Emotional Support, Health, and Burden among Caregivers of People with Neurological Conditions

by

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A.A., Douglas College, 2013
B.A. (Hons), University of Victoria, 2014

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ABSTRACT

From 2011 to 2031, the Canadian population living with neurological conditions is expected to double, but the population able to give informal care is not keeping pace, leading to a greater care burden. One element of this increasing care burden is emotional care. However, the effects of giving emotional care on caregiver health outcomes have not been sufficiently explored in the caregiving literature, where the majority of studies focus on instrumental forms of care, or fail to differentiate between different aspects of caregiving. This problem is further complicated by findings from other contexts which indicate that emotional supporting and helping others actually benefits the supporter or helper. Informed by the stress process and other ancillary theories, I use data from the 2012 General Social Survey to test several hypotheses which may help us understand the mental health, functional health, and caregiver burden of caregivers of persons with neurological conditions who emotionally support their care receivers, and of caregivers who are the sole provider of emotional support. The results suggest that emotionally supporting a care receiver with a neurological condition is detrimental to caregiver mental health, and that being the sole emotional supporter is detrimental to caregiver mental health, functional health, and experience of burden. A significant interaction effect also exists between emotional supporting and caregiver gender for functional health. These findings have important implications for future research, for intervention planners, and for caregivers themselves.

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DEDICATION

To my grandfather John, and everyone who helped him in his struggle with ALS.

And to my wife, with good reason.

CHAPTER 1. INTRODUCTION

1.1 Background

The cost and burden of neurological conditions, such as Alzheimer's disease, dementia, Parkinson's disease, multiple sclerosis (MS), and amyotrophic lateral sclerosis (ALS), is a growing global problem. In 2010, the global dementia population alone was estimated at 35.6 million people, and is expected to double by 2030 (Wong, Gilmour and Ramage-Morin 2016). The total cost of dementia in 2010 was $604 billion USD, or nearly one percent of the global economy for that year (Wong, Gilmour and Ramage-Morin 2016). When compared to the economies of countries (in GDP), 'dementia costs' would rank 19th between Indonesia and Switzerland, and higher if all neurological conditions were considered. Since the incidence, or risk of developing these conditions, is much higher among people at least 65 years of age compared to younger age groups, and is particularly high among people aged 80 and older, global costs will only increase as more countries complete the demographic transition (i.e. the transformation from high to low fertility and mortality rates that typically occurs as a country industrializes) and face population aging.

Canada, having completed the demographic transition, is on the forefront of this trend in neurological condition prevalence. The Canadian population living with dementia is estimated at anywhere between 340,000 and 747,000 people for the year 2011, and is expected to double by 2031 (Manual et al. 2016; Wong, Gilmour and Ramage-Morin 2016). Alzheimer's and Parkinson's disease prevalence is expected to increase similarly for the same period (Gaskin et al. 2017). Neurological conditions are the diagnostic category with the largest total cost to the Canadian economy: in 2008,

neurological conditions cost the economy $11.4 billion in direct costs, such as hospitalization, and $1.0 billion in indirect costs, such as lost productivity (Gaskin et al. 2017). As per the population trend, these costs are expected to double after twenty years; the total cost of dementia alone is expected to reach $18.2 billion by 2031 (Manuel et al. 2016). None of these predictions account for the estimated 30% of people who remain undiagnosed (Manuel et al. 2016). Neither do they account for neurodegeneration that does not meet diagnostic criteria but which nevertheless carries its own cost and burden.

These trends are not due to any sort of neurological disease epidemic. In fact, the age-specific incidence of neurological conditions is largely static, and there is even some evidence of age-specific incidence decline in developed countries (Winblad et al. 2016; Alzheimer's Association 2018). Rather, these trends are largely attributed to the demographic transition and population aging. A consequence of declining mortality is that a larger share of people are expected to live to advanced ages where neurological conditions are common; increased longevity means that neurological conditions have a larger window in which to develop, and that people may spend more years living with their condition. Even a slight age-specific incidence decline may bode ill given increases in longevity: in prediction scenarios where good health delays dementia onset, the increase in years with dementia caused by greater longevity outweighs the benefits of delayed onset (Zissimopoulos et al 2018). That is, a person's average years lived with dementia increases regardless.

The other half of the demographic transition, declining fertility, means that people are having fewer children on average as more women delay childbearing or forgo it entirely. Consequently, people with neurological conditions may have fewer sources of

support, and there are fewer people who can contribute to the economic cost of these conditions. Population aging occurs as a result of both halves of the demographic transition: the average age of the population increases as older people make up a larger share. Thus, not only are there more people in the oldest age groups, but there are more in proportion to younger groups, a sort of double jeopardy for people with neurological conditions that require care. As per the increase in the population with neurological conditions, the number of these people receiving informal care from family or friends is expected to double between 2011 and 2031 (Manual et al. 2016). Studying care receivers with dementia in particular, Manuel and colleagues (2016) estimated yearly hours of care per working-age person (age 25-65) for 2011 at 52.3 hours. In the absence of population aging, we might expect yearly hours of care to remain constant. However, it is projected to increase to 100.4 hours by 2031 (Manuel et al. 2016). That is, the care need is growing relative to the population able to provide care. This may result in three potentially overlapping scenarios: providing care to a family member or friend with a neurological condition will become a more common experience; caregivers will be required to care for more hours; and more people suffering from neurological conditions will go without the care they require.

1.2 Care Need

People living with neurological conditions tend to require a lot of care, much of which takes the form of informal family caregiving. Informal caregiving usually refers to unpaid assistance to family and friends who are unable to fulfill their needs on their own, often involving help with activities of daily living, instrumental activities, and emotional

care (Drentea 2007). In the case of dementia, in Canada 85% of people with this condition rely at least in part on family and friends for assistance and only 43% receive some form of formal assistance to supplement their informal care (Wong, Gilmour and Ramage-Morin 2016). Most people living with dementia require help with medical care, home maintenance, meal preparation, transportation, and personal management; at least half need help with personal care, such as dressing, bathing, and toileting (Wong, Gilmour and Ramage-Morin 2016). Additionally, 90% of people living with dementia need some form of emotional support (Wong, Gilmour and Ramage-Morin 2016).

For many caregivers of persons with neurological conditions, care is intensive. One-third of caregivers of persons with neurological conditions report assisting their care receiver for at least 22 hours per week (Gaskin et al. 2017). Neurological conditions are also financially costly for caregivers. For example, Gaskin and colleagues (2017) found that half of all caregivers of persons with Parkinson's disease spend at least $500 annually on medication and assistive devices, and two-thirds of caregivers spend at least $500 annually on home care services. Caregiving costs also increase with the severity of the neurological condition: for caregivers of persons with Alzheimer's disease, a greater number of care receiver behavioural problems is associated with a rise in both direct and indirect costs (Gaskin et al. 2017). In sum, caregiving has the potential to be both time-consuming and expensive.

1.3 Why Neurological Conditions?

There are other reasons to focus on neurological conditions, and to consider them as a group rather than focusing on each condition individually. Although most non-

dementia neurological conditions are less common than dementia-type conditions (Public Health Agency of Canada and Neurological Health Charities Canada 2014), recent initiatives (such as the 2014 ALS Ice Bucket Challenge) have resulted in more public awareness of these conditions. Subsequently, many people have become more open to sharing their experiences regarding these conditions, and perhaps even more people have realized they know someone affected by these conditions. Even people with rare conditions may affect a large network of people around them. Second, the literature reveals that caring for people with neurological conditions affects caregivers in similar ways, regardless of the specific condition being studied, with few differences or peculiarities, especially regarding the most important indicators; this will be discussed in greater detail in the literature review in the next chapter.

Third, neurological conditions are often comorbid. A person with one neurological condition is likely to have another neurological condition, or to have other health problems (Chiò et al. 2010; Wong, Gilmour and Ramage-Morin 2016). There are two reasons for comorbidity: people in the age group most affected by neurological conditions are exposed to the problems normally associated with aging, and the degenerative nature of many neurological illnesses can create the necessary conditions for another to develop. For example, Chiò and colleagues (2010) found that half of all people with ALS participating in their study exhibited neurobehavioural problems related to frontotemporal dementia (FTD). Likewise, Wong, Gilmour and Ramage-Morin (2016) found that nearly one-third of people with dementia have another neurological condition, and were more likely to have other health problems, such as heart disease or incontinence, than the general population of similar age.

Finally, caring for people with neurological conditions is more stressful than other types of caregiving. Gaskin and colleagues (2017) found that 28% of caregivers of persons with neurological conditions report symptoms of distress, compared to only 13% of other caregivers. The greater distress experienced by these caregivers is likely due to the unyielding nature of neurological conditions. Not only do caregivers need to dedicate substantial time to their care receiver, but their efforts may not seem to help; they must watch as their family member's or friend's ability deteriorates all the same. Of course, caring for people with neurological conditions comes with other costs besides time, money and distress. The literature focuses on three main areas: mental health, functional or physical health, and caregiver burden.

1.4 Caregiving and Mental Health

Caregivers of persons with neurological conditions tend to have poor mental health. Mental health refers to a person's mental or psychological well-being, and good mental health usually means the absence of mental illness. The caregiving literature tends to focus on depression and anxiety, as mood and anxiety disorders are among the most common mental health issues and they are no less common among caregivers of persons with neurological conditions. The prevalence of depression is much higher in caregivers than in non-caregivers, and caregivers tend to overestimate their mental health. Fonareva and Oken (2014) found that 25% of dementia caregivers acknowledged that they were depressed, but 55% of caregivers reached clinical depression levels when subsequently assessed. The prevalence of depression among the population over 55 years of age

(caregiving studies typically have a high mean age) is estimated to be only 6-9% (Fonareva and Oken 2014).

Across the board, caring for someone with a neurological condition is associated with poor mental health (e.g. Weitzenkamp et al. 1997; Wright et al. 1999; Aoun et al. 2012; Corrêa et al. 2016; Mallya and Fiocco 2018). Caregiver mental health also tends to deteriorate with time. Neundorfer and colleagues (2001) found a decline in caregiver mental health between study waves, and Lou and colleagues (2015) found that greater duration of caregiving years was associated with greater caregiver depression. Poor caregiver mental health is also a problem for the people they provide care for. Lwi and colleagues (2017) found poor caregiver mental health was associated with higher mortality among care receivers with dementia, even when accounting for care receiver mortality risk factors. That is, caregivers with poor mental health might not always be effective caregivers.

1.5 Caregiving and Functional Health

Caregivers of persons with neurological conditions tend to have poor health-related quality of life and physical or functional health. Health-related quality of life is a comprehensive measure of health, focusing not just on disease but on the impact a person's overall health status can have on their ability to live a fulfilling life. Health-related quality of life assessment tools typically cover many domains, including sensory ability, pain, mobility, cognitive function, and emotions. There is some overlap with mental health, but this tends to be only one domain among many in an otherwise physical-health-focused assessment. Other tools are oriented toward functional health: the

real physical functioning of a person and limitations inflicted by disease, regardless of diagnosis. Functional health is similar to health-related quality of life, but does not always include emotional and social aspects of health. As such, I have grouped health-related quality of life, physical health, and functional health together, preferring to use the term ‘functional health.’

Again, there is consensus in the literature: caregivers of persons with neurological conditions have poorer functional health than non-caregivers. This has been demonstrated in the case of Alzheimer's disease (Välimäki et al. 2016), dementia (Mallya and Fiocco 2018), Parkinson’s disease, ALS, and other atrophy disorders (Miyashita et al. 2011). Caregivers also tend to do poorly on more specific markers of physical health. The stress of caring for someone with dementia is associated with immune suppression, increasing the likelihood that caregivers will experience health problems (Vitaliano, Zhang and Scanlan 2003; Bailey and Gordon 2016). Caregivers also tend to have higher blood pressure and glucose levels, and are at greater risk of carotid artery and coronary heart disease than they otherwise should be (Vitaliano, Zhang and Scanlan 2003; Fonereva and Oken 2014). At the same time, caregivers are less likely to seek medical care for themselves, and are at greater risk of hospitalization and premature mortality than their non-caregiving peers (Bailey and Gordon 2016). In sum, caregiving for someone with a neurological condition appears to be a real physical health risk.

1.6. Caregiving and Caregiver Burden

Caregivers of persons with neurological conditions tend to experience a high level of caregiver burden. Caregiver burden is a comprehensive reflection of caregiver well-

being encompassing objective and subjective aspects of caregiving, including physical, psychological, emotional, social, and financial domains (Bastawrous 2013). Due to the wide variety of measures used, evidence regarding caregiver burden can at times be inconsistent, but taken as a whole it points one way: caring for people with neurological conditions is not good for caregiver well-being. Since the concept of caregiver burden is caregiver-specific, caregivers are not usually compared to non-caregivers in this area. However, the evidence overwhelmingly suggests that greater hours of caregiving is more burdensome for caregivers (e.g. Chappell and Reid 2002; Peters et al. 2013; Park et al. 2015). Likewise, a longer duration of caregiving is associated with greater caregiver burden (e.g. D'Onofrio et al. 2015; Lou et al. 2015). Overall, caregivers exposed to greater caregiving challenges and stressors tend to have poorer well-being than those who are not.

1.7 Other Caregiving Problems

Caregivers of persons with neurological conditions face a number of other problems related to their health and well-being that make them a priority concern. First, these caregivers are more likely to be socially isolated than other caregivers and non-caregivers, having smaller, less versatile social networks (Aoun et al. 2012; Bailey and Gordon 2016). This means these caregivers have fewer people they can turn to for help or social support. Second, caregivers of persons with neurological conditions, particularly those experiencing high stress or poor mental health, are likely to experience some degree of cognitive decline (Vitaliano et al. 2009; Fonareva and Oken 2014). This can decrease their competency as caregivers which, as previously discussed, can negatively affect care

receiver outcomes. Finally, caregivers are at risk of developing neurological conditions themselves. High-stress caregiving is associated with immune system overproduction of Interleukin 6 (IL-6) and C-reactive protein (CRP) as a response to inflammatory stimuli; brain inflammation is linked to Alzheimer's disease and other dementias (Fonereva and Oken 2014; Bailey and Gordon 2016). In sum, caregivers of persons with neurological conditions are least likely to receive support from others, and due to the high stress of their caregiving situation may end up doing more harm than good.

1.8 The Role of Social Support

The consequences of caring for people with neurological conditions can be buffered by social support. Social support usually means assistance rendered from one person to another, and can be instrumental, informational, appraisal, or emotional in nature (Krause 1986; Thoits 1995). In the caregiving literature, social support often refers to emotional and appraisal aspects, while informal instrumental assistance is treated separately. Support is an important mediator of stress in the stress process, devised by Pearlin and colleagues (1981). The stress process model reconceptualised stress as a process: instead of focusing on discrete life events, the model emphasizes chronic life strains (Pearlin et al. 1981). Mediators such as social support can explain how different people experience the same stressors in different ways (Pearlin et al. 1981). A modification of the stress process, the appraisal model of Yates, Tennstedt and Chang (1999), views caregiving itself as a process: caregivers do not passively absorb stress; rather, they determine how much care they give, and appraise how stressful or

burdensome their caregiving tasks are, which introduces non-mediating subjective elements to the stress process.

We know a lot about the role of received social support in the stress and caregiving processes. Caregivers who receive a greater level of social or emotional support tend to have better mental health (Patterson et al. 1998; Miller et al. 2001), better health-related quality of life (O'Connor and McCabe 2011), and experience lower caregiver burden (Goldsworthy and Knowles 2008; Aoun et al. 2012; Rodakowski et al. 2012) than caregivers who receive lower levels of support. Likewise, caregivers with larger social support networks or who are more socially integrated have better mental health (Williams 2005; Piercy et al. 2013) and experience lower burden (Rodakowski et al. 2012) than other caregivers. In short, caregivers who receive social or emotional support tend to do better than those who go without.

1.9 Emotional Supporting

Despite our knowledge of the role of support receiving in the stress process, we know very little about the role of support giving, or support provided by the caregiver for the care receiver, in influencing caregiver well-being. Emotional supporting, by which I mean empathy, compassion, and other emotional rather than instrumental or informational aspects of social supporting, remains relatively untouched in the caregiving literature, even though a large proportion of caregivers claim to provide emotional support. As mentioned, Wong, Gilmour and Ramage-Morin (2016) found that 90% of caregivers of persons with dementia provide emotional support. Pearlin (1989) identified this gap in the hope of encouraging research in this area, apparently without success.

While we know about the role of received support, we might ask where supporting, or support giving, fits within the stress process. Since not all caregivers provide emotional support, we might also ask what is particular about these caregivers.

Outside of the caregiving literature there are two theoretical perspectives that may explain how support giving affects caregivers: helper therapy and compassion fatigue. The helper therapy principle, formulated by Riessman (1965), stipulates that helping others is beneficial to the people who provide help - often more beneficial than the help was to the receiver. Compassion fatigue describes a very different situation: emotional drain, exhaustion, and apathy experienced by nurses and other formal caregivers exposed to chronic stress (Lynch and Lobo 2012). People who experience compassion fatigue stop caring about their patient's problems, and frequently experience physical and psychological symptoms (Lynch and Lobo 2012). To my knowledge neither approach has been tested with regard to informal caregivers. Giving support may fit as either a resource or stressor in the stress process model.

As with stress and caregiving, we might think about support as a process. Pearlin (1989) criticized how previous research had considered 'support' as a single attribute, when support giving and receiving is inherently interactional; a blemish on a literature that otherwise considers phenomena in terms of process. Support may happen as a single event, but to have a meaningful impact on chronic stressors, support giving or receiving would need to occur persistently over a long period. Caregivers form networks of support, drawing support from many different sources depending on availability and their appraisal of their support needs. Whether or not caregivers give support, or how much support they give, may depend on their appraisal of how much support their care receiver

needs, and whether or not there are other people available to provide that support. Thus, giving social or emotional support to a care receiver once may not meaningfully impact a caregiver in the long-term, but giving support frequently may, especially if the caregiver is the care receiver's only source of support.

One mechanism that could explain a potential relationship between emotional supporting and caregiver health and well-being is the concept of emotional contagion, elaborated by Hatfield, Cacioppo and Rapson (1993). Emotional contagion describes how people automatically and subconsciously mimic the emotional expressions of others in social interactions, and how this mimicry feeds back on one's own emotional state; in short, we 'catch' the emotions of people we interact with (Hatfield, Cacioppo and Rapson 1993). Although it is unlikely that a single interaction will have lasting effects on a caregiver's mood, it is plausible that repeated exposure to either positive or negative interactions could have a cumulative effect. Through emotional contagion, receiving emotional support may be beneficial to caregivers, but repeated emotional supporting may be detrimental. By reconceptualising support as an ongoing process rather than an event or resource, we should be able to gain a better understanding of how it affects caregivers, and particularly those caregivers in the most stressful caregiving contexts.

1.10 Other Research Gaps

A few other problems exist in the neurological disease caregiving literature. The first is generalizability: much of the literature is based on small studies, usually involving non-random clinical samples that are not guaranteed to represent the population under study. In their review, Fonareva and Oken (2014) note the median sample size of studies

of caregivers of persons with dementia is 44 participants. Clinical samples may not be generalizable because they typically include care receivers who are known to medical practitioners and require the most care (Chappell and Penning 1996). Second, some of the studies are missing important variables in their analyses. Fonareva and Oken (2014) and Vitaliano, Zhang and Scanlan (2003) note that the severity of care receiver's symptoms, use of respite care, income, and social support are not consistently evaluated in the majority of studies. Last, some of the research is not theory-driven, or explains how it fits into a theoretical model only vaguely. Trends must have explanations if sociology is to escape accusations of 'social arithmetic.' All of these problems reduce the efficacy of caregiving research and must be addressed.

1.11 The Present Study

This research attempts to find answers regarding caregivers and emotional supporting. Does providing emotional support to care receivers help caregivers, or does it hurt them? Using the 2012 Canadian General Social Survey (Cycle 26: Caregiving and Care Receiving) I study the informal family caregivers of people living with neurological conditions. I assess the impact that emotional supporting, and being the sole emotional supporter, has on mental health, functional health, and caregiver burden. This research will also identify or confirm other determinants of health and well-being for the Canadian population of caregivers of persons with neurological conditions, given the use of a nationally representative and comprehensive data source.

In the following sections, I provide an overview of the literature on caregiving, with regard to the influence it has on the mental health, functional health, and well-being

of the support giver. I also touch on emotional supporting literature from outside the caregiving context, and some of the literature on volunteering. I summarize the literature's strengths and weaknesses, and applicability to the neurological condition caregiving context. I then provide a more thorough discussion of the theoretical frameworks that guide this study, as well as how this study fits into them. These are: the stress process theory of Pearlin and colleagues (1981), and its more recent modifications; the helper therapy principle of Riessman (1965); compassion fatigue, which emerges from the nursing literature; and emotional (or stress) contagion, emerging from social psychology, which explains the mechanisms by which giving emotional support may affect support givers themselves. I end the discussion of theory by advancing a number of hypotheses that follow from these perspectives.

I then discuss the data source and methodology, and explain why they are appropriate to the research. I describe the sample, and justify the selection of variables used in the analysis. I discuss the results of this study, which suggest that emotional supporting is detrimental to caregiver mental health, and to burden in certain circumstances. I find that being the sole emotional supporter to the care receiver is detrimental to caregiver mental health, functional health, and experience of caregiver burden. I also find an interaction between emotional supporting and gender for functional health, suggesting that functional health may depend in part on the fulfillment of gendered expectations.

I conclude with a discussion of limitations, but also of possible implications and contributions of the research to our understanding of caregiving in general. In particular, I focus on the potential for future research in this area and for the application of

interventions targeting caregivers. Finally, I suggest that it is important for caregivers to understand how certain aspects of caregiving – particularly those which could seem to them to be completely harmless – carry with them real consequences for their health and well-being.

CHAPTER 2. LITERATURE REVIEW

2.1 What is Caregiving?

As noted by Aoun and colleagues (2012), the nature of caregiving and what it means to be a caregiver are often not clearly defined. Caregiving generally refers to unpaid help, assistance, or support done by family or friends made necessary by illness, disability, or aging when the care receiver cannot fulfill all their needs on their own (Donelan et al. 2002; Drentea 2007). However, the type of help considered caregiving is not always consistent. Some have limited their definition of caregiving to include only tangible aid or instrumental tasks. For example, Donelan and colleagues (2002) consider help with chores, finances, medical care, and activities of daily living to be caregiving tasks. Nevertheless, much mental and emotional labour is often performed in caregiving (Calasanti and Bowen 2006). It is also worth noting that Gottlieb (1978), building a classification system of helping behaviours, found emotional and informational forms of help were cited more frequently than instrumental forms of help by receivers. As such, emotional and informational forms of help are now often included in definitions of caregiving. For example, Bastawrous (2013) considers caregiving to involve both physical and emotional support; Drentea (2007) considers caregiving to involve instrumental, emotional, and informational caring; Hermanns and Mastel-Smith's (2012) definition involves physical, mental, emotional, and social forms of care. It is clear that emotional aspects of care, such as listening, empathy, affection, and reassurance are an essential part of good caregiving.

Another question pertains to whether caregiving is distinct from everyday caring or other forms of support that takes place in relationships. Drentea (2007) suggests that caregiving is distinct from other kinds of care since it takes place outside of normal or expected roles; for instance, parents caring for an adult child are not parenting but caregiving. Caregiving can also be involuntary, driven by obligation rather than service ethic (Drentea 2007). Misra (2007) suggests that caregiving is not "a natural and uncomplicated response to those in need, but actually hard physical, mental, and emotional work" (2007:402), and many prefer the term 'carework' rather than caregiving to describe this labour. However, caregiving and other care may not always be seen as distinct by caregivers themselves. Spousal caregivers, for instance, may be more inclined to view caregiving as a natural part of their relationship with their significant other (Calasanti and Bowen 2006). As such, Calasanti and Bowen suggest avoiding a "one-size-fits-all approach" (2006:262) to caregiving; what may be considered tough and undesirable carework to some may be considered a normal part of the evolution of a relationship for others.

2.2 What are Social and Emotional Support?

Social support refers to help or assistance given to others by family and friends. Social support can be broken down into four types: instrumental (tangible help, as in chore assistance or financial aid), emotional (empathy, love, and caring), informational (information provided for problem-solving), and appraisal (information provided for self-evaluation) (Krause 1986; Thoits 1995; Langford et al. 1997). Breaking down social support into different types is helpful because people's preferences for type of support

vary depending on the context or circumstance that requires support (Reblin and Uchino 2008). Krause (1986) and Langford and colleagues (1997) define emotional support in particular as involving empathy, caring, love, and trust. Thoits (1995) includes understanding, esteem, and assurance of value. Slevin and colleagues (1996) also consider expressed concern, affection, reassurance, encouragement, listening, and talking about problems as emotional supporting activities. As per Gottlieb's (1978) finding that emotional help is among the most frequently cited forms of help, House (1981) asserts that emotional support may be the most important type, at least so far as perceived support is concerned; emotional support is primarily what people recall when asked about supporting behaviours.

