium, .22. Table 9 contains the means and the standard deviations on burden for the two groups. Wives had higher mean scores on time-dependence burden, developmental burden and physical burden in comparison to non-spousal caregivers. Non-spousal caregivers had slightly higher mean scores on social burden and emotional burden in comparison to spousal caregivers. The finding with social burden could reflect the impact that caregiving responsibilities might have had on the key relationships of non-spousal caregivers (e.g., the challenges introduced in terms of relationships with a partner) and other obligations felt by the caregiver (e.g., taking care of other family members).

Table 8

Correlation Between Proactive Coping and Social Support

Social Support	Proactive Coping
Practical support	.05
Emotional support	.05
Informational support	.05
Social Support Total	.04

Note. No significant results.

Table 9

MANOVA: Results Comparing Burden Levels for Spousal Caregivers versus Other Caregivers

	Wife (N =80)		Other (N =74)				
CBI	*M*	*SD*	*M*	*SD*	*F*(1,141)	*p*	*Eta*^{2}
Time-dependence burden	10.81	5.55	8.99	5.60	3.82	.053	.03
Developmental burden	10.79	4.63	6.7	4.45	28.98	<.001	.17
Physical burden	6.85	4.12	5.27	3.95	5.45	.021	.04
Social burden	3.30	4.42	3.56	3.98	.83	.36	.01
Emotional burden	2.53	3.55	2.61	3.53	.01	.95	.00

Note. CBI = Caregiver Burden Inventory; df = degrees of freedom.

Analyses of variances (ANOVA) on each burden subscale were conducted as follow-up tests to the MANOVA. To control for the type 1 error rate, the Bonferroni was used (i.e., each ANOVA was tested at the .01 level). The ANOVA on developmental burden was significant, *F* (1,141) = 28.98, *p* < .001, eta-squared = .17. Results indicated that the spousal caregiver group reported greater developmental burden than the non-spousal caregivers.

Burden Levels and Mood States of Caregivers to the Cognitively Impaired Versus the Lucid

As noted in the introduction, a key distinction was made between being the caregiver of someone who is or is not lucid in terms of level of cognitive functioning. A one-way multivariate analysis of variance (MANOVA) was conducted to determine the effect of caring for a confused individual versus a lucid individual on the five CBI subscales. Significant differences were found among the mental state of the care-receiver and how that effected the burden levels of the caregivers. Wilks's lambda = .814, *F* (5, 137) = 6.25, *p* < .001. The multivariate eta-squared was relatively small at .19. Table 10 contains the means and the standard deviations on the burden levels for the two groups. Analysis of variances (ANOVA) on each burden sub-scale were conducted as follow-up tests to the MANOVA. Using the Bonferroni method, each ANOVA was tested at the .01 level. The ANOVA on the time-dependence burden was significant, *F* (1,141 = 23.65, *p* < .001, eta-squared = .14. Caregivers looking after the confused elderly reported greater time-burden stress than those caring for the lucid elderly. This outcome accords with the notion that when viewed temporally, caregiving of a confused family member is more of a chronic stressor. The ANOVA on developmental burden was significant, *F* (1,141) = 13.55, *p* < .001, eta-squared = .09. Caregivers looking after the confused elderly reported more developmental burden than those caring for the lucid elderly. The ANOVA on physical burden was significant, *F* (1, 141) = 8.39, *p* =.004, eta-squared = .06. Results indicated that those caring

Table 10

MANOVA to Compare Burden Levels of Caregivers Who Care for the Lucid Elderly versus Those Who Care for the Cognitively Impaired Elderly

	Lucid ($N = 83$)		Cognitively Impaired ($N = 60$)				
CBI	*M*	*SD*	*M*	*SD*	*F* (1,141)	*p*	*Eta*^{2}
Time-dependence burden	8.11	5.21	12.42	5.25	23.65	<.001	.14
Developmental burden	7.54	4.54	10.52	5.07	13.55	<.001	.09
Physical burden	5.25	3.62	7.22	4.47	8.39	.004	.06
Social burden[a]	1.49	1.27	1.13	1.28	2.83	.095	.20
Emotional burden[b]	1.13	1.03	1.16	1.27	.02	.896	.00

Note. CBI = Caregiver Burden Inventory.

[a] Square root of social burden. [b] Square root of emotional burden. The square root was used for the above variables because they were not normally distributed.

for the confused elderly reported experiencing more physical burden than those caring for lucid individuals. Further comparisons using MANOVAS (for social support and POMS) and an ANOVA (for PCI) were made on the lucid versus the cognitively impaired. These analyses yielded no significant group differences.

Comparisons of the respective correlations were conducted to further examine caregivers to the lucid elderly versus those caring for the cognitive impaired (refer to Table 11). Overall, significant differences were typically not found in the magnitude of correlations. However, one statistically significant difference did emerge. Specifically, there was a much stronger correlation between caregiver burden and negative mood for the caregivers for a family member with cognitive impairment versus the caregivers for a family member who is lucid, $z = 1.77$, $p < .04$. This difference reflected a strong correlation between the POMS and caregiver burden found among those providing care to people with cognitive impairment, $r =.61$, p < .001.

Impact of Social Support, Proactive Coping, and Negative Mood in Predicting Burden

A hierarchical regression examined social support, proactive coping, and negative mood as predictors of overall burden after controlling for socio-demographic variables. The relationship of the caregiver (1=spouse, 0=other) and whether the person who was being cared for was lucid or not (1=yes, 0=no) were entered in block 1. Proactive coping, social support and negative mood (POMS) were entered in block 2. Results of the hierarchical linear regression analysis are presented in Table 12. The socio-demographic variables predicted burden. More specifically, the variable reflecting lucid or not was significant ($t = -2.57$, $p < .02$) as was the variable comprised of spouse/not spouse ($t = -3.36$, $p < .01$). Subsequent entry of the second block found that it too was significant and accounted for 38.46% of the additional variance, F change = 17.43, $p < .001$. Social support was not significant, but POMS was significant, thus

Table 11

Respective Correlations Found for Caregivers Who Care for the Lucid Elderly (L)versus Those Who Care for the Cognitively Impaired (CI)

	CBI				PCI				SS				POMS			
	CI	L	z	p	CI	L	z	p	CI	L	z	p	CI	L	z	p
CBI					.12.	-.04.	0.91	0.181	-.11.	-.16	0.289	0.386	.61***	.38**	1.768*	0.039
PCI									.15	-.04	1.096	0.136	-.27*	-.16	-0.672	0.251
SS													-.16	-.05	-0.653	0.257
POMS																

Note. CBI = Caregiver Burden Inventory; PCI = Proactive Coping Inventory; SS = Social Support; POMS = Profile of Mood States; CI = cognitively impaired; L = lucid.

z-test is based on comparing the magnitude of the correlation found with caregivers who take care of the cognitive impaired versus the magnitude of the correlation found with caregivers who do not care for the cognitive impaired.

**p* < .05. ***p* < .01. ****p* < .001.

Table 12

Hierarchical Regression Predicting Overall Burden

Block	Variable	B	SE	β	*t*	*p*
1[a]	Lucid	-9.549	-9.549	-.21	-2.6	.01
	Spouse	-8.449	2.512	-.28	-3.4	.00
2[b]	Lucid	-7.866	3.218	-.18	-2.4	.02
	Spouse	-8.005	2.258	-.27	-3.5	.00
	Social Support	-.203	.195	-.08	-1.0	.30
	Proactive coping	.433	.170	-.19	-2.6	.01
	Negative mood	.300	.044	.50	6.8	.00

[a]Model accounted for 12.4% of the variance in CBI total score (F (2,127) = 8.99, $p < .001$)

[b]Model accounted for 38.4% of the variance in CBI total score (F (5,124) = 15.45, $p < .001$)

greater negative mood uniquely predicted higher levels of burden as expected. The PCI was also significant. However, in this instance, the direction of the beta suggests that those with proactive coping actually had higher burden, which was not expected.

A second hierarchical regression examined social support and proactive coping as predictors of overall mood after controlling for socio-demographic variables. The relationship of the caregiver (1=spouse, 0=other) and whether the person who was being cared for was lucid or not (1=yes, 0=no) were entered in block 1. Proactive coping and social support were entered in block 2. Results of the hierarchical linear regression analysis are presented Table 13. None of the socio-demographic variables predicted mood. Social support and proactive coping added a significant proportion of variance in POMS scores, *F* change = 3.88, $p < .04$. Social support was not statistically significant but proactive coping did predict the POMS and in a direction suggesting that greater proactive coping was associated with less negative mood, as expected. Essentially, beyond the caregiver variables, proactive coping is linked with less negative mood on the POMS (i.e., those with lower proactive coping scores reported more negative mood) while social support is not significant.

Summary of Results

To summarize, the analyses indicated that:

1) The relationship between burden and proactive coping fell short of statistical significance. Similarly, analyses with the social support measures found that total support was not associated significantly with total burned scores. However, total support was associated negatively with social burden. All three types of social support (i.e., emotional, informational, and practical) were associated significantly with lower reported levels of social burden. However, results involving the social

Table 13

Hierarchical Regression Predicting Mood

Block	Variable	B	SE	β	*t*	*p*
1[a]	Lucid	-1.894	6.458	-.02	-.29	.77
	Spouse	-7.412	4.261	-.15	-1.74	.08
2[b]	Lucid	-1.191	6.435	-.02	-.185	.85
	Spouse	-4.588	4.390	-.09	-1.04	.30
	Social Support	-.538	.377	-.12	-1.43	.16
	Proactive coping	-.750	.330	-.20	-2.27	.02

[a] Model accounted for 2.3% of the variance in POMS total score ($F(2,134) = 1.56$, $p = .21$)

[b] Model accounted for 7.7% of the variance in POMS total score ($F(4, 132) = 2.76$, $p = .03$)

support subscales (i.e., emotional, informational, and practical) are each based on measures with a low number of items and, as a result, correlations involving these measures are best interpreted with caution. Developmental burden, physical burden, social burden and emotional burden were positively related with the POMS. Vigour-activity was negatively related. The correlation fell short of significance for time-dependence burden on all components of the POMS with the exception of fatigue-inertia.

2) Proactive coping positively correlated with vigour-activity and negatively correlated with depression-dejection as well as with the POMS total. No correlation was found between proactive coping and social support.

3) Spousal caregivers had greater levels of time-dependence burden and developmental burden than non-spousal caregivers.

