

“If you’re not healthy...”: Informal caregivers and the ideological imperative to be healthy

by

Emily Anne Pridham
B.A., University of Victoria, 2009

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Supervisory Committee

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Abstract

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The care provided by informal caregivers is an important part of the support needed by older adults with chronic health concerns. As the demand for caregivers grows, so does an interest in helping caregivers be healthy in order to fulfill this role. As of yet, no research has explored what being healthy means to caregivers. I explore caregivers' beliefs about being healthy and how their beliefs are consistent with or a challenge to the values present in the health promotion discourse targeting caregivers.

I incorporate qualitative data from three sources: interviews with caregivers, interviews with people responsible for creating and updating health promotion brochures (producers), and a critical discourse analysis of health promotion brochures. I explore what being healthy means to caregivers, and I also explore what caregivers do to be healthy. The meaning of being healthy is often discussed by caregivers in terms consistent with the values of neoliberal ideology and individual responsibility. However, the means by which caregivers can be healthy are both consistent with and a challenge to these values.

Policy makers interested in finding ways to help caregivers be healthy should take into account that the meaning of being healthy is non-static and multi-dimensional. In addition, the means by which caregivers are able to be healthy are composed of multiple layers. The ability to be healthy depends on each caregiver making healthy decisions and living a healthy lifestyle.

However, each caregiver's ability to make and execute these choices is predicated on their ability to access to a wide spectrum of services and support. Encouraging caregivers to access services and supports is a vital part of helping caregivers be healthy.

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Dedication

For all of those who care.

Chapter 1: Introduction

The aim of public health and the healthcare system is to maximize Canadians' health (Frank, Di Ruggiero & Moloughney, 2003). Health promotion in particular is founded on the understanding that health is impacted by more than individual lifestyle decisions: socioeconomic factors are important indicators of health status (Quinlan & Dickinson, 2009). Health promotion is increasingly being integrated into Canadian strategies to improve population health. At the same time, neoliberal rhetoric about the importance of taking individual responsibility prevails. Although we know that income, education and occupation impact people's ability to engage in healthy lifestyle behaviours (Coburn, 2000), Canadians are frequently told how to be healthy as if these factors did not matter.

A century ago, the average Canadian could expect to live 60 years (Statistics Canada, 2011). Heart and kidney diseases were the leading cause of death, followed by infectious diseases (Crompton, 2000). In contrast, the average Canadian born today will live 81 years. The leading causes of death today are cancer and heart disease, accounting for 30% and 21% of all causes of death, respectively (Statistics Canada, 2011). What this means is that Canadians are living longer, living healthier, and dying differently than we did in the past. Health care in Canada came of age as this transition was in progress. The Medical Care Act was passed in 1966, and by 1972 Medicare was universally available across Canada (Chappell & Penning, 2009). However, only hospitals and physician services are universally insured. Our healthcare system copes reasonably well with acute care needs, and will respond when there is a crisis. However, the healthcare system has had limited success in managing the complexity of the chronic health conditions with

which many Canadians live (Quinlan & Dickinson, 2009).

Informal caregivers are the family members and friends who often fill the gaps in service not covered by our healthcare system. This is nothing new: informal care has long been the dominant form of care in any society (Chappell & Penning, 2009). Family and friends are the people to whom we turn when we need help. As Canada's population ages and more people live longer with chronic health conditions, the demand for informal caregivers is increasing. While caregiving is often a positive experience for caregivers, it can also be a source of stress and burden (Ornstein et al., 2009). Most caregivers can manage the demands of being a caregiver through self-care (Chappell & Dujela, 2008) and may at times take more action to improve their physical health than non-caregivers (Castro et al., 2007). Nonetheless, there is a growing concern about how well caregivers are faring.

A better understanding of what being healthy means to caregivers is needed in order to improve the policies and programs that aim to support caregivers' desires to be healthy. In this research, I explore the ways in which caregivers are being urged to take individual responsibility for being healthy in order to maintain their role as a caregiver. Being healthy is a multidimensional concept that means different things to different people (e.g., Perry & Woods, 1995; Saltonstall, 1993; Miller & Iris, 2002). To date, no research has been published that explores what being healthy means to informal caregivers. This study is guided by the following research question:

- in what ways are caregivers' beliefs about being healthy consistent with or a challenge to the values present in the health promotion discourse targeting caregivers?

I use qualitative methodology in order to explore caregivers' lived experience of the imperative to be healthy. My research incorporates multiple methods and perspectives in order to approach the research question with both depth and breadth.

In Chapter 2, I provide a review of the literature in order to contextualize my research and provide the necessary sociological background. Chapter 3 describes the methodological orientation that guides this research and details the methods I used to explore my research question. In Chapter 4, I present and discuss my results. Finally, Chapter 5 summarizes my findings, provides insight into how this research could be used by policy makers interested in supporting caregiver health, and suggests avenues for future research.