If one were to adopt the view that caregiving and care are conceptually different, this should also apply to caregiving and social support. Given that care receivers' care networks tend to be smaller than their social support networks (Keating et al. 2003), caregiving and social support can certainly be distinguished from one another on a structural level. That is, we can differentiate between emotional support received as part of caregiving, and emotional support received from others who are not part of a person's care network. However, when it comes to emotional care, caregiving and emotional supporting are probably not functionally different. Caregivers and emotional supporters do the same work: they provide a source of empathy, caring, love, trust, listening, and reassurance to others who need it. Put another way, not all emotional supporters are caregivers, but all caregivers who do emotional work are emotional supporters.

This does pose a problem for any discussion of the literature wishing to separate out different aspects of caregiving or support. Since emotional supporting is inherent to

caregiving (at least for most caregivers), many studies focus on caregiving without differentiating the different aspects of care. Others focus only on one aspect of caregiving, particularly instrumental forms of care, and ignore emotional and informational aspects altogether. However, these studies may still be informative, and are worth surveying.

2.3 Caregiver versus Non-caregiver Health Outcomes

In studies comparing caregivers to non-caregivers, caregivers typically have poorer mental health than non-caregivers. Roth and colleagues (2009), who included all kinds of caregivers in their study, found that caregivers have poorer mental health scores than non-caregivers as measured by both the mental health component of the SF-12 and the 4-item version of the CES-D. Likewise, Alpass and colleagues (2013) found that caregivers have poorer mental health than non-caregivers as measured by the SF-36, and Trivedi and colleagues (2014) found that caregivers were more likely than non-caregivers to experience greater than 15 poor mental health days in a month. A number of studies of caregivers of persons with neurological conditions have arrived at similar conclusions. Corrêa and colleauges (2016), studying caregivers of persons with Alzheimer's disease, found that caregivers tend to have greater depression and anxiety than non-caregivers, as well as higher cortisol levels, indicating sustained stress. Wright and colleagues (1999), studying caregivers of persons with either Alzheimer's disease or stroke, found that both types of caregivers had greater depression than non-caregivers at baseline, but depression increased only for caregivers of persons with Alzheimer's disease across study waves. Mallya and Fiocco (2018) found that caregivers of persons with dementia were more

likely to meet the CES-D depression cut-off compared to non-caregivers, and had higher self-perceived stress. Peters and colleagues (2013) found that caregivers of persons with ALS, MS, or Parkinson's disease tend to score lower than the population norm on the mental health component of the SF-12. Weitzenkamp and colleagues (1997) found that spousal caregivers of people with spinal cord injury experience greater depression and emotional stress than non-caregiving spouses. The consensus is clear: caregiving, or at least some aspect of caregiving, tends to be hazardous to mental health, since caregivers consistently fare poorer than their non-caregiving counterparts across a variety of mental health measures.

Caregivers also typically have poorer functional health than non-caregivers. In studies including caregivers of any type, caregivers tend to have poorer physical health summary scores compared to non-caregivers on the SF-36 and its derivatives (Roth et al. 2009; Alpass et al. 2013). In contrast, Trivedi and colleagues (2014) found that, when asked to rate their general health on a 5-point scale, caregivers were more likely than non-caregivers to rate their health as excellent, very good, or good, as opposed to fair or poor. These findings are difficult to reconcile. There is probably some degree of selection at work: people who are physically healthy may be more likely than less healthy individuals to become caregivers, and may be more resilient to the physical demands of caregiving. Conversely, it's possible that, even if they begin caregiving in good health, the demands of caregiving may erode caregivers' functional capacities over time. Self-rated health may also be conceptually distinct from, and thus not entirely comparable to, other physical or functional health measures.

Studies of caregivers of persons with neurological conditions in particular are in greater harmony regarding caregiver/non-caregiver functional health differences. In the case of Alzheimer's disease, Välimäki and colleagues (2016) found caregiver functional health was significantly poorer than the general population, particularly in vision, breathing, and vitality dimensions. Garzón-Maldonado and colleagues (2017) found that, 12 months after baseline, caregivers of persons with Alzheimer's disease exhibited lower scores on all SF-36 dimensions except physical and social functioning, which indicates physical role problems, increased problems with bodily pain, poorer vitality, and worse general health. In reviews and meta-analyses, caregivers of persons with dementia are found to be at increased risk of immune suppression, carotid artery and coronary heart disease, high blood pressure, high glucose levels, hospitalization, and premature mortality compared to non-caregivers (Vitaliano, Zhang and Scanlan 2003; Fonareva and Oken 2014; Bailey and Gordon 2016). Caregivers of persons with dementia also tend to do poorly compared to non-caregivers on cognitive aspects of functional health, exhibiting signs of cognitive decline including poor verbal fluency, memory, concentration, attention, processing speed, and executive function (Fonareva and Oken 2014; Bailey and Gordon 2016; Mallya and Fiocco 2018). Caregivers of persons with other neurological conditions fare no better: ALS, MS, Parkinson's disease, spinocerebellar ataxia (SCA), and multiple system atrophy (MSA) caregivers all score lower than non-caregivers in the general population on the physical health component of the SF-36 and its derivatives (Patti et al. 2007; Miyashita et al. 2011; Peters et al. 2013). Again, a clear relationship between caregiving and functional health is apparent, if only for neurological conditions or particular aspects of functional health.

2.4 Undifferentiated Caregiving and Caregiver Health Outcomes

Studies of neurological condition caregiver mental health which do not differentiate the type of care provided, but instead use general measures of caregiving (e.g. caregiving hours) or use multiple measures, offer mixed results. For instance, Peters and colleagues (2013), studying caregivers of persons with ALS, MS, or Parkinson's disease, found that greater weekly hours of caregiving was associated with poorer mental health, as measured by the SF-12 mental health summary score. In contrast to this finding, Lou and colleagues (2015) found no association between hours of caregiving and Alzheimer's disease caregiver anxiety or depression, but did find that care receiver behavioural problems – particularly anxiety, depression, aggression, and irritability – were associated with poorer caregiver mental health. These alternative findings may merely highlight the unique challenges facing caregivers of persons with different conditions. However, it may also be telling that dealing with behavioural problems, which can be emotionally taxing and may require the provision of emotional support, can influence caregiver mental health. Finally, in a study of caregivers of persons with dementia, Liu and colleagues (2017) found that caregiving demand, measured with the Family Caregiving Inventory (FCI) scale (87 binary items, 12 on emotional care and the rest related to ADLs and IADLs), had an indirect effect on caregiver depressive symptoms via sense of balance. That is, the more tasks a caregiver did, the worse their sense of balance, and the poorer their mental health. Unfortunately, Liu and colleagues (2017) offer no analysis of FCI subdomains, so it is difficult to say how influential emotional aspects of caregiving were to their findings.

The results of other caregiving studies are more consistent. In meta-analyses of studies focusing on caregivers of older adults, Pinquart and Sörensen (2003; 2007) have found that greater weekly hours of caregiving and care receiver behavioural problems are associated with greater caregiver depression, but found no relationship between caregiver mental health and the number of caregiver tasks or care receiver ADL/IADL difficulties. Using a path model, Yates, Tennstedt and Chang (1999) found no direct effect of caregiving hours, ADL/IADL impairment, or behavioural problems on older adult caregiver mental health, but did find that these impact mental health indirectly via overload, or a sense of feeling overwhelmed by caregiving responsibilities. Studies that include all informal caregivers report similar conclusions to the above: greater weekly or daily hours of care are associated with poorer caregiver mental health, usually in the form of depression (Roth et al. 2009; Chang, Chiou and Chen 2010).

Fewer studies focused on functional health, but at least one involved caregivers of persons with neurological conditions. Again, using the SF-12 physical health summary score, Peters and colleagues (2013) found that caregivers of persons with ALS, MS, or Parkinson's disease who provided more weekly hours of caregiving had poorer physical health than caregivers who provided fewer hours. Among caregivers of older adults, Pinquart and Sörensen (2007) were unable to find any relationship between either weekly hours of caregiving or ADL/IADL difficulty and caregiver functional health, but did find that caregivers who performed fewer caregiving tasks tended to have poorer health than caregivers who did a greater number of tasks – attributed to the healthy caregiver effect, whereby physically healthier people are more likely to select into and remain in caregiving roles than the unhealthy. Studies including all informal caregivers are mixed;

both Roth and colleagues (2009) and Alpass and colleagues (2013) found no relationship between weekly hours of caregiving and physical health, whereas Trivedi and colleagues (2014) found greater weekly hours of care to be associated with poorer general health. Chang, Chiou and Chen (2010) found higher daily hours of care to be associated with poorer self-perceived health only indirectly. It is difficult to know why the results of these studies are inconsistent; some samples may be more prone than others to selection, some measures may be more sensitive than others to differences in health, and the primary cause of caregiving need (such as aging or the presence of a neurological condition) may matter.

Studies of caregiver burden among caregivers of persons with neurological conditions using undifferentiated measures (e.g. weekly hours of caregiving) depend on the type of condition. Studies including caregivers of persons with conditions of the dementia-type offer mixed results. For instance, in studies focused on Alzheimer's disease, Lou and colleagues (2015) found no relationship between daily hours of caregiving and caregiver burden, whereas Park and colleagues (2015) found caregivers who have a greater number of daily caregiving hours tend to experience greater burden; both found behavioural problems to be associated with greater burden, and Park and colleagues (2015) also found IADL dependency, but not ADL dependency, to be significantly related to burden. Dementia studies are similar: Chappell and Reid (2002) found greater hours of care and behavioural problems to be associated with greater caregiver burden, with ADL difficulties associated with burden indirectly, whereas Liu and Huang (2018) found no relationship between any of these three variables and caregiver burden.

Studies of other condition types are more consistent. Greater daily and weekly hours of caregiving are associated with greater burden for caregivers of persons with ALS, MS, or Parkinson's disease (Peters et al. 2013; Oh et al. 2015; Galvin et al. 2016; Jones et al. 2017). In addition to caregiving hours, Oh and colleagues (2015) and Jones and colleagues (2017) found that caregivers of persons with ALS or Parkinson's disease tend to experience greater burden when their care receivers have ADL difficulties. Among caregivers of older adults, Pinquart and Sörensen (2003; 2007) found in meta-analyses that behavioural problems, ADL/IADL difficulties, a greater number of caregiving tasks, and greater weekly caregiving hours are associated with greater caregiver burden. Chang, Chiou and Chen (2010), who included all informal caregivers, also found that caregivers who spend more daily hours caregiving experienced greater burden than caregivers who spend fewer hours. For non-dementia caregivers, by which I mean caregivers with care receivers for which dementia-type conditions are not the primary reason assistance is needed, either because no dementia is present or a more severe condition takes precedence, it is clear that more time spent caregiving increases the burden experienced by caregivers.

In sum, non-dementia caregivers who spend more time caregiving have poorer mental health and experience greater burden than caregivers who spend less time. For caregivers of persons with conditions of the dementia-type, as well as for functional health outcomes of all caregivers, the relationship is less clear. In studies that use a single variable measuring caregiving, this may measure instrumental, informational, and emotional elements of care, and is impossible to disentangle. In many of these studies, general caregiving variables (e.g. hours of care) were used alongside variables denoting

instrumental aspects of care (e.g. ADL difficulties), and often demonstrated significant independent effects which, again, could indicate informational or emotional aspects of care at work. When included, behavioural problems were usually significantly related to the outcome variables and some of the most influential problems included depression, anxiety, apathy, anger, and irritability. Dealing with these problems likely requires caregivers to emotionally care for their care receivers, so it is possible that this variable denotes emotional elements of care.

2.5 Instrumental Caregiving and Caregiver Health Outcomes

A number of studies only include instrumental aspects of caregiving, usually measuring the impact of care receiver functional dependency on the caregiver. Additionally, care receiver behavioural problems and cognitive disability are often included as a way of controlling for condition severity. Studies testing the relationship between instrumental caregiving and mental health are mixed, and in many cases no relationship can be established. Among caregivers of persons with Alzheimer's disease, Clyburn and colleagues (2000) found that ADL dependency and behavioural problems were only indirectly related to caregiver depression, whereas Miller and colleagues (2001) found greater behavioural problems to be associated with greater caregiver depression but found no relationship between ADL/IADL dependency and caregiver mental health. In Neundorfer and colleagues' (2001) longitudinal study, greater IADL dependency was associated with greater caregiver depression at baseline, as well as a greater increase in depression across study waves, but ADL dependency was not related. Among caregivers of persons with dementia, Chappell and Penning (1996) found

behavioural problems and IADL impairment, but not ADL impairment, to be associated with greater caregiver depression. However, Fisher and colleagues (2011) and Piercy and colleagues (2013) both found behavioural problems, but not ADL or IADL dependency, to be associated with caregiver mental health. Overall, there is not much evidence that instrumental caregiving influences caregiver mental health for conditions of the dementia-type; rather, caregiver mental health is driven by behavioural and perhaps emotional elements.

Instrumental caregiving may be influential on caregiver mental health when the primary condition that requires assistance is not of dementia-type. Figved and colleages (2007), studying caregivers of persons with MS or Parkinson's disease, found that greater care receiver behavioural problems and functional disability (measured by EDSS score) were associated with greater caregiver distress. Likewise, Mickens and colleagues (2018), studying caregivers of persons with MS, found that greater care receiver impairment was associated with poorer caregiver mental health, where impairment was measured using a latent variable including functional, behavioural, and emotional impairments among others. Studying spousal caregiving in general, Sugiura and colleagues (2009) found that greater ADL dependency was associated with greater depressive symptoms for husband caregivers taking care of wives, but not for wives taking care of husbands, reflecting gender role expectation differences; IADL dependency was not significantly related to mental health.

Again, studies testing the relationship between instrumental caregiving and caregiver burden offer mixed results, particularly for conditions of the dementia-type. Studying caregivers of persons with Alzheimer's disease, both Clyburn and colleagues

(2000) and Garre-Olmo and colleagues (2016) found ADL dependency to be related to caregiver burden only indirectly. Haro and colleagues (2014) found IADL dependency to be associated with greater burden for caregivers of persons with Alzheimer's disease, but found no relationship between ADL dependency and burden. In contrast, Raggi and colleagues (2015) found both ADL and IADL dependency to be associated with burden for caregivers of persons with Alzheimer's disease. For caregivers of persons with dementia, Chappell and Penning (1996) found care receiver IADL impairment, but not ADL impairment, to be associated with greater caregiver burden. The relationship between behavioural problems and caregiver burden is similarly mixed in these studies: many found a direct positive relationship where greater behavioural problems were associated with greater burden (Chappell and Penning 1996; Clyburn et al. 2000; Raggi et al. 2015), but Garre-Olmo and colleagues (2016) found only an indirect relationship, and Haro and colleagues (2014) found no relationship. Overall, studies that only include ADL impairment find it to be related to burden indirectly, whereas studies that include both ADL and IADL impairment tend to find only IADLs to be related to burden; behavioural problems have some relationship to burden in most studies.

In caregiving studies where neurological conditions aside from dementia were the primary focus, instrumental caregiving is typically associated with greater caregiver burden. Studying caregivers of persons with Parkinson's disease, Goldsworthy and Knowles (2008) found ADL and IADL dependency, as well as behavioural problems, to be associated with greater caregiver burden. Studies of caregivers of persons with spinal cord injury are conflicting, but generally point to an effect of instrumental care on burden: Rodakowski and colleagues (2012) found ADL dependency, but not IADL

dependency, to be associated with greater burden, whereas Tough and colleagues (2017) found the opposite (only IADL dependency was associated with greater burden). Among caregivers of older adults generally, Verbakel, Metzelthin and Kempen (2018) found a greater number of IADL tasks and greater weekly hours of care (including instrumental caregiving tasks only) to be associated with greater burden. Swinkels and colleagues (2019), studying spousal caregivers, found greater hours of caregiving (instrumental caregiving tasks only) to be associated with greater burden for husbands caring for wives, but not wives caring for husbands, possibly due to differing gender role expectations; spouses' ADL difficulties affected burden indirectly.

In studies focusing on instrumental aspects of care, there is a clear association between ADL or IADL dependency and caregiver burden. The relationship between instrumental care and mental health is less clear, but it appears that behavioural problems, which can be emotionally draining or require emotional care, may be a greater driver of mental health outcomes. I did not identify any studies that focused solely on instrumental care and functional health. Overall, caregiving studies tend to focus on general, undifferentiated caregiving measures, on instrumental measures, or on some combination of the two. If other aspects of caregiving, such as informational or emotional care, are included, they are only included as part of undifferentiated measures or measured indirectly through other variables such as behavioural problems. Therefore, it is difficult to ascertain how influential these aspects of caregiving are on caregiver health outcomes. Differentiating aspects of caregiving will be helpful since instrumental, emotional, and informational care can have different requirements on the part of caregivers, may affect health outcomes differentially, and may require different kinds of intervention.

2.6 Emotional Supporting and Supporter Health Outcomes

Research on emotional supporting that occurs outside the caregiving context may be informative to anyone wishing to differentiate emotional care from other aspects of care, whether this care is given formally or informally, although care must be taken to ascertain its applicability. In the literature on emotional supporting, the relationship between supporting and mental health may depend on whether the support is informal or formal. In a study of people with multiple sclerosis, Schwartz and Sendor (1999) instructed informal peer supporters to give monthly 15-minute support calls to other participants. At the end of their study, they found that peer supporters scored better on mental health than participants who did not make support calls (Schwartz and Sendor 1999). However, the same size was very small: Schwartz and Sendor (1999) only recruited 5 peer supporters to make calls to 67 other participants. Peer supporters were also recruited based on personal qualities making them suitable as supporters, introducing major selection issues (Schwartz and Sendor 1999). Although the finding of this study is optimistic, the generalizability is dubious.

In another study, Schwartz and colleagues (2003) examined informal supporters in a church setting. Emotional support was operationalized as listening to others' concerns (Schwartz et al. 2003). They found that church members who gave emotional support to other members had better mental health than members who did not give support (Schwartz et al. 2003). Although this study used a random, representative sample, the nature of the sample is still concerning: church members were in relatively good physical and mental health to begin with (Schwartz et al. 2003). This is in sharp contrast

to the situation typically experienced by caregivers, where, for example, the prevalence of depression may be as high as 55% (Fonareva and Oken 2014).

In a formal context, emotional supporting may be detrimental to one's mental health. Studying compassion fatigue among social workers, Adams, Boscarino and Figley (2006) found that social workers with a high level of compassion fatigue experience poorer mental health than those without compassion fatigue. Compassion fatigue in the social work context refers to secondary trauma and burnout from listening to and helping with other's problems (Adams, Boscarino and Figley 2006). Social workers experience fatigue in part from providing formal emotional support. Although a social worker may not be focused as intensively on the problems of a single person as a caregiver would, the chronic nature of the support may make this finding applicable to the caregiving context.

In research on functional or physical health, there is some evidence that emotional supporting is protective of health. Krause and colleagues (1999) found that older adults who often emotionally support others tend to rate their physical health more favourably than those who do not give emotional support frequently. Similarly, Gruenewald and colleagues (2007) found that older adults who feel a sense of usefulness to others tend to have a lower level of disability than those who do not feel useful. In regard to health-related quality of life, Warner and colleagues (2010), studying older adults with multiple illnesses, found that despite illness, older adults who provide emotional support have better physical quality of life than older adults who don't provide support. Additionally, emotional support affected quality of life indirectly via self-esteem (Warner et al. 2010). The primary weakness in studies of health among older adults is that causal direction is difficult to identify due to potential selection issues. Does emotional supporting aid a

person's physical health, or are the physically healthy more available to provide support to others? The literature does not provide a strong answer to this question.

Other research casts some doubt on the idea that emotional supporting can enhance a person's functional health. Schwartz and colleagues (2003) found only a bivariate relationship between emotionally supporting fellow church members and physical functioning. However, the sample was physically healthy, having little variation in health status, so it's possible the sample was simply unsuitable for detecting a relationship in multivariate analyses. Likewise, in their study of undergraduate student peer supporters, Piferi and Lawler (2006) were unable to find a direct relationship between giving social support (emotional and informational support in this context) and physical health. Nonetheless, they did find an indirect relationship via self-efficacy and stress: students who gave social support to other students had improved self-efficacy, which resulted in lower stress, which resulted in better physical health, compared to students who did not provide any support (Piferi and Lawler 2006). Unfortunately, since this finding was based on a convenience sample of undergraduate students, its utility is limited.

Overall, the evidence on functional or physical health is weak. There are hints that a relationship between supporting and physical health may exist, in some form, but nothing substantive has emerged. Aside from the possibility of incongruous concepts, unsuitable populations, and poor sampling, this may also be due to the use of inconsistent measures. For instance, Krause and colleagues (1999) used a combination of three self-rated health measures (one 5-point and two 3-point) to represent physical health, whereas Piferi and Lawler (2006) used physical measures such as systolic blood pressure. These

measures may not be as robust or sensitive as comprehensive measures of health-related quality of life or functional health such as the WHO Quality of Life (WHOQoL), Short-Form Health Survey (SF-36), or Health Utilities Index (HUI) instruments.

Mortality, or health so poor it results in death, is also worth discussing because supporting is associated with a decline in mortality risk. Brown and colleagues (2003) found older adults who emotionally support their spouses have lower mortality risk than those who don't support, but supporting other family and friends had no effect. This indicates that emotional supporting may only be beneficial in the closest, most intense relationships. Although this research was not caregiving-focused, adults in the studied age group (age 65 and older) are expected to have chronic conditions requiring assistance, and spouses are among the most frequent caregivers, making this finding relevant to the caregiving context (Lee, Cigolle and Blaum 2009; Wong, Gilmour and Ramage-Morin 2016). Similar to Brown and colleagues' (2003) finding regarding family and friends, Krause (2006) found no direct relationship between providing emotional social support to a fellow church member and mortality among older adults who are practicing Christians. This confirms the notion that emotional supporting does not reduce mortality risk if the support receiver is not particularly close to the support giver. However, Krause (2006) did find that providing emotional social support moderates the effect of financial strain on mortality. That is, older adults who provide social support to fellow church members do not feel the impact of financial stress on their health to the same extent as those who don't provide support to others.

In the emotional supporting literature, two papers have examined well-being. Schwartz and Sendor's (1999) study of multiple sclerosis peer-supporters found that

peer-supporters who provided monthly support calls had better well-being than participants who did not make such calls. Again, this study suffers from a small sample size and severe selection issues. Krause and Shaw (2000), studying adults age 65 and older, found that people who provide emotional support to others have higher self-esteem than people who don't give support. Although self-esteem is usually considered a resource or moderator in the stress process, the concept is similar to aspects of well-being such as positive affect.

2.7 Volunteering and Volunteer Health Outcomes

The volunteering literature may also be informative, since volunteering often takes the form of instrumental, emotional, or informational supporting, and much of the research has focused on the health outcomes of volunteers. In the volunteering literature, there is strong evidence that people who volunteer have better mental health than those who do not volunteer. There is some disagreement about whether the effect of volunteering varies with age. Kim and Pai (2010) found that people who volunteer had fewer depressive symptoms at baseline than people who don't volunteer, regardless of age. Likewise, Yeung, Zhang and Kim (2018) found volunteers had better mental health than non-volunteers regardless of age, provided the volunteering was other-oriented (e.g. humanitarian) rather than self-oriented (e.g. skill acquisition). Most studies report that the relationship between volunteering and mental health only exists in older age groups, but the age cut-off used is inconsistent. Some have found that volunteers only do better than non-volunteers if they belong to the oldest age groups (age 60 and older), and that volunteering has no influence on mental health at younger ages (Musick and Wilson

2003; Lum and Lightfoot 2005; Li and Ferraro 2006). Others have found that volunteering promotes good mental health as young as age 40 or 50 (Tabassum, Mohan and Smith 2016; Salt, Crofford and Segerstrom 2017). Although Kim and Pai (2010) did not find an age difference at baseline, they discovered that volunteering could only predict mental health trajectory among people age 65 and older; that is, older adults who volunteered had consistently better mental health over time than non-volunteers.

There are a couple of other findings of note on the relationship between volunteering and mental health. First, the amount of time people spend volunteering appears to influence mental health. People who engage in sustained volunteering over a long period of time have been found to have better mental health than people who volunteer only intermittently, particularly among people at retirement age (Musick and Wilson 2003; Jenkinson et al. 2013). Second, in Jang and Tang's (2016) study of grandparents raising grandchildren, grandparents who volunteered had fewer depressive symptoms than grandparents who did not volunteer. Volunteering also moderated the influence of high stress on mental health (Jang and Tang 2016). Grandparents caring for grandchildren had significantly higher stress and poorer mental health compared to other grandparents (Jang and Tang 2016). Parenting might be considered a chronic stressor, since it is an unexpected role for grandparents, and in all the volunteering literature this situation comes closest to caregiving.

The volunteering literature on physical aspects of health is mixed. There is a clear association between volunteering and health-related quality of life: in their review of the volunteering literature, Cattan, Hogg and Hardill (2011) find that adults age 55 and older who engage in volunteering tend to have better quality of life than non-volunteers.