4) Caregivers looking after the cognitively impaired elderly reported greater time-dependence burden, developmental burden, and physical burden in comparison to those caring for the lucid elderly. Furthermore, a much stronger correlation between caregiver burden and negative mood was detected for the caregivers of family members with cognitive impairment versus the caregivers of family members who were lucid. This difference reflected a strong correlation between the POMS and caregiver burden found among those providing care to people with cognitive impairment.

5) Variables representing whether a patient being lucid or not as well as whether or not someone was a spousal caregiver were both significant in predicting burden. Although social support was not significant in predicting burden, the POMS was

significant, where greater negative mood uniquely predicted higher levels of burden as expected. The PCI was also significant, however, in this instance it was not expected as this indicates that those with high proactive coping scores had higher burden. This maybe a result of a suppressor effect or because the most appropriate form of coping was not utilized.

6) Neither level of confusion (i.e., whether or not a patient is confused) nor relationship of caregiver (i.e., whether or not someone was a spousal caregiver) predicted mood. Social support and proactive coping added a significant proportion of variance in POMS scores. Social support was not significant but proactive coping did predict the POMS, suggesting that greater proactive coping was associated with less negative mood as expected.

Results from Stress Survey and Open-Ended Responses

Qualitative analyses were also performed to complement the quantitative findings. The open-ended component of this study was conducted to get a better understanding of the specific nature and causes of the stress these caregivers experienced. Given the uniqueness of this caregiving population (i.e., caregivers to relatives who reside outside of the home), the goal was to obtain a comprehensive overview of their specific stresses. Having these caregivers rank their stressors made it easy to identify which stressors were the most problematic for these participants. The top four ranked stressors included the physical and/or mental change in their relative, feelings of guilt, the change in relationship with their loved ones, and the pressure of having to respond to caregiving demands. It is not surprising that the top stressor reported was the physical and/or mental change in their relative. As was mentioned earlier, there is additional burden for caregivers who look after relatives with cognitive impairment. These results attest to the burden and distress inherent in the caregiver role and provide insights into which caregivers are more likely to experience burden and distress.

Questions number 25 and 26 in part C comprised of the qualitative portion of the questionnaire. Although 154 participants were in this study, not all participants completed these two questions (refer to Table 14). In total, 136 participants completed question 25, that asked respondents to rank their stresses, and 108 individuals completed question 26, providing an explanation as to why the item they ranked as most stressful causes her so much stress. The 10 potential stressors listed were selected based on stressors outlined in the caregiving literature, feedback from the staff working with these patients and their relatives, and finally input from the caregivers themselves. Each of the 10 items are summarized below, providing explicit details and examples of participants' responses. Refer to Table 14 to see the frequencies of each of the ranked items.

O'Donnor and Gibsons's (2003) step-by-step guide to qualitative data analysis was implemented. The first step involved organizing the collected data (O'Donnor & Gibson, 2003). All responses were thoroughly read and examined in order to obtain a genuine feeling of what was expressed by the participants. Following, the data was organized in a way that made it relatively easy for concepts, ideas and themes to be identified (O'Donnor & Gibson, 2003). The goal was to relate different ideas and themes to one another where similar information was grouped into categories.

Once response categories were established, the focus was to build over-arching themes in the data (O'Donnor & Gibson, 2003). Each response category had one or more associated themes that gave a deeper meaning to the data. Different categories were then collapsed under one main over-arching theme. Lastly, all data associated with each of the newly derived themes were

Table 14

Qualitative Data Frequencies

Frequencies of item ranked as most stressful (Question 25)

	N=136	*%*
Physical and/or mental change in your relative as a result of illness	68	50.0
Feelings of guilt	14	10.3
Change in your relationship with your loved one	13	9.6
The pressure of having to respond to caregiving demands	10	7.4
No one is available to assist with caregiving responsibilities	9	6.6
No longer able to engage in activities/hobbies previously enjoyed	7	5.1
The pressure of conflicting demands from others	7	5.1
Change in your social life	5	3.7
You no longer have time for yourself	2	1.5
No one understands what you are experiencing	1	0.7

Frequencies of responses explaining why item selected was most stressful (Question 26)

	N=108	*%*
Physical/mental change in relative	50	46.3
Feelings of guilt	12	11.1
Pressure of Conflicting demands	10	9.3
Change in relationship with your loved one	10	9.3
No one available to assist with caregiving responsibilities	8	7.4
No longer able to engage in activities/hobbies once enjoyed	7	6.5
The pressure of having to respond to caregiving demands	6	5.6
Change in your social life	4	3.7
You no longer have time to yourself	1	0.9
No one understands what you are experiencing	0	0.0

analyzed for patterns and similarities. For some of the items, sub-categories were devised in order to narrow the focus and provide a more specific cause of the stressor. The data was further assessed for any potential outliers from the patterns, none of which were identified.

Below is a description of the findings associated with each of the individual stressor categories. Among these individual categories, several overarching themes were identified. They include: mourning for the relationship the caregivers once had, the pressure of conflicting demands, guilt over putting a loved one in an institution as well as not visiting enough, and the lack of social support given to the caregiver. These will be touched upon below within each of the individual stressor categories.

(1) ***Physical and Mental Change in Care-Receiver:*** The greatest reported cause of caregiver stress was physical and mental change in caregivers' relatives. Fifty individuals (46.3%) selected this as being their greatest source of caregiver stress. Within the various responses, four primary themes were established: caregiver lacks control over the situation; care-receiver was different from the person they once knew; care-receiver is now helpless and lacks independence; and the physical/mental decline in the care-receiver. One individual described the stress they experienced from not being able to control the situation by stating that, "It is frustrating not being able to find and/or give a band-aid solution to the problem." Similarly, another said, "[I] cannot bear to see [my husband] suffer and not be able to help him." A third caregiver stated, "changes are not under my control nor predictable-[I] cannot prepare for what may occur each day."

Many participants described their primary stress resulting from the fact that their loved ones are not the persons they once knew. One individual expressed that she experiences so much stress because her husband "can't be the person I've always known." Another subject said she misses her “real dad.” Similarly, a daughter caregiver said it is very upsetting when the child becomes the parent and the parent the child.

Several respondents indicated that their relative’s helplessness caused them to experience stress. One individual wrote, “The sight of the individual having lost his ability to participate and control his own life is very sorrowful”. Another caregiver said, “My father was very independent all of his life and suddenly became paralyzed from the waist down. A third participant expressed a similar view by stating that she was most stressed by the fact that her and her family had to “watch a vital, intelligent take control person become dependent.”

Many individuals expressed that a predominant source of stress for them was the decline in their relative’s health status. One person said, “he is my husband of 60 years. It bothers me to see him falling apart.” Similarly, another individual indicated that she was highly stressed as a result of the “unfairness of life for my husband, who always exercised, walked, watched his weight and lived a moderate lifestyle, and now must deal with a slow breakdown of his health.” A third participant said she feels “sadness at seeing my husband deteriorate physically and then mentally, and witnessing his suffering.” Many of the statements written above indicate a sense of helplessness in being able to make their loved ones better. They also suggest the mourning and loss of the people these caregivers once knew.

(2) Feelings of Guilt: The second greatest source of caregiver stress following the physical and mental change in one’s loved one was feelings of guilt. Twelve individuals (11.1%) selected this as being their greatest source of caregiver stress. After examining all of the responses, two common themes were established: relative was living in an institution; and not spending enough time visiting with their relative.

Many responses associated with feelings of guilt focused on the fact that the caregiver’s relative was living in an institution. One woman indicated this by stating “John agreed to go to Sunnybrook Hospital. But [he] wants to come home so badly and this causes me great stress. I cry constantly.” Another spouse said, “You have spent many years building a home for your retiring years and all of a sudden they can no longer enjoy it. You have a nice home to live in. They are sharing a room in a hospital.” A daughter caregiver described similar feelings when discussing her situation in caring for her mother by saying: “I promised my mother never to place her in a nursing home-this was her object[sic] fear.”

Several participants expressed feelings of guilt associated with not spending enough time with their relative. One caregiver said: “I feel guilty that I don’t spend more time with my husband and that I can’t do more for him.” Similarly, another caregiver said: “I should do more and visit more.” It appears as though these caregivers are struggling with feelings of abandonment by placing their loved ones in an institution, which in turn has caused them to experience guilty feelings. These caregivers also appear to experience guilt over not spending enough time with their loved ones. The theme of guilt will be discussed in greater detail in the discussion section.

(3) Pressure of Conflicting Demands: Ten individuals (9.3%) selected “the pressure of conflicting demands from others” as causing them the most stress. Three common themes associated with conflicting demands were described: conflicting demands with tasks, conflicting demands with relationships and conflicting demands with personal desires.

Several individuals indicated that they feel extreme pressure from having to plan out their schedules so that they are able to cater to all of their responsibilities. One woman stated: “[in addition to her father] I also look after [my]elderly mother who lives on [her]own. My brother helps very little. I have to work as well and fit it all in.” Another caregiver expressed similar feelings of pressure by saying: “I feel I should give as much time as possible to my elderly parents and yet I have other responsibilities and relationships. It makes me feel like an octopus being pulled in many directions.”

Several people who saw this as causing them the most stress said it was because their caregiving responsibilities prevented them from being able to engage with individuals other than the care-receiver. One woman wrote, “My immediate family needs my attention too even though they usually understand the conflicting demands.” Another spousal caregiver wrote, “I would like to be able to see my children who live out of town and feel very tied down.” A third caregiver expressed similar feelings by saying, “My plate is too full now- I cannot spend time with my grandchildren which I deeply resent.” This pressure of conflicting demands will be discussed in greater detail in the discussion section.

(4) Change in Relationship: Ten participants (9.3%) selected the change in their relationship with their loved one as being the most stressful item. After reviewing responses, it was found that individuals who selected this item did so because they were stressed as a result of the role change that took place in their relationship with their loved one. A daughter of a resident deeply expressed how her relationship has changed with her father by saying, “My dad is no longer the dad I grew up with and knew. He is like a child now not a parent.” Many other caregivers expressed similar views with regards to their husbands. One woman said, “I have become more of a parent than a spouse and cannot share feelings and responsibilities.” A third spouse expressed that she has become her husband’s mother. These responses indicate a sense of mourning and loss for the relatives they once knew.

(5) Lack of Assistance with Caregiving Responsibilities: Eight individuals (7.4%) indicated that they were most stressed by the fact that there was a lack of assistance in carrying out caregiving responsibilities. After reviewing their responses, two themes were established: others are not available, or alternatively, others are available but are unwilling to help. It appears as though these caregivers do not feel like they are receiving any type of social support.