Chapter 2: Review of the literature

Aging in Canada and the role of informal caregivers

According to the 2006 census, 13% of the Canadian population is aged 65 years or older (Statistics Canada, 2008). The proportion of Canadians older than 65 is projected to increase: last year, the front edge of the baby boom cohort reached age 65, and this group as a whole currently comprises 30 percent of the Canadian population (McPherson & Wister, 2008). Although life expectancies are increasing (Thomas-Maclean & Poudrier, 2009; Chappell & Penning, 2009), this increase does not necessarily correspond with improved quality of life. For example, the average Canadian can expect to live 11 years with some form of mental or physical disability before they die (McPherson & Wister, 2008). Data from the 2003 Canadian Community Health Survey show that 81 percent of people aged 65 and older have one or more chronic condition (Gilmour & Park, 2009). In addition to having longer life expectancies than men, older women are more likely to report having one or more chronic conditions than older men (Chappell & Penning, 2009): 29 percent of women aged 65 and older (compared to 15 percent of men in this age group) have some sort of dependency involving instrumental activities of daily living (e.g., dressing, grooming, homemaking) (Gilmour & Park, 2009).

An increase in the proportion of Canadians who are older and experiencing chronic health concerns will have an impact on the family members and friends who are called on to help as caregivers. In addition to the demands of paid employment and their own family responsibilities, many people provide unpaid support to older family members or close friends (Cranswick & Dosman, 2008). Caregivers play a significant role in the care of older adults who can no longer function as independently as they once

did (Chappell, McDonald & Stones, 2008). Hebert and colleagues (2001) estimate that 70 to 80 percent of the care provided to older adults in private households is provided by informal caregivers, the majority of whom are female (Cranswick & Dosman, 2008). In 2007, nearly six in 10 Canadian caregivers (57%) were female (Cranswick & Dosman, 2008). Largely, it is women who care for partners and daughters who care for parents. However, men are caregivers too, and demographic trends suggest that men will increasingly become informal caregivers for older adults (Sanders, 2007).

Informal care can have very positive benefits for the older adults who receive it: support from family and friends can help people live independently for longer, as well as help to maintain physical and emotional health and wellbeing (McPherson & Wister, 2008). Being a caregiver can also benefit the caregiver, for example by providing the satisfaction of helping others, postponing institutionalization, and increasing intimacy. Even though less than five percent of caregivers indicate that they are not coping well with their role at any given time (Cranswick & Dosman, 2008), being a caregiver nonetheless may have negative physical and emotional health consequences for many people at some point during their time as a caregiver.

Caregivers' health

There is conflicting evidence about the amount and quality of physical health behaviours caregivers engage in. Some caregivers report higher levels of health-promoting behaviours than non-caregivers (Lo, 2009) or are more likely to meet physical recommendations for exercise than non-caregivers (McGuire, Bouldin, Andresen & Anderson, 2010). McKibbin and colleagues (1999) report that approximately half of all caregivers exercise regularly. Other studies are less optimistic. According to Etkin,

Prohaska, Connell, Edelman & Hughes (2008) the majority (60%) of caregivers do not engage in consistent, regular physical exercise, and less than a quarter meet or exceed current physical activity recommendations. However, it should not be assumed that caregivers are not taking part in enough physical exercise. Fredman and colleagues (2006) found that although elderly caregivers report less leisure-time physical activity than non-caregivers, the overall difference in physical activity level between caregivers and non-caregivers was not statistically significant. They hypothesize that this is because caregiving tasks are physically demanding, leading caregivers to be physically active during their regular activities.

The relationship between health behaviour and caregiver status is also unclear. High levels of caregiver stress correlate with poorer self-rated health, more symptoms, and higher levels of depression, but also with more self-care behaviours (Yueh-Feng & Wykle, 2007). However, another report finds that there is not a significant difference between the modifiable health behaviours (e.g., fruit and vegetable consumption, smoking, drinking alcohol) of caregivers and non-caregivers (McGuire, Bouldin, Andresen & Anderson, 2010). Other researchers have found that caregivers are more likely to drink alcohol than non-caregivers (McKibbin et al., 1999). Rural caregivers may report higher levels of burden coupled with fewer healthy behaviours, whereas urban caregivers may not experience this relationship (Bedard, Koivuranta & Stuckey, 2004). The majority (95%) of caregivers interviewed by Carter (2002) experienced moderate to severe sleep deprivation, which often results in depression. However, other research suggests that caregivers perceive higher sleep deprivation but experience similar sleep patterns compared to non-caregivers (Castro et al., 2009).

The mental and physical health impacts of caregiving can negatively affect caregivers' abilities to engage in healthy lifestyle behaviours. However, this is not always the case. Although Castro and colleagues (2007) found that overall, rural caregivers did not engage in enough daily exercise, caregivers were not unique in this respect: less than one third of both caregivers and non-caregivers in their sample met daily recommendations for physical activities. Additionally, the caregivers in this study reported significantly more hours per week of walking for exercise than non-caregivers (Castro et al., 2007). Interestingly, although caregivers and non-caregivers were equally likely to have seen a medical doctor in the past year, significantly more caregivers reported asking about stress reduction (Castro et al., 2007). This research suggests that many caregivers are aware of the impact that caregiving can have on their lives and are already taking preventive action to maintain or improve their health.