Likewise, sustained volunteering seems to be better for quality of life than intermittent volunteering, and people who are more committed to volunteering have better quality of life than people who are less committed (Cattan, Hogg and Hardill 2011). Studies that use other physical health outcomes are not as certain. Yeung, Zhang and Kim (2018) found people who volunteer have better physical health than people who don't volunteer, and Lum and Lightfoot (2005) found this to be true among people age 70 and older. However, Piliavin and Siegl (2007) found that volunteering was only beneficial to physical health for people who volunteered consistently. In a review by Jenkinson and colleagues (2013), no consistent relationship between volunteering and physical health could be identified. Provided that volunteering and giving support are similar, there may be a relationship between giving support and physical health, but it may depend on other factors such as consistency or some peculiarity of the population in question.

Volunteering may also decrease the mortality risk of volunteers. Lum and Lightfoot (2005) found that adults age 70 and older who volunteered had lower risk of mortality than those who did not volunteer. Likewise, in their review, Jenkinson and colleagues (2013) determined that volunteers have lower mortality than non-volunteers regardless of age or other factors. Again, these studies may suffer from selection issues. It is difficult to determine whether volunteering causes lower mortality, or if healthier people were both more likely to volunteer and less likely to die between study waves.

The volunteering literature is the most consistent on well-being indicators. Regardless of age, volunteers tend to have better well-being and life satisfaction than non-volunteers (Jenkinson et al. 2013; Yeung, Zhang and Kim 2018). Among older adults in particular, volunteering is associated with high perceived life purpose and

positive affect (feelings of happiness, peacefulness, satisfaction, and so on) (Greenfield and Marks 2004; Pilkington, Windsor and Crisp 2012; Salt, Crofford and Segerstrom 2017). Volunteering has also been found to buffer the negative effect of role-identity absences, such as not having a partner, being unemployed, or being childless, on feelings of purpose in life (Greenfield and Marks 2004). As with mental health, people who volunteer consistently appear to gain the greatest well-being benefit from volunteering (Piliavin and Siegl 2007). However, too much volunteering may be detrimental to well-being. Windsor, Anstey and Rodgers (2008), studying adults age 64 to 68, found that both people who volunteer at high levels and people who don't volunteer at all have poorer well-being than people who volunteer moderately. In sum, consistent volunteering appears to be beneficial to well-being, but this benefit is lost if volunteers overwork themselves. This is consistent with research on burden: caregivers who perceive positive aspects of caregiving (for example, a sense of purpose) tend to experience lower burden than other caregivers (Rodakowski et al. 2012; Xue et al. 2018). Likewise, caregivers who spend the greatest number of hours caring tend to experience the greatest burden (e.g. Peters et al. 2013; Park et al 2015).

2.8 Social Structure: Gender, Caregiving, and Emotional Supporting

The health and well-being of caregivers isn't determined solely by the amount and type of caregiving they do. Health is socially determined; that is, stress and health are intertwined with social structure, and a person's location within that structure (their 'social location') can influence the stressors they are exposed to, the resources they have available to them in dealing with those stressors, and the outcome of those stressors on

their health and well-being (e.g. Pearlin 1989). Social location may influence whether or not a person becomes or remains a caregiver, and what kind of caregiving work they do. It may also influence a person's likelihood of giving emotional social support to others. One of the strengths of sociological research has always been the ability to bridge milieu, the personal and particular, with structure; this is the essence of Mills' (1959) sociological imagination, the interplay between private troubles and public issues. It can be tempting to think of stress, health, and emotional troubles as personal problems, which raises the question of why sociologists would bother with them instead of leaving the work to psychologists and health science researchers. However, we are not merely studying these personal phenomena, but social roles and the expectations thereof, where both roles and expectations are determined by social structural factors outside the control of individuals. When a person experiences a stressor or health state because they are a member of a social group that is more likely than others to experience these things, we firmly enter the realm of sociology.

Sociologists have long known that social location influences exposure to stressors. People from disadvantaged groups can be affected more than others by particular stressors, either by having a greater chance to be exposed to these stressors or by being more reactive to these stressors; age, marital status, socioeconomic status, ethnicity, and sexual identity are all elements of social location substantiated in the literature as influencing exposure to stress in various contexts (Thoits 1995; Meyer, Schwartz and Frost 2008). Gender is another key element of social location and is particularly relevant to caregiving and emotional support; Thoits (1995) notes that women are more likely than men to be affected by events that occur to other people in

their social network. It is well-established that caregiving women tend to fare poorer than caregiving men when it comes to health and well-being: caregiving women tend to have poorer mental health than men, usually in the form of greater depression and anxiety (Miller et al. 2001, Neundorfer et al. 2001; Amirkhanyan and Wolf 2006; Pinquart and Sörensen 2006; Peters et al. 2013; Raggi et al. 2015), poorer health-related quality of life (Patti et al. 2007; Garzón-Maldonado et al. 2017), poorer functional health (Patterson et al. 1998; Pinquart and Sörensen 2006; Vitaliano, Zhang and Scanlan 2003), and experience greater caregiver burden than their male counterparts (Chappell and Penning 1996; Pinquart and Sörensen 2006; Akpinar, Küçükgüçlü and Yener 2011; Aoun et al. 2012; Peters et al. 2013; D'Onofrio et al. 2015; Garre-Olmo et al. 2016; Verbakel, Metzelthin and Kempen 2018; Swinkels et al. 2019). Clearly, gender is a key component in how people experience the stress of caregiving.

A number of findings in the caregiving literature are contingent on the gender of the caregiver. Studying spousal caregivers, Sugiura and colleagues (2009) found that ADL dependency was associated with greater depressive symptoms for husbands taking care of wives, but not for wives taking care of husbands. Penning and Wu (2016) found that caregiving men, but not women, who saw their care receiver daily had poorer self-rated mental health than those who saw their care receiver less often, whereas seeing a care receiver daily compared to less frequently was more stressful for caregiving women but not for caregiving men. Swinkels and colleagues (2019) found that women and men tend to experience burden via different pathways; men tend to experience greater burden through greater hours of caregiving, whereas women tend to experience greater burden through the relational and financial problems caused by caregiving. In the emotional

supporting literature, Väänänen and colleagues (2005) found that women who give more support than they receive were physically healthier than other women, whereas men who receive more support than they give were physically healthier than other men. These findings have at least one thing in common: they reflect people's expectations of their gender roles. That is, women may not experience ADL impairment or caregiving hours in the same way as men because they already expect to have to do this work, whereas for men this may be a new challenge that requires adjustment. Thus, it is prudent to account for gender differences in caregiving and supporting, as well as possible interactions.

Gender determines not just how stress is experienced, but whether a person will be exposed to those stressors. This is one reason many sociologists prefer to use the term 'carework' rather than 'caregiving': there is inequality in the distribution of carework, and some take on more of this work than others (Drentea 2007; Misra 2007). Women are more likely than men to become caregivers: in 2012, 30% of Canadian women claimed to provide care, compared with only 26% of men (Turcotte 2013). For caregivers of persons with dementia in particular, Wong, Gilmour and Ramage-Morin (2016) found that in 2011, 58% of spousal caregivers and 71% of adult-child caregivers caring for parents were women. Emotional supporting is similar. Antonucci and Akiyama (1987) report that men are more likely than women to provide their spouse with emotional social support, but women are more likely than men to support other family members or friends. Similarly, Taylor and colleagues (2000) note that women tend to provide emotional support more frequently, and more effectively, than men. Since emotional aspects of care may be part of women's role expectations, a gender/emotional support interaction effect may exist.

2.9 Limitations of the Literature

I have already specified some specific limitations of particular studies, and also noted a few instances where the literature may be helpful to our understanding of emotional support. Nonetheless, there are some general limitations to the literature that need elucidating. Although emotional elements of caregiving are likely captured within other caregiving variables, they are not typically differentiated from other aspects of care. Other caregiving literature focuses on instrumental aspects of care and care receiver characteristics, ignoring other aspects of caregiving completely. This is problematic considering that most definitions of caregiving are comprehensive, including emotional aspects of care, and that emotional care is a major component of perceived support. The caregiving literature also has a number of general methodological problems: much of the literature is based on small, non-random clinical samples, or is missing key variables. For example, as previously discussed, the median sample size in studies of caregivers of persons with dementia is only 44 participants (Fonareva and Oken 2014). This poses a major problem for the generalizability of the findings.

The non-caregiving emotional supporting and volunteering literatures also have a number of limitations. First, volunteering and caregiving contexts are quite different. Other-oriented volunteering and emotional supporting are similar in a roundabout way: in both cases, people can be motivated by altruism or the desire to ‘give back’. However, volunteering is entirely voluntary, whereas caregivers may not feel they are able to opt-out in the same way they could opt-out of volunteer activities. Even though caregivers may provide care by choice, a sense of familial obligation or guilt could potentially be a stronger deciding factor. Likewise, many caregivers may be sole caregivers who feel

trapped in the caregiving role. Whether emotional support is given willingly or if caregivers do not feel there is an alternative will be an important differentiator. Another problem with this comparison is volunteering can be emotional support (such as a help line), instrumental support (such as community litter cleanup), or both (such as coaching). The literature does not differentiate between these forms of volunteering.

Another difference is the mechanism by which volunteering and emotional supporting affect health and well-being. The benefits of volunteering arise from continued social engagement, the development of new social resources, and feelings of usefulness or belonging (e.g. Musick and Wilson 2003; Li and Ferraro 2006). Supporting someone with a neurological condition does not necessarily foster social engagement. The opposite is probably true, since these caregivers tend to have the smallest, least robust social networks (Aoun et al. 2012; Bailey and Gordon 2016). Alternatively, caregivers might form an intense, meaningful bond with those they care for, with others in the care network, or with people with similar care experiences. Emotional supporting may help caregivers feel useful, but the act of support itself is unlikely to provide caregivers with new social resources, and many caregivers sacrifice their normal social activities to accommodate their duties.

The benefits of volunteering may be due to selection. It is possible that healthier people are more able to volunteer; the causal direction is difficult to determine. The same may apply to supporting. Warner and colleagues' (2010) finding that emotional supporting benefits the physical well-being of people with multiple illnesses casts doubt on selection in the case of emotional support, but given that people in the studied age category are reasonably likely to have multiple conditions, selection cannot be ruled out

entirely. I believe it unlikely that selection is at work in the case of caregivers of persons with neurological conditions. It is established that these caregivers have poorer health and well-being than non-caregivers and other caregivers. Likewise, a large proportion of caregivers emotionally support their care receivers. The notion that people with the poorest health are able to do the most caregiving and provide the most emotional support would be difficult to substantiate theoretically.

Finally, for non-caregiving emotional support studies, the context and frequency of support is drastically different from what we may expect for caregivers of persons with neurological conditions. The volunteering and support giving studies identified typify low-stress, low-frequency situations. Caregivers experience enough stress due to their responsibilities that their health and well-being can deteriorate, and typically spend a lot of time providing care (for instance, Gaskin and colleagues (2017) reported that one-third spend at least 22 hours per week). Emotional supporting may be especially taxing for caregivers of persons with neurological conditions, since care receivers often suffer from cognitive impairment and have trouble managing their emotions. Caregivers may have more in common with formal care workers, such as social workers or nurses experiencing compassion fatigue, than to support givers in low-risk informal settings.

2.10 Summary

The literature is in agreement about the effect of caregiving for and supporting others on our health and well-being, with a few points of contention. Caregiving is detrimental for mental health, functional health, and well-being, and in most cases is likely to be more detrimental when more care work is required. Emotional supporting in

general is beneficial for mental health, functional health, and well-being, with some limited evidence of a mortality benefit. Volunteering is beneficial for mental health and well-being, particularly at older ages. There is some evidence that volunteering is beneficial for health-related quality of life or functional health, but the variety of measures used makes the synthesis of this research difficult. Sustained volunteering is more beneficial than intermittent volunteering, but volunteering too much is no better than abstaining altogether. However, the literature is not without problems. The failure of volunteering literature to differentiate between types of volunteering makes its applicability limited. The context, motivation, and mechanisms behind volunteering and emotional supporting as present in the literature and behind emotional support giving as done by caregivers may be different. Glaring methodological problems, such as sampling limitations, make generalizability difficult, and possible selection issues make causation difficult to determine.

We have two options in applying the literature to caregivers of persons with neurological conditions. It could be that, despite contextual and motivational differences, emotional supporting helps caregivers. Perhaps emotional supporting helps caregivers to better deal with their own emotional problems, to form or maintain a close relationship with their care receiver, or to perceive positive aspects of caregiving (such as a feeling of life purpose). This aligns with the helper therapy principle of Riessman (1965). Alternatively, caregivers might perceive emotional supporting as an obligation and another source of stress. In this case, emotional care may cause compassion fatigue, and accumulation of negative support experiences may deteriorate health and well-being via emotional contagion. These positions are explained in greater detail in the next chapter.

CHAPTER 3. THEORETICAL PERSPECTIVES

Theories that address stress and caregiving are well-developed and address the roles of both support-receiving and instrumental supporting on caregiver outcomes. However, these theories have not considered the independent role of emotional supporting on caregiver outcomes, or where emotional support might fit within the stress process. The stress process can provide the framework, but to explain where emotional support fits in the model and how it works I advocate for the integration of theories from outside the caregiving literature. These perspectives are not always complementary; rather, they offer opposing explanations that have yet to be tested in the caregiving context. It is important to note that not all aspects of these theories will be testable with the available data, so I focus on those which have been measured, in the hope that this work will serve as a starting point for future research and theory to build upon.

3.1 Stress Process Theory

The single most important theoretical approach to the study of caregiving is the stress process model. The stress process is conceptualized as encompassing three conceptual domains: sources of stress, mediators and modifiers of stress, and manifestations of stress (Pearlin et al. 1981). Although previous research had focused on individual stress domains, or combinations between two, Pearlin and colleagues (1981) were the first to identify all three domains as being part of an interconnected process. The stress process arises from and is influenced by the structural arrangements in which people are embedded, which determines which stressors they are exposed to, which

mediators they can make use of, and the manner in which they experience stress (Pearlin 1989). As such, stressful experiences can be traced back to one's location within social structures, such as socioeconomic status, ethnicity, gender, and age (Pearlin 1989). Inhabiting major institutionalized roles, such as family roles, can exert a persistent structuring force on experience which can be stressful when problems occur and the roles become chronic strains (Pearlin 1989). Stress originates within the social order, so structural context is not simply a list of variables to be controlled but an intrinsic part of the sociological study of stress and the stress process (Pearlin 1989). Pearlin and colleagues (1990) later referred to structural influences as the 'context of stress', now identified as the fourth conceptual domain of stress.

Sources of stress, or stressors, fit into two categories: discrete life events and continuous life strains (Pearlin et al. 1981). Life events often exert their effects via life strains, either by bringing these strains into focus or by creating or intensifying them (Pearlin et al. 1981). Events and strains are more likely to cause stress when they result in diminishment of self, particularly with regard to mastery and self-esteem (Pearlin et al. 1981). Many continuous strains originate in people's social roles, of which Pearlin (1989) identifies five: role overload, where the demands of a role exceed a person's capability to meet them; interpersonal conflicts, where people in complementary roles have problems or difficulties; inter-role conflict, where people have trouble satisfying the incompatible demands of multiple roles; role captivity, where a person performs a role unwillingly; and role restructuring, where alterations in long-established patterns are forced. However, not all continuous strains are role strains; ambient strains, such as having a chronic illness or living in poverty, cut across roles (Pearlin 1989).

Stress process theory distinguishes between primary and secondary stressors. Stressors rarely occur singularly; if someone is exposed to one stressor, it is likely they are exposed to others (Pearlin 1989). These stressors form clusters of related events and strains (Pearlin 1989). Primary stressors are those that occur first, and may be either a life event, such as a job loss, or a continuous strain, such as living in an unhappy marriage (Pearlin 1989). Secondary stressors are a consequence of primary stressors, such as economic stress caused by a job loss (Pearlin 1989). The labels primary and secondary are strictly temporal, and do not refer to the importance of the stressors themselves.

Pearlin (1989) specifically uses family caregivers of impaired relatives as an example to demonstrate stressors. Informal caregiving to family members who require assistance is an instance of the role restructuring continuous strain, since caregiving usually occurs within and causes alterations to long-established husband-wife or parent-child relationships (Pearlin 1989). Although caregiving is a normal part of any close relationship, prolonged impairment can turn caregiving from an ordinary activity into the "dominant, overriding component" of the relationship where it becomes a major source of stress (Pearlin et al. 1990). Primary stressors might include vigilance in monitoring the care receiver, psychological losses accumulated due to the care receiver's deterioration, caregiver exhaustion, and overload (Pearlin 1989). Later, Pearlin and colleagues (1990) identified care receivers' cognitive status, behavioural problems, and functional difficulty as primary stressors, since many of a caregiver's other problems grow from these care receiver needs. Secondary stressors include increased conflict with others (including inter-role conflict), economic strain from diminished income or increased expenditure, and loss of social relationships or outside activities due to having less free time (Pearlin

1989). They might also include other role strains, as discussed above, and intrapsychic strains, which have to do with diminished self-concept (Pearlin et al. 1990). That is, disruptions caused in one area of life, such as the need to provide care to family members, can cause subsequent disruptions in other areas.

Stress outcomes are affected by mediators, which are behaviours, perceptions, and cognitions people use to protect themselves from stress (Pearlin et al. 1981). Stress mediators are sometimes referred to as resources when they reduce the effect of stressors on manifestations or outcomes. Pearlin identifies three types of mediators: social support, coping, and self-concept (Pearlin et al. 1981; Pearlin 1989). Social support depends not only on the size of one's social network, but on the quality of social relations within that network (Pearlin et al. 1981). Social support refers only to the social resources that a person actually uses to deal with their stressors; typically, the resources available to a person are less than what their social network might otherwise suggest (Pearlin 1989). Coping falls into three categories: people can modify the situation to reduce stress, they can modify the meaning of the situation so they interpret it as less stressful, or they can find ways to manage their stress (Pearlin et al. 1981). Since different people use different coping methods to deal with stressors, and some may use no coping at all, it is important that stress research be sensitive to coping (Pearlin 1989). A person's self-concept can also buffer the effects of stressors on stress outcomes (Pearlin 1989). Aspects of self-concept can include: mastery, or a person's belief in their ability to control and change their life; self-efficacy, or a person's belief in their ability to succeed and accomplish tasks; and self-esteem, or a person's confidence and belief in their self-worth. Mediators can

intervene at many places in the stress process, and explain how people experiencing the same stressors can have different stress outcomes (Pearlin et al. 1981).

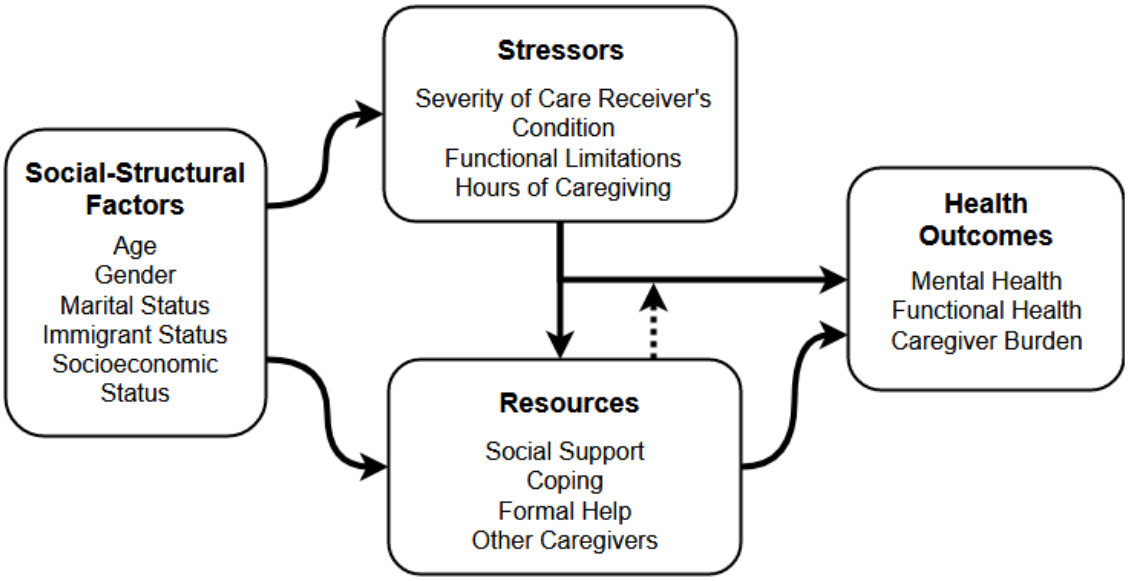
Manifestations of stress, or stress outcomes, are people's responses to stressful conditions. Pearlin and colleagues (1981) use depression as a stress outcome because it is sensitive to chronic undesired experiences and to change in self-concept. However, stress can influence other aspects of mental health, such as anxiety. Likewise, it may have effects on other aspects of general health, and previously studied stress outcomes include: health histories, physical symptoms, drug and alcohol abuse, and social disruption (Pearlin 1989). Since none of these outcomes have a compelling theoretical priority over another, the use of multiple outcomes is preferred in stress research (Pearlin 1989). Additionally, Pearlin (1989) suggests sociologists use knowledge about many aspects of health, emanating from other disciplines such as biology or medicine, to demonstrate the consequences of social structure.

The stress process as well as example variables that pertain to the caregiving of people with neurological conditions are illustrated in Figure 1.

3.2 Caregiver Appraisals and the Stress Process

Although the stress process model has been subject to many modifications, one is particularly relevant to caregiving: the appraisal model of Yates, Tennstedt and Chang (1999). The appraisal model adds caregivers' appraisal of the stressors they experience and resources they use to the stress process model in order to view caregiving as a process involving active participants (Yates, Tennstedt and Chang 1999). Caregivers are not passive objects absorbing stress, but have agency in determining how much strain

Figure 1. The Stress Process



Source: Pearlin et al. 1990.

they are exposed to, whether they perceive potential strains as stressful, and how they react to stress.

The appraisal model distinguishes between primary appraisals and secondary appraisals. In the stress process, ‘hours of care’ is usually considered a stressor. In the appraisal model it might be considered a primary appraisal because hours of care is determined by the caregiver based on how much care they believe is needed, or are capable of giving (Yates, Tennstedt and Chang 1999). Caregivers appraise the situation, and respond to it. In the stress process model, ‘overload’ is also considered a stressor, but is considered a secondary appraisal in the appraisal modification because it is a subjective measure based on a caregiver’s evaluation of their feelings (Yates, Tennstedt and Chang 1999). For secondary appraisals, a caregiver considers their strains, and how much their primary appraisals have exposed them to these strains, and determines if this has resulted in a caregiving situation that is too stressful. The appraisal model helps explain why care receivers with similar needs receive different levels of care, and why caregivers with similar stressors giving similar levels of care experience stress differently (Yates, Tennstedt and Chang 1999). In sum, appraisals are non-mediating parts of the stress process that have subjective elements. The primary advantage of the appraisal model is that it allows us to think of caregiving as a dynamic process involving active participants, and it provides a theoretical justification for variability between caregivers.

3.3 Helper Therapy Principle

Despite Pearlin’s protestation, the distinct role of emotional supporting has not been investigated in the caregiving context, and so its place within the stress process is

unknown. I turn to other theories and concepts to explore the influence of supporting and suggest the place it might have in the stress process. The first of these is the helper therapy principle of Riessman (1965), which describes the tendency of people who give help to benefit from their role, even when the people who actually receive the help do not benefit. Helper therapy has been applied successfully in drug addiction therapy, criminal recidivism, academic tutoring and teaching, and leadership training. Helper therapy works because helpers have high commitment to their helping role, and demonstrate improved self-concept due to the role (Riessman 1965). Depending on context, other mechanisms can include the feeling of improved status or importance of gaining a new helping role, diversion from their own problems, and learning through teaching (helpers must be more knowledgeable in a subject than the people they help in order to teach effectively) (Riessman 1965). Helper therapy also has potential dangers: therapist projection, whereby helpers project their own problems onto the person they are helping; psychological contagion, whereby affect is transferred from the helper to the person they are helping or vice versa; and helper awareness, where the benefits of helper therapy are undermined if a helper is aware they have been placed in a role for their own benefit (Riessman 1965).

The helper therapy principle has been substantiated in the volunteering and emotional support literature. Giving support to others has benefits for the person giving support, namely for health and well-being. However, the context of past research explainable by the helper therapy principle is different from caregiving for someone with a neurological condition, enough so that the application of the principle cannot be assumed. In accordance with past research, if the helper therapy principle is capable of

explaining the effect of emotional supporting a care receiver, we might expect caregivers who give emotional support to have better health and well-being than caregivers who do not provide such support to their care receivers. Given that people with neurological conditions often suffer from degeneration of their cognitive function and behavioural inhibition, caregivers to these people might find emotional supporting to be more arduous than usual, which may open the door to emotional contagion and undermine the helper therapy principle.