One woman indicated that being a sole caregiver is very difficult. She said, "There is no respite because of being the only one here available." Another woman expressed a similar feeling by stating that she has sole responsibility. A third caregiver said she supposes if she were younger it wouldn't seem so stressful. One caregiver expressed her stress with the unwillingness of others to help by stating, "There are other relatives that could help out by just visiting once in a while but they don't."

(6) No Longer Able to Engage in Activities/Hobbies: Seven individuals (6.5%) indicated that they were most stressed by the fact that they were no longer able to engage in activities/hobbies once enjoyed. Three themes associated with this option include: being unable to do things with their relative; caregiving leaves little time to do other things; and their lives now revolve around their relative. All three themes indicate the pressure of competing demands.

One spouse described the fact that she and her husband are no longer able to do things together by stating, "We are no longer able to enjoy physical activities-lawn bowling, square dancing, traveling, theatre, and restaurant dining." Another spouse expressed a similar view by saying that her husband is confined to a wheelchair and as a result, they are no longer able to attend shows, drive to visit friends, be physically active or engage in bridge games.

One spouse expressed her stress was related to no longer being able to engage in hobbies. She said, "Visiting the hospital 6 or 7 times a week leaves me little time for other things." Several individuals expressed the view that their life now revolves around their relative. One woman said, “Life is not balanced now.” A daughter who was caring for her father said that, “My life is structured around my father. I can’t go away-I feel guilty.”

(7) Pressure of Having to Respond to Caregiving Demands: Six (5.6%) individuals selected the “pressure of having to respond to caregiving demands” as their most stressful option. Responses indicated that this option was the most stressful for them because they found their relative hard to please. One spouse indicated that at times, her husband is hard to please or help. Another individual expressed a similar view about her mother by stating, “My mother is incredibly demanding and hard to please. Her cognitive problems make this worse than ever.”

(8) Change in Social Life: Four participants (3.6%) felt that the change in their social life was the most stressful. One spouse said that the change in her social life caused her a great deal of stress because prior to her husband getting sick, she used to serve on several committees, which included church meetings. Because she now spends most of her time visiting her husband, she no longer has time for these committees. Consequently, she misses out on the social component associated with them. Another spouse indicated that she is stressed by the fact that she needs male companionship, which her husband is no longer able to provide. A third spouse said she misses going out as a couple. These statements also reflect a sense of mourning and loss for the relationships they once had.

(9) No Longer Have Time for Self: Finally, one individual (0.9%) selected the fact that they “no longer have time for themselves” as their greatest source of caregiver stress. The individual who selected this item as her greatest source of stress indicated that it was because she was limited in the number of outdoor and social activities that she was able to engage in.

(10) No One Understands What You Are Experiencing: None of the participants selected this option as their greatest source of caregiver stress.

As was demonstrated above, several overarching themes were identified after reviewing the individual stressor categories. To summarize, the experience of mourning and loss of the relationship the caregivers once had with their loved ones was commonly identified by many of the caregivers throughout several of the stressor categories. A second theme that was often noted was the pressure associated with conflicting demands, whether they be conflicting tasks or relationship obligations. Guilt over placing a loved one in an institution as well as not visiting enough were two other common themes identified by the caregivers. Lastly, some of the participants described a lack of social support, whether it be emotional support or physical support in helping to carry out caregiving tasks.

Discussion

This discussion section begins by reiterating the outcomes of the present study and how they relate to the stated hypotheses. First, however, focus will be given to the nature of the sample and how it is characterized according to the descriptive results. Next, a discussion on types of caregivers is provided, where the effect of relatedness of caregiver to care recipient (i.e., spousal caregiver versus others) is examined. Additionally, attention is given to the experience of those caregivers looking after family members with cognitive impairment versus those who care for the lucid elderly. Insights obtained from open-ended responses are then reviewed, followed by a discussion of the limitations as well as contributions of the current study. Lastly, this section concludes with an overview of potentially meaningful directions for future research.

Descriptive Information

The current research was based on a sample of participants who varied substantially in age. The mean age of the caregiver participants was 67.25 years. Examination of the age distribution indicated that 52 participants were 78 years of age or older. The model length of caregiving was 2 to 5 years. Most participants were the primary caregiver but were not the sole caregiver. Most participants had little or no paid help. The two main caregiver categories were wife (51.9%) and daughter (28.6%). The modal amount of visiting was 3-4 visits per week, but 30 caregivers reported visiting every single day.

Descriptive analyses of mean scores indicated that most means were in keeping with existing norms. However, the mean level of caregiver burden reported in this sample was considerably higher than the mean level of burden reported originally by Novak and Guest (1989). The CBI mean found in the current sample falls in the 24-36 score category, which according to De Fazio et al. (2015) reflects the need to seek some form of respite care. Scores of 37 and above signify risk of burnout. Secondary analysis indicated that 56 individuals (36.4%) had a CBI score of 37 or higher, so it can be inferred that at least 1 in 3 participants were at risk for burnout.

Substantive Findings

The results of this study yielded some unique insights into the effects of caregiver burden and the institutionalized elderly. A primary focus of this investigation was to examine the association that caregiver burden had with proactive coping, social support, and mood states in a sample of caregivers. Differences in the nature of the caregiver role were also examined. Specifically, comparisons were made of the burden levels of spousal caregivers versus non-spousal caregivers as well as the lucidity of the care-receiver and how that impacted the burden scores of the caregiver. The outcomes of the present study and how they relate to the hypotheses, are discussed below.

In order to address the outcomes of this study, it is first helpful to reiterate the hypotheses and their associated outcomes. The first hypothesis was that those with higher burden scores would have lower proactive coping scores. However, in contrast to expectations, the relationship between burden and proactive coping fell short of statistical significance. While this was not anticipated, this was a unique issue that was tested.

The results yielded some evidence in keeping with the hypothesis that individuals experiencing more burden would have lower levels of social support. Total scores on burden and social support were not significantly associated. Social burden was negatively correlated with overall social support, with the strongest associations evident between social burden and lower levels of emotional and practical support. However, as noted earlier, results involving specific types of support are best interpreted with caution due to the low number of items reflecting the various types of support. Nevertheless, other analyses indicated that developmental burden was negatively correlated with emotional support, indicating the more emotional support the caregiver received, the less developmental burden she experienced. As discussed below, developmental burden was also linked with negative mood states.

It was also anticipated that caregivers with higher burden scores would have more negative mood states. Analyses indicated that developmental burden, physical burden, social burden, and emotional burden were all associated broadly and significantly with negative mood states. When the focus was on the total sample, as can be seen in Table 6, the strongest associations were found between the negative mood states and scores on the physical burden and developmental burden subscales. The link between depressed mood and developmental burden seems quite understandable given the nature of the caregiving situation as reflected in the open-ended responses and what is meant by developmental burden. This subscale has items that capture such themes as feelings of missing out, wishing for an escape, being emotionally drained, and expecting life to be different.

Further inspection of burden subscale scores indicated that the correlations fell short of statistical significance for time-dependence burden on all POMS components with the exception of fatigue-inertia, which was positively correlated with time-dependence burden. The more time-dependence burden one experienced, the more tired she typically was. Thus, it can be said that (with the exception of vigour-activity), the more burden one experienced, the more negative her mood states were.

Other analyses indicated that vigour-activity was associated negatively with caregiver burden. The negative correlation between vigour-activity and various CBI subscales (i.e., developmental burden, physical burden, and emotional burden) showed that the more burden one experienced, the less vigour-activity was reported.

A related hypothesis was that caregivers who were proactive in their coping approach would experience more positive affect and less negative affect. Findings revealed that proactive coping was positively correlated with vigour-activity and negatively correlated with depression-dejection and with the POMS total. This finding extends past research with other types of participants (e.g., Greenglass & Fiksenbaum, 2009; Katter & Greenglass, 2013) by showing that proactive coping and emotional reactions are associated among caregivers. By planning ahead, caregivers who tend to be more proactive may be able to minimize feelings of being overwhelmed and inundated with their caregiving responsibilities. However, it is important to caution here that causal associations cannot be inferred from correlational evidence.

Conversely, those caregivers who implemented fewer proactive coping tactics tended to report more depression. This is in keeping with the feeling of being overtaken by the caregiver role and how much of the stress and distress is rooted in the emotional reactivity to daily events that are often unforeseeable (see van Knippenberg et al., 2018). If one has many caregiving tasks to oversee at once it can become very exhausting and draining and thus lead to feelings of depression-dejection. As suggested above, the current results extend what is known about proactive coping in more general contexts by showing its relevance within the caregiving realm. However, while this study established links between proactive coping and mood states, the overall magnitude of the obtained associations was moderate and this likely reflects the many potentially relevant factors that can impact mood state.

It was further hypothesized that caregivers who have more social support would likely be more proactive copers. However, proactive coping and social support were not significantly associated in the current study.

Regarding social support, the quantitative findings showed that social support was associated with burden, but the degree of the association varied across the various dimensions of social support and burden. The strongest associations were found between social burden and lower levels of emotional support and practical support. This link between social burden and lower social support may reflect an insidious element of needing to assume a caregiving role. Excessive engagement may alienate other people and push them away at a time when their support is especially needed by the caregiver. It would be interesting in future research to focus not only on a paucity of social support, but also the destructive experience of negative social interactions and experiences of others who grow resentful and add to the stress experienced by caregiving.

Social support may help ameliorate feelings of caregiver burden as well as contribute to better coping, but not all caregivers have access to a support system, as was the case for certain participants in this study. There are many reasons why some participants experience relatively little to no support or perceive this to be the case. First, among older individuals, it is possible that various friends and family members who would typically be the providers of such support are deceased or are unwell themselves, causing these caregivers to lack the necessary social support. Another potential reason for the absence of support is that that caregivers' children are preoccupied with families of their own in addition to demanding jobs. A low level of support may also be due to the fact that relatives and friends do not live in the same city as the caregiver. Several caregivers reported that their children lived out of town and were thus not in regular contact. Clearly, the complexities inherent in individual lives and life circumstances serve as a reminder of the heterogeneity that exists even among caregivers who share a common theme (e.g., taking care of a cognitively confused spouse). This is important to keep in mind when considering the next segment which examines the results for various caregiver types.

Types of Caregivers

Comparisons highlighted the need to consider differences in the situations and challenges facing caregivers. When examining the effect of the relationship of the caregiver to care recipient (i.e., spousal caregiver versus other) on the five CBI subscales (time-dependence burden, developmental burden, physical burden, social burden and emotional burden), significant differences were found between spousal and non-spousal caregivers. Analyses indicated that the spousal caregiver group reported greater developmental burden than did their non-spousal caregiving counterparts. The difference obtained here illustrates the need to take into account the nature of the relationship that exists between the person giving and the person receiving care. Because a spousal caregiver has a greater degree of emotional investment in providing care in addition to a more intense relationship with the care-receiver, it is expected that spousal caregivers would experience more burden than their non-spousal counterparts. Furthermore, because spousal caregivers tend to spend more time providing care (both in the number of hours and in the number of days a week), it likely underscores the comparatively higher level of caregiver burden, relative to the level of burden reported by nonspousal caregivers.