Much academic research has focused on the stress and burden of being a caregiver. Caregiving can take an emotional and physical toll on those who provide care. This tends to be greatest when the care recipient has dementia or lives with the caregiver (Razani et al., 2007; Melis et al., 2009). Caregivers who feel overloaded by the amount of care they provide are at higher risk for depression, although this risk is mediated by the quality of their relationship with the care recipient (Yates, Tennstedt & Chang, 1999). Higher levels of care recipient behaviour problems, as well as older caregiver age, lower socio-economic status, and lower levels of informal support are all significantly associated with poorer caregiver health (Pinquart & Sorensen, 2007). Caregivers' mental and physical health are impacted in different ways by the stress of being a caregiver. Mental health (e.g., depression and anxiety levels) is affected by burden and stress, social

isolation, and reduced quality of life. Physical health is particularly impacted by fatigue and poor sleep, but also by physiological changes, morbidity, medication and service use, and health behaviours (Bedard, 2009).

It is difficult to evaluate caregiver health behaviours without accounting for socioeconomic and other demographic factors. Social determinants of health are the key to differential health outcomes and inequalities in health across populations: socio-demographic factors (e.g., education, employment, income) predict about half the variation of life expectancy (Raphael, 2006). There is evidence that social determinants of health are as influential on health status as individual behaviour and the type of medical care available (Thomas-MacLean & Poudrier, 2009). People who are advantaged in terms of education, occupation and income generally live longer and live longer without disability than people who do not have these advantages (Chappell & Penning, 2009). The ability to exercise agency (and take on healthy lifestyles) is differentially affected by socioeconomic status and class position within society (McKinlay, 1994). Incorporating an understanding of the social determinants of health is an important part of trying to understand caregivers' health behaviours.

Research on the health impact of caregiving is influenced by the definition of 'health' that researchers adopt, and there are many definitions to choose from. In 1946, the World Health Organization (WHO) defined health holistically as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (WHO, 1946). Alternatively, some researchers define health in three distinct ways: in biomedical terms, as the ability to function, and as subjective wellbeing (Fagerlind, Ring, Brulde, Feltelius & Lindblad, 2010). Definitions of health can include one component or

encompass more than one, but the definition that researchers choose can influence how health is measured and therefore the results obtained. Only measuring health according to biomedical definitions can lead to the conclusion that people are unhealthy when they perceive themselves as healthy, and vice versa. For instance, people who live with chronic illnesses describe themselves as healthy if they have adapted to their illness (Tomlinson, McDonagh, Barid Crooks & Lees, 2004). Perry and Woods (1995) found that if older women with chronic illnesses or functional limitations (biomedical measures of health) feel that they have energy, independence, and realistic optimism (subjective measures of health), they will state that they feel healthy despite their illness. To this end, some researchers have investigated subjective experiences of health and being healthy in order to broaden our understanding of what health means.

Litva and Eyles (1994) found a significant distinction between opinions about health and being healthy in their research in a small town in Ontario. According to their research, people believe that different factors affect health and being healthy. For example, a behaviour such as smoking may be seen as bad for one's health (e.g., because of its association with lung cancer), but part of being healthy if it helps manage stress or improve psychological health (Litva & Eyles, 1994). The authors argue that being healthy is an important part of living up to normal expectations of social order. The concept of being healthy is part of our cultural system and shapes our health attitudes and behaviours. We receive information about what to do to be healthy from health care providers and the media, yet responsibility for maintaining health rests with the individual (Smith-DiJulio, Windsor & Anderson, 2010). Despite this, living healthy lifestyles is not solely dependent on having sufficient information and willpower: health

is constructed and maintained from within social structures. People make sense of the concepts of health and healthy behaviours based on their social environment and cultural context (Smith-DiJulio, Windson & Anderson, 2010).

The definition of being healthy is subject to individual interpretation. When people are asked what being healthy means to them, their answers vary. Perry and Woods (1995) developed the following definition of being healthy based on interviews with ten women aged 79 to 91 years:

health involves an appreciation of life, experiencing joy and happiness. To be free from sickness does not guarantee health. Likewise, health can be experienced despite chronic illness and disability, because being healthy is a philosophy or a way of living (pp. 53).

Saltonstall (1993) conducted open-ended interviews with 21 middle-class men and women aged 33-55 years to explore the lived experience of being healthy. Participants' definitions of health encompassed dimensions of physicality, consciousness, emotions, spirituality, and sociality. Men and women defined health in a comprehensive way, as both a state of being and the ability to function. In focus groups with men and women, Miller and Iris (2002) found that when asked to define "health," participants universally talked about what being healthy meant to them. For the focus group participants, being healthy was described as a multi-dimensional concept in which psychological and physical wellbeing are consistently interdependent. Although several researchers have explored what being healthy means to a variety of people, no research has been published to date that specifically explores this topic with informal caregivers.