3.4 Compassion Fatigue

A concept that will help explain emotional supporting is compassion fatigue. Usually applied to health workers in formal settings such as nurses, compassion fatigue describes the emotional drain, exhaustion, and cynicism experienced by caregivers who were previously dedicated to their work (Lynch and Lobo 2012). It usually occurs after caring for people with progressive illnesses or when experiencing other chronically stressful situations (Lynch and Lobo 2012). Compassion fatigue is often described as a secondary traumatic stress reaction, but the two concepts are unique in that compassion fatigue occurs as a result of empathy and the desire to help (Lynch and Lobo 2012). The defining attributes of compassion fatigue are empathy, an established relationship between caregiver and care receiver, shared experiences, and chronic stress, which result in a psychological response (Lynch and Lobo 2012). The consequences of compassion fatigue include: psychological effects, such as apathy, depression, anxiety, isolation, and loss of objectivity; physical symptoms, such as exhaustion, weight change, hypertension, and sleep disturbances; social symptoms, such as chemical or food abuse, loss of social

contact, and frustration with others; spiritual symptoms, such as doubting ones' beliefs and values, and losing the ability to feel joy; and professional symptoms, such as job dissatisfaction and overworking (Lynch and Lobo 2012).

Compassion fatigue has been applied to informal family caregivers. Lynch and Lobo's (2012) review found that many family caregivers experience symptoms of compassion fatigue, even though none of the studies reviewed made use of the concept; Day and Anderson (2011) came to the same conclusion, reviewing the literature on caregivers of persons with dementia specifically. The concept seems to match the family caregiving experience well. Even though family caregivers are unlikely to have exposure to as many care receivers for as many hours as nurses, many have intense and frequent interactions with their care receiver, and are driven by empathy and a desire to help people they have an established relationship with. Day and Anderson (2011) suggest that caregivers with strong attachment to their care receiver may be especially at risk of compassion fatigue, since they may not be able to distance themselves.

Compassion fatigue has the opposite effect of the helper therapy principle. Instead of benefiting the helper, compassion fatigue represents a decline in the health and well-being of caregivers who are emotionally invested in their care receivers. Emotional supporting fundamentally requires empathy and emotional investment. If compassion fatigue is capable of explaining the effect of emotional supporting, we might expect caregivers who emotionally support to have poorer health and well-being than caregivers who do not provide support.

3.5 Emotional Contagion

Emotional contagion is a possible mechanism for the effect of emotional supporting on caregivers' health and well-being. Hatfield, Cacioppo and Rapson (1993) were integral to the development of the concept of emotional contagion, sometimes referred to as psychological contagion, stress contagion, or the perception-action model of empathy. Emotional contagion describes the transference of emotional state or stress from one person to another. As with any stressor or mediator in the stress process, it is possible that chronic exposure to a particular affect and the transfer of this affect from care receiver to caregiver may influence caregiver outcomes. Since people typically need emotional support to help them with negative affect or other problems, and since the degradation of care receiver's cognitive abilities and inhibitions often leads to emotional instability, it is likely that caregivers will experience consistent negative affect and that this exposure will deteriorate their mental health (and potentially other aspects of health and well-being).

Hatfield, Cacioppo and Rapson (1993) define emotional contagion as "the tendency to automatically mimic and synchronize expressions, vocalizations, postures, and movements with those of another person's and, consequently, to converge emotionally" (Hatfield, Cacioppo and Rapson 1993:96). The key to emotional contagion is that emotions are more than just feelings: they are 'emotional packages' which include many components, such as facial, vocal and postural expression, neurophysiological and autonomic nervous system activity, and instrumental behaviours (Hatfield, Cacioppo and Rapson 1993). The brain is capable of processing these emotional components even if we do not consciously detect them, and different emotional components can interact because

the brain integrates the emotional information it perceives and projects rather than sequestering it (Hatfield, Cacioppo and Rapson 1993). Thus, emotional contagion is more subtle and automatic than empathy. Buchanan and colleagues (2012) note that emotional contagion is thought to be critical for group behaviour, interpersonal understanding, and empathy.

The first mechanism of emotional contagion Hatfield, Cacioppo and Rapson (1993) identify is mimicry. People subconsciously track and mimic the emotional expressions of other people they observe; often, these changes are so subtle they are only detectable via electromyography (Hatfield, Cacioppo and Rapson 1993). Likewise, people tend to mimic the vocal tempo (such as speech rate or response latency) and posture of people they interact with (Hatfield, Cacioppo and Rapson 1993). Mimicry happens almost instantly and is not done deliberately. In fact, people are generally not very good at conscious mimicry, which tends to appear as obviously fake to others (Hatfield, Cacioppo and Rapson 1993).

The second mechanism of emotional contagion is feedback. A person's outward emotional expressions and inward emotional feelings or brain activity form a feedback loop. In experiments, subjects' emotional experiences tend to be affected by the facial expressions and vocal patterns they adopt; if a participant is made to smile throughout an experiment, they end up with higher positive affect, whereas frowners end up with higher negative affect (Hatfield, Cacioppo and Rapson 1993). A similar relationship has been found between facial expressions and autonomic nervous system activity: making particular facial expressions generates the accompanying autonomic nervous system arousal (Hatfield, Cacioppo and Rapson 1993). By merely acting a certain way, we can

affect our mental state. As a consequence of people's automatic mimicry of others' emotional behaviour, and the subsequent emotional feedback loop, we tend to 'catch' the emotions of people we interact with.

Emotional contagion is well substantiated in the research literature, which has recently focused on the contagion of stress response. For instance, in an experiment with speaker-observer pairs where speakers had to make a speech defending themselves, Buchanan and colleagues (2012) found that observer cortisol levels rose relative to speaker cortisol levels. Observer cortisol response was significantly higher in observers with greater tendency for empathic concern, relative to other observers (Buchanan et al. 2012). Engert and colleagues (2014) ran a similar experiment, but with speaker-observer pairs that were either partners or strangers, using either in-person or video observation. Not only did observer cortisol levels rise relative to speaker cortisol levels, but partner observers experienced a significantly greater cortisol response than stranger observers (Engert et al. 2014). Observers doing real-life observation also had a significantly greater cortisol response than observers watching videos (Engert et al. 2014). Building on this, Dimitroff and colleagues (2017) found that observers viewing stressful situations on video experienced cardiac deceleration, indicating a freezing stress response; this is typical when people experience passive stressors that require no immediate behavioural response. These examples demonstrate that emotional contagion is not simply vicarious, as in people feeling stress because they are viewing a stressful situation, but resonance; people feel stress because people around them, and particularly people they are close to, are stressed.

Emotional contagion has been demonstrated in contexts outside of speaker-observer experiments. Waters, West and Mendes (2014) found that infants pick up on their mother's emotional state and react physiologically, meaning the contagion of emotion can happen at virtually any age, even before a person has developed empathic capacity. In a business management context, Pugh (2001) found that customers who interacted with employees who displayed positive emotions were likely to experience positive affect, and to give positive evaluations of their service. This demonstrates that emotional contagion can occur even in short-term, casual interactions between strangers – even when the emotion being transmitted is not necessarily genuine but part of the emotional labour of a job.

Importantly, emotional contagion has been substantiated in caregiving contexts. Lwi and colleagues (2018), studying spousal caregivers of persons with Alzheimer's disease and frontotemporal dementia, found that caregivers of spouses who gave more frequent and more intense genuine (Duchenne) smiles had better health than caregivers of spouses who did not smile as frequently or intensely. Likewise, greater frequency of fake smiles was associated with poor caregiver mental health (Lwi et al. 2018). People can detect when emotions are genuine or non-genuine, and the distinction between the two matters for social interactions between people who are close. Also from a caregiving context, but this time caregivers of older adults with multiple chronic conditions, Duggleby and colleagues (2016) found caregivers with personality traits that included empathy and compassion were more likely than other caregivers to have poorer mental health. While not emotional contagion per se, it is telling that the people with personality

traits that make them most suitable to do emotional work also tend to fare the poorest in mental health.

When caregivers emotionally support, they may be vulnerable to emotional contagion. Since people with neurological conditions are likely to have emotional instability due to cognitive degeneration and reduced behavioural inhibition, and since people typically need emotional support in order to deal with problems they have, caregivers who emotionally support are more likely to be exposed to negative affect and stress than to positive affect. Since caregivers tend to have close relationships with the people they care for, caregivers are at greater risk for contagion than in other contexts to which they might provide support, and whether caregivers interpret care receiver emotions to be genuine becomes important to their outcomes.

3.6 Summary of Hypotheses

Although the stress process model and appraisal model provide excellent frameworks with which to investigate the health and well-being of caregivers, the place of emotional supporting within the model cannot be assumed. Since supporting by caregivers has not been investigated empirically, other theories and concepts used to explain supporting elsewhere can be applied to the caregiving context. These are the helper therapy principle, which holds that helping others is beneficial to the helper via high commitment and improved self-concept even if the person receiving help does not benefit, and compassion fatigue, which holds that empathic caregivers exposed to chronic stressors experience emotional drain, exhaustion, and mental strain. A possible mechanism for these theories is emotional contagion, the process by which emotions are

transferred from one person to another. Since both explanations are viable, I do not favour one over the other. However, given that informal caregiving appears somewhat similar to care in formal contexts and dissimilar to supporting in volunteering contexts, I suspect that compassion fatigue explanation is more likely. Informed by the above theories, the following hypotheses will guide the analysis and following discussion.

1. If the helper therapy principle holds true, I expect that caregivers who emotionally support their care receiver will have better overall mental health than caregivers who do no supporting.
2. If the helper therapy principle holds true, I expect that caregivers who emotionally support their care receiver will have better functional health than caregivers who do no supporting.
3. If the helper therapy principle holds true, I expect that caregivers who emotionally support their care receiver will experience lower caregiver burden than caregivers who do no supporting.
4. If the helper therapy principle holds true, being the sole provider of emotional support to the care receiver should be irrelevant, and I would not expect it to be related to caregiver health and well-being.
5. If compassion fatigue is at work, I expect that caregivers who emotionally support their care receiver will have poorer overall mental health than caregivers who do no supporting.

6. If compassion fatigue is at work, I expect that caregivers who emotionally support their care receiver will have poorer functional health than caregivers who do no supporting.
7. If compassion fatigue is at work, I expect that caregivers who emotionally support their care receiver will experience greater caregiver burden than caregivers who do no supporting.
8. If the contagion of negative affect is at work, being the sole provider of emotional support may be especially cumbersome because caregivers may not feel they have a choice in providing the support, and care receivers may have no other outlets for their negative affect. As such, I expect caregivers who are the sole providers of emotional support to have poorer overall mental health than caregivers who have others to help with emotional support provisioning.
9. Likewise, if the contagion of negative affect is at work, I expect caregivers who are the sole providers of emotional support to have poorer functional health than caregivers who have others to help with emotional support provisioning.
10. Likewise, if the contagion of negative affect is at work, I expect caregivers who are the sole providers of emotional support to experience greater caregiver burden than caregivers who have others to help with emotional support provisioning.

CHAPTER 4. DATA AND METHODOLOGY

In this section, I elaborate on the data source and methods used to examine the relationship of emotional supporting among caregivers of persons with neurological conditions to health and well-being. It is divided into five main subsections: (1) data source; (2) study sample; (3) measures; (4) statistical models; and (5) summary. The first subsection details the data source to be used in the analysis. The second subsection details the sample selection criteria, where I elaborate on why participants are included or excluded from the study subsample. The third subsection details the dependent, explanatory, and control variables used in the analysis, justifies their inclusion, and explains how they will be measured or transformed. The fourth subsection details the statistical models or tests used, including diagnostics. In the last subsection, I provide a brief summary of the methodology.

Altogether, I draw a subsample from the 2012 General Social Survey to build mean comparison tests and OLS regression models in order to determine the impact of emotional supporting, and being the sole emotional supporter, on the health and well-being of caregivers of persons with neurological conditions. Mental health, functional health, and caregiver burden scales are constructed and used as dependent variables in these models. I also include a number of substantiated control variables, and test others that may be influential but lack consensus or are otherwise unproven, in order to account for caregivers' individual contexts, behaviours, resources, and social location.

4.1 Data Source

The data used in this study comes from the twenty-sixth cycle of the General Social Survey (2012 GSS), conducted by Statistics Canada in 2012. The topic of the 2012 GSS is caregiving and care receiving, and this is the sixth time caregiving or social support has been included in the GSS. Covering a broad range of care-related topics, the 2012 GSS includes questions on care receiving, caregiving tasks, caregiving frequency, caregiving network characteristics and sources of support, end-of-life care, consequences of caregiving (including modules on personal and social life, healthy behaviours, employment, and education), health and well-being, and demographic characteristics. Because the 2012 GSS offers information on such a wide variety of caregiving behaviours and caregiver characteristics, it is a good data source for any study focused on the Canadian caregiver population, and is particularly suited to this study. To be specific, I utilize the Public Use Microdata File in the following analysis.

The 2012 GSS dataset is a nationally representative sample of 23,093 people. It includes people age 15 and older, and excludes people who live on reserves or who are full-time residents of institutions. The 2012 GSS only surveyed people who live in Canada's 10 provinces; residents of Yukon, Nunavut, and Northwest Territories are excluded. All respondents were interviewed by telephone, and households without a landline telephone were excluded. Households without a telephone or which only have cellular service represent about 14% of the population, and the data has been weighted to account for these households (Statistics Canada 2014). When a respondent did not speak one of Canada's official languages, or was unable to participate due to a health problem or disability, a proxy was allowed to answer questions on their behalf; 4% of interviews

were completed by proxy (Statistics Canada 2014). The 2012 GSS used stratified random sampling: the provinces were divided into strata based on geography and Census Metropolitan Areas, for a total of 27 strata. Random digit dialing was used to reach respondents within these strata. Data were collected from March 2012 to January 2013. The overall response rate was 65.7%.

4.2 Study Sample

The study sample is restricted to people who provided informal care to someone with a neurological condition in the last twelve months, and who provided at least two hours of care to their care receiver every week, as discussed below. Caregivers are included in the sample regardless of primary caregiver status. Caregivers must also be caring for someone who needs help due to a neurological condition, such as Alzheimer's disease, dementia, Parkinson's disease, multiple sclerosis, spina bifida, or cerebral palsy. Since this study focuses on health and well-being of caregivers, respondents who were interviewed by proxy were excluded from the sample; proxies were not asked many questions pertaining to respondents' health or mental state, as answers would be unreliable. Respondents must also have answered questions pertaining to the dependent and independent variables. With these restrictions, I am left with a sample size of 746 caregivers.

4.2.1 Weekly Hours of Caregiving and Primary Caregiver Status

The cut-off of two weekly caregiving hours was decided by Statistics Canada, who elected not to ask people with fewer than two weekly hours questions about the

consequences of caregiving to avoid unnecessary respondent burden. Since these questions are a key part of this research, respondents who do caregiving work for fewer than two hours every week are excluded. I have not required a higher cut-off for a number of reasons. First, I would like to use a sample size that is as large as reasonably possible, without imposing arbitrary restrictions. I am interested in caregivers as a whole, not only the most or least dedicated ones. The effect of caregiving hours on caregiver health and well-being is already clearly established, and since the variable is continuous in the 2012 GSS statistical models can easily account for it. Second, caregiving is an increasingly common part of family life in developed countries, and neurological conditions are among the toughest for caregivers to deal with. It's reasonable to assume that any exposure to this kind of caregiving may affect a person's health and well-being, so it seems wrong to only include caregivers who have had the most exposure. Third, 'caregiving hours' is a product of a caregiver's appraisal of their capabilities and their care receiver's needs. That is, it is a subjective element potentially influenced by many other factors. It should not be treated as an objective cut-off, because we don't know the reasons behind a caregiver's provision of hours. Last, and related to the previous point, not caregiving when care is required can also be a source of stress for caregivers (Amirkhanyan and Wolf 2006). Caregivers who are not able to provide as many hours of care as they want, or as they feel their care receiver needs, tend to feel a sense of guilt and still feel many of the same caregiver strains.

I have chosen to include caregivers regardless of whether they consider themselves, or are considered by their care receiver, to be the primary caregiver. This is because of the complex nature of caregiving networks. The notion that care networks

have a single ‘primary’ caregiver does not accurately describe most care networks. For instance, Marcum, Ashida and Koehly’s (2018) study of care networks revealed that the majority of care networks have multiple ‘primary’ caregivers, whereas only 6 of the 30 studied networks had a single primary caregiver. Additionally, network members did not always agree on who might be considered a ‘primary’ caregiver (Marcum, Ashida and Koehly 2018). Thus, primary caregiver status is not a good sample criterion, despite its use elsewhere.

4.2.2 Disease Type

The 2012 GSS divides neurological conditions into two categories. These are neurological conditions of dementia type (such as Alzheimer’s disease), and other neurological conditions (such as Parkinson’s disease or ALS). In order to be included in the sample, the care receiver’s primary reason for needing care must fall into one of these categories. As previously discussed, both categories of neurological conditions are included because the predictors of health and well-being of caregivers are similar across neurological conditions, and because neurological conditions tend to be comorbid. By including both neurological condition categories in the analysis (rather than one or the other, or a split model), the sample size is increased, which may reduce sampling error and increase the statistical power of the analysis.

4.3 Measures

4.3.1 Dependent Variables

I use three different measures in order to analyse the effects of caregiving and emotional supporting on health and well-being in a comprehensive manner. For mental health, I have constructed a scale based on ten dichotomous variables which have been summed. Caregivers were asked if, in the past 12 months, their caregiving duties had caused them to feel tired, feel worried or anxious, feel overwhelmed, feel lonely or isolated, feel short-tempered or irritable, feel resentful, feel depressed, experience loss of appetite, experience disturbed sleep, or experience any other similar symptoms. I constructed this scale since the 2012 GSS did not include an established mental health scale. However, this scale shares many questions with the Center for Epidemiological Studies Depression Scale (CES-D) and Patient Health Questionnaire (PHQ-9) mental health instruments, with the notable exclusion of questions on suicidal thoughts. Although this scale is fairly short and uses dichotomous questions, it should also be noted that short mental health scales using dichotomous questions have been found to perform as well, or nearly as well, as their longer counterparts. For instance, Cheung, Liu and Yip (2007) found that 10- and 9-item versions of the CES-D performed very closely to the full 20-item version, and that a 5-item version was only slightly inferior. Likewise, Kohout and colleagues (1993) compared shortened forms of the CES-D and found that a 10-item version using dichotomous questions performed nearly as well as the full CES-D. This mental health scale is an epidemiological tool rather than a clinical one, and a general estimate of the respondent's mental state should be sufficient. The scale has a

range of 0-10, where 0 indicates perfect mental health and 10 indicates poor mental health, and has a Cronbach's alpha of 0.84 indicating high internal consistency. For ease of reference, and to differentiate this scale from others, I refer to this mental health scale as the Caregiving Responsibilities and Mental Health (CRMH) scale.

Functional health is measured using the Health Utilities Index 3 (HUI3) instrument. The HUI3 is a generic, comprehensive measure of health-related quality of life and functional health, and is capable of describing 972,000 unique health states (Horsman et al. 2003). The HUI3 is validated for Canada, and is included in the 2012 GSS. It covers many dimensions of health, including vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. Conventionally, HUI3 has a range of 0-1, where a score of 1 indicates perfect health and a score of 0 indicates death. The HUI3 also allows negative scores for health states that are considered worse than death, for a minimum score of -0.36. The total range is -0.36 to 1. A difference of at least 0.03 on the total HUI3 score is considered clinically significant.

Caregiver burden is measured using a modified version of Robinson's (1983) Caregiver Strain Index (CSI). This measure was chosen because, even though respondents were not asked questions with burden in mind specifically, the scale can still be constructed using information collected in the 2012 GSS. Aspects of strain that make up the CSI include: sleep problems, inconvenience (caregiving takes up too much time or requires a long drive), physical strain, feeling confined (caregiving restricts free time), family adjustments, changes to personal plans (such as turning down a job or cancelling a vacation), emotional adjustments (due to severe arguments or otherwise), upsetting care receiver behaviours, feeling upset that care receiver has changed or declined, work

adjustments, financial strain, and feeling overwhelmed. Each aspect is coded dichotomously and summed. In cases where multiple variables are used to triangulate one aspect, an affirmative answer to any of these variables is counted as an affirmative answer to the aspect. The CSI has a range of 0-12, where 0 indicates no burden and 12 indicates intense burden, and has a Cronbach's alpha of 0.77, indicating an acceptable level of internal consistency. Given that this scale is constructed based on other answers, it may not include all contributors to caregiver burden, and therefore may underestimate the burden actually experienced by caregivers.

4.3.2 Explanatory Variables

There are two explanatory variables of interest measuring subjective, or self-perceived, emotional supporting based on three questions in the 2012 GSS. First, I am interested in whether caregivers provide emotional support to their care receivers generally. Second, I am interested in whether caregivers provide emotional support to their primary care receiver in particular. Last, I am interested in whether caregivers who provide emotional support to their care receivers feel that there is anyone else who can give support, and thus whether they feel they have a choice in providing emotional support. All three questions are dichotomous in the 2012 GSS. The first two questions are combined into a single variable with three possible outcomes: supports primary recipient, supports care recipients but not primary recipient, and no supporting. Since the third question, whether there is anyone else who can provide emotional support, was only asked of respondents who provide emotional support to their primary care receiver, it is recoded to include a third category ('no emotional supporting') to construct the second

variable of interest. Caregiver network characteristics are controlled for to ensure this variable is not simply measuring care network size. Using both explanatory variables provides a more comprehensive account of caregivers' supporting experiences. In addition, since women are more likely to provide emotional support and typically experience different health outcomes compared to men, I include an interaction term for emotional support and gender.

4.3.3 Control Variables

4.3.3.1 Stressors

Three primary stressors are included in the analysis: severity of the care receiver's symptoms, care receiver's functional limitations, and weekly hours of care. Since the 2012 GSS is not specifically focused on neurological conditions, it does not include information on the care receiver's cognitive or behavioural problems. However, since these problems tend to increase with condition severity, severity may serve as a viable replacement. Greater condition severity has been found to be associated with poorer caregiver mental health (Patti et al. 2007; Raggi et al. 2015; Mickens et al. 2018) and functional health (Patti et al. 2007; Fonareva and Oken 2014), as well as greater caregiver burden (Vetter et al. 1999), for caregivers of persons with Alzheimer's disease, dementia, or multiple sclerosis. The condition severity variable is coded as 'mild,' 'moderate,' 'severe,' and 'dead' for those care receivers whose condition was so bad it resulted in death. Since severity can depend on the neurological condition in question, disease type is included as a control. This is dichotomous, coded as 'neurological conditions of

dementia type' and 'other neurological conditions'. This variable will control for differences between dementias and the other less common neurological conditions.

How frequently the respondent helps their care receiver with their functional limitations is measured using questions about the care receiver's activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Respondents were asked whether or not they help, and how often they help, with various activities of daily living, including: transportation; meal preparation, cleaning, and laundry; maintenance or outdoor work; personal care such as bathing, dressing, and toileting; taking medication or changing bandages; scheduling, coordinating, or making appointments; finances; and anything else. Each ADL/IADL item is a 5-point scale, coded from 0 to 4, and care receivers indicate whether they help with each ADL/IADL 'daily', 'at least once a week', 'at least once a month', 'less than once a month', or 'never'. The exception is the 'anything else' category, which is dichotomous, coded as 0 and 1. ADL/IADL helping frequencies are summed to form a scale with a range of 0-29, where 0 means the caregiver provides no help with care receiver functional limitations, and 29 represents maximum helping.

Functional limitations are an important component of the model. Caregivers caring for persons who are functionally impaired (usually measured using ADLs/IADLs), and who therefore provide ADL/IADL assistance, tend to have poorer health and well-being than caregivers of persons who are functionally autonomous. This is well-established in the literature. For mental health, this effect of functional limitation has been found in the case of Alzheimer's disease (Neundorfer et al. 2001; Raggi et al. 2015), dementia (Chappell and Penning 1996; Wang et al. 2018), CIND (Fisher et al. 2011),

Parkinson's disease and multiple sclerosis (Figved et al. 2007), and all neurological conditions as a group (Mitchell et al. 2015). For caregiver burden, this effect has been found in the case of Alzheimer's disease (Conde-Sala et al. 2010; Haro et al. 2014; Park et al. 2015; Raggi et al. 2015; Garre-Olmo et al. 2016), dementia (Chappell and Penning 1996), Parkinson's disease (Goldsworthy and Knowles 2008), spinal cord injury (Rodakowski et al. 2012; Tough et al. 2017), ALS and motor neuron disease (Aoun et al. 2012; Oh et al. 2015). This effect is less certain in the case of health-related quality of life or functional health, but has been found among caregivers of persons with dementia or Parkinson's disease (Goldsworthy and Knowles 2008; Wang et al. 2018). Functional limitations may also impact health and well-being indirectly, such as through weekly hours of care (Yates, Tennstedt and Chang 1999).