Although most caregivers in this study were spouses, it is essential to recognize that not all primary caregivers fall into this category. Non-spousal caregivers-particularly adult children, should be recognized as a distinct group within caregiver support programs. As was demonstrated in this research, they often experience substantial emotional and social burdens due to role conflict, guilt, and the competing demands of caregiving, employment, and family responsibilities, including raising children and supporting spouses. To address these challenges, access to financial assistance, respite care, and therapeutic and educational programming-particularly within the workplace-should be expanded to reflect their unique needs.

Although existing Canadian policies, such as Employment Insurance (EI) caregiving benefits (Government of Canada, 2025a) and the Canada Caregiver Credit (Government of Canada, 2025b), acknowledge the contributions of nonspousal caregivers, recognition alone is not enough. These individuals require coordinated and accessible formal supports to manage their responsibilities effectively. For example, adult child caregivers would likely benefit from greater workplace flexibility, including remote work options, negotiable hours, and regular check-ins from supervisors, all of which could likely help alleviate their burden. Additionally, support groups tailored to nonspousal caregivers that offer practical tools for time management, emotional regulation, and goal setting-could also likely help them maintain personal well-being and greater overall balance in their daily lives.

Significant differences in levels of caregiver burden were also found when comparing the reports of participants who did or who did not have family members who were experiencing cognitive issues. A strong correlation was found between caregiver burden and negative mood (i.e., POMS) for caregivers for family members with cognitive impairment versus caregivers for family members who are lucid. This significant outcome appears to coincide with limited literature related to this possibility. It is important to note that a large portion of research to date focusing on burden of AD caregivers compares the burden levels of these individuals with non-caregivers. Nevertheless, Beatie's (2021) research investigation (discussed earlier in the introduction) compared anxiety and burden levels of dementia caregivers with those caregivers looking after MCI relatives. More specifically, this researcher demonstrated that there were clinically significant differences in anxiety and caregiver burden; that is, dementia caregivers endorsed more clinically significant anxiety and caregiver burden than those who were caregivers to individuals with MCI. This researcher attributes these differences to care recipient depression and behaviour problems, but not memory deficits (i.e., because memory deficits are an obvious symptom and thus are expected and tolerated better).

As noted earlier, research conducted by Leinonen et al. (2001) showed that the burden of spouses with a person suffering from dementia was higher than that of the group of depressive patients' spouses. Similarly, also as discussed earlier, Karlin and Bromley (1996) reported that caregivers of AD relatives differed from caregivers of lucid chronically ill family members in the level of expressed emotional burden and in the amount of revealed fatigue/inertia.

Caregivers looking after the confused elderly, relative to those caregivers caring for lucid elderly people, reported greater time-dependence burden, developmental burden, and physical burden. These findings reflect the reality that there are unique aspects to the caregiving role based on individual situations and circumstances, depending on whether one is caring for someone who suffers from cognitive impairment versus someone who does not. A study conducted by Sung et al. (2021) identified four types of caregiving experiences among caregivers in Singapore, namely, balanced, satisfied, intense and dissatisfied. Results from this study found that in comparison to caregivers with balanced and satisfied experiences, those with dissatisfied and intensive caregiving experiences had greater burden levels. There are myriad factors that likely underscore this difference. The person trying to provide care and comfort to a family member with cognitive impairment will be faced constantly with reminders that this person is no longer who they used to be and may not even recognize or remember the caregiver. These family members are also likely higher in dependency and less able to express gratitude for the care they receive.

Returning to the current study, a statistical analysis was performed to evaluate whether the various predictor variables of proactive coping, social support and mood could predict burden beyond the variance accounted for by caregiver status and cognitive functioning of the care receiver. Although it may appear as though this was an instance of statistically controlling for differences among respondents in this study, the outcomes have shown that these predictors are useful beyond these broad distinctions and apply to the literature at large.

Findings revealed that variables reflecting whether a care-receiver being lucid or not as well as whether or not someone was a spousal caregiver were both significant in predicting burden. Although social support was not significant in predicting burden, the POMS was significant, where greater negative mood predicted higher levels of burden after taking into consideration the caregiver relationship and the cognitive status of the person receiving care. This finding indicates that any model predicting caregiver burden should also include current mood states. It is likely that they impact each other and for this reason no causal assumption is warranted.

The regression analysis also showed that the PCI was a significant predictor but the result was unanticipated. That is, participants with higher proactive coping scores had higher burden. These results may reflect the presence of a suppressor effect. According to Martinez-Gutierrez and Cribbie (2021), suppressors are third variables that increase the predictive power of one or more predictors by suppressing their irrelevant variance when included in a regression model. Essentially, suppressors unmask relationships between predictor(s) and outcomes, increasing each suppressed variable's predictive power. Lancaster (1999) defines a suppressor variable as a predictor that has zero correlation with the dependent variable while still contributing to the predictive validity of the test battery.

Another potential reason for this outcome is substantive rather than statistical. The possibility exists that some caregivers are actually increasing their stress levels by needing to and trying to employ proactive coping tactics in this caregiving situation, but their efforts are not paying off (e.g., putting a protective measure in place for a family member who then subsequently refuses it). One interpretation of this pattern of results is that the controllability of the context and the desired outcomes needs to be given considerable weight. As is described by Forsythe and Compass (1987), coping effectiveness is dependent on the match or goodness of fit between coping efforts and other variables in the stress and coping process, such as the controllability of events. Coping strategies appear to differ for events appraised as controllable versus those that are deemed uncontrollable. These researchers went on to say that implementing a coping tactic that is not considered a good fit with a particular stressor (based on whether or not a stressor is controllable), may in fact cause an increase in stress as opposed to a decrease. When one does not have control over their situation, which is the case with these caregivers who lack full control over the provision of care for their loved ones because they are in a facility, certain kinds of coping tactics are more effective than others in reducing stress. According to Forsythe and Compass (1987), when an individual lacks control over their situation, it is more effective to employ emotion focused coping versus coping tactics which focus on the problem itself. Having said that, in this situation where individuals lack control over the provision of care to their loved ones, the use of proactive coping could, in fact, be a hindrance or a significant source of frustration and related feelings of distress.

When the coping results are considered as a whole, there were some results that emerged from the analyses involving the PCI, but generally it was the case that associations were either not robust or negligible. This could be interpreted as evidence that individual differences in coping are simply not that relevant when it comes to the caregiver experience, but this conclusion does not jibe with what was learned from the open-ended responses, which are discussed below. Perhaps an alternative approach to individual differences in coping is needed. Most work, including the current study, examines individual differences in the ways of coping or the styles of coping. There is likely much to be learned from an alternative perspective that focuses on whether the caregiver is someone who is engaged in coping or is someone who does not seem to be coping at all or at least not very much. When the caregiver burden and life situations of some people seem to be overwhelming, perhaps it is more meaningful to focus on who is trying to cope versus who is feeling helpless and hopeless and has given up because the sense of burden and burnout is just too much.

A first step in taking this approach to coping is to ascertain how many caregivers reach the point of seemingly giving up. A related focus is to directly assess how caregivers perceive their effectiveness and their own level of functioning in their roles. Fortunately, some Canadian data suggest that the number of these people who are not doing well and who might give up is not extensive, at least in terms of the proportion of caregivers. However, this becomes a bigger issue when the number of caregivers across Canada are considered. National survey data gathered in 2007 from over two million caregivers (family members or friends) aged 45 and over indicated that 4% said they were not doing very well or not well at all. Another 42% said they were generally managing, while the remaining 54% said they were coping very well (see Cranwick & Dosman 2008).

Insights Obtained from the Open-Ended Responses

As described earlier, this research also involved obtaining open-ended responses. Recall that participants were given a list of 10 items and were asked to rank them in terms of stress, with "10" being the most stressful and "1" being the least. Following, caregivers were asked to elaborate and explain why the item they ranked as "10" caused them the most stress in comparison to the other items listed. All of the responses were organized according to common concepts, ideas, and themes. Similar content was grouped into response categories in order to produce over-arching themes in the data. Patterns and similarities within the associated data were identified in order to establish findings.

Some of the overarching themes that emerged were mourning for the relationship the caregivers once had, the pressure of conflicting demands, guilt over putting a loved one in an institution and not visiting enough, and the lack of social support given to the caregiver. Greater attention will be given to the central themes of guilt and pressure. They will be discussed in detail below. First, however, it is worth noting that the social support findings from these open-ended questions coincided with the quantitative results, which revealed that burden was negatively correlated with social support. Caregivers who felt like they did not have support listed the lack of emotional and physical support as one of their sources of caregiver stress. They felt stressed by the fact that others were not available to help or that others were not willing to help.

As mentioned above, two key themes-namely guilt and pressure-were highlighted by participants in their open-ended responses. With regards to guilt, many caregivers in this study expressed feelings of guilt over placing their loved ones in an institution. According to Davis et al. (2017), guilt is a core feature of AD caregivers' experiences following placement. These caregivers also expressed feelings of guilt as a result of not visiting with their relative often enough or not attending to their needs as well or as often as they should be. One spousal caregiver expressed this by stating that she feels guilty that she doesn't spend enough time with her husband and that she cannot do more for him. Another spouse stated that she had feelings of guilt over having to put her husband in a nursing home which he cannot leave.

The salience of guilt among these caregivers is in keeping with previous results. For instance, Gonyea et al. (2008) analyzed guilt by rating answers to an open-ended question posed to 66 caregivers of elderly relatives ("Some women tell us that they feel guilty about their caregiving: how guilty would you say you feel about it?"). These authors found that guilt was positively correlated with burden and that it accounted for a significant amount of the variance in the caregiver's sense of burden. These researchers stressed the importance of clinicians to help guilt-ridden caregivers revise their evaluative standards and engage in self-forgiveness and self-acceptance (Gonyea et al., 2008).

Guilt has also been analyzed in informal caregivers of patients suffering from AD and/or related disorders as one of the components of burden by researchers (see Ankri et al., 2005). One finding that emerged from this earlier study is that guilt and fear of inadequacy increased with the severity of illness and with signs of poor quality psychological life of their relative, such as sadness, depression or aggressiveness.