In summary, most caregivers can meet the demands of their role without becoming dysfunctional. In addition, Chappell and Dujela (2008) found that caregivers can be both burdened and experience good or high levels of wellbeing at the same time.

This said, caregiving can place heavy demands on caregivers and the importance of being healthy enough to meet these demands should not be underestimated. However, the push for caregivers to be healthy is a value-laden imperative tied to neo-liberal ideals of personal responsibility. The discourse about the importance of taking individual responsibility for being healthy plays an important role in the construction of individual beliefs, but it does not fully determine these beliefs. People engage with and challenge dominant discourses in different ways.

The following sections elaborate on the roles that discourse and ideology, neoliberalism, health promotion policy and campaigns, and differing views on responsibility play in determining caregivers' experience of the imperative to be healthy. These areas provide the background that will guide my interpretation of the data I collect from interviews with caregivers, producers, and critical discourse analysis.

Discourse and ideology

Purvis and Hunt (1993) describe discourse as social networks of communication characterized by a system of linked signs. Discourses not only convey social experience but also play a part in the constitution of specific types of social structures and roles that people play within these structures. Discourses limit what can be said and done by limiting what can be experienced and the meaning that can be ascribed to that experience. This is not a process of complete social control: according to Purvis and Hunt (1993), discourses channel, rather than control, the discursive possibilities, making some thoughts easier to say and impeding some from becoming reality. It is not a given that every individual exposed to a particular discourse will internalize its inherent values. People can use discourse as a method of attempting to enact specific outcomes, but this

process cannot guarantee the achievement of outcomes because we subjectively interpret the discourse and grant it personal meaning. For example, the health-promotion discourse may encourage caregivers to exercise more, but the effectiveness of this discourse depends on how it is transmitted, by whom it is transmitted, what consequences individuals believe follow it (or fail to do so), and whether people have the resources (whether social, financial, or cultural) necessary to make changes to their lifestyles.

Ideology can influence what type of information is transmitted through discourse and also describe the individually-internalized beliefs about how things are that we learn through discourse. Foucault (1982) argues that we need to have historical awareness of the present circumstances of reality in order to understand the discourse we study. Our society does not exist independent of the past, and discourse is not produced independently from the past. In other words, it is not enough to study discourse on its own: to really understand discourse we need to look at the underlying ideology that has influenced its creation. Outlining neoliberal ideology and how it has influenced health promotion policy in Canada contextualizes the way in which the current discourse about being healthy has been constructed.

Neoliberalism and health care

The neo-liberal ideology is predicated on three main tenets: reduction of state control, market de-regulation, and the elimination of trade barriers (Navarro, 2008). It is also associated with the treatment of individuals as consumers rather than citizens (Raphael, 2008). A neo-liberal approach to health care stresses withdrawal of government support, increased marketization, privatization and consumerization (Raphael, 2008; Chappell & Penning, 2009). With this, we also tend to see the dismantling of health

infrastructure and a return to biological and behavioural explanations for ill health (Navarro, 2008). Neo-liberal ideology is associated with the decline of the welfare state, which is seen as interfering with normal market functioning (Coburn, 2000). The individual lifestyle approach has been widely adopted by governments because it is perceived as cost-effective and consistent with societal valuation of individual responsibility (Jackson & Riley, 2007). After all, individual-level solutions are easier to implement at the local level (and evaluate by researchers and policy makers) than structural-level solutions (Bolaria & Bolaria, 2009), despite assertions that it makes more sense to conceptualize health as part of the society in which it is embedded rather than as separate from society (Coburn, 2000).

Neo-liberal healthcare policies are often associated with a rhetoric of personal agency and empowerment (Chappell & Penning, 2009) which is then linked to an ideology of individualism that places the responsibility for ill health on individuals rather than socio-economic conditions (Bolaria & Bolaria, 2009). The end result, especially when the neo-liberal policies are combined with decreased access to formal services, is that the responsibility for health care is directed towards individuals, families, and community organizations (Dickinson, 2009). For example, Teghtsoonian (2009) notes a tendency in BC's *Provincial Depression Strategy* and *Mental Health Addictions Information Plan* to encourage people to draw on resources available through the private rather than public sector and concludes that this focus on private resources is consistent with a neoliberal approach to public policy. Encouraging people to use resources from the private sector implies that people should take individual responsibility for their health (and the cost of maintaining their health), rather than rely on the sense of collective

responsibility that welfare states are predicated on.

Responsibility

Responsibility for social and individual wellbeing is here conceptualized as comprised of three spheres: collective, individual, and familial responsibility. Under collective responsibility, all members of a society are responsible for the care and wellbeing of each other, though not through direct personal involvement. In Canada, collective responsibility is most evident in the idea of the welfare state (Funk, 2010), whereby all members of society are deemed deserving of social, economic and physical support. Furthermore, under collective responsibility the State is seen as the appropriate resource to provide this support. Collectivist viewpoints are positively correlated with a belief that governments are obligated to care for citizens (Killian & Ganong, 2002). All members of society are collectively responsible for each other, but support is provided through taxes paid to the State. The State is in turn responsible for administering appropriate services to those in need. In the context of the imperative to be healthy, a belief in collective responsibility for health would promote reliance on state-provided supports such as home support and adult day programs.