'Weekly hours of care' is included as a continuous variable with a range of 2-100; the variable is right-censored so that caregivers who provide over 100 hours of weekly care are considered to provide 100 hours. Previous studies have found that caregivers of persons with neurological conditions who contribute a greater number of daily or weekly hours of care tend to have poorer mental health (Peters et al. 2013; Mitchell et al. 2015) and experience greater caregiver burden (Chappell and Reid 2002; Peters et al. 2013; Oh et al. 2015; Park et al. 2015; Galvin et al. 2016) than caregivers who contribute fewer hours. The relationship between caregiving hours and functional health or health-related quality of life is less clear: both Pinquart and Sörensen (2007) and Peters and colleagues (2013) found that caregivers who contribute a greater number of hours to have poorer physical health than other caregivers, but Hooker and colleagues (2002) found no relationship in the case of dementia. Hours of care must be included in the model as an

important predictor of mental health and burden, but its inclusion may also help to further elucidate its effect on health-related quality of life.

4.3.3.2 Appraisals

Use of relief/respite care and whether the respondent feels they had a choice in taking on their caregiving duties are included as appraisal variables. Use of relief or respite care is coded dichotomously; either the caregiver has had relief, or they have not had relief. Caregivers take breaks from caregiving as a result of their appraisal of their capabilities; if a caregiver does not find caregiving stressful, they may not be inclined to take breaks. However, use of respite or relief is also contingent on availability of access to respite or relief services. There is some evidence in the literature that caregivers who take breaks from caregiving or who are able to take advantage of respite services have better functional health (Goldsworthy and Knowles 2008) and experience less caregiver burden (Chappell and Reid 2002; Goldsworthy and Knowles 2008; Liu and Huang 2018) than caregivers who do not. Whether or not caregivers felt that they had a choice in taking on their care duties may also be influential in how they perceive their care experiences. For example, it's reasonable to think that caregivers who do not take on their duties willingly may be unable to perceive positive aspects of caregiving, and may be more likely to view their duties as stressful. Whether caregivers felt they had a choice in taking on their duties is coded as a dichotomous variable; either caregivers felt they had a choice, or they felt they had no choice.

4.3.3.3 Caregiver Resources

Caregiver resources included in the analysis are coping, care network size, informal help, and formal help. The research literature is unclear about the effect of various coping styles or methods on health and well-being, and findings often contradict each other or seem counter-intuitive. Explanations for this include cultural differences in acceptable coping methods, and indeterminate causal direction. Whatever the direction of the relationship, it is clear that coping is an important part of the caregiving process. As such, coping is included as a dichotomous variable. Respondents were asked if they have used any specific coping methods to help them deal with their caregiving responsibilities; respondents could answer either ‘yes’ or ‘no’.

Care network size is measured as the number of other people providing care to the care receiver. It is a continuous variable with a range of 0-60. In the case of Alzheimer’s disease, having a greater number of caregivers is associated with poorer caregiver mental health (Lou et al. 2015); that is, care receivers who require the most help affect caregiver mental health the most. The number of caregivers can be considered a measure of informal support. Past research demonstrates that caregivers with greater levels of informal instrumental support actually tend to have better mental health and experience less caregiver burden than caregivers without such support (Clyburn et al. 2000; Miller et al. 2001). Given that this finding flows in a different direction, it is prudent to include a separate informal support variable. This informal help variable is a dichotomous variable; respondents indicated that they either received informal help from extended family, friends, neighbours, or their community, or they did not receive informal help.

Formal help is measured as weekly hours of formal help received from professionals. This variable has a range of 0-5, where 0 is ‘no help’, 1 is ‘less than 1 hour’, 2 is ‘1 hour to less than 3 hours’, 3 is ‘3 hours to less than 5 hours’, 4 is ‘5 hours to less than 10 hours’, and 5 is ’10 hours or more’. Research on the effect of formal help on health and well-being is mixed, but it is still important to account for it. For instance, Miller and colleagues (2001) and Williams (2005) found that caregivers who utilize formal services tend to have poorer mental health than caregivers who don’t use formal services. Mitchell and colleagues (2015) found the opposite: formal services utilization was associated with good caregiver mental health. These findings are not necessarily contrary, and may reflect measurement differences, requiring care in interpretation. For example, using formal care may improve a caregiver’s mental health, but caregivers who are at the point where formal care is required may already be doing poorly.

4.3.3.4 Caregiving Context

Contextual variables include caregiver’s relationship to the care receiver, coresidence, institutionalization, primary caregiver status, and number of children less than 15 years of age living in the household. The first contextual variable is the caregiver’s relationship to their care receiver. The 2012 GSS contains 25 different possible relationships. These are collapsed and recoded into 6 categories of who the respondent is caring for: ‘spouse’, ‘parent’, ‘child’, ‘other family’, ‘friend or neighbour’, or ‘other’. The caregiver’s relationship to the person they care for is an important predictor of health and well-being. The literature is not clear on whether people caring for their spouses or for their parents, who together make up the overwhelming majority of

caregivers, have better health outcomes. However, both groups tend to have poorer health and well-being than people caring for other family and friends (Chappell and Penning 1996; Park et al. 2015). The caregiver's relationship to their care receiver may also interact with caregiver gender (Penning and Wu 2016).

Caregiver coresidence with their care receiver is included as a dichotomous variable: either caregivers live with their care receiver, or they do not. Coresidence may impact caregiver outcomes because coresiding caregivers may not feel that they are able to escape from the stresses of caregiving; they engage in caregiving constantly. Past research demonstrates that this is the case: caregivers who coreside with their care receivers tend to have poorer mental health (Roth et al. 2009; Mitchell et al. 2015) and physical health (Pinquart and Sörensen 2007; Farina et al. 2017), and experience greater caregiver burden (Rodakowski et al. 2012; Raggi et al. 2015) than caregivers who live apart. Coresidence may only affect the burden experienced by adult-child caregivers, and not spousal caregivers (Conde-Sala et al. 2010; Viñas-Diez et al. 2017). On the other hand, Garre-Olmo and colleagues (2016) found that caregivers who live apart from their care receiver experienced greater burden than coresiders, and Galvin and colleagues (2016) found no relationship between coresidence and burden. The effect of coresidence is not entirely settled, and worth examining in its own right.

Care receiver institutionalization is included as a dichotomous variable. Respondents were asked if their care receiver lives in an institution or care facility, such as a hospital or nursing home; if the respondent answered affirmatively, the care receiver counts as institutionalized. Most research on caregiving does not include institutionalized care receivers, and this is exacerbated by the literature's reliance on clinical convenience

samples. Institutionalized care receivers typically have advanced disease progression and are difficult for family to care for alone. As such, institutionalization may offer relief to caregivers, but may affect their health and well-being in other ways, such as through feelings of guilt. Clyburn and colleagues (2000) found no relationship between institutionalization and the mental health of caregivers of persons with Alzheimer's disease, but did find that caregivers of institutionalized care receivers experienced less caregiver burden than caregivers of community-living care receivers. On the other hand, Farina and colleagues (2017) found that caregivers of institutionalized care receivers had poorer health-related quality of life than caregivers of community-living care receivers. It appears that institutionalization can be either helpful or harmful to caregivers; in any case, it must be controlled for.

Although primary care status has not been used as a sample inclusion criterion, I include it as a control variable. Respondents were asked if they believe their care receiver considers them to be the primary caregiver. This is coded as a dichotomous variable. This variable may be telling of the caregiver's importance to the care receiver's care network, or of their personal importance to the care receiver in particular, or perhaps the caregiver's perception of their own importance. Finally, I include the number of children age 0 to 14 years living in the caregiver's household. The presence of children is typically not covered in the research literature, but might represent a competing need on caregiver's time. Thus, caregivers without young children may have an advantage regarding their health and well-being outcomes. This variable may not be relevant to caregivers of persons with Alzheimer's disease or other dementias, who tend to be older in age, but may still be relevant to caregivers of persons with other neurological

conditions. This variable is continuous and has a range of 0-3; it is right-censored, so that any number of children greater than three counts as three.

4.3.3.5 Social-Structural Factors

I use caregiver age, sex, marital status, immigrant status, education, employment, and household income, as well as care receiver age and sex, to indicate social location. The literature is in agreement that older caregivers tend to have better mental health, but poorer functional health than younger caregivers (Patterson et al. 1998; Williams 2005; Patti et al. 2007; Peters et al. 2013). However, the relationship between age and burden is less clear. Some have found greater caregiver age to be associated with less burden (Haro et al. 2014; Garre-Olmo et al. 2016), or with greater burden (Oh et al. 2015). Others have found no relationship between the two (Conde-Sala et al. 2010; Galvin et al. 2016). The 2012 GSS does not provide a continuous caregiver age variable in single-age categories; rather, age is collapsed into groups. I have further collapsed the youngest groups so that the caregiver age variable consists of 13 groups of 5, from '15 to 19' to '75 to 79', with a censored '80 years and over' category at the end for a total of 14 groups. I also include an age-squared variable to account for non-linearity in age; even though age is not properly continuous, non-linearity may still be apparent. I also include care receiver age, which is grouped into 5-year categories (with the exception of ages 11 to 14, which form a 4-year category), but is left-censored at '10 years or younger' and right-censored at '100 years and over' for a total of 20 categories. Mitchell and colleagues (2015) have found that caring for an older person tends to be more detrimental to caregiver's mental health than

caring for a younger person. Penning and Wu (2016) found the opposite, but only for male caregivers; care receiver age and caregiver gender may interact.

Caregiver and care receiver gender are both dichotomous variables, categorized as either ‘male’ or ‘female’. The literature agrees almost unanimously that caregivers who are women tend to have poorer mental health (Miller et al. 2001; Neundorfer et al. 2001; Peters et al. 2013; Raggi et al. 2015), poorer health-related quality of life (Patterson et al. 1998; Vitaliano, Zhang and Scanlan 2003; Patti et al. 2007), and experience greater caregiver burden (Chappell and Penning 1996; Akpinar, Küçükgüçlü and Yener 2011; Aoun et al. 2012; Peters et al. 2013; D’Onofrio et al. 2015; Garre-Olmo et al. 2016) than caregivers who are men. Thus, caregiver sex is a particularly important indicator of a caregiver’s social location. There is some evidence that care receiver sex can also affect caregiver health outcomes: caring for a male care receiver is associated with both poorer mental health and greater caregiver burden compared to caring for a female care receiver (Haro et al. 2014; Mitchell et al. 2015).

Caregiver’s marital status is included as a categorical variable with four categories. These are ‘married/living common-law’, ‘widowed’, ‘separated/divorced’, and ‘single, never married’. Unmarried, divorced, and separated caregivers have been found to have poorer mental health compared to married caregivers (Amirkhanyan and Wolf 2006; Trivedi et al. 2014; Penning and Wu 2016). Unmarried, separated, and divorced caregivers likely have fewer sources of family support to draw upon when needed. No strong evidence exists for a relationship between marital status and health-related quality of life or caregiver burden; however the effect on mental health is enough to justify inclusion.

Caregiver's highest level of education completed is included as an ordinal variable. The categories are collapsed to form 5 ranked categories from low to high. These categories are 'less than high school', 'high school', 'trade school, college, or university below bachelor's level', 'bachelor's degree', and 'university above bachelor's level'. Evidence of a relationship between educational attainment and caregiver health and well-being is mixed. In the case of Alzheimer's disease and dementia, Piercy and colleagues (2013) found greater education to be associated with good mental health, whereas Lou and colleagues (2015) found greater education to be associated with poor mental health, and Hooker and colleagues (2002) found no relationship between the two. Likewise, no relationship has been substantiated for health-related quality of life or caregiver burden. However, the possibility of an educational influence on health means this variable cannot be ignored.

As with education, the evidence for a relationship between employment status and caregiver health and well-being outcomes is mixed. Many caregivers are at retirement age, where employment status is less relevant. Others may spend their time caregiving as an alternative to employment, or have no choice but to leave employment for their caregiving duties. As a result, past research is unclear. Some have found that employed caregivers have poorer mental health and experience greater burden than either unemployed or retired caregivers (Rodakowski et al. 2012; Raggi et al. 2015). Penning and Wu (2016) found that both employed and retired caregivers tend to have better mental health than caregivers primarily engaged in other activities. Garre-Olmo and colleagues (2016) found that unemployed caregivers tend to experience greater burden than employed caregivers. The lack of consensus means that employment status cannot

be ignored as a control variable. For employment status, respondents were asked what their main activity was in the last year. This variable is recoded as ‘employed’, ‘retired’, and ‘other’.

Although not often covered in the literature, immigrant status is included as a control in case it is related to cultural differences in caregiving experiences. In Canada, caregiving immigrants face a number of problems that can contribute to difficulty in caregiving, including inflexible employment and barriers to the utilization of formal services due to language difficulty or lack of cultural relevance (Stewart et al. 2006). Studying Chinese-Canadians, Lai (2007) found that immigrant caregivers tended to experience greater caregiver burden than caregivers born in Canada. Immigrant status was also the most important cultural predictor, with a greater magnitude than filial piety (Lai 2007). In the United States, Rote and Moon (2018) found that immigrant caregivers also tend to engage in caregiving activities much more frequently than caregivers born in the U.S. As such, I have included immigrant status is a dichotomous variable, consisting of whether the respondent was born in Canada or another country.

Caregiver’s household income is a variable with 13 ranked but unequal categories, from ‘no income or loss’ through ‘$150,000 or more’. In the literature, caregivers with greater household income tend to have better mental health (Miller et al. 2001; Williams 2005), better health-related quality of life (O’Connor and McCabe 2011; Farina et al. 2017), and experience less caregiver burden (Andrén and Elmståhl 2007) than caregivers with lower household income. However, many studies have also found no relationship between household income and caregiver outcomes, so it should not be surprising if no relationship is found in the present study. Income survey questions also

typically suffer from high non-response and measurement error, which may decrease the utility of the variable.

Although commonly included in caregiving studies, particularly in the United States, I have not included a variable for ethnicity. Given the complex nature of the variable as given in the 2012 GSS, it was difficult to recode in a way that would remain meaningful while simultaneously lending itself to statistical analysis.

4.4 Statistical Models

The analysis was conducted using ordinary least squares (OLS) multiple regression. Multiple regression is a commonly used statistical method which is capable of including, and controlling for the effects of, many variables in predicting one dependent variable (Allison 1999). Another advantage of regression is that it separates out the effect of each independent or control variable, allowing them to be examined on an individual basis (Allison 1999). Ordinary least squares regression in particular is a form of linear, non-weighted (ordinary) regression which seeks the smallest prediction error possible by minimizing the sum of squared residuals (least squares) (Allison 1999). Regression has since served as the basis for many statistical techniques since, including logistic, hierarchical, and structural equation models.

OLS regression is based on a number of assumptions that must be met. Variables must be related to one another in a linear way; error terms must be independent and uncorrelated to one another; and error terms should be homoscedastic, meaning the error should not vary depending on the value of the variable in question. Realistically these assumptions are only met in an approximate way when social science data is used, since

many variables are fundamentally related to one another (such as education and employment), and others tend to be related non-linearly (such as age). Even so, regression is a robust method, and many violations of its assumptions can be detected and corrected for. Non-linear relationships are the easiest to correct for because they simply require variable transformation, such as the inclusion of a quadratic term. In the analysis, a quadratic term is included for caregiver age (age-squared), since age is frequently non-linearly related to other variables.

Other violations include multicollinearity and heteroscedasticity. Multicollinearity occurs when two or more independent or control variables are related to one another, which can make it appear that neither is significantly related to the dependent variable when they actually are (Allison 1999). Multicollinearity is diagnosed by calculating variance inflation factors (VIF). When VIF is above 10, this indicates that multicollinearity is high enough to be a problem. Usually, this can be solved by dropping one of the correlated variables since they will be largely redundant. Heteroscedasticity occurs when the variation changes depending on the level of an independent variable (such as if variation in mental health declined with increasing age) and has the potential to produce biased standard errors (Allison 1999). Heteroscedasticity is diagnosed with the Breusch-Pagan/Cook-Weisberg test, and is solved by using robust standard errors; since robust standard errors tend to produce larger standard errors while leaving coefficients intact, they typically produce more conservative estimates. Both multicollinearity and heteroscedasticity were tested for. No problematic multicollinearity was found; VIF values were typically between 1 and 2, and slightly higher for some categories of

categorical variables. Heteroscedasticity was found and corrected for by using robust standard errors.

Missing values are handled using mean substitution and dummy variables when more than two percent of cases are missing from a variable; otherwise, listwise deletion is used. Variables with a substantial number of missing values were income (17.8% missing, or 140 cases), number of other caregivers (3.8% missing, or 30 cases), weekly hours of formal help (3.1% missing, or 24 cases), and ADL/IADL assistance (3.7% missing, or 29 cases). Three of these variables are very close to the cut-off for mean substitution, and in the analysis there are no significant differences between caregivers with missing values and caregivers without missing values in these variables. Given the large number of missing values for income, this variable must be interpreted with care.

Generation of descriptive statistics, t-tests, OLS regression analysis, and any other necessary statistical tests were conducted using Stata 13, a statistical software package.

4.5 Summary

In sum, I use a variety of measures to determine the impact of emotional supporting, and being the sole emotional supporter, on the health and well-being of caregivers of persons with neurological conditions. In particular, the dependent variables under investigation are mental health, functional health, and caregiver burden. I include a variety of control variables which are substantiated in the literature as being influential for caregiver health and well-being, as well as some which the literature lacks consensus on such as education and employment status. I also include some controls which might be influential but are as yet unproven, such as the presence of children in the household. In

order to accomplish this, I draw a subsample from the 2012 GSS which is representative of Canadian caregivers. OLS regression is used to build the model and examine direct effects.

CHAPTER 5. RESULTS

5.1 Description of the Sample

My empirical analysis begins with a description of the sample. Table 1 shows summary statistics for variables used in the analysis. On average, caregivers of persons with neurological conditions have a CRMH (mental health) score of 3.64 and a CSI (caregiver burden) score of 4.75, indicating a low to moderate level of mental health symptoms and caregiver burden. Caregivers of persons with neurological conditions have a HUI3 (functional health) score of 0.83 on average, indicating that these caregivers tend to have generally good functional health. The standard deviation of each dependent variable indicates a fairly high variability around the mean. For CRMH and CSI, the range indicates that respondents scored across the entire scale, from best mental health and least burden to poorest mental health and greatest burden. Respondents also scored across nearly the entire HUI3 scale, from 1 indicating perfect health to below 0, indicating a state considered to be worse than death. Figure 2 shows the frequency distribution for CRMH; mental health is positively skewed, but with a high degree of variability. Figure 3 shows the frequency distribution for HUI3; functional health is negatively skewed and, although it has a large range, responses are mostly concentrated among fairly good health states. Figure 4 shows the frequency distribution for CSI; burden is negatively skewed with high variability.

To get a better sense of the health status of caregivers of persons with neurological conditions, I compared them to a sample of 4,865 other caregivers. These caregivers were selected using the same criteria as the caregivers of persons with

Table 1. ***Descriptive Statistics of Variables Used in the Analysis***

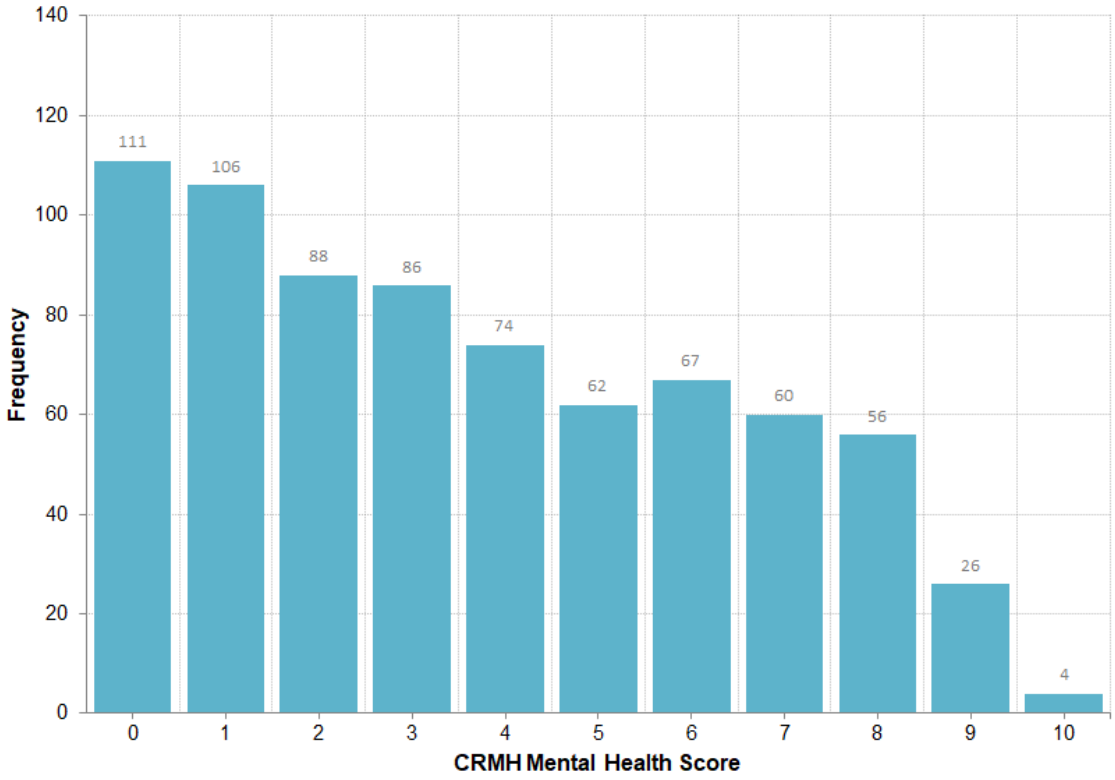
Variable	x̄ or %	SD	Min	Max	N
Caregiving Responsibilities and Mental Health (CRMH)	3.64	2.76	0	10	740
Health Utilities Index (HUI3)	0.83	0.22	-0.228	1	729
Caregiver Strain Index (CSI)	4.75	2.86	0	12	722
Emotional support					746
Supports primary care receiver	95.17%	–	–	–	710
Supports other care receivers, not primary receiver	1.07%	–	–	–	8
Provides no support	3.75%	–	–	–	28
Emotional support					737
No others available to provide support to care receiver	18.32%	–	–	–	135
Others available to provide support to care receiver	76.66%	–	–	–	565
Provides no support	5.02%	–	–	–	37
Severity of care receiver's condition	2.40	0.77	1	4	746
Condition type					746
Neurological conditions of dementia type	60.32%	–	–	–	450
Other neurological conditions	39.68%	–	–	–	296
ADL/IADL help frequency	9.94	6.52	0	28	746
Weekly hours of care	19.24	27.29	2	100	746
Had relief or respite					746
No	76.27%	–	–	–	569
Yes	23.73%	–	–	–	177
Had a choice in taking on care duties					746
No	56.43%	–	–	–	421
Yes	43.57%	–	–	–	325
Uses specific coping methods					746
No	60.59%	–	–	–	452
Yes	39.41%	–	–	–	294
Number of other caregivers	3.47	4.07	0	40	746
Receives informal help from others					746
No	43.57%	–	–	–	325
Yes	56.43%	–	–	–	421
Weekly hours of formal help	1.47	1.87	0	5	746
Respondent is caring for a…					746
Spouse	13.67%	–	–	–	102
Parent	43.43%	–	–	–	324
Child	7.10%	–	–	–	53
Other family	24.26%	–	–	–	181
Friend or neighbour	9.79%	–	–	–	73
Other	1.74%	–	–	–	13
Coresides with primary care receiver					746
No	73.32%	–	–	–	547
Yes	26.68%	–	–	–	199
Primary care receiver is institutionalized					746
No	73.73%	–	–	–	550
Yes	26.27%	–	–	–	196
Is primary caregiver					746
No	48.39%	–	–	–	361
Yes	51.61%	–	–	–	385
Number of children aged 0 to 14 in household	0.28	0.70	0	3	746

Table 1. ***Continued***

Variable	x̄ or %	SD	Min	Max	N
Caregiver age group (groups of 5 years)	8.30	2.99	1	14	746
15 to 39	16.49%	–	–	–	123
40 to 49	17.56%	–	–	–	131
50 to 59 (mean, median, mode)	30.83%	–	–	–	230
60 to 69	22.52%	–	–	–	168
70 to 79	9.65%	–	–	–	72
80 years and over	2.95%	–	–	–	22
Care receiver age group (groups of 5 years)	14.01	4.13	1	19	746
49 years or younger	13.54%	–	–	–	101
50 to 59	6.97%	–	–	–	52
60 to 69	8.58%	–	–	–	64
70 to 79 (mean, median)	21.18%	–	–	–	158
80 to 89 (mode)	38.34%	–	–	–	286
90 years and over	11.39%	–	–	–	85
Caregiver sex		–	–	–	746
Male	34.58%	–	–	–	258
Female	65.42%	–	–	–	488
Care receiver sex					746
Male	35.39%	–	–	–	264
Female	64.61%	–	–	–	482
Marital status					746
Married/common-law	64.21%	–	–	–	479
Widowed	6.43%	–	–	–	48
Separated/divorced	12.47%	–	–	–	93
Single, never married	16.89%	–	–	–	126
Immigration status					
Born in Canada	86.86%	–	–	–	648
Born outside Canada	13.14%	–	–	–	98
Educational attainment	2.80	1.11	1	5	746
Less than high school	11.53%	–	–	–	86
High school	31.10%	–	–	–	232
Trade school, college, university below bachelor's level	30.97%	–	–	–	231
Bachelor's degree	18.63%	–	–	–	139
University above bachelor's level	7.77%	–	–	–	58
Employment status					746
Employed	53.89%	–	–	–	402
Retired	27.48%	–	–	–	205
Other	18.63%	–	–	–	139
Annual household income (13 groups)	9.50	2.51	1	13	746

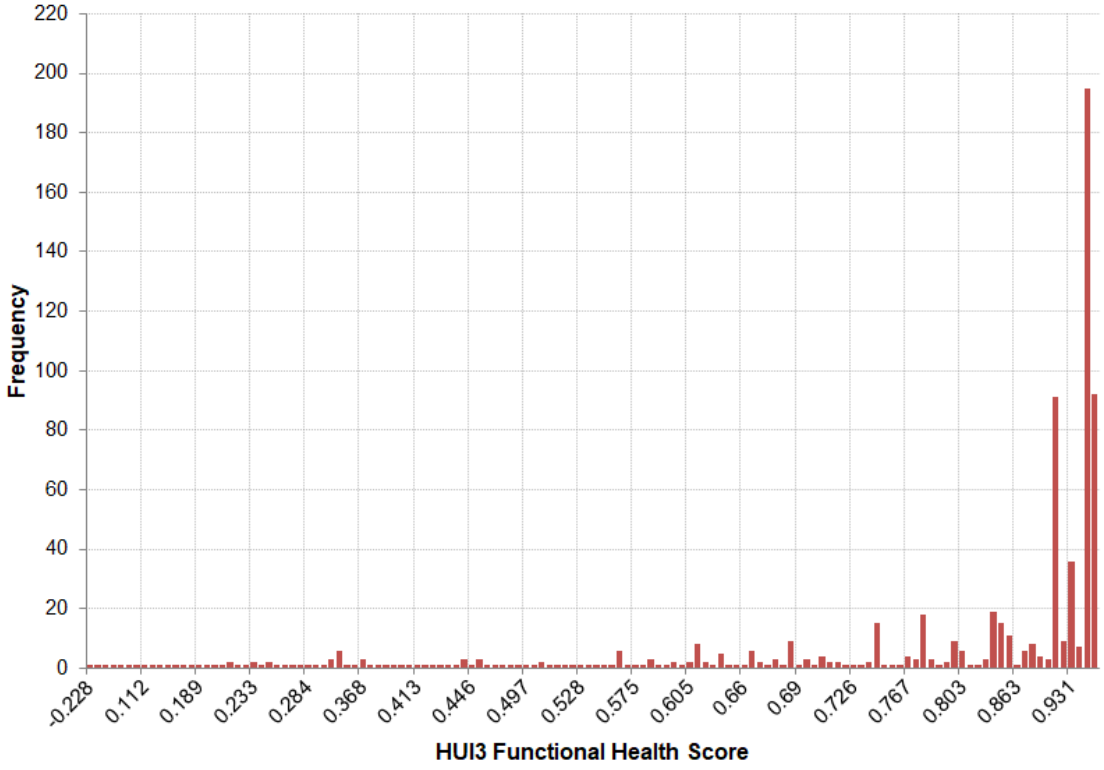
Source: Statistics Canada, General Social Survey, 2012.