Clearly, it is important to address feelings of guilt when considering interventions for caregivers and helping them to acknowledge and manage these feelings as a way of reducing their stress/burden (Losada, 2010). In this regard, reductions in feelings of guilt could come from helping caregivers to adjust their expectations and standards in relation to their obligations and capacities, to accept their limitations and weaknesses, and to acknowledge their needs (see Losada, 2010).

It was of interest to determine whether there was a difference in CBI and POMS (i.e., negative mood) scores between those who ranked guilt as their first or second greatest cause of caregiver stress versus those who did not. In order to assess this, it was necessary to go back and review all of the questionnaires to see who selected guilt as their second greatest cause of caregiver stress (i.e., those who ranked it a 9) and combine these participants with those who ranked guilt as their number one stressor (i.e., those who ranked it a 10). Collectively, this group consists of 26 individuals out of 136 (14 who selected it as their greatest stressor and 12 who selected it as their second greatest stressor). It made the most sense to only include those who selected guilt as their first or second greatest stressor (and not consider additional rankings) as very few indicated that it was their third greatest source of caregiver stress. A series of independent samples t-tests was performed comparing mean scores on overall negative mood and burden as well as each of the subscales of individuals who ranked guilt as the greatest or second greatest cause of caregiver stress and individuals who did not. Because no significant differences between the two groups were found, there was no further examination.

Nevertheless, this study has underscored the central role of guilt in the caregiving experience. Given its emotional intensity and complexity, it is important to consider how guilt may have influenced key psychosocial variables-most notably, the seeking and reception of social support. Specifically, caregivers' feelings of guilt may have shaped both their willingness to seek assistance and their capacity to recognize or accept support when it was offered.

Caregivers experiencing heightened guilt-particularly guilt resulting from feelings of inadequacy, resentment, or ambivalence-may internalize caregiving as a moral responsibility or obligation. With this mindset, seeking help can be perceived as a personal failure or a violation of one's caregiving duties, resulting in a strong reluctance to request or accept assistance. These caregivers may feel undeserving of support or they may worry that asking for help would burden others or indicate shortcomings in their caregiving performance. Furthermore, guilt may distort how support is perceived and interpreted. Emotional support through expressions of reassurance or validation may be misinterpreted as pity, while offers of instrumental support-such as help with caregiving tasks or social visits-may be viewed as intrusive or implicitly critical. These distorted appraisals can inhibit both the initiation of support-seeking behaviours and the emotional benefits typically associated with receiving such support. As a result, caregivers experiencing elevated guilt may report lower levels of perceived or effective support, even when tangible assistance is readily available and explicitly offered.

This dynamic may help explain findings in the present study in which the availability of support did not consistently correspond with reductions in caregiver burden or stress. Taken together, these findings suggest that guilt may diminish the protective effects of social support, thereby influencing the relationship between caregiver stress and psychological outcomes. These insights illustrate the importance of considering variables such as guilt, when designing interventions aimed at improving support utilization as well as promoting overall caregiver well-being.

Pressure was another recurring theme identified by many participants in this study. Pressure and how it relates to caregiver burden will be addressed below. First it is important to establish a definition of pressure. Weiten (1988; 1998) defined pressure as the perception of expectations and demands that one behave in a certain manner. Two subtypes are differentiated: (a) pressure to perform various tasks and responsibilities successfully and efficiently, and (b) pressure to conform to others' expectations about how one ought to act and think (Weiten, 1988; 1998). Pressure may also come in the form of a self-imposed pressure that is internal rather than external (Weiten, 1988; 1998). Pressure is assumed to be a relatively mild form of everyday stress.

Based on their open-ended responses, the participants in the current study expressed feelings of pressure not only in meeting their caregiving demands but also as a result of conflicting demands from others. For example, one caregiver stated that it is difficult to juggle her own schedule with multiple responsibilities. A daughter of one of the care-receivers said she experienced immense pressure to meet all of her mother's demands, which were becoming increasingly consuming as her mother's cognitive impairment worsened. Another participant described her feelings of pressure by stating that she feels like she should give as much time as possible to her elderly parents yet she has other responsibilities and relationships. She went on to say that she feels like an octopus being pulled in many directions. Lastly, a spousal caregiver said that her plate is too full now and as a result she cannot spend time with her grandchildren which she deeply resents.

Even though pressure and how it relates to burden has shown to be meaningful within this study, pressure has been given little attention by researchers investigating the dynamics of stress. Weiten (1988; 1998) is one of the few researchers who has conducted pressure research in order to demonstrate its importance as a type of stress, that of which differs from typical stress research focusing on change and major life events. The current findings suggest that the pressures experienced by caregivers represent an important context for future research on pressure and its impact. In this instance, it was as if the pressure could have stemmed from a sense of obligation rooted in societal expectations that could not be avoided and offered little satisfaction or sense of reward.

Certain responses provided by the caregivers in this investigation suggest that perfectionistic caregivers may be especially susceptible to feeling burdened and becoming burned out; perfectionists tend to feel overly responsible for outcomes and many of them experience socially prescribed perfectionism, which involves needing to live up to impossible expectations and demands (see Hewitt & Flett, 1991). These extreme pressures have been linked with greater susceptibility to health and mental health problems (Flett, Hewitt, & Molnar, 2016; Flett, Hewitt, & Nepon, 2016) and interventions such as mindfulness training could potentially offer some relief for caregivers struggling with pressures imposed on them to be perfect (for a discussion, see Flett et al., 2020).

It is important to consider the open-ended and qualitative aspect of this research from a critical perspective. It is entirely conceivable that these results reflect, at least to some degree, the personal perceptions and any biases or preconceptions of the researcher. Of course, this is typically a concern in terms of general biases and preconceptions, but it can also reflect ongoing life events. More specifically, in this instance, at the time this research was being conducted, my father became unwell, and this resulted in me, along with my mother, taking on the caregiver role in order to help oversee his needs. It is for this reason the current study was put on hold for an extended period of time, so that I could focus my attention on my father's care-in addition to addressing the needs of my own immediate family and children. Consequently, it is important to recognize that the author's personal experiences and direct involvement with providing care to her loved one may indeed have impacted the way in which the results were analyzed and the interpretations and conclusions drawn.

It is also quite possible that some key themes were not included in this study. The opportunity to conduct pilot testing in a phased approach would have been useful and further informed the topics that were considered. Nevertheless, some potentially useful insights emerged from this aspect of the research and the original suggestion to consider including this element was clearly well-taken.

In summarizing the findings collectively, the outcomes of this study have provided a greater understanding of the burdens and strains experienced by caregivers of the institutionalized elderly. There were no significant links between caregiver burden factors and proactive coping. It was found that caregiver burden was correlated with social support and most POMS subscales. Significant associations were found between proactive coping and vigour-activity while proactive coping was negatively correlated with depression-dejection as well as with mood states total. Proactive coping and social support were not significantly associated. Spousal caregivers had greater levels of burden (i.e., developmental burden and physical burden) than non-spousal caregivers. Lastly, caregivers looking after the confused elderly experienced greater burden in comparison to those caring for the lucid elderly.

Limitations of the Current Study

Before general conclusions can be deduced from the present study, it is important to acknowledge its limitations. One potential issue is that the terms burden and stress were used interchangeably. Even though this is often practiced within the caregiver literature at large, as was mentioned earlier, other researchers believe it is erroneous to view these terms as equivalent. More specifically, these researchers state that by viewing these variables as synonymous it often results in adopting inappropriate assessments (Grandon et al., 2008). If this study were to be replicated today, separate measures for stress and burden would have been utilized.

Another limitation stems from the use of a correlational design. It is difficult though not impossible to go beyond correlational designs when conducting research with people going through highly stressful life circumstances. However, as with all correlational studies, this study cannot provide conclusive reasons as to why there is a relationship between variables. It can only acknowledge that a relationship between variables exists with no assumption that causal associations have been detected.

One additional limitation is the length of time it took to complete data collection. The SARS outbreak posed as a massive hindrance to my data collection. My questionnaires were literally disposed of once visitors to the hospital were no longer permitted. This caused a very long delay in all aspects of my study. Once the SARS outbreak abated and visitors were allowed back in the hospital, I was granted permission to bring in more questionnaires for distribution. Although considerable time has passed since these data have been collected, the practical challenges and considerations underscore and inform the issues that researchers face at present in terms of trying to conduct research during the Covid-19 pandemic. A key part of learning and development is being able to adapt and become a resilient researcher who tries to proactively address and resolve practical issues in a pragmatic manner.

It is also worth noting that although the procedure and questionnaire was identical for all participants, ideally, I would have used a different participant pool for the qualitative component and gleaned additional insights from the quantitative component. Given the pragmatic circumstances discussed above, I did not have additional access to caregivers or resources. For this reason, I had to use the participant pool available to me.

Also, many caregivers expressed that the questionnaire itself was emotional for them to complete. This emotional aspect may have affected the authenticity of their answers. Lastly, even though I clearly indicated that individuals' answers had absolutely nothing to do with the treatment that their relative/friend would receive, some participants may still have been afraid to honestly express themselves. They may have been more focused (intentionally or unintentionally) on providing socially acceptable answers over honest ones.

This study was based solely on female participants. Because I did not distribute the questionnaires, I am not certain if this is because only female caregivers chose to participate in this study or because there was a lack of male caregivers in this unit of the hospital during the particular time frame that the study ran. Is this really a coincidence though? It must to some degree reflect who is more likely to take on these roles, but probably also who is willing to volunteer. For this reason, specific gender differences were not investigated. Clearly, this would have made for an interesting area of study to further enhance the findings and contributions of this research. The results of the present study are limited to a female population and thus inferences can only be applied to female caregivers of family members or friends residing within an institution. A gender comparison in caregiving experiences would likely have broadened the significance and scope of the findings.

It is also important to acknowledge that several key terms used in this study-most notably *confusion* and *lucid*- were not operationally defined. Similarly, certain response options were not operationally defined, thus perhaps blurring the distinction between sometimes versus moderately, for instance. This lack of definitional clarity raises concerns regarding construct validity. Although caregiver assessment of care recipients' cognitive status was central to the analysis, these terms were neither clearly specified nor systematically quantified. In the absence of standardized definitions, assessments relied on caregiver interpretation, increasing the potential for subjective bias and inconsistent application. If the terms *lucid* and *confused* were understood differently across respondents, then comparisons between caregiver groups (i.e., those caring for confused versus lucid care recipients) may not reflect true cognitive differences but rather perceived differences.