This is in contrast to individual responsibility, wherein individuals are considered responsible for their circumstances and actions, as well as for meeting their own needs (Weiner, 1995, as cited in Killian & Ganong, 2002). Individual responsibility emphasizes self-reliance, independence, and minimal state involvement (Hooyman & Gonyea, 1995). This includes the obligation to avoid being a burden to others or to the state. Institutional care is considered the least-desirable alternative, and is reserved for those with demonstrated need. Problems are conceptualized at the individual level, and solutions are

aimed at restoring the individual's independence. For example, an elderly woman returning home after hospitalization due to a fall could be offered home support for a few weeks. The goal of this home support would be to provide the short-term assistance necessary to ensure the woman could remain independent in her own home once she heals. A belief in individual responsibility for health is linked to emphasis on self care and personally taking action to promote health and conquer disease. Risk is also individualized: individuals bear the consequences of their decisions, for good or ill (Beck, 2002).

Finally, familial responsibility refers to a sense of responsibility for the wellbeing of kin. It is closely linked to filial responsibility, which refers to the sense of responsibility children feel for the wellbeing of their parents (Funk, 2010). It is also related to individual responsibility, in that both familial and individual responsibility emphasize self-determination, privacy, and freedom from intrusion (Hooyman & Gonyea, 1995). However, the emphasis in this sphere of responsibility is on the family rather than the individual. Continuing the example of an elderly woman returning home after hospitalization for a fall, a resolution consistent with familial responsibility would be to assign a home care nurse to teach the woman's family how to care for her. The family would then assume responsibility for ensuring the wellbeing of the elderly woman while she recuperates at home. In terms of the imperative to be healthy, familial responsibility places more emphasis on ways family members help each other be healthy. Typically, this refers to the supports that primary caregivers provide to their care recipients. However, as I find in this research, familial responsibility extends more broadly. In some instances, extended family members feel a sense of familial responsibility towards the

wellbeing of the caregiver. Familial responsibility can both resonate with and challenge neoliberal ideology, depending on how it is enacted. For example, reliance on family members and in particular unpaid caregivers relieves the burden placed on the State, in adherence to neoliberal emphasis on reduced State involvement. At the same time, the sense of familial responsibility for the wellbeing of others challenges the neoliberal emphasis on individual responsibility for oneself.

Not clearly included in this trio of collective, individual, and familial responsibility is the idea of communal responsibility. In my conceptualization of responsibility, communal responsibility relates to the way broader networks of people feel directly responsible for each other, rather than indirectly through the State. These communal networks include friends, neighbours, volunteers, and other acquaintances. In the context of caregiving, being supported by a communal sense of responsibility can be an important part of being healthy. Communal responsibility tends to be enacted in a way that challenges neoliberal values. For example, a friend may drop in unannounced with food when she knows the caregiver is struggling to manage alone.

Individuals are embedded in complex social worlds, making it difficult to classify people as adherents of any one particular viewpoint on responsibility. In fact, adherence to one of these viewpoints does not preclude adherence to others (Killian & Ganong, 2002). Instead, people often feel that care can and should come from many sources, depending of the exigencies of the situation. There is overlap between the three principle spheres of responsibility. For example, Killian and Ganong (2002) find that people perceive that obtaining support from the government will enable them to maintain their independence: they use collective means for individualistic ends. Generous social

programs enable familial and individual responsibility (Baker, 1996, as cited in Armstrong & Kits, 2004) by ensuring that people have the capacity to act for themselves, regardless of the socioeconomic status.

The focus on health promotion in Canada

By the early 1990s, the global shift away from the welfare state model towards a neoliberal economic model became evident, exemplified by a decline in the influence of the World Health Organization and an increase in influence of transnational corporations and global economic institutions (O'Neill, Pederson, Dupere & Rootman, 2007). An example of the shift towards a neo-liberal worldview is found in Porter's (2005) comparison of the Ottawa Charter for Health Promotion to the subsequent 2005 Bangkok Charter. The Bangkok Charter scales back the health promotion goals of the Ottawa Charter and focuses on improving health opportunities instead of centring on social justice goals such as equality of health outcomes. The Ottawa Charter discusses social relationships in the context of mutuality, wherein people take care of each other, their community, and the environment. The language of the more recent Bangkok Charter describes people as consumers, who should exercise their power through the marketplace – and calls for policy to support ethical and responsible business practices. Porter (2005) finds that rather than building on the policy goals set out in the Ottawa Charter, the Bangkok Charter is grounded in principles of a global capitalism, obscuring the importance of the social determinants of health.