Figure 2. Caregiving Responsibilities and Mental Health Frequency



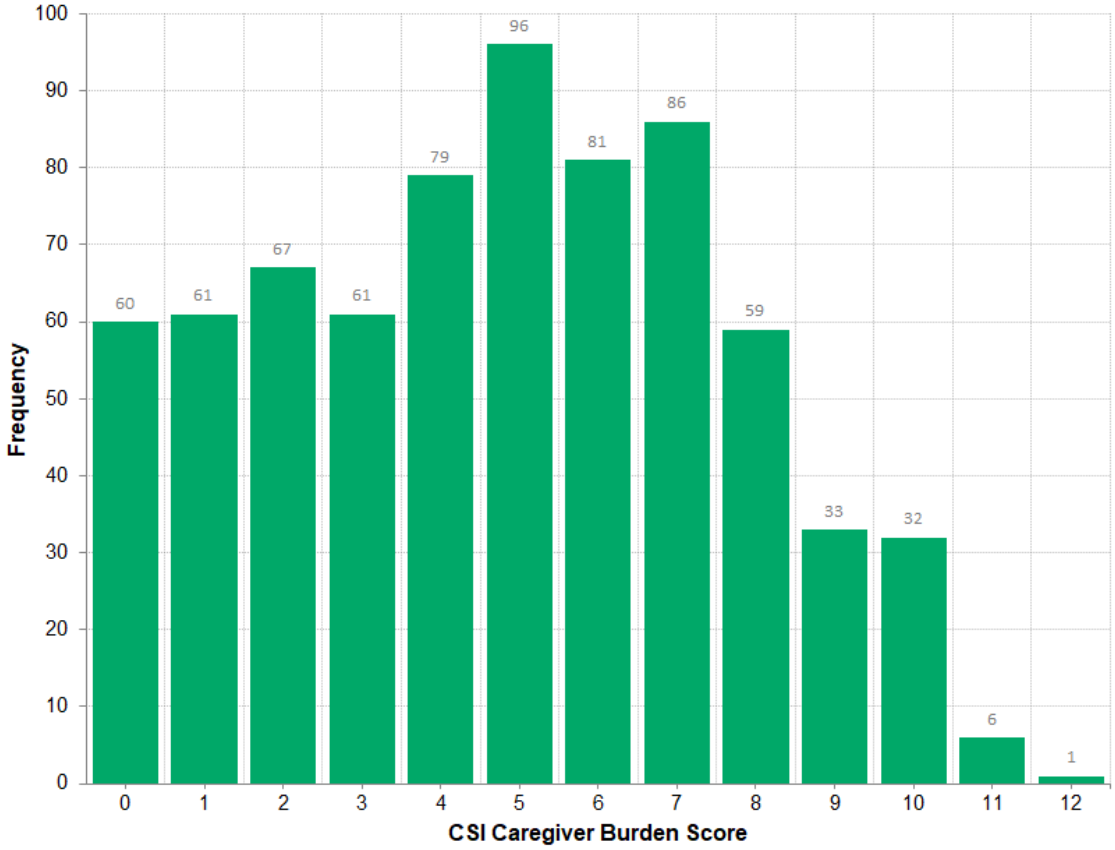
Source: Statistics Canada, General Social Survey, 2012.

Figure 3. Health Utilities Index Frequency



Source: Statistics Canada, General Social Survey, 2012.

Figure 4. Caregiver Strain Index Frequency



Source: Statistics Canada, General Social Survey, 2012.

neurological conditions, except that the primary condition which requires care can include any condition or problem that is not a neurological condition. Table 2 shows summary statistics for this sample of non-neurological-condition caregivers. On average, non-neurological-condition caregivers have a CRMH score of 2.77, a HUI3 score of 0.85, and a CSI score of 3.88. These scores all indicate better health and well-being compared to caregivers of persons with neurological conditions. I conducted a two-sample mean difference test (t-test) to determine if the differences between the two samples were statistically significant. Table 3 shows the results of this test. Tests for all three variables were statistically significant, indicating real differences between the samples. In sum, caregivers of persons with neurological conditions have poorer mental health and experience greater caregiver burden than non-neurological-condition caregivers, on average. Although the difference in HUI3 was significant, the average difference was only 0.02; differences only as low as 0.03 are considered to be clinically significant in the HUI3 scale.

Descriptive statistics for the independent variables generally line up with what is known about caregivers of persons with neurological conditions in the literature. Not surprisingly, a very large proportion (95%) of caregivers of persons with neurological conditions claim to emotionally support their primary care receiver. This aligns with Wong, Gilmour and Ramage-Morin's (2016) finding that 90% of dementia care receivers require emotional support. Among caregivers who emotionally support their primary care receiver, nearly 77% claim that there are others within the support network who are able to provide this type of care to the care receiver; just over 18% claim that there is no one else within the network who can provide this care, meaning that they are the sole

Table 2. ***Summary Statistics of Dependent Variables for All Other (Non-Neurological) Caregivers, N = 4865***

Variable	$\bar{x}$	SD	Min	Max
Caregiving Responsibilities and Mental Health (CRMH)	2.77	2.67	0	10
Health Utilities Index (HUI3)	0.85	0.20	-0.196	1
Caregiver Strain Index (CSI)	3.88	2.79	0	12

Source: Statistics Canada, General Social Survey, 2012.

Table 3. ***Mean Difference Tests for Dependent Variables Comparing Neurological Condition Caregivers to All Other Caregivers***

Variable	$\bar{x}$ Neurological	$\bar{x}$ Other	Difference	t	p
Caregiving Responsibilities and Mental Health (CRMH)	3.635	2.771	0.864***	8.159	<0.0005
Health Utilities Index (HUI3)	0.826	0.848	0.022***	2.740	0.006
Caregiver Strain Index (CSI)	4.749	3.885	0.864***	7.74	<0.0005

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$ (two-tailed test)

Source: Statistics Canada, General Social Survey, 2012.

emotional supporter.

Descriptive statistics for the control variables are typical of samples used in caregiving research. Sixty percent of caregivers were caring for people with dementia-type conditions, such as Alzheimer's disease or frontotemporal dementia, whereas 40% of caregivers were caring for people with other neurological conditions such as ALS, MS, or Parkinson's disease. Care receivers had a condition severity of 2.4 on average, indicating moderate to high severity. ADL/IADL help frequency was 9.9 on average; on a scale from 0 to 29 with a standard deviation of 6.5 this should indicate a low to moderate level of ADL/IADL assistance on average. Weekly hours of care was 19 hours on average, although some respondents indicated spending 100 weekly hours or more caregiving. This recalls Gaskin and colleagues (2017) finding that one-third of caregivers of persons with neurological conditions spend at least 22 hours per week caregiving.

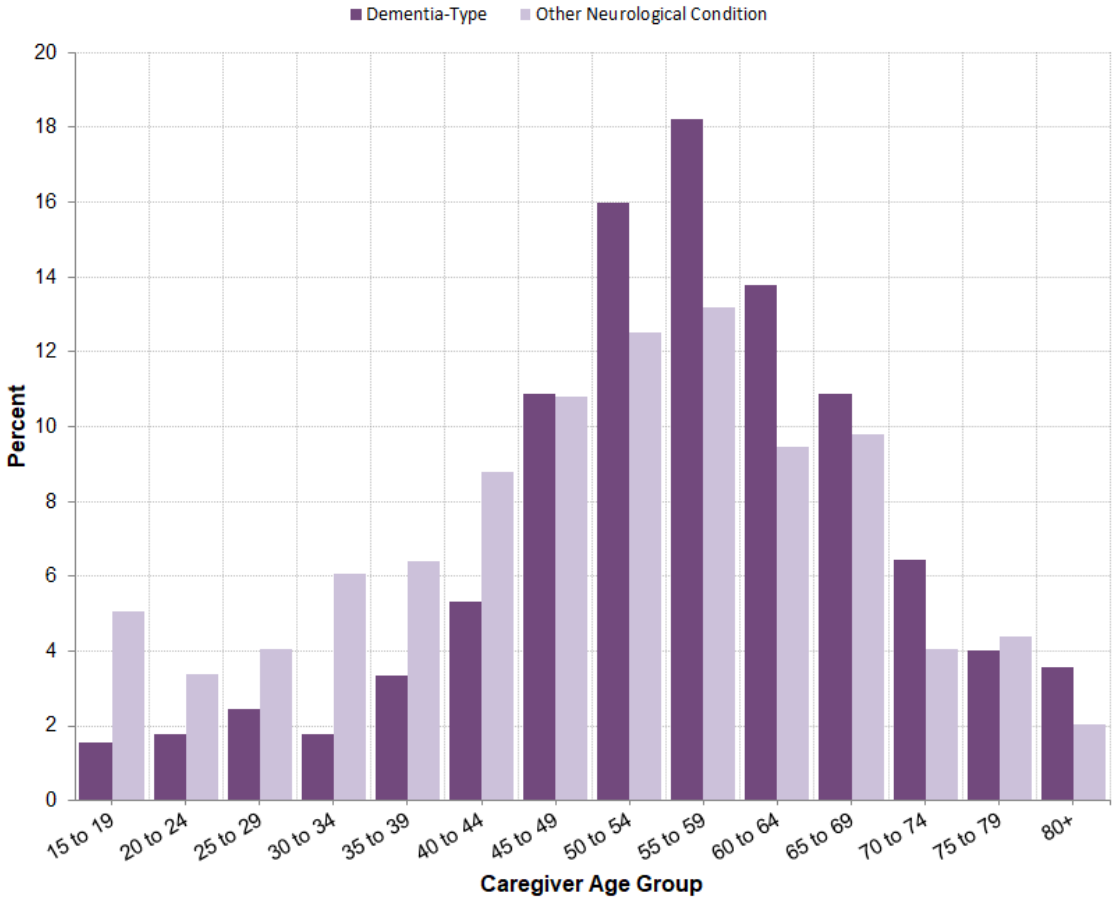
Regarding caregiver appraisals, only 24% of caregivers had relief or respite from caregiving, and just fewer than 44% felt they had a choice in taking on their caregiving role and duties. Regarding caregiver resources, only 39% of caregivers indicated that they used specific coping methods, and 56% indicated that they receive informal help from others. Weekly hours of formal help was 1.5 on average, somewhere between 'less than 1 hour' and '1 hour to less than 3 hours' per week. The average number of other caregivers in the care network was 3.5, with a high standard deviation of 4.1, indicating high variability in care network size. Regarding caregiving context, only about 14% of caregivers were caring for a spouse, whereas 43% of caregivers were caring for a parent, 7% for a child, and 24% for other family. About 27% of caregivers indicated that they coreside with their care receiver, and about 26% indicated that their care receiver is

institutionalized. Nearly 52% of respondents indicated that they are the primary care receiver. The average number of children aged 0 to 14 in the household was 0.28, indicating that many households no longer had young children.

Social-structural variables are also fairly typical. For caregiver age, the mean falls in the '50 to 54' age category; the median and modal age category is '55 to 59'; caregivers of persons with neurological conditions tend to be adults nearing retirement age. For care receiver age, the mean falls in the '70 to 74' age category; the median age category is '75 to 79' and the modal age category is '80 to 84'. This indicates that people with neurological conditions tend to be concentrated in the oldest age groups; half of the care receivers were age 80 or older and over two-thirds were at least age 70. However, caregiver age and care receiver age differ by condition type. Figure 5 shows the percentage frequency distribution for caregiver age by neurological condition type. Caregivers for persons with dementia-type conditions tend to be more concentrated in ages 50-64 compared to caregivers of persons with other neurological conditions. Figure 6 shows the percentage frequency distribution for care receiver age by neurological condition type. Care receivers with dementia-type conditions tend to be concentrated in older age groups, whereas care receivers with other neurological conditions are spread fairly evenly among age groups.

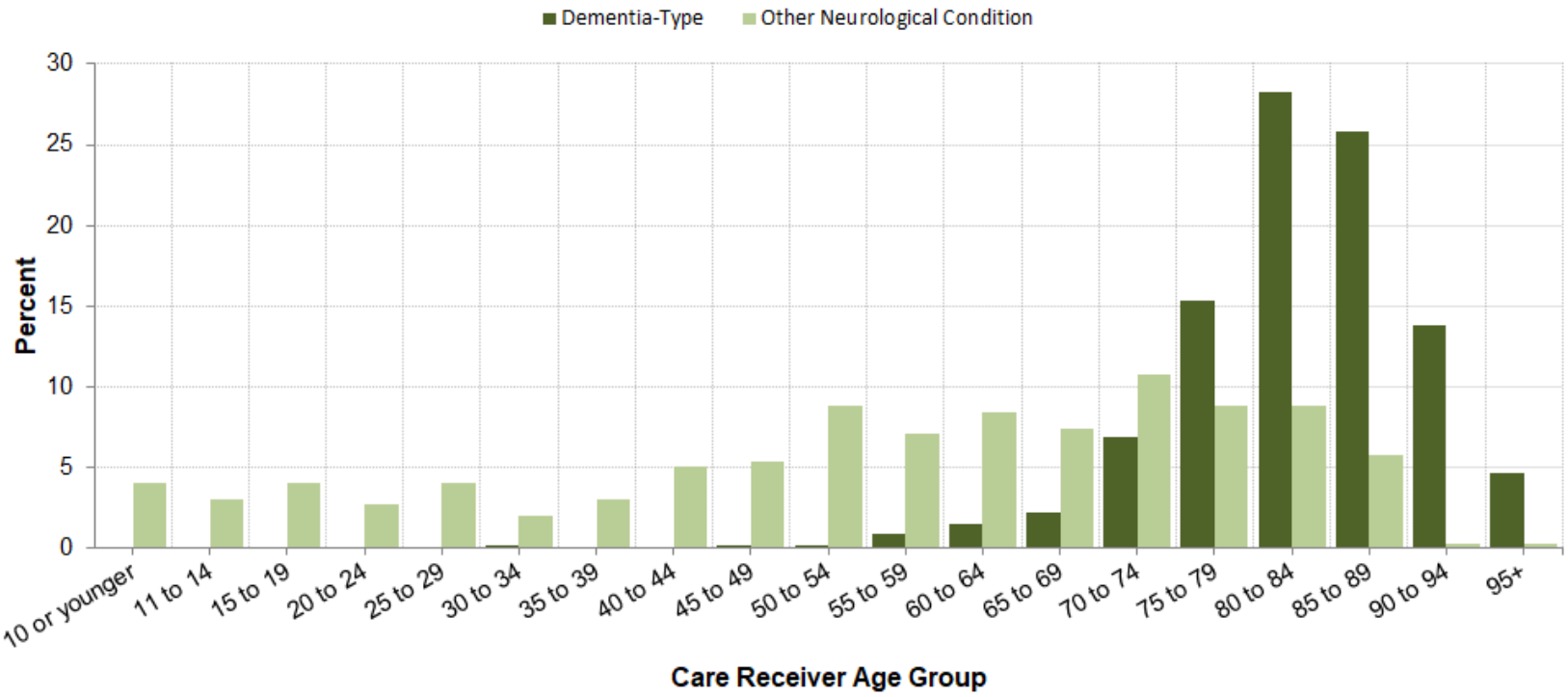
Women represented the majority of both caregivers and care receivers - 65% for each. Married and cohabiting caregivers made up the majority of the sample at 64%; 6% is widowed, 12% separated or divorced, and 17% single. The vast majority of caregivers (87%) were born in Canada. Caregivers' average level of education is 2.8, which falls between 'high school' and 'trade school, college, or university below bachelor's level';

Figure 5. Caregiver Age Proportions by Condition Type



Source: Statistics Canada, General Social Survey, 2012.

Figure 6. Care Receiver Age Proportions by Condition Type



Source: Statistics Canada, General Social Survey, 2012.

these two categories account for nearly two-thirds of caregivers in this sample. Just over half (54%) of caregivers were employed, and just over a quarter (27%) of caregivers were retired. Average annual household income was 9.5, which falls between '$50,000 to $59,000' and '$60,000 to $79,000'.

5.2 Mental Health Models

Next, I estimated the effect of emotional supporting on caregiver mental health by way of two regression models. The results of the first model, estimating self-perceived emotional supporting on caregiver mental health, are given in Table 4. The overall model is significant ($F = 19.36$; $p < 0.00005$) and explains 41.5% of the variance in caregiver mental health. Self-perceived emotional supporting is significantly related to caregiver mental health in this model. Holding other factors constant, caregivers who emotionally support their primary care receiver tend to have poorer mental health on average than caregivers who claim they do not do any emotional care by a difference of 0.839 ($p = 0.028$), nearly a full step on the CRMH scale. An interaction between gender and emotional supporting was tested for, but no significant interaction was found and the interaction term was removed from the model.

The results of the second mental health model, estimating the availability of other emotional supporters on caregiver mental health, are given in Table 5. The overall model is significant ($F = 20.02$; $p < 0.00005$) and explains 42.7% of the variance in caregiver mental health. The availability of other emotional supporters is significantly related to caregiver mental health in this model. Caregivers who report that there are others available who can emotionally support the care receiver ($\beta = -0.995$; $p < 0.0005$) and

Table 4. ***Ordinary Least Squares Regression Model Estimating Effect of Emotional Supporting on Mental Health***

Variable	β		Robust SE	t	p
Emotional support					
Provides no support[a]	–		–	–	–
Supports other care receivers, not primary receiver	1.146		0.973	1.18	0.239
Supports primary care receiver	0.839	*	0.380	2.21	0.028
Severity of care receiver's condition	0.322	**	0.110	2.93	0.004
Condition type					
Neurological conditions of dementia type[a]	–		–	–	–
Other neurological conditions	-0.624	*	0.244	-2.56	0.011
ADL/IADL help frequency	0.081	***	0.018	4.54	<0.0005
Weekly hours of care	0.008	†	0.005	1.84	0.066
Had relief or respite					
No[a]	–		–	–	–
Yes	-0.155		0.221	-0.70	0.484
Had a choice in taking on care duties					
No[a]	–		–	–	–
Yes	-1.006	***	0.189	-5.34	<0.0005
Uses specific coping methods					
No[a]	–		–	–	–
Yes	1.228	***	0.186	6.61	<0.0005
Number of other caregivers	-0.011		0.022	-0.50	0.617
Receives informal help from others					
No[a]	–		–	–	–
Yes	-0.281	†	0.170	-1.66	0.096
Weekly hours of formal help	0.152	**	0.050	3.02	0.003
Respondent is caring for a…					
Spouse[a]	–		–	–	–
Parent	-0.342		0.392	-0.87	0.383
Child	-1.004	*	0.491	-2.04	0.042
Other family	-1.116	**	0.408	-2.73	0.006
Friend or neighbour	-1.502	**	0.478	-3.14	0.002
Other	-1.539	**	0.580	-2.65	0.008
Coresides with primary care receiver					
No[a]	–		–	–	–
Yes	0.035		0.303	0.12	0.908
Primary care receiver is institutionalized					
No[a]	–		–	–	–
Yes	0.334		0.249	1.34	0.181
Is primary caregiver					
No[a]	–		–	–	–
Yes	0.475	*	0.219	2.17	0.030
Number of children aged 0 to 14 in household	0.204		0.134	1.52	0.128
Caregiver age group (groups of 5 years)	0.262	†	0.140	1.87	0.062
Caregiver age group (squared)	-0.021	*	0.009	-2.45	0.015

Table 4. ***Continued***

Variable	β		Robust SE	t	p
Care receiver age group (groups of 5 years)	-0.015		0.040	-0.38	0.701
Caregiver sex					
Male[a]	–		–	–	–
Female	0.598	***	0.177	3.37	0.001
Care receiver sex					
Male[a]	–		–	–	–
Female	-0.025		0.178	-0.14	0.889
Marital status					
Married/common-law[a]	–		–	–	–
Widowed	0.180		0.322	0.56	0.576
Separated/divorced	0.480	†	0.290	1.65	0.099
Single, never married	0.299		0.278	1.08	0.282
Immigration status					
Born in Canada[a]	–		–	–	–
Born outside Canada	0.228		0.263	0.87	0.387
Educational attainment	0.013		0.081	0.16	0.873
Employment status					
Employed[a]	–		–	–	–
Retired	0.075		0.252	0.30	0.767
Other	0.114		0.259	0.44	0.660
Annual household income (13 groups)	-0.050		0.042	-1.18	0.237
Missing: ADL/IADL help frequency	-0.026		0.452	-0.06	0.954
Missing: Number of other caregivers	-0.263		0.528	-0.50	0.618
Missing: Weekly hours of formal help	0.674	†	0.382	1.77	0.078
Missing: Annual household income	0.106		0.231	0.46	0.647
Intercept	1.102		1.032	1.07	0.286
R^2	0.415				
N	740				

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; † $p < 0.1$ (two-tailed test)

[a] Reference group.

Source: Statistics Canada, General Social Survey, 2012.