This limitation is important given that core constructs-such as burden, mood, support and coping-are closely linked to the cognitive status of the care recipient. Without clear parameters, it becomes difficult to determine whether reported differences in caregiver outcomes reflect actual cognitive impairment or caregivers' subjective perceptions. For example, although higher caregiver burden was associated with reports of confusion, this correlation may reflect perceived cognitive difficulty rather than objective impairment.

It is likely that the inclusion of a standardized caregiver rated tool, such as the Family Confusion Assessment Method (FAM-CAM; Steis et al., 2012), would have strengthened the methodological foundation. The FAM-CAM is an 11-item questionnaire designed to help caregivers identify and describe changes in their loved one's cognitive functioning. It includes both multiple-choice items and open-ended responses. Using such a tool would have provided an operational framework for defining and assessing confusion, thereby reducing reliance on individual interpretation and enhancing the study's overall methodological rigor, reliability and validity.

Beyond the definitional gaps in cognitive status terminology, several qualitative items may also have lacked sufficient conceptual clarity and operational descriptions. For instance, the item *the pressure of having to respond to caregiving demands* does not specify what constitutes caregiving demands or what is meant by pressure. Given the variability in caregiving experiences, participants may have interpreted the item in highly individualized ways. Furthermore, the item does not clarify whether it targets emotional conflict, time-related burden, physical demands or another dimension of stress, thereby making it difficult to compare responses consistently and meaningfully across participants.

Similarly, the item *feelings of guilt* lacks a clear conceptual framework. Respondents are not provided with a definition of guilt in the caregiving context. This leaves considerable room for subjective interpretation, as guilt can stem from various sources such as resentment toward the care recipient, frustration with uninvolved family members, perceived inadequacy over provision of care, or regret over caregiving decisions such as institutional placement. Without clarification, participants may base their responses on highly personal interpretations, thereby reducing the consistency and comparability of the data.

Another qualitative item with ambiguous phrasing is *no one is available to assist with caregiving responsibilities*. The term *caregiving responsibilities* is not defined, nor is the nature of "assistance." For some, assistance may mean physical help; for others, it may imply emotional support and validation or even respite care through social visits. The lack of specificity makes it difficult to determine what type of support participants perceive they are lacking.

Likewise, the item *no one understands what you are experiencing* is also conceptually vague. It is not clear who “no one” refers to-is it family members, healthcare professionals, or society at large. Additionally, the notion of “understanding” is left undefined.
Does it entail emotional empathy, practical support, verbal affirmation and acknowledgement or the recognition of sacrifices made by the caregiver? Without guidance, respondents may apply personal meanings to this item, thereby restricting comparability across responses.

Furthermore, the open-ended prompt *why does the item you ranked as most stressful cause you so much stress?* lacks structure in guiding participant reflection. Without cues to consider emotional, relational, or practical dimensions of stress, responses may vary substantially in depth, focus, and clarity. One participant might offer a detailed account of emotional distress, another may cite identity loss; while a third participant may respond briefly with “because it is hard.” Such variability in responses jeopardizes thematic cohesion and limits the utility of the data for rigorous qualitative analysis.

Taken together, the above discussion underscores the need for clear operational definitions and structured guidance in both quantitative and qualitative components. Ambiguity in item phrasing and construct definition not only reduces the reliability of item rankings but may also compromise the overall validity and interpretability of the study’s findings.

A final limitation to consider, as noted earlier, the response rate for this study was approximately 18%. Thus, it may reflect only a small proportion of the target population and may not be fully representative. Although the respondents reported moderately elevated burden and mood scores-suggesting that the study captured caregivers experiencing considerable levels of stress, it is possible that those experiencing the highest levels of burden were unable or unwilling to participate in this research perhaps due to limited time, energy or emotional capacity. This raises concern that the most burdened caregivers may be underrepresented, potentially leading to an underestimation of overall burden levels. It is possible that caregivers experiencing extreme strain may have self-excluded, while others may have avoided participation due to feelings of guilt or emotional disengagement from the institutional setting. Furthermore, because this study was conducted post-SARS, some highly burdened individuals may have remained isolated or reluctant to return to the caregiving environment due to lingering fear, likely preventing them from receiving recruitment information and materials. While this potential sampling bias does not diminish the value of the study's findings, it does suggest that the results may most accurately reflect the experiences of caregivers with moderate levels of burden rather than capturing the full spectrum of caregiving experiences.

Contributions of This Study

The findings of this study contribute to the current caregiving literature and our understanding of caregivers in various ways. First, they help reveal why some individuals are more susceptible to experiencing caregiving burden than are others (i.e., based on differences in proactive coping levels, social support levels and mood states). Much of the current caregiving research fails to acknowledge these important individual differences. Rather, the literature tends to just confirm that many caregivers do in fact experience burden without accounting for these significant individual differences. This is an important area of study because it not only helps to identify individuals who may be more susceptible to experiencing burden based on personal factors, but it also contributes to the development of appropriate interventions.

For example, this study demonstrated that caregivers who implemented proactive coping tactics tended to be more vigorous and less depressed. In applying this finding to current caregivers, perhaps they could be educated on how to actively use proactive coping skills to improve their overall well-being. More specifically, by implementing proactive coping ideals right from the very start, caregivers can be taught to view upcoming events as challenges where goals are set and opportunities for growth are created. This may help remove some of the negativity associated with the caregiving role if one's entire view of his/her caregiver role is shifted early on. Furthermore, it may help caregivers build skills that are essential in being able to healthily navigate their caregiving role as well as increase their sense of resiliency towards their caregiving challenges. Caregivers can also be encouraged to anticipate the needs of their relative and work towards fulfilling as many of these needs in advance to reduce feelings of being overwhelmed and depressed by their demanding caregiver role.

As was discussed above, much of the literature on social support and coping discusses the power of social support and how it can help individuals to become better copers. Knowing the valuable connection between social support and coping, caregivers can be encouraged to seek out support from their social networks to help strengthen their coping skills. If it is found that a person lacks a social network, which may have been the case with these participants (i.e., if one is elderly and many friends and relatives have passed away), perhaps the community can create groups where individuals in the same predicament of lacking a social network, can come together to offer and seek out the much needed social support.

Another way in which this study adds to the current literature is by illuminating the specific stresses that individuals who care for the institutionalized elderly experience. This knowledge could be incorporated into revision and adaptations of existing interventions such as the seemingly effective online intervention developed in Canada by Duggleby et al. (2018). To date, to our knowledge, few studies have been conducted that have focused exclusively on caregivers of the institutionalized elderly. It is hoped that the results of this study will help to determine the interventions that are most appropriately suited for this type of population, as it is likely that the needs of these individuals would differ from those who are looking after relatives at home. For example, the second largest cause of stress reported by the participants of this study was feelings of guilt associated with having to place a loved one in a facility. Clearly, this is a unique feeling experienced only by someone who has to go through the stressful experience of having their family member placed in a facility. One participant even mentioned that she promised her mother she would not institutionalize her, but sadly circumstances beyond her daughter's control arose which made it next to impossible for her to honour her mother's wishes (i.e., her level of care exceeded what her daughter was capable of providing at home). Perhaps more widespread implementation of effective psychosocial interventions to reduce caregiver burden and depression prior to the transition to facility placement can ameliorate the symptoms of burden and depression (Gaugler et al., 2010).

Lastly, many studies conducted within the area of caregiving for the elderly have demonstrated that spousal caregivers tend to experience greater levels of burden than non-spousal caregivers; however, little research has been conducted that has examined whether or not this finding holds within an institutional setting. This study addresses this research question by comparing the burden levels of spouses who care for their institutionalized husbands with those of non-spouses caring for the institutionalized elderly. This is an important area of research that is highly lacking, and thus warrants investigation.

Directions for Future Research

Clearly, there are several potentially meaningful directions for future research. It has been established in this research that providing care to the elderly is a global phenomenon that will continue to be increasingly relevant. For this reason, research on caregiver burden of family members is a crucial area of study that should be vastly expanded to include many other facets and perspectives that are relevant to today's caregiving society. For example, future caregiving research could expand the breadth in types of caregivers across sex/gender, ethnic/cultural groups, age, and perhaps the health status of the caregiver. This will help to ensure that this indispensable population of family caregivers is receiving the care that they require in order to be able to effectively carry out this important caregiving role. Ideally, future research will be longitudinal whenever this proves possible. Longitudinal research on caregiver burden has yielded some complex and somewhat counterintuitive findings at times (see Connors et al., 2020), but research of this nature best reflects the long-term process experiences by many caregivers.

Knowing that family caregivers represent a pillar in future care, it is highly relevant to determine how support can be provided to the most burdened caregivers (Steenfeldt et al., 2021). More specifically, it is worth reflecting on how family caregivers can be helped to manage their life situations, accounting for both practical and emotional challenges (Steenfeldt et al., 2021). Perhaps advice and wisdom from past caregivers would help provide current caregivers with essential direction and guidance. This kind of support would also provide validation of thoughts and feelings, both negative and positive, as well as challenges, that are uniquely experienced by caregivers. Hovland and Mallett (2021) conducted qualitative research by interviewing 30 family caregivers of older persons who died of dementia, to gain insight on ways in which these caregivers could effectively help other family caregivers. Suggestions, advice, and recommendations were given to current caregivers based on what these caregivers learned as a result of their caregiver role as well as their experiences as a caregiver. Four main themes were identified that were thought to be helpful for other caregivers: not to do all the caregiving alone and to be receptive to accepting offered help; to practice patience, love and kindness in order to deal with challenges; to make sure caregivers take care of themselves where they prioritize and nurture their own health, other relationships and interests, in order to avoid emotional and physical exhaustion; and lasty, that these caregivers get educated on what to expect as a caregiver, especially if looking after someone with dementia (Hovland & Mallett, 2021). This study demonstrates that if caregivers are given tools such as these from past caregivers, they may find their caregiving role to be less taxing both mentally and physically. Furthermore, such personal advice provides a sense of hope knowing that these suggestions were effective in helping other caregivers successfully navigate their way through their caregiving roles.

One key direction for future research is to explore mattering within the caregiver context. Mattering is a key psychological resource that has the potential to ameliorate caregiver burden and associated mental health and physical health difficulties. Mattering is a term introduced by sociologists Rosenberg and McCullough (1981). These researchers suggest that "mattering is a motive: the feeling that others depend on us, are interested in us, are concerned with our fate, or experience us as an ego-extension exercising a powerful influence on our actions (Rosenberg & McCullough, 1981). Essentially, it reflects our need to feel like we are significant and have meaningful connections with other people (Flett & Zangeneh, 2020). Recent developments in the mattering field have established that mattering is a protective factor that is linked with numerous consequential outcomes at the individual, relationship, and societal levels (see Flett, 2018, 2022). According to Rosenberg and McCullough (1981), the crucial aspects of mattering are: dependence (feeling that we are depended on by others); importance (feeling that another person cares about what we want, think and do); attention (feeling that we are noticed by others) and ego-extension (feeling that others will be proud of our accomplishments or saddened by our failures). Rosenberg (1985) added an additional component to mattering, the feeling that other people would miss us if we were no longer around.