In the Canadian context, Raphael (2008) argues that the lag in implementing health promotion policy that addresses the social determinants of health is due to Canada's liberal political economy, which “places the market-place, rather than the State,

as the primary institution and arbiter of resource distribution...within society” (pp. 484). The result is that although policy makers recognize the influence of socioeconomic factors (such as income and occupation) on health outcomes, strategies for improving population health tend to stress individual factors. For example, the Lalonde report identified environmental issues that affect health. However, the policy outcomes of the report targeted automobile accidents, occupational health, and alcoholism, all of which are conceptualized as outcomes of individual lifestyle decisions (Raphael, 2008). Jackson and Riley (2007) also note that despite an initial rhetoric about creating public health care policy that addresses the social determinants of health, individual lifestyle activities were instead emphasized in activities implemented at the local level (such as healthy school, workplace and hospital initiatives).

According to Raphael (2008),

Canadians are being bombarded on a daily basis by government agencies, public health agencies, disease organizations and the media by lifestyle messaging that promotes healthy diets, physical activity, and reduction in tobacco use. Perusal of any public health document or disease agency publication gives lip service to the broader determinants of health but quickly succumbs to exhortations about making healthy choices in the service of health (pp. 488).

To a certain extent, individual action is a necessary part of being healthy. The individual plays a role in deciding whether or not to engage in healthy activities such as diet, eating well, or exercising. Individual action remains a visible part of current health promotion efforts, while little is said by these agencies and organizations about how the social determinants affect health and peoples’ capacity to take action to improve it.

The long-term efficacy of media-based health promotion campaigns targeting individual behaviour has not been established academically (Brawley & Latimer, 2007; Berry et al., 2009). Additionally, Brawley and Latimer (2007) are critical of health

promotion campaigns that focus on individual action because they only tell people what to do and not how or why to incorporate the health-promotion behaviours into part of an overall lifestyle. Such health promotion campaigns all assume that individuals have the means and ability to make the suggested changes. They emphasize individual agency and not the structural factors that lead to poor health in the first place. Emphasizing individual action is consistent with a neoliberal ideology of individual responsibility because it stresses that people should take care of themselves rather than rely on the State or a general sense of collective responsibility.

Older adults and access to health care in Canada

Under Canada's Health Care Act, health care services in Canada must be universal, accessible, comprehensive, portable, and publicly administered (Health Canada, 2011). Medicare covers medically-necessary in- and out-patient services. Despite this mandate, problems with the Canadian healthcare system, in particular access to services that older Canadians need, are well documented. Fifteen percent of Canadians report difficulty accessing routine care from general physicians, and 23% of Canadians have difficulties accessing care for immediate (though non-life-threatening) conditions (Sanmartin & Ross, 2006).

In BC, there is no charge for some home and community care services (i.e., case management, nursing, physiotherapy, occupational therapy, dietician services, and social work). However, other key services that many caregivers rely on such as home support, respite, assisted living, and residential care are partially-subsidized and means-tested (Vancouver Island Health Authority, 2010). Recipients are required to pay for a portion of these services. Given Canada's aging population, demand for home and community

care services is projected to increase (Sarma, Hawley & Basu, 2009). Although the province of BC has increased the number of assisted living and residential care beds available, these increases have not kept pace with the aging population, leading to a net decrease in British Columbians' access to assisted living and residential care (Cohen, Tate & Baumbusch, 2009). The province of BC reports that wait times for residential care beds has decreased from one year in 2001 to less than 90 days in 2009, but the waitlist process has also changed. Only people who are anticipated to require residential care within three months are eligible to be waitlisted (Canadian Centre for Policy Alternatives, 2009). Access to home and community care services continues to be problematic.

Canadian families are being called on to provide care not accessible through the health care system. In particular, female family members are frequently expected to supplement state-provided home supports without pay and at the expense of their own income, career development, and wellbeing (Anderson & Kits, 2004). Formal care does not replace informal care (Anderson & Kits, 2004), and caregivers' responsibilities do not stop once the care recipient receives support from the health care system.

Summary

Just as health is the outcome of multiple interrelated factors, beliefs about being healthy result from the interaction of multiple factors – both structural and individual. Nonetheless, Canadians regularly encounter discourses informing us of the imperative to be healthy. Although how and to what extent we choose to internalize this imperative varies, being healthy is a goal that many people share. My thesis explores what being healthy means to caregivers as well as how caregivers' beliefs about how to be healthy are consistent with or challenge the neo-liberal, individualist values demonstrated in

health promotion brochures targeting informal caregivers.

Chapter 3: Methodological approach and methods

Phenomenology on its own would be appropriate if my research question was only about what constitutes the essence of being healthy for caregivers. In this research, I also explore how caregivers' beliefs about the importance of being healthy relate to neo-liberal values. Therefore, my research question calls for the incorporation of a critical framework. In particular, I draw on critical gerontology, which states that the lived experience of aging needs to be understood in relation to society as a whole and the historical processes that have led us to where we are (Estes, 1999). This approach incorporates a political economy lens by arguing that structural influences (such as societal institutions) influence the social construction of aging in a given society (Estes, 1999). The same holds true for the lived experience of the imperative to be healthy. Our beliefs about health and being healthy are not purely concepts developed independently by individuals: they are also shaped by the societies in which we live.