Table 5. ***Ordinary Least Squares Regression Model Estimating Effect of Availability of other Emotional Supporters on Caregiver Mental Health***

Variable	β		Robust SE	t	p
Emotional support					
No others available to support care receiver[a]	–		–	–	–
Others available to support care receiver	-0.995	***	0.255	-3.90	<0.0005
Provides no support	-1.413	***	0.412	-3.43	0.001
Severity of care receiver's condition	0.294	**	0.109	2.69	0.007
Condition type					
Neurological conditions of dementia type[a]	–		–	–	–
Other neurological conditions	-0.613	*	0.243	-2.52	0.012
ADL/IADL help frequency	0.081	***	0.018	4.47	<0.0005
Weekly hours of care	0.006		0.005	1.29	0.196
Had relief or respite					
No[a]	–		–	–	–
Yes	-0.092		0.220	-0.42	0.677
Had a choice in taking on care duties					
No[a]	–		–	–	–
Yes	-0.958	***	0.191	-5.02	<0.0005
Uses specific coping methods					
No[a]	–		–	–	–
Yes	1.202	***	0.185	6.50	<0.0005
Number of other caregivers	-0.001		0.022	-0.05	0.963
Receives informal help from others					
No[a]	–		–	–	–
Yes	-0.217		0.172	-1.26	0.209
Weekly hours of formal help	0.163	***	0.051	3.22	0.001
Respondent is caring for a…					
Spouse[a]	–		–	–	–
Parent	-0.390		0.393	-0.99	0.323
Child	-0.850	†	0.481	-1.77	0.078
Other family	-1.122	**	0.415	-2.70	0.007
Friend or neighbour	-1.613	***	0.481	-3.35	0.001
Other	-1.898	**	0.606	-3.13	0.002
Coresides with primary care receiver					
No[a]	–		–	–	–
Yes	-0.092		0.301	-0.30	0.761
Primary care receiver is institutionalized					
No[a]	–		–	–	–
Yes	0.344		0.248	1.39	0.166
Is primary caregiver					
No[a]	–		–	–	–
Yes	0.374	†	0.220	1.70	0.089
Number of children aged 0 to 14 in household	0.188		0.134	1.40	0.161
Caregiver age group (groups of 5 years)	0.268	†	0.141	1.90	0.057
Caregiver age group (squared)	-0.022	*	0.009	-2.45	0.014

Table 5. ***Continued***

Variable	β		Robust SE	t	p
Care receiver age group (groups of 5 years)	-0.006		0.040	-0.15	0.881
Caregiver sex					
Male[a]	–		–	–	–
Female	0.585	***	0.176	3.33	0.001
Care receiver sex					
Male[a]	–		–	–	–
Female	-0.074		0.177	-0.42	0.676
Marital status					
Married/common-law[a]	–		–	–	–
Widowed	0.275		0.321	0.85	0.393
Separated/Divorced	0.474		0.295	1.61	0.108
Single, never married	0.352		0.275	1.28	0.202
Immigration status					
Born in Canada[a]	–		–	–	–
Born outside Canada	0.198		0.272	0.73	0.468
Educational attainment	-0.012		0.081	-0.15	0.880
Employment status					
Employed[a]	–		–	–	–
Retired	0.065		0.250	0.26	0.794
Other	0.185		0.255	0.73	0.468
Annual household income (13 groups)	-0.030		0.042	-0.72	0.472
Missing: ADL/IADL help frequency	-0.020		0.428	-0.05	0.962
Missing: Number of other caregivers	-0.140		0.545	-0.26	0.798
Missing: Weekly hours of formal help	0.672	†	0.352	1.91	0.057
Missing: Annual household income	0.130		0.231	0.56	0.574
Intercept	2.599	*	1.034	2.51	0.012
R^2	0.427				
N	731				

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; † $p < 0.1$ (two-tailed test)

[a] Reference group.

Source: Statistics Canada, General Social Survey, 2012.

caregivers who claim they do no emotional care ($\beta = -1.413$; $p = 0.001$) have better mental health compared to caregivers who report that they are the sole emotional supporter for their care receiver. That is, holding other factors constant, being the sole emotional supporter is related to poorer caregiver mental health. Considering the range of the CRMH scale, these effects are large in magnitude. An interaction between gender and the availability of other emotional supporters was tested for, but no significant interaction was found and the interaction term was removed from the model.

The two mental health models are nearly identical in regard to the control variables, with only small differences in beta coefficients and p-values. That is, for statistically significant control variables, the direction and magnitude of the effects are the same. In both models, caregivers who have a care receiver with a dementia-type condition, who help the care receiver with ADLs and IADLs more frequently, who make use of specific coping methods, who receive greater weekly hours of formal help, who consider themselves to be the primary caregiver, and who are women tend to have poorer mental health than caregivers of care receivers with other neurological conditions, who help the care receiver with ADLs and IADLs less frequently, who do not use coping methods, who receive fewer weekly hours of formal help, who do not consider themselves to be the primary caregiver, and who are men, holding other factors constant. Likewise, caregivers who felt they had a choice in taking on their care duties had better mental health than caregivers who felt they had no choice. Caregivers caring for ‘other family’, ‘a friend or neighbour’, and ‘other’ have better mental health than caregivers caring for a spouse; caregivers of a child only had better mental health than caregivers of spouses in the first model, and there was no difference between caregivers caring for a

spouse and parent in either model. Caregiver age is non-linearly related to caregiver mental health, forming an inverted u-shape that peaks in the ‘age 40 to 44’ category; that is, greater age is associated with poorer mental health for younger age groups, but the effect peaks between ages 40 to 44 and greater age becomes associated with better mental health for older age groups. Other control variables were not significantly related to caregiver mental health at the $p < 0.05$ level.

5.3 Functional Health Models

Next, I estimated the effect of emotional supporting on caregiver functional health using two regression models, similar to the previous two mental health models. The results of the first model, estimating self-perceived emotional supporting on caregiver functional health, are given in Table 6. The overall model is significant ($F = 2.33$; $p < 0.00005$) and explains 11.6% of the variance in caregiver functional health. Self-perceived emotional supporting was not significantly related to caregiver functional health in this model. However, the interaction term for gender and emotional supporting was statistically significant. Predictive margins for the interaction are shown in Table 7, and these margins are visualized in Figure 7. The interaction term and margins demonstrate that there is no significant difference between women and men who emotionally support their primary care receiver. For caregivers who claim to do no emotional care, on average women have poorer functional health than men. For caregivers who do emotional care but not for the primary care receiver, men tend to have much poorer functional health than women, but this difference may be a result of a very small number of respondents within this category.

Table 6. ***Ordinary Least Squares Regression Model Estimating Effect of Emotional Supporting on Functional Health***

Variable	β	Robust SE	t	p
Emotional support				
Provides no support[a]	–	–	–	–
Supports other care receivers, not primary receiver	-0.265	0.208	-1.27	0.204
Supports primary care receiver	-0.008	0.057	-0.14	0.886
Emotional support/gender interaction				
Supports other care receivers * female	0.474 *	0.226	2.10	0.036
Supports primary care receiver * female	0.114	0.094	1.21	0.225
Severity of care receiver's condition	-0.017 †	0.010	-1.68	0.094
Condition type				
Neurological conditions of dementia type[a]	–	–	–	–
Other neurological conditions	0.037 †	0.021	1.76	0.079
ADL/IADL help frequency	-0.001	0.002	-0.51	0.613
Weekly hours of care	-0.0003	0.0005	-0.70	0.486
Had relief or respite				
No[a]	–	–	–	–
Yes	0.023	0.020	1.12	0.263
Had a choice in taking on care duties				
No[a]	–	–	–	–
Yes	0.030 †	0.018	1.67	0.096
Uses specific coping methods				
No[a]	–	–	–	–
Yes	-0.032 †	0.018	-1.83	0.068
Number of other caregivers	0.001	0.002	0.35	0.724
Receives informal help from others				
No[a]	–	–	–	–
Yes	0.003	0.018	0.16	0.873
Weekly hours of formal help	0.0001	0.005	0.02	0.981
Respondent is caring for a…				
Spouse[a]	–	–	–	–
Parent	0.061	0.040	1.51	0.130
Child	0.013	0.048	0.27	0.789
Other family	0.067 †	0.040	1.66	0.097
Friend or neighbour	0.047	0.046	1.01	0.314
Other	0.067	0.050	1.36	0.175
Coresides with primary care receiver				
No[a]	–	–	–	–
Yes	-0.031	0.029	-1.07	0.285
Primary care receiver is institutionalized				
No[a]	–	–	–	–
Yes	-0.009	0.024	-0.39	0.695
Is primary caregiver				
No[a]	–	–	–	–
Yes	0.022	0.021	1.05	0.295

Table 6. ***Continued***

Variable	β		Robust SE	t	p
Number of children aged 0 to 14 in household	0.001		0.012	0.07	0.943
Caregiver age group (groups of 5 years)	-0.027	*	0.012	-2.21	0.028
Caregiver age group (squared)	0.001	†	0.001	1.70	0.090
Care receiver age group (groups of 5 years)	-0.001		0.003	-0.28	0.776
Caregiver sex					
Male[a]	–		–	–	–
Female	-0.118		0.093	-1.26	0.206
Care receiver sex					
Male[a]	–		–	–	–
Female	0.005		0.019	0.27	0.789
Marital status					
Married/common-law[a]	–		–	–	–
Widowed	0.001		0.038	0.03	0.973
Separated/divorced	-0.041		0.030	-1.36	0.176
Single, never married	-0.030		0.028	-1.08	0.280
Immigration status					
Born in Canada[a]	–		–	–	–
Born outside Canada	0.042	*	0.021	1.99	0.047
Educational attainment	0.020	**	0.008	2.57	0.010
Employment status					
Employed[a]	–		–	–	–
Retired	0.011		0.026	0.42	0.673
Other	-0.043		0.026	-1.62	0.105
Annual household income (13 groups)	0.007	†	0.004	1.93	0.054
Missing: ADL/IADL help frequency	0.0010		0.051	0.03	0.980
Missing: Number of other caregivers	-0.011		0.050	-0.23	0.822
Missing: Weekly hours of formal help	-0.051		0.050	-1.02	0.308
Missing: Annual household income	-0.0003		0.022	-0.01	0.989
Intercept	0.823	***	0.101	8.19	<0.0005
R^2	0.116				
N	729				

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; † $p < 0.1$ (two-tailed test)

[a] Reference group.

Source: Statistics Canada, General Social Survey, 2012.

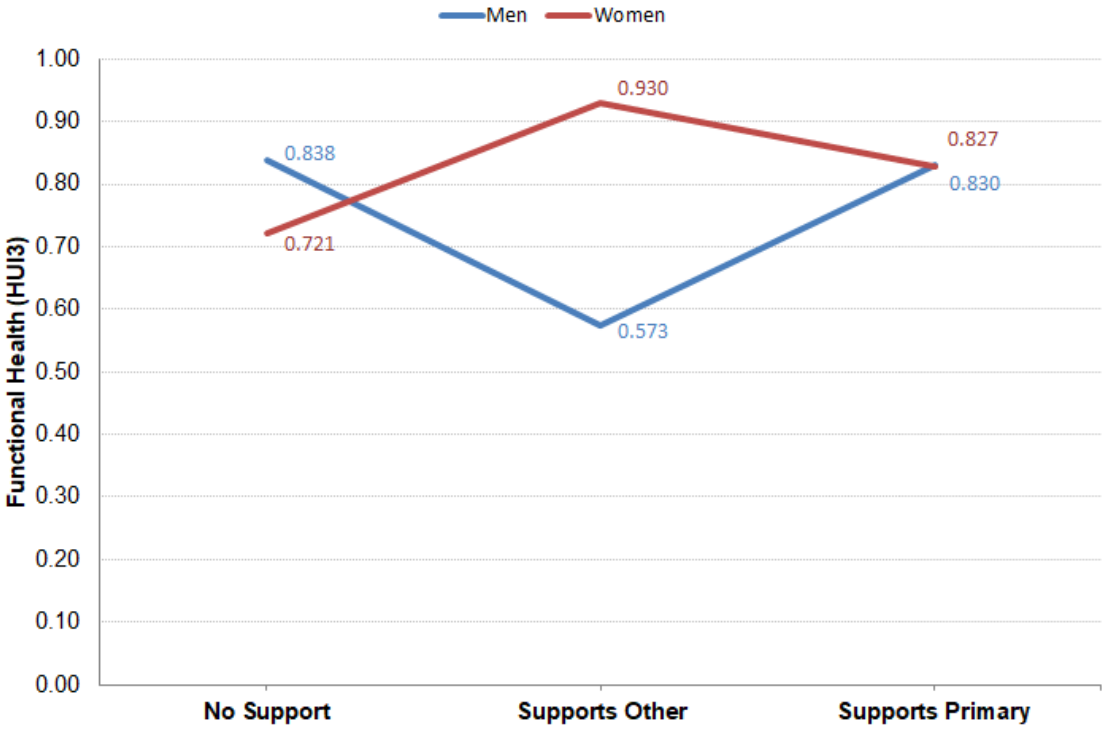
Table 7. ***Predictive Margins of Functional Health for each Emotional Support/Gender Interaction Combination***

Variable	Margin	Delta-method Std. Err.	t	p
Male				
Provides no support	0.838 ***	0.056	14.950	<0.0005
Supports other care receivers, not primary receiver	0.573 **	0.200	2.87	0.004
Supports primary care receiver	0.830 ***	0.014	58.71	<0.0005
Female				
Provides no support	0.721 ***	0.074	9.70	<0.0005
Supports other care receivers, not primary receiver	0.930 ***	0.053	17.40	<0.0005
Supports primary care receiver	0.827 ***	0.009	87.04	<0.0005

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$ (two-tailed test)

Source: Statistics Canada, General Social Survey, 2012.

Figure 7. Predictive Margins of Functional Health



Source: Statistics Canada, General Social Survey, 2012.

The results of the second functional health model, estimating the availability of other emotional supporters on caregiver functional health, are given in Table 8. The overall model is significant ($F = 2.10$; $p = 0.0002$) and explains 11.3% of the variance in caregiver functional health. The availability of other emotional supporters is significantly related to caregiver functional health in this model. Caregivers who report that there are others available who can emotionally support the care receiver ($\beta = 0.062$; $p = 0.016$) have better functional health compared to caregivers who report that they are the sole emotional supporter for their care receiver. That is, holding other factors constant, being the sole emotional supporter is related to poorer caregiver functional health. The size of this difference is small (0.062), but meets the HUI3 criteria for clinical significance ($\geq$ 0.03). An interaction between gender and the availability of other emotional supporters was tested for, but no significant interaction was found and the interaction term was removed from the model.

Like the mental health models, the two functional health models are nearly identical in regard to the control variables. In both models, caregivers who were younger in age, who were born outside of Canada, and who had a greater level of educational attainment had better functional health on average than caregivers who were older in age, who were born in Canada, and who had a lower level of educational attainment, holding other factors constant. Other control variables were not significantly related to caregiver functional health at the $p < 0.05$ level.

Table 8. ***Ordinary Least Squares Regression Model Estimating Effect of Availability of other Emotional Supporters on Caregiver Functional Health***

Variable	β		Robust SE	t	p
Emotional support					
No others available to support care receiver[a]	–		–	–	–
Others available to support care receiver	0.062	*	0.026	2.41	0.016
Provides no support	0.015		0.049	0.31	0.754
Severity of care receiver's condition	-0.013		0.010	-1.26	0.209
Condition type					
Neurological conditions of dementia type[a]	–		–	–	–
Other neurological conditions	0.035	†	0.021	1.65	0.099
ADL/IADL help frequency	-0.0005		0.002	-0.28	0.780
Weekly hours of care	-0.0003		0.0005	-0.64	0.519
Had relief or respite					
No[a]	–		–	–	–
Yes	0.015		0.020	0.74	0.457
Had a choice in taking on care duties					
No[a]	–		–	–	–
Yes	0.026		0.019	1.42	0.155
Uses specific coping methods					
No[a]	–		–	–	–
Yes	-0.032	†	0.018	-1.81	0.071
Number of other caregivers	0.0002		0.002	0.10	0.920
Receives informal help from others					
No[a]	–		–	–	–
Yes	-0.002		0.018	-0.13	0.898
Weekly hours of formal help	0.001		0.005	0.15	0.882
Respondent is caring for a…					
Spouse[a]	–		–	–	–
Parent	0.070	†	0.042	1.69	0.091
Child	0.015		0.048	0.32	0.752
Other family	0.071	†	0.041	1.73	0.084
Friend or neighbour	0.064		0.048	1.33	0.182
Other	0.101	†	0.052	1.95	0.051
Coresides with primary care receiver					
No[a]	–		–	–	–
Yes	-0.019		0.029	-0.65	0.516
Primary care receiver is institutionalized					
No[a]	–		–	–	–
Yes	-0.007		0.024	-0.30	0.764
Is primary caregiver					
No[a]	–		–	–	–
Yes	0.026		0.020	1.26	0.208
Number of children aged 0 to 14 in household	0.002		0.012	0.18	0.856
Caregiver age group (groups of 5 years)	-0.027	*	0.013	-2.09	0.037
Caregiver age group (squared)	0.001	†	0.001	1.67	0.096

Table 8. ***Continued***

Variable	β		Robust SE	t	p
Care receiver age group (groups of 5 years)	-0.002		0.003	-0.55	0.581
Caregiver sex					
Male[a]	–		–	–	–
Female	-0.002		0.017	-0.11	0.909
Care receiver sex					
Male[a]	–		–	–	–
Female	0.009		0.019	0.49	0.622
Marital status					
Married/common-law[a]	–		–	–	–
Widowed	0.001		0.040	0.04	0.972
Separated/divorced	-0.042		0.030	-1.40	0.162
Single, never married	-0.028		0.029	-0.99	0.322
Immigration status					
Born in Canada[a]	–		–	–	–
Born outside Canada	0.043	*	0.021	2.01	0.045
Educational attainment	0.020	*	0.008	2.50	0.013
Employment status					
Employed[a]	–		–	–	–
Retired	0.010		0.026	0.38	0.702
Other	-0.043		0.027	-1.59	0.113
Annual household income (13 groups)	0.006		0.004	1.56	0.119
Missing: ADL/IADL help frequency	0.002		0.052	0.04	0.965
Missing: Number of other caregivers	-0.025		0.050	-0.51	0.612
Missing: Weekly hours of formal help	-0.060		0.052	-1.16	0.247
Missing: Annual household income	-0.010		0.022	-0.45	0.655
Intercept	0.760	***	0.101	7.54	<0.0005
R^2	0.113				
N	721				

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; † $p < 0.1$ (two-tailed test)

[a] Reference group.

Source: Statistics Canada, General Social Survey, 2012.

5.4 Caregiver Burden Models

Finally, I estimated the effect of emotional supporting on caregiver burden using two regression models, akin to the prior caregiver health outcomes. The results of the first model, estimating self-perceived emotional supporting on caregiver burden, are given in Table 9. The overall model is significant ($F = 21.41$; $p < 0.00005$) and explains 45.3% of the variance in caregiver burden. Self-perceived emotional supporting was not significantly related to caregiver burden in this model. An interaction between gender and emotional supporting was tested for, but no significant interaction was found and the interaction term was removed from the model.

The results of the second caregiver burden model, estimating the availability of other emotional supporters on caregiver burden, are given in Table 10. The overall model is significant ($F = 21.51$; $p < 0.00005$) and explains 45.8% of the variance in caregiver burden. The availability of other emotional supporters is significantly related to caregiver burden in this model. Caregivers who report that there are others available who can emotionally support the care receiver ($\beta = -0.752$; $p = 0.002$) and caregivers who claim they do no emotional care ($\beta = -1.097$; $p = 0.009$) experience less caregiver burden compared to caregivers who report that they are the sole emotional supporter for their care receiver. That is, holding other factors constant, being the sole emotional supporter is related to greater caregiver burden. Considering the range of the CSI scale, these effects are large in magnitude. An interaction between gender and the availability of other emotional supporters was tested for, but no significant interaction was found and the interaction term was removed from the model.

Table 9. ***Ordinary Least Squares Regression Model Estimating Effect of Emotional Supporting on Caregiver Burden***

Variable	β		Robust SE	t	p
Emotional support					
Provides no support[a]	–		–	–	–
Supports other care receivers, not primary receiver	0.218		0.722	0.30	0.762
Supports primary care receiver	0.598		0.457	1.31	0.191
Severity of care receiver's condition	0.437	***	0.115	3.81	<0.0005
Condition type					
Neurological conditions of dementia type[a]	–		–	–	–
Other neurological conditions	-0.465	*	0.233	-1.99	0.047
ADL/IADL help frequency	0.110	***	0.018	5.94	<0.0005
Weekly hours of care	0.008	†	0.005	1.81	0.070
Had relief or respite					
No[a]	–		–	–	–
Yes	-0.087		0.226	-0.39	0.700
Had a choice in taking on care duties					
No[a]	–		–	–	–
Yes	-1.099	***	0.198	-5.57	<0.0005
Uses specific coping methods					
No[a]	–		–	–	–
Yes	1.404	***	0.183	7.66	<0.0005
Number of other caregivers	-0.035		0.023	-1.53	0.126
Receives informal help from others					
No[a]	–		–	–	–
Yes	0.022		0.175	0.12	0.901
Weekly hours of formal help	0.179	***	0.051	3.50	<0.0005
Respondent is caring for a…					
Spouse[a]	–		–	–	–
Parent	-0.008		0.400	-0.02	0.984
Child	-0.375		0.496	-0.76	0.450
Other family	-0.685	†	0.401	-1.71	0.088
Friend or neighbour	-0.966	*	0.477	-2.02	0.043
Other	-1.406	*	0.636	-2.21	0.027
Coresides with primary care receiver					
No[a]	–		–	–	–
Yes	0.164		0.286	0.57	0.567
Primary care receiver is institutionalized					
No[a]	–		–	–	–
Yes	0.549	*	0.260	2.12	0.035
Is primary caregiver					
No[a]	–		–	–	–
Yes	0.257		0.224	1.15	0.251
Number of children aged 0 to 14 in household	0.306	*	0.144	2.12	0.034
Caregiver age group (groups of 5 years)	-0.032		0.147	-0.22	0.827
Caregiver age group (squared)	-0.002		0.009	-0.23	0.821

Table 9. ***Continued***

Variable	β		Robust SE	t	p
Care receiver age group (groups of 5 years)	0.007		0.041	0.17	0.863
Caregiver sex					
Male[a]	–		–	–	–
Female	0.357	*	0.180	1.99	0.047
Care receiver sex					
Male[a]	–		–	–	–
Female	-0.301	†	0.180	-1.67	0.095
Marital status					
Married/common-law[a]	–		–	–	–
Widowed	-0.146		0.340	-0.43	0.668
Separated/divorced	-0.105		0.311	-0.34	0.736
Single, never married	-0.544	†	0.289	-1.88	0.060
Immigration status					
Born in Canada[a]	–		–	–	–
Born outside Canada	0.110		0.254	0.43	0.664
Educational attainment	0.040		0.083	0.48	0.632
Employment status					
Employed[a]	–		–	–	–
Retired	-1.130	***	0.244	-4.63	<0.0005
Other	-0.973	***	0.261	-3.73	<0.0005
Annual household income (13 groups)	-0.033		0.041	-0.80	0.422
Missing: ADL/IADL help frequency	-0.386		0.512	-0.75	0.452
Missing: Number of other caregivers	-0.247		0.567	-0.44	0.663
Missing: Weekly hours of formal help	0.841		0.535	1.57	0.116
Missing: Annual household income	-0.084		0.231	-0.36	0.716
Intercept	2.852	**	1.068	2.67	0.008
R^2	0.453				
N	722				

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; † $p < 0.1$ (two-tailed test)

[a] Reference group.

Source: Statistics Canada, General Social Survey, 2012.