The potential relevance of mattering within the caregiver context is reflected by two key developments in the mattering field. First, Schlossberg (1989) added the component of feeling appreciated by someone. The appreciation component was proposed after Schlossberg (1989) examined the perceptions and experiences of caregivers who tied their sense of mattering to expressions of appreciation from care recipients. A caregiver who feels heard and knows that they are listened to and feels visible and understood should experience less burden and this individual will likely have less stress and perceived burden versus someone who does not have these feelings.

Second, some research has documented the relevance of feelings of mattering in the experience of caregivers. Pearlin and LeBlanc (2001) examined mattering and its correlates in a longitudinal study of 555 caregivers who were providing assistance to either spouses or parents with Alzheimer's disease. Interviews were conducted once a year for a six-year period. Mattering in this context was in terms of mattering to the afflicted spouse or parent and the focus was on the caregiver's loss of perceived mattering as their family member declined and ultimately died. Greater levels of loss of mattering were associated with taking care of a spouse (versus a family member), greater role overload, less emotional support, depression, and an experience of loss of self. Another key factor was perceived closeness between the caregiver and the care recipient with loss of mattering being linked with more closeness. Collectively, these results suggest that mattering is highly salient among caregivers and it can be a part of their identity. Moreover, according to Pearlin and LeBlanc (2001), mattering is “a potential latent reward” (p. 299) for many people while they are in the caregiving role and the impact of a loss of mattering points to mattering being important in terms of the caregiver experience.

Our recent analysis and review led us to conclude that mattering is a potential vital resource that buffers caregiver burden and stress (Flett & Goldstein-Reuben, 2024). Moreover, a sense of mattering among caregivers should be one of the salient benefits and positive aspects of being a caregiver (Flett & Goldstein-Reuben, 2024). Feelings of mattering not only allow a caregiver to develop a strong sense of purpose and worth, but it also enables him or her to recognize how instrumental they are to the overall health and well-being of the care-receiver. Mattering is also associated with greater self-efficacy and capability to be resilient and adaptable (Flett & Goldstein-Reuben, 2024). Although mattering is not a solution or remedy to caregiving at large, especially when faced with highly challenging circumstances, it can contribute to more positive life orientation and daily experiences (Flett & Goldstein-Reuben, 2024).

Given these considerations, future research should prioritize examining the associations among mattering, burden, mood, and the physical health of caregivers. This could help further caregiver research by revealing whether or not such feelings of mattering play an important role in reducing caregiver burden and strain, as well as provide a valid explanation as to why some caregivers are less stressed (i.e., those who have feelings of mattering) than others when all other variables are accounted for. If it is shown that mattering helps to alleviate caregiver burden then supportive programs for caregivers can be established, which set out to help caregivers identify and develop strong feelings of mattering within their lives. Likewise, perhaps programs could be established to focus on the care-receiver, and how they could learn to overtly express feelings of mattering to their caregiver.

Although the above discussion underscores the relevance of mattering within the caregiving context, it is worth noting that none of the participants identified the item *"no one understands what you are experiencing"* as a significant source of caregiver stress within the qualitative portion of this study. This suggests that participants may not have interpreted this item as a reflection of mattering-nor was it explicitly designed to measure whether they felt that they mattered. However, it is important to recognize the possibility that some participants may have interpreted this item as indirectly related to their sense of mattering, depending on their individual perceptions.

The absence of endorsement for this item may imply that participants felt understood and recognized in their caregiving roles. Rather than interpreting this item as assessing their social significance or worth, they may have viewed it more narrowly as a question of whether others understood and respected the realities and demands of their caregiving situations.

These findings highlight the importance of carefully crafting qualitative questions to ensure alignment with the constructs being examined. In future research, if the aim is to explore whether mattering-or the absence thereof-contributes to caregiver stress, it would likely be valuable to frame items more explicitly around perceived feelings of worth and social value. A clearer form of assessment might directly ask participations whether they feel they matter, asking questions related to whether they feel they are useful, needed, important and appreciated by the care recipient.

An additional area of caregiver research that would also be worthwhile examining is programmatic research on the positive aspects of the caregiver role. Although much of the current research on family caregivers focuses primarily on burden, their consequences and their management, it is becoming increasingly apparent that there is much to be gained by examining the positive dimensions of caregiving, including experiences, appraisals, emotions and the strength and resources that caregivers can use to help manage the challenges they face (Zarit, 2012). Beatie et al. (2021) reported that several of their participants described their caregiving role as admirable, important and powerful, and provided them with a sense of purpose. Abdollahpour et al. (2018) defined positive aspects of caregiving (PAC) as the gains or satisfaction feelings resulting from the caregiving experience. In order for clinicians to truly comprehend the caregiver experience and identify risk factors for negative caregiver outcomes, they should inquire about the positive aspects of caregiving too (Cohen et al., 2002). Semiatin and O'Connor (2012) further emphasized the importance and benefits of considering the positive aspects of caregiving by stating that such desirable aspects of the caregiving experience may buffer caregivers from the many negative psychological and physical consequences of caregiving. These researchers proposed that it would be highly beneficial to the caregivers themselves, if studies would focus on identifying the factors which relate to positive aspects of caregiving for these individuals to have the desired positive experiences. Folkman (2008) proposed that the inclusion of this kind of future study would help to address an imbalance between research and clinical practice due to decades of nearly exclusive concern with the negative emotions.

Summary

In summary, the current study sought to further understanding of caregiver burden by investigating the associations among burden, proactive coping scores, social support and mood states. This study also evaluated the relationship between proactive coping and social support, as well as the link between proactive coping and less negative mood and more positive mood. Furthermore, this research validated the heterogeneity of the caregiver experience determined by factors such as the relationship one has to the care receiver (i.e., whether or not someone is a spouse) and whether or not the care-receiver suffers from cognitive decline.

The results indicated that burden and proactive coping were not significantly correlated, yet burden was correlated with most subscales of the POMS and social support. Proactive coping positively correlated with vigour-activity and negatively correlated with depression-dejection as well as with the POMS total. No link was evident in the current study between proactive coping and social support. Results indicated that spousal caregivers had greater levels of burden than non-spousal caregivers. Lastly, caregivers looking after the confused elderly experienced greater burden in comparison to those caring for the lucid elderly.

When considered together, the results of the current investigation further illustrated the burden being experienced by caregivers. Some potentially useful insights were obtained about the nature of the caregiver experience and the burden inherent in the caregiver role. This study also provided insights into which caregivers are more likely to experience stress and distress. The potential benefits of developing a proactive approach rather than a reactive approach were also explored. While there may be some benefits to caregiving by allowing individuals to feel like they are giving back to loved ones as well as providing an increased sense of meaning and purpose to life, it has been shown to negatively impact a person’s physical and mental health (Hango, 2020). Furthermore, caregiving has tremendous effects on family caregivers’ social activities, finances, emotions and general health (Doyle, 2018). For these reasons the health and well-being of caregivers is an emerging public health issue of paramount concern (Jull, 2010). The findings of this research emphasize the necessity of implementing interventions designed specifically to ameliorate these burdens to help improve the mental health and overall well-being of these essential caregivers.

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Appendix A

CAREGIVER QUESTIONNAIRE

Part A-**Demographic Information**

Some background Information. Please circle the number that best describes you.

1. How old are you?
   ________ years

2. How are you related to the person you are providing care for?

1. Wife
2. Daughter
3. Sister
4. Daughter-in-law
5. Niece
6. Neighbour
7. Friend
8. Granddaughter

3. How long have you been providing care for your relative?

   1. One month or less
   2. 2-6 months
3. 7 months-1 year
4. 2-5 years
5. 6-10 years
6. 11 or more years

4. Are you the sole caregiver or are there other family members/friends available to provide care?

   1. Sole caregiver 2. Others available to provide care

5. Within an average week, how often do you visit your relative?

1. Less than once a week
2. 1-2 days a week
3. 3-4 days a week
4. 5-6 days a week
5. 7 days a week

6. On average, how long do you visit?

1. Less than 1 hour
2. 1-3 hours
3. 4-6 hours
4. 7-9 hours
5. 10-12 hours
6. More than 12 hours

7. Is your relative ever confused?
   1. Never 2. Sometimes 3. Moderately 4. All the time

Part B-**Questions Related to Pre-Caregiver Role Experiences**

1. a) PRIOR to caring for your relative, did you ever seek medical treatment for a health problem?
   1. yes 2. no

   b) If yes, please indicate for which of the following problems you have sought medical attention.

1. heart disease
2. high blood pressure
3. depression
4. ulcers
5. sleep difficulty
6. migraines/headaches
7. weight loss or gain
8. other____

2. PRIOR to caring for your relative, how often did you take the following?

	A lot	quite often	occasionally	seldom	never
	1	2	3	4	5
1. Pain medication	1	2	3	4	5
2. Tranquilizers/valium	1	2	3	4	5
3. Sleeping pills	1	2	3	4	5
4. Antidepressants	1	2	3	4	5

3. PRIOR to caring for your relative, on average, how many cups of coffee did you drink per day?

1. None
2. 1 to 3 per day
3. 4 to 6 per day
4. 7 to 10 per day
5. more than 10 per day

4. a) Do you smoke cigarettes?

1. Yes 2. No

b) If yes, PRIOR to becoming a caregiver, how many cigarettes did you smoke per day?