Critical phenomenology links the study of human intentions with an examination of social structures and constraints. It also enables an exploration of normative claims made by people (Dallmayr, 1981). Critical phenomenology aims to understand the meaning of human experience; humans are seen as having the power to use intentionality to question both themselves and their environment. Welton (1987) argues that phenomenology becomes critical when we realize that it is not possible to only study phenomena reflectively, and instead understand that it is also necessary to consider the role of historical factors that are often not even spoken about. The world of politics is both made up of phenomena with pre-determined meaning and is a domain where people can take initiative and be critically reflective of their own agency (Dallmayr, 1981). In

the same way, the experience of developing a personal definition of being healthy is both constrained by structural forces and subject to interpretation through individual agency.

The concepts of structure and agency are central to many sociological endeavours, but there is considerable debate about the relationship between the two. The approach I adopt reflects a critical realist analytical separation of structure and agency. Bhaskar (1989, as cited in Williams, 2003) describes structure and agency as ontologically interdependent and epistemologically distinct. Structure and agency can be analyzed independently, but when drawing conclusions about how change happens over time, it is important to pay attention to how the two interact – because by definition they interact in reality. Bhaskar (1989) continues by describing the duality of structure and agency: society both predates humans and is continually reproduced through human action; humans both consciously and unconsciously reproduce the conditions of production (i.e., society). This conceptualization of structure and agency emphasizes that we are born into pre-existing social worlds but have the creative ability to change – or reproduce – the society in which we live (Archer, 1995). Thus change happens when people interact with society, but it is not a given that interaction will lead to change.

My research is qualitative. Critical phenomenology lends itself to a qualitative approach because it emphasizes understanding meaning and personal experience. Qualitative researchers often use methods triangulation to increase the representativeness of their research (Palys & Atchison, 2008). Triangulating by including multiple perspectives increases the validity of research (Kidd & Kral, 2005). I include both multiple methods and multiple perspectives. To incorporate multiple methods, I collected data through in-person interviews and a critical discourse analysis of health promotion

brochures. I include multiple perspectives by interviewing both caregivers and people who are responsible for the types of health-promotion brochures included in the discourse analysis component (I refer to this second interview group as the “producers”). In-depth interviews with informal caregivers explore what being healthy means to them and how these beliefs manifest in their own lives. Interviews with producers explore what being healthy means from different institutional perspectives and why these organizations think that caregivers should be healthy. I compare the findings from the in-depth interviews to the critical discourse analysis (conducted for a directed studies course in the winter of 2010). I compare and contrast caregivers’ and producers’ interpretations of being healthy with the messages present in the health promotion brochures.

The following sections describe the methods used with each data source.

Critical discourse analysis

I conducted a critical discourse analysis of health promotion brochures targeting informal caregivers in order to explore the underlying ideological messages that are both explicit and implicit within these brochures. Understanding the underlying ideological structures that influence behaviour is an important step in researching caregivers’ experiences of health and being healthy. In addition, probing for ideological messages in health promotion brochures helps understand how health and the responsibility for health are represented in the discourse targeting informal caregivers. Although interpretation is a subjective process and thereby subject to limitations, my approach was guided by the methods of critical discourse analysis outlined in *Methods of Critical Discourse Analysis* (Wodak & Meyer, eds., 2009). Critical discourse analysis, as outlined by the contributing authors to the aforementioned book, is a structured process that aims to capture the

qualitative range of what can be said and how it is said. Discourse is made up of recurring themes and symbols; I use the literature on neoliberalism and responsibility to tie the themes and symbols in the brochures I collected to ideological structures and thereby comment on how the imperative to be healthy is transmitted to caregivers. Interviews with producers at some of the agencies who produced the documents I analyze are a validity check of my interpretation (this validity check turns out to be important: in Part 2 of Chapter 4 I show that there are significant differences between the values expressed in the brochures and by the producers).

Although medical professionals are an important source of information about health, many people supplement the information they receive from professionals with information available through print media and the internet (Tio, LaCaze & Cottrell, 2007; Britigan, Murnan, & Rojas-Guyler, 2008). Health promotion documents are available as both on-line and print resources. I included both in the critical discourse analysis because it is likely that caregivers use either or both to access information about being healthy.

I collected documents produced by the Canadian federal government, the BC provincial government, and service/disease agencies that have a presence in BC because these documents are available to my population of interest (caregivers in BC). I limited my sample to these types of organizations because they are non-profit organizations and as such would be likely to demonstrate neoliberal ideology to a lesser degree than organizations – such as pharmaceutical companies – that operate on a for-profit basis. Nonetheless, given that these brochures are probably based on Canadian health-promotion policy and that other authors (e.g., Teghtsoonian, 2009; Porter, 2005; Raphael, 2008; Jackson & Riley, 2007) have demonstrated neoliberal currents in health-promotion

policy, I expected that neoliberal tendencies would still be visible in the health promotion brochures. As such, brochures produced by non-profit agencies are a conservative test of the extent to which neoliberal ideology shapes self-care advice: if it is present in the documents I included, it is also likely to be present in documents produced by for-profit organizations.