Table 10. ***Ordinary Least Squares Regression Model Estimating Effect of Availability of other Emotional Supporters on Caregiver Burden***

Variable	β		Robust SE	t	p
Emotional support					
No others available to support care receiver[a]	–		–	–	–
Others available to support care receiver	-0.752	**	0.239	-3.15	0.002
Provides no support	-1.097	**	0.421	-2.60	0.009
Severity of care receiver's condition	0.391	***	0.115	3.41	0.001
Condition type					
Neurological conditions of dementia type[a]	–		–	–	–
Other neurological conditions	-0.483	*	0.233	-2.07	0.039
ADL/IADL help frequency	0.109	***	0.018	5.92	<0.0005
Weekly hours of care	0.006		0.005	1.37	0.170
Had relief or respite					
No[a]	–		–	–	–
Yes	0.0030		0.224	0.01	0.989
Had a choice in taking on care duties					
No[a]	–		–	–	–
Yes	-1.067	***	0.199	-5.35	<0.0005
Uses specific coping methods					
No[a]	–		–	–	–
Yes	1.350	***	0.182	7.42	<0.0005
Number of other caregivers	-0.027		0.023	-1.19	0.233
Receives informal help from others					
No[a]	–		–	–	–
Yes	0.080		0.178	0.45	0.652
Weekly hours of formal help	0.175	***	0.051	3.44	0.001
Respondent is caring for a…					
Spouse[a]	–		–	–	–
Parent	-0.005		0.397	-0.01	0.991
Child	-0.355		0.485	-0.73	0.464
Other family	-0.642		0.401	-1.60	0.110
Friend or neighbour	-1.079	*	0.481	-2.24	0.025
Other	-1.616	*	0.641	-2.52	0.012
Coresides with primary care receiver					
No[a]	–		–	–	–
Yes	0.067		0.282	0.24	0.814
Primary care receiver is institutionalized					
No[a]	–		–	–	–
Yes	0.548	*	0.259	2.12	0.035
Is primary caregiver					
No[a]	–		–	–	–
Yes	0.209		0.227	0.92	0.357
Number of children aged 0 to 14 in household	0.295	*	0.143	2.06	0.040
Caregiver age group (groups of 5 years)	-0.050		0.146	-0.34	0.731
Caregiver age group (squared)	-0.0004		0.009	-0.04	0.964

Table 10. ***Continued***

Variable	β		Robust SE	t	p
Care receiver age group (groups of 5 years)	0.008		0.041	0.19	0.851
Caregiver sex					
Male[a]	–		–	–	–
Female	0.362	*	0.179	2.02	0.044
Care receiver sex					
Male[a]	–		–	–	–
Female	-0.349	†	0.178	-1.96	0.051
Marital status					
Married/common-law[a]	–		–	–	–
Widowed	-0.074		0.339	-0.22	0.826
Separated/divorced	-0.074		0.315	-0.24	0.814
Single, never married	-0.553	†	0.286	-1.93	0.054
Immigration status					
Born in Canada[a]	–		–	–	–
Born outside Canada	0.101		0.259	0.39	0.697
Educational attainment	0.034		0.082	0.42	0.675
Employment status					
Employed[a]	–		–	–	–
Retired	-1.161	***	0.245	-4.74	<0.0005
Other	-0.932	***	0.260	-3.59	<0.0005
Annual household income (13 groups)	-0.016		0.041	-0.39	0.700
Missing: ADL/IADL help frequency	-0.323		0.517	-0.62	0.533
Missing: Number of other caregivers	-0.176		0.576	-0.31	0.760
Missing: Weekly hours of formal help	0.817		0.527	1.55	0.121
Missing: Annual household income	-0.041		0.233	-0.18	0.859
Intercept	4.085	***	1.023	3.99	<0.0005
R^2	0.458				
N	714				

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; † $p < 0.1$ (two-tailed test)

[a] Reference group.

Source: Statistics Canada, General Social Survey, 2012.

As with the prior caregiver health outcomes, the two caregiver burden models are nearly identical in regard to the control variables. In both models, caregivers who have a care receiver with greater condition severity, who have a care receiver with a condition of the dementia-type, who help the care receiver with ADLs and IADLs more frequently, who make use of specific coping methods, who receive greater weekly hours of formal help, who care for a care receiver who is institutionalized, and who are women tend to experience greater caregiver burden on average than caregivers who have care receivers with less severe conditions, who have care receivers with other neurological conditions, who help the care receiver with ADLs and IADLs less frequently, who do not use coping methods, who receive fewer weekly hours of formal help, who care for community-living care receivers, and who are men, holding other factors constant. Likewise, caregivers who felt they had a choice in taking on their care duties experienced lower caregiver burden than caregivers who felt they had no choice. Spousal caregivers tended to experience greater burden than caregivers caring for a 'friend or neighbour' or 'other'; there were no significant differences between spousal caregivers and those caring for a parent, child, or other family member. On average, employed caregivers tend to experience greater burden than caregivers who are retired or who are primarily engaged in other activities. Finally, caregivers with a greater number of children between 0 and 14 years of age living in their household tend to experience greater burden than caregivers with fewer children, controlling for other factors. Other control variables were not significantly related to caregiver burden at the $p < 0.05$ level.

CHAPTER 6. DISCUSSION AND CONCLUSION

Emotional care is a key element of caregiving. This is especially true for the care of people with neurological conditions, the overwhelming majority of whom require emotional support from their caregivers (Wong, Gilmour and Ramage-Morin 2016). In corollary, when people think back on support they receive, they tend to think of emotional forms of support more than any other (Gottlieb 1978; House 1981). As noted in the literature review, caregiving studies have tended to focus on caregiving in a general sense, or have selected variables that are oriented toward instrumental aspects of care. Likewise, related literature on emotional supporting and volunteering may not be strictly compatible with the caregiving context due to differences in motivation, obligation, social engagement, support frequency, and possible selection effects. It is not entirely clear whether emotional care is protective of or detrimental to caregiver health and well-being. There are compelling perspectives pointing in either direction, in particular the helper therapy principle of Riessman (1965) on the side of protection, versus the compassion fatigue and emotional contagion perspectives as elaborated by Lynch and Lobo (2012), Day and Anderson (2011), and Hatfield, Cacioppo and Rapson (1993) on the side of detriment. This leaves us with a number of questions. What effect, if any, does emotional supporting or care have on caregiver health and well-being? How do social-structural factors or elements of social location, such as caregiver gender, come into it? And, as Pearlin (1989) asked so many years ago, where does emotional supporting fit within the stress process?

6.1 Reviewing the Results

My results demonstrate an effect of emotional supporting on caregiver health and well-being, although the effect varies depending on the specific outcome variable in question. Comparing caregivers of persons with neurological conditions to other caregivers, I found that caregivers of persons with neurological conditions tend to have poorer mental health and experience greater caregiver burden than other caregivers. This aligns with Gaskin and colleagues' (2017) finding that caregivers of persons with neurological conditions are more likely than other kinds of caregivers to experience symptoms of distress. It also indicates that the results of the multivariate analysis are specific to caregivers of persons with neurological conditions rather than being the product of caregiving in general. While these results could possibly apply to other types of caregivers, they are not guaranteed to do so, given differences between caregivers of persons with neurological conditions and other caregivers.

In multivariate analysis, using self-perceived emotional supporting as the independent variable, I found that caregivers who emotionally support tend to have poorer mental health than those who do not. Using the availability of other emotional supporters as the independent variable, I found that caregivers who are the sole emotional supporters for their care receivers tend to have poor mental health compared to caregivers who report that there are others available who can emotionally support the care receiver. These findings are consistent with the neurological condition caregiving literature if we take 'hours of caregiving' and 'emotional problems' to be indirect indicators of supporting that encapsulate emotional forms of care (Peters et al. 2013; Lou et al. 2015). They are also somewhat consistent with the findings of Liu and colleagues (2017), who

included several items related to emotional care in their caregiving scale and found an indirect effect. However, these findings contradict the non-caregiving emotional supporting literature, where informal emotional supporting is known to be associated with good supporter mental health (Schwartz and Sendor 1999; Schwartz et al. 2003). These findings also stand in contrast to the volunteering literature, where volunteers tend to have better mental health than non-volunteers (Kim and Pai 2010; Yeung, Zhang and Kim 2018). Of all non-caregiving focused studies, caregivers of persons with neurological conditions are most similar to the compassion-fatigued social workers described by Adams, Boscarino and Figley (2006) who also experienced poor mental health in emotionally-draining circumstances. Clearly, emotional care performed in the context of neurological condition caregiving has mental health effects that differentiate it from emotional care in other contexts.

Using self-perceived emotional supporting as the independent variable and utilizing an emotional supporting/gender interaction term, I found that caregiver functional health depends on a combination of emotional supporting and gender. Using the availability of other emotional supporters as the independent variable, I found that caregivers who are the sole emotional supporter for their care receiver tend to have slightly poorer functional health compared to caregivers who report that there are others available who can emotionally support the care receiver. It is not entirely surprising that the effect of emotional supporting on functional health is not very large considering inconsistency in the literature on this health outcome. Although Peters and colleagues (2013) and Trivedi and colleagues (2014) found greater hours of caregiving to be associated with poorer functional health, Roth and colleagues (2009) and Alpass and

colleagues (2013) found no relationship. We must note, however, that these studies did not differentiate emotional care from other types. In the non-caregiving emotional support and volunteering literature, helping others is generally associated with better functional health (Krause et al. 1999; Gruenewald et al. 2007; Warner et al. 2010; Cattan, Hogg and Hardill 2011; Yeung, Zhang and Kim 2018). Some have found no relationship between the two (e.g. Schwartz et al. 2003; Piferi and Lawler 2006), but none have suggested a negative relationship, so again the effect of emotional supporting in the neurological condition context is differentiated from other contexts.

Regarding caregiver burden, I found no relationship between the self-perceived emotional supporting variable and caregiver burden. However, when comparing caregivers who are sole emotional supporters to caregivers who claim to provide no emotional care, emotional supporting has an effect on caregiver burden. These differences might help explain some of the inconsistencies in the caregiving literature on burden outcomes, particularly among caregivers of persons with Alzheimer's disease or other conditions of the dementia-type. Studies in this area have variously found that caregiving hours and behavioural problems are associated with greater burden (Chappell and Reid 2002; Park et al. 2015), that behavioural problems but not caregiving hours are associated with greater burden (Lou et al. 2015), and that neither hours nor problems have any association with burden (Liu and Huang 2018). The results of the present study suggest that emotional care has consequences for the burden experiences of some caregivers, but not for others. I also found that caregivers who are the sole emotional supporter for their care receiver tend to experience greater burden compared to caregivers who report that there are others available who can emotionally support the care receiver.

These findings support some of my hypotheses, and give cause to reject others. The helper therapy principle of Riessman (1965) predicts that emotional supporting should be associated with better caregiver mental health, better functional health, and lower caregiver burden compared to no supporting, and caregiver health outcomes should not be related to whether the caregiver is the sole emotional supporter. For the most part, the results do not support these predictions: emotional supporting is not related to good mental health or low caregiver burden, and being the sole emotional supporter is related to caregiver health outcomes. The exception is found in the emotional supporting-gender interaction: emotional supporting was associated with better functional health, but only for women who supported care receivers other than their primary care receiver with a neurological condition; men of the same category experienced poorer functional health than any other category.

Even here, the helper therapy principle is dependent upon the caregiver's social location. That is, for this group of caregivers, emotional supporting may have an effect contingent on gender because emotional supporting may be considered an expression of gender roles. Emotional supporting might be protective of women's functional health because it is an expected part of female gender roles, whereas it might be detrimental for men's functional health because it's an unexpected, new role that requires adjustment. This aligns with Calasanti and Bowen's (2006) finding that men and women tend to experience caregiving in different ways due to differing life courses. For caregivers emotionally supporting their primary care receiver with a neurological condition, it might be that this care is stressful enough to neutralize any protective effects, or that the emotional problems that accompany neurological conditions may be considered an

expected part of the work for both men and women. In sum, there is some support for hypothesis 2, but I reject hypotheses 1 and 3. The helper therapy principle may be at work for a specific subset of caregivers, but clearly does not apply to the majority of emotional care. Since being the sole provider of emotional support to the care receiver is relevant to caregiver health outcomes, hypothesis 4 is rejected completely.

Alternatively, the compassion fatigue and emotional contagion perspectives predict that emotional supporting should be associated with poorer caregiver mental health, poorer functional health, and greater caregiver burden compared to no supporting. Likewise, they predict that sole emotional supporters should have poorer mental health, poorer functional health, and experience greater burden than caregivers who have others to help with emotional support provisioning, since caregivers may not feel they have a choice in providing emotional care and care receivers may have no other outlet for their negative affect. For the most part, the results uphold these predictions. Caregivers who emotionally supported a care receiver with a neurological condition tended to have poorer mental health than caregivers who claimed to do no emotional care, but there did not appear to be any functional health or burden differences using the first explanatory variable. A burden difference did appear when sole emotional supporter caregivers were compared to caregivers who provided no emotional care, indicating that emotional supporting is burdensome for a particular subset of caregivers. Thus, hypothesis 5 is partially supported while hypotheses 6 and 7 are rejected, since emotional supporting is more detrimental for mental health than for functional health or burden. Being the sole emotional supporter was associated with poorer mental health, poorer functional health, and greater burden. Mental health and burden effects were large in magnitude, and

although the functional health effect was small it was clinically significant. Consequently, hypotheses 8, 9, and 10 are supported completely.

Overall, emotionally supporting a care receiver with a neurological condition was detrimental to caregiver mental health generally and to caregiver burden for those caregivers who are sole emotional supporters. Being the sole provider of emotional care was detrimental to all three aspects of caregiver health and well-being that were investigated. Rather than providing caregivers with a source of therapy, emotional care was more likely to result in compassion fatigue; the repeated exposure to care receiver's negative affect is a possible contributor to this fatigue via emotional contagion. Caregivers, particularly sole emotional supporters, may be a captive audience to this negative affect, and may feel a lack of control over their situation.

Another question pertains to the role of emotional supporting in the stress process. Since helper therapy can be safely ruled out in the case of caregivers of persons with neurological conditions, it is clear that emotional supporting cannot be positioned as a resource in the stress process model, as might otherwise be suggested by the non-caregiving emotional supporting literature (e.g. Krause et al. 1999; Schwartz et al. 2003). Since the evidence suggests that emotional supporting is associated with poor mental health and high burden, emotional supporting should be positioned as a stressor, alongside other stressors such as instrumental care (e.g. ADL/IADL dependency), at least when mental health and caregiver burden are considered as outcomes. The lack of a strong effect of emotional supporting on functional health is puzzling, but may be a result of factors unaccounted for, such as selection. Fredman and colleagues (2010) note a

healthy caregiver effect, whereby physically healthy people are more likely to become and remain caregivers; this effect may be at work here.

Although the relationship of emotional supporting to caregiver health and well-being does not depend on gender in most of the models, it is clear that gender is still an important aspect of caregiving in its own right. The results show that women make up the majority of caregivers, and caregiving women tend to have poorer mental health and experience greater caregiver burden than caregiving men when other influential factors are held constant. On a social-structural level, women are more likely to be selected for this kind of strenuous care work (Turcotte 2013; Wong, Gilmour and Ramage-Morin 2016). The research literature clearly demonstrates that women are also affected by the strains of caregiving to a greater extent than men, tending to experience poorer mental health (Miller et al. 2001; Neundorfer et al. 2001; Peters et al. 2013; Raggi et al. 2015) and greater caregiver burden (Chappell and Penning 1996; Akpinar, Küçükgüçlü and Yener 2011; Aoun et al. 2012; Peters et al. 2013; D'Onofrio et al. 2015; Garre-Olmo et al. 2016). The findings of the present analysis are in accord with previous research on caregiving and gender, with the exception of functional health, and serve to further strengthen the consensus.

Unsurprisingly, other elements of caregivers' social location were influential for health and well-being. I found that older caregivers tend to have poorer functional health than younger caregivers. This finding is in agreement with prior research, which has found an association between caregiver age and physical health (Patterson et al. 1998; Peters et al. 2013) or health-related quality of life (Patti et al. 2007). However, I also found that the relationship between age and mental health is non-linear; that is, older

caregivers have better mental health than younger caregivers, but only to a point. For younger caregivers, older age is associated with poorer mental health, but around age 40 to 44 this trend begins to reverse and older age becomes associated with better mental health. This partially contradicts prior research, which tended to test for a linear relationship between caregiver age and mental health (e.g. Williams 2005; Peters et al. 2013). Similar to Conde-Sala and colleagues (2010) and Galvin and colleagues (2016), I found no relationship between age and caregiver burden. Neither care receiver gender nor age were influential in any model but, as prior research suggests, these variables may depend on the caregiver's gender (e.g. Penning and Wu 2016), gender-separated models may be more appropriate to detect these effects.

The only other variables to have a significant effect on functional health are social-structural in nature: immigrant status and educational attainment. The effect of immigrant status on functional health is likely attributable to the immigration process: people are more likely to willingly emigrate if they are already in good health to begin with, and the immigration screening process frequently prevents people in poor health from immigrating to Canada (Health Canada 1999). This effect is somewhat unexpected, as the literature suggests immigrant status should be associated with poorer well-being (e.g. Lai 2007). Since the analysis only included one dichotomous variable for immigration status, it's possible this finding is skewed by missing information, such as years since immigration or other cultural variables.

Educational attainment may be a reflection of caregivers' socioeconomic status; caregivers with more education will have had more opportunity to learn about or be exposed to healthy behaviours, will be better equipped to examine their own behaviours

critically, and better positioned to act on these behaviours. Interestingly, a relationship between caregiver educational attainment and caregiver functional health has not, as far as I am aware, been previously substantiated in the literature for neurological condition caregivers as a group; Hooker and colleagues (2002) found no relationship between education and physical health for caregivers of persons with dementia, while Farina and colleagues (2017) found only very limited evidence of a relationship between education and health-related quality of life in their review of the literature, again for caregivers of persons with dementia. A relationship between education and functional health is not unheard of for other caregiver groups, however: Pinquart and Sörensen (2007) found that highly-educated caregivers of older adults tend to have better functional health than their less-educated counterparts. Since the majority of care receivers suffering from neurological conditions are older in age, Pinquart and Sörensen's (2007) finding may be relevant here. It is notable that the factors which influence caregiver functional health are mostly social-structural in nature; caregiver resources and other contextual factors are mostly irrelevant.

Another major finding relates to the different aspects of care inherent in caregiving. In the analysis results, emotional supporting (emotional care) and ADL/IADL helping (instrumental care) typically exhibited independent effects, demonstrating that both of these aspects of care are important for caregiver health and well-being outcomes. Interestingly, 'weekly hours of care' was not significantly related to caregiver outcomes in any model when emotional supporting and ADL/IADL helping were also present. This stands in contrast to many other caregiving studies, where 'hours of care' was found to be a significant predictor of caregiver mental health (Peters et al. 2013; Mitchell et al. 2015)

and experiences of burden (Chappell and Reid 2002; Peters et al. 2013; Oh et al. 2015; Park et al. 2015; Galvin et al. 2016). Multicollinearity between these variables was very small. It could be that, once both instrumental and emotional aspects of care are accounted for, hours of care has little extra predictive value. In other words, it might be more effective to measure different aspects of care directly rather than indirectly.

Some variables warrant discussion for methodological reasons. It is notable that caregivers who felt they had a choice in taking on their caregiving duties had better mental health and experienced less burden than those who had no choice. This effect existed independently of the second explanatory variable, which measured whether caregivers were the sole emotional supporter. This means that the independent variable was not acting as a proxy for choice; in other words, it was likely measuring what it was intended to measure. Likewise, the care network size variable, number of other caregivers, while not significant in any model was also not multicollinear with these variables. This offers some reassurance that network size was not being unintentionally measured by another variable. Rather, care network size was probably not relevant to caregiver outcomes; the size or quality of a caregivers' own support network may be more relevant. Indeed, I only identified one study which found a relationship between care network size and health among caregivers of persons with neurological conditions: Lou and colleagues (2015) found caregivers of persons with Alzheimer's disease with larger care networks tended to have poorer mental health than those with smaller networks. Ultimately, care network size may not be that important for caregivers themselves, at least beyond some unknown minimum.

The informal help variable was not significantly related to caregiver health outcomes, but this may also have a cause rooted in methods. In the literature, caregivers of persons with neurological conditions with greater levels of informal support tend to have better mental health and experience less burden than their less-supported counterparts (Clyburn et al. 2000; Miller et al. 2001), which runs contrary to the present findings. The informal help variable may not have been significantly related to caregiver outcomes because it is dichotomous; ideally, it might differentiate the type, quality, and quantity of help or support received.

Three variables were significant but had unexpected directions: coping, formal help, and the presence of children. The use of coping methods and greater use of formal help were associated with poor mental health and high burden, whereas caregivers with young children experienced greater burden than those with fewer or no children. Coping and formal help are likely instances of reversed causal direction. It is unlikely that the use of coping methods or formal help actually cause caregivers to have poor mental health or high burden. Rather, caregivers who already have poor mental health and high burden are likely to use coping or formal services to aid them. The formal help finding aligns with those of Miller and colleagues (2001) and Williams (2005), but is contrary to Mitchell and colleagues' (2015) finding that formal services use is associated with good mental health. I had expected that children might act as a source of help or support for caregivers; however, it appears the opposite is true. Rather than helping caregivers, children likely act as another demand on caregivers' time and resources.

6.2 Limitations

This study is not without limitations. First, while I find that emotional supporting does impact caregiver health and well-being outcomes, merely identifying emotional care as a determinant of health ignores the complexity and variety of caregiving experiences. That is, the amount of time spent doing emotional care, the quality of the care provided, and subtypes of emotional care activities might play a role in determining caregiver outcomes. The emotional supporting variables used in this analysis are dichotomous and trichotomous, which means they are missing information about the type, quality, and quantity of emotional care provided. Using these variables it is impossible to know, for example, how much emotional supporting is too much; it is possible that emotional supporting is non-linearly related to health, so that some supporting is beneficial to caregivers but above a certain level it becomes detrimental. Unfortunately, this limitation is imposed by the dataset.

Likewise, the 2012 GSS does not include detailed information about care receiver's cognitive status or behavioural problems, which are commonly used as controls (or even main explanatory variables) in caregiving research. This is not entirely a problem for the present research, since this information can be partially gleaned by using the 'severity of symptoms' variable. Also, since caregivers appraise how much help their care receivers need, this information will be partially present in caregiver's weekly hours of care. Other relevant caregiver appraisals of care receiver ability or deterioration, such as whether they find getting along with their care receiver to be stressful, are included in the caregiver burden measure, so care receiver ability or deterioration will be reflected there.

Since this study is cross-sectional, causal direction is difficult to determine for certain. This is a limitation of all cross-sectional research, and is why having a firm theoretical basis by which to explain social trends is so important. The stress process and appraisal models provide a strong theoretical rationale for causation, but cannot overcome this limitation entirely. The results do, however, fulfill or approach fulfillment of several of Austin Bradford Hill's (1965) criteria for causation: the mental health and caregiver burden findings are large in magnitude, indicating a strong effect; the results are largely consistent with past research, even though most of the past research did not separate out types of caregiving in this way; the effects in question were found among a very specific population; and the proposed mechanisms for the effects in question are plausible, supported by evidence in other contexts.

6.3 Implications

My findings point to a new direction for caregiving research. As previously discussed, there is more to caregiving than those aspects which are instrumental in nature; emotional care has real implications for caregivers. Since aspects of caregiving are differentiable and may have differing requirements or effects, future research should continue to analyse these aspects independently when possible. At the least, I hope that future research will account for emotional care performed by caregivers – as first recommended by Leonard Pearlin thirty years ago. Other aspects of caregiving or supporting, such as informational care or appraisal support, might also be investigated in the future. Likewise, it is important that these findings be confirmed by more comprehensive datasets, so that the limitations of the research can be accounted for, or in

other contexts to test the universality of the findings. This will only become more important going forward, as caregiving to people with neurological conditions is expected to become a more common experience. The present study provides a foundation, using a population-based, generalizable data source, and tests a multitude of known determinants of caregiver health but, as discussed, is not without limitations.

Since instrumental and emotional care have independent effects on caregiver health, an intervention on one may not impact the other. The findings of this study are particularly relevant for policy-makers or others planning interventions for caregivers. For instance, providing caregivers with formal sources of help, such as prepared meal programs or other instrumental assistance, may intervene on the detrimental effects of instrumental care while leaving the effects of emotional care untouched. Interventions on emotional care will need to be tailored toward what that care entails; this could mean providing formal therapy for care receivers, or emotional intelligence training for caregivers to help them better understand and process their feelings. Such interventions may be necessary to mitigate the large (and growing) economic impact of neurological conditions, particularly the indirect impacts that arise from the strain of caregiving on caregivers.

For people who are currently caregivers to someone with a neurological condition, or who will one day become a caregiver, it is important to know the risks involved. This is not meant to deter anyone from becoming a caregiver, but it should be known that even activities like emotional supporting, which may appear harmless on a surface level, can have real, detrimental effects on one's health and well-being. I further stress this point because both caregiving and emotional supporting may be done out of a

sense of obligation toward family and friends, rather than done gladly and willingly, and this care work is stratified by social-structural factors more than it is an individual choice. It is also important for caregivers to be aware of these risks for the sake of their care receivers' own well-being: poor caregiver mental health is associated with greater care receiver mortality (Lwi et al. 2017). Caregivers with poor mental health may at times being doing more harm than good. Prudent caregivers must make sure that they take care not only of their care receiver but of themselves.

6.4 Conclusion

One of the strengths of sociology is the ability to examine social phenomena in a comprehensive manner. This is reflected in the sociological imagination, but also in specific areas of research. It is responsible for our comprehensive approach to health which emphasizes not just specific elements of physical health, such as disease, but also mental health, functioning, quality of life, and well-being. It urges us to emphasize all forms of received support, including emotional, instrumental, informational, and appraisal support. It is peculiar, then, that caregiving research has neglected emotional aspects of care in favour of instrumental aspects, or has relied on general measures that are unable to differentiate aspects of care. Emotional care and supporting is a common and important part of the caregiving experience.

This study contributes to our understanding of this gap. Not only do I differentiate emotional care from instrumental care, but I find that emotional care has a significant effect independent from and alongside instrumental care. Emotional care can be considered as a stressor on caregiver outcomes in the stress process. Unlike emotional

supporters in other contexts, informal caregivers are more akin to nurses and other formal workers who experience compassion fatigue as a result of their chronically stressful duties. With a better understanding of how different aspects of caregiving affect caregiver health and well-being, alongside other determinants, we can better mitigate the detrimental effects of caregiving and plan for the population changes that will make caregiving a more common experience.

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