1. 10 or less
2. 11-20
3. 21-30
4. more than 30

Part C-**Caregiver Burden Inventory**

Below is a list of questions associated with different types of stresses that you may experience as a result of your caregiving role.
After each question, choose the response that most closely describes your feelings.
0 for never; 1 for rarely; 2 for sometimes; 3 for quite frequently; or 4 for nearly always

	Never	Rarely	Some-times	Quite frequently	Nearly always
	0	1	2	3	4
Time Burden Scale					
1. My relative needs my help to perform many daily tasks.	0	1	2	3	4
2. My relative is dependent on me.	0	1	2	3	4
3. I have to watch my relative constantly.	0	1	2	3	4
4. I have to help my relative with many basic functions.	0	1	2	3	4

5. I don’t have a minute’s break from my caregiving chores.	0	1	2	3	4

Developmental Burden Scale

6. I feel that I am missing out on life.	0	1	2	3	4
7. I wish I could escape from this situation.	0	1	2	3	4
8. My social life has suffered.	0	1	2	3	4
9. I feel emotionally drained due to caring for my relative.	0	1	2	3	4
10. I expected that things would be different at this point in my life.	0	1	2	3	4

Physical Burden Scale

11. I’m not getting enough sleep.	0	1	2	3	4
12. My health has suffered.	0	1	2	3	4
13. Caregiving has made me physically sick.	0	1	2	3	4
14. I’m physically tired.	0	1	2	3	4

Social Burden Scale

15. I don’t get along with other family members as well as I used to	0	1	2	3	4
16. My caregiving efforts aren’t appreciated by other family members	0	1	2	3	4
17. I’ve had problems with significant relationships.	0	1	2	3	4
18. I don’t get along as well as I used to with others.	0	1	2	3	4

19. I feel resentful of other relatives who could, but do not, help.	0	1	2	3	4

Emotional Burden Scale

20. I feel embarrassed by my relative's behaviour.	0	1	2	3	4
21. I feel ashamed of my relative.	0	1	2	3	4
22. I resent my relative.	0	1	2	3	4
23. I feel uncomfortable when I have friends over.	0	1	2	3	4
24. I feel angry about my interactions with my relative.	0	1	2	3	4

Qualitative Questions

25. What is your greatest source of caregiver stress? Please rank the items below with 10 being the most stressful and 1 being the least stressful.

- The physical and/or mental change in your relative as a result of his/her illness
- The change in your relationship with your loved one
- The change in your social life
- You no longer have time for yourself
- The pressure of having to respond to caregiving demands
- Feelings of guilt
- No one is available to assist with caregiving responsibilities
- No one understands what you are experiencing
- You are no longer able to engage in activities and/or hobbies that you previously enjoyed
- The pressure of conflicting demands from others (i.e., work, children, spouse)

26. Why does the item that you ranked as most stressful (item ranked #10) cause you so much stress?

Employment Question

27. If you are currently employed, does your employer allow you to take time off with pay, in order to care for your relative?

1. yes 2. No 3. Not employed

Part D-**Social Support Scale**

The following questions deal with how people around you generally behave. For each question, circle the number that best describes the people around you.

	Very Much	Some-what	A Little	Not at All
	4	3	2	1
1. How much do people go out of their way to make things easier for you?	4	3	2	1
2. How much advice or guidance do people give you that you find helpful?	4	3	2	1
3. How much are people helpful to you when things get tough?	4	3	2	1
4. How much useful information do people provide you when you really need it?	4	3	2	1
5. How much can people be relied on to provide you with the assistance when you need it most?	4	3	2	1
6. How much useful feedback do you get from others?	4	3	2	1
7. How much do people boost your spirits when you feel low?	4	3	2	1
8. How much are people willing to listen to your problems?	4	3	2	1

Part E-**Profile of Mood States**

Below is a list of words that describe feelings people have. Please read each one carefully and then circle the number to the right that best describes how you have been feeling during the past week including today.

	Not at all 0	A Little 1	Moderately 2	Quite a bit 3	Extremely 4
1. Angry	0	1	2	3	4
2. Worn out	0	1	2	3	4
3. Unhappy	0	1	2	3	4
4. Lively	0	1	2	3	4
5. Confused	0	1	2	3	4
6. Peeved	0	1	2	3	4
7. Sad	0	1	2	3	4
8. Active	0	1	2	3	4
9. On edge	0	1	2	3	4
10. Grouchy	0	1	2	3	4
11. Blue	0	1	2	3	4
12. Energetic	0	1	2	3	4
13. Hopeless	0	1	2	3	4
14. Uneasy	0	1	2	3	4
15. Restless	0	1	2	3	4
16. Unable to concentrate	0	1	2	3	4
17. Fatigued	0	1	2	3	4
18. Annoyed	0	1	2	3	4
19. Discouraged	0	1	2	3	4
20. Resentful	0	1	2	3	4
21. Nervous	0	1	2	3	4
22. Miserable	0	1	2	3	4
23. Cheerful	0	1	2	3	4
24. Bitter	0	1	2	3	4

25. Exhausted	0	1	2	3	4
26. Anxious	0	1	2	3	4
27. Helpless	0	1	2	3	4
28. Weary	0	1	2	3	4
29. Bewildered	0	1	2	3	4
30. Furious	0	1	2	3	4
31. Full of pep	0	1	2	3	4
32. Worthless	0	1	2	3	4
33. Forgetful	0	1	2	3	4
34. Vigorous	0	1	2	3	4
35. Uncertain about things	0	1	2	3	4
36. Bushed	0	1	2	3	4
37. Tense	0	1	2	3	4

Part F-**Proactive Coping Scale**

The following statements deal with reactions you may have to various situations. Indicate how true each of these statements is depending on how you feel about the situation. Do this by checking the most appropriate box.
In scoring responses, 1 is assigned to "not at all", 2 to "barely true", 3 to "somewhat true", and 4 to "completely true"

	Not at all true 1	Barely 2	Somewhat 3	Completely 4
1. I am a "take charge" person.	1	2	3	4
2. I try to let things work out on their own.	1	2	3	4
3. After attaining a goal, I look for another, more challenging one.	1	2	3	4
4. I like challenges and beating the odds.	1	2	3	4
5. I visualize my dreams and try	1	2	3	4

to achieve them.

6. Despite numerous setbacks, I usually succeed in getting what I want.	1	2	3	4
7. I try to pinpoint what I need to succeed.	1	2	3	4
8. I always try to find a way to work around obstacles; nothing really stops me.	1	2	3	4
9. I often see myself failing so I don’t get my hopes up too high.	1	2	3	4
10. When I apply for a position, I imagine myself filling it.	1	2	3	4
11. I turn obstacles into positive experiences.	1	2	3	4
12. If someone tells me I can’t do something, you can be sure I will do it.	1	2	3	4
13. When I experience a problem, I take the initiative in resolving it.	1	2	3	4
14. When I have a problem, I usually see myself in a no-win situation.	1	2	3	4

Part G-**Questions Related to Experiences Since Becoming a Caregiver**

1. a) SINCE becoming a caregiver for your relative, have you sought medical treatment for a health problem?

1. Yes 2. No

b) If yes, please indicate for which of the following problems you have sought medical attention.

1. heart disease
2. high blood pressure

3. depression
4. ulcers
5. sleep difficulty
6. migraines/headaches
7. weight loss or gain
8. other____

2. SINCE becoming a caregiver for your relative, how often do you take the following:

	A lot 1	quite often 2	occasionally 3	seldom 4	never 5
1. Pain medication	1	2	3	4	5
2. Tranquilizers/valium	1	2	3	4	5
3. Sleeping pills	1	2	3	4	5
4. Antidepressants	1	2	3	4	5

3. SINCE becoming a caregiver for your relative, how many cups of coffee do you drink per day?

1. None
2. 1 to 3 per day
3. 4 to 6 per day
4. 7 to 10 per day
5. more than 10 per day

4. SINCE becoming a caregiver for your relative, how many cigarettes do you smoke per day?
1. I do not smoke
2. 10 or less
3. 11-20
4. 21-30
5. more than 30

THANK YOU FOR YOUR TIME IN FILLING OUT THIS QUESTIONNAIRE

Appendix B

York University

Faculty of Arts

INFORMATION SHEET

February 12th, 2003.

My name is Lesley Goldstein-Reuben. I am a doctoral student at York University. I am interested in conducting research on caregiver stresses of the elderly. A great deal of literature exists that emphasizes the stresses and strains associated with caring for an elderly person. I am interested in examining the specific causes of caregiver stress. I also intend to explore the relationship between stress and individuals' health status. Lastly, I am interested in looking at how coping and social support may help to reduce caregiver stress.

Research of this nature is very important because it will help show why some individuals are more likely to experience caregiver stress than others. Most of the current caregiving research does not address this issue. This is an essential area of study because it helps to identify people who may be more likely to experience stress. Furthermore, it helps to determine how these people can be assisted most effectively. The results of this study will also show the types of stresses that people who care for the elderly living within institutions, experience. To date, few studies have been conducted that have focused on these types of caregivers. This is an important area of research that is limited and therefore requires examination.

Because you are a caregiver to an individual aged 50 or older, you are being asked to participate in this study. As a participant, you will be asked to complete a questionnaire on an anonymous basis. The questionnaire will take approximately 15-30 minutes to complete. All questionnaires will be completely confidential. Your name will not be written anywhere on the questionnaire. Participation in this study is completely voluntary. You are taking part in this study of your own free will.

If you are interested in participating, arrangements will be made for us to meet at a time that is convenient for you. During our meeting, I will be available to answer any questions that you may have regarding this research study.
Please feel free to contact me in the meantime with any concerns or questions you may have.

Thank you very much for your time.

Lesley Goldstein-Reuben

Appendix C

York University
Faculty of Arts

CONSENT TO PARTICIPATE IN STUDY

My name is Lesley Goldstein-Reuben. I am a doctoral student at York University. I am interested in conducting research on caregiver stresses of the elderly. Because you are a caregiver to an elderly person (someone aged 50 or older) you have been asked to participate in this study. The goal of this research project is to learn how coping and social support may help to reduce caregiver stresses.

Your participation in this study involves filling out the enclosed questionnaire, which will take approximately 15-30 minutes to complete. Once you have completed the questionnaire, please place it in the self-addressed stamped envelope (the enclosed folded envelope) and kindly mail it.

You can be assured that the information collected through the questionnaire is completely confidential and anonymous. Your name will not be written anywhere on the questionnaire. No one other than I will view these questionnaires. You should be aware that your participation in this study is entirely voluntary, and therefore you will not be paid for your participation. If you decide to participate, you are free to stop participating at any time. If you decide to discontinue participation, it will not affect the care that your loved one receives in any way. You may also leave any question(s) blank that you do not wish to answer. There are no foreseeable risks or discomforts associated with your participation in this study.

Please note that you may contact me with any comments or concerns you may have regarding your participation in this study. You may also contact the Graduate Programme in Psychology at York University at telephone number 736-5290.

Your participation and assistance in this project are greatly appreciated. Thank you very much for your time.

My signature on this consent form means that I agree to take part in this study.
This form is for you to keep.

TWO COPIES OF THIS FORM ARE INCLUDED. PLEASE SIGN BOTH COPIES. KEEP ONE COPY FOR YOUR OWN RECORDS AND RETURN THE SECOND COPY WITH THE COMPLETED QUESTIONNAIRE.

______________________________	______________________________
Signature of Participant	Date
______________________________	______________________________
Signature of Witness	Date