To begin, I collected documents from as many sources as possible in order to obtain a heterogeneous sample of the information that is available for caregivers. I searched for sources that are caregiver-oriented (e.g., the Family Caregivers Network Society), disease-oriented (e.g., the Alzheimer Society of B.C.), and health-oriented but with a focus on caregivers (e.g., sections on HealthLinkBC's website). Including a wide variety of sources is important because caregivers themselves have diverse experiences, information needs, and methods of accessing information and services. Where possible, I visited the agencies in person, introduced myself as a UVic Master's student, explained my research, and asked what documents they would give me if I was a caregiver asking for health- or stress-related information. When I could not visit agencies in person, I collected documents from websites. In order to include sources that I was not originally aware of, I asked agencies to suggest other resources that they recommend to caregivers. Several organizations (such as the Victoria Epilepsy and Parkinson's Centre) have lists of community resources, which I used to expand my search. I also used internet searches to widen my sample. During data collection, I did not limit the material I was offered based on what I had already collected or whether I thought the material would be suitable for my research. Instead, I collected all the material I was offered.

I collected documents from the following service agencies in the Greater Victoria

area:

- Alzheimer Society of B.C., 202-306 West Burnside Rd.
- Family Caregivers' Network Society, 526 Michigan St.
- MS Society, 1004 North Park St.
- Victoria Epilepsy and Parkinson's Centre, 813 Darwin Ave.

as well as from the following websites:

- Canadian Cancer Society (<http://www.cancer.ca>)
- Canadian Women's Health Network (www.cwhn.ca/en)
- Caregiver Connect: From Caring to Sharing (www.caregiver-connect.ca)
- HealthLinkBC (www.healthlinkbc.ca)
- Mood Disorders Association of British Columbia (www.mdabc.net)
- 50Plus.com
- Veterans Affairs Canada (www.vac-acc.gc.ca/general)

Although I originally collected 37 documents, I purposely selected a sub-sample of documents to analyze (leaving me with 12 documents). Documents were included based on the following criteria:

- The document specifically targets informal caregivers;
- A major focus of the document (or section of document if it is a newsletter/magazine) is on some aspect of caregiver health or wellbeing;
- The health advice in the document is contextualized in some form (i.e., documents that only list actions caregivers can take are excluded); and,
- The document provides original content or an original interpretation of suggestions from another document (i.e., documents that summarize

others without specifically tailoring the advice are excluded).

The focus of the critical discourse analysis is caregivers of older adults, but some of the brochures included in the analysis do not specifically target this group. Although some disease-specific brochures target caregivers of people with diseases which tend to afflict older adults (e.g., Alzheimer's and Parkinson's diseases), other brochures target caregivers of people with conditions that are not specific to older adults (e.g., Multiple Sclerosis, mental health disorders) or do not mention the age or condition of the care recipient (and focus primarily on the caregiver). Nevertheless, the latter two groups do not exclude caregivers of older adults; excluding brochures not specifically targeting caregivers of older adults would unnecessarily limit this research.

Interviews

The following sections describe the methods used to interview caregivers and producers, including sampling, sample size, interview guides, and data analysis.

Procedures used for caregivers and producers are separated as there are some differences between methods used with these two groups.

Interviews with caregivers

From a phenomenological perspective, in order to understand human behaviour, we need to understand how people perceive and make sense of the world around them (Palys & Atchison, 2008). The aim of phenomenological interviews is to collect in-depth information from a group of people who have experienced the phenomenon of interest (in this case, the imperative for caregivers to be healthy) in order to describe the phenomenon with rich detail (Creswell, 2007). My interviews focus on two broad questions (adapted from Creswell, 2007):

- “What are your experiences of being healthy?” and,
- “What contexts or situations have typically influenced or affected your experiences of being healthy?”

Probes were used for each question to help the participant reflect on different aspects of each question. I began the interviews by asking each participant to talk about their experience as a caregiver. This was done for two reasons: so that I understood each person’s experience as a caregiver, and so that the interviewee would reflect on their experience of being healthy in the context of their role as a caregiver. In addition, as I probed about the contexts and situations that influence the caregiver’s experience of being healthy, I asked the caregivers to reflect specifically on how their role as a caregiver affected this. I also asked their opinions about how their current views about being healthy (or during times of higher caregiver burden, if applicable) compare to their views about being healthy during other times in their lives. This was in order to distinguish what being healthy means to caregivers in their everyday lives with what being healthy means in the context of being a caregiver. As I demonstrate in the results chapter, caregivers’ initial responses about what being healthy means are consistent with other research on what being healthy means. It is when I explore what being healthy means during periods of higher caregiver responsibility that a different experience of being healthy emerges. The interview schedule, including probes, is included in Appendix III.

Incorporating other types of data is consistent with phenomenological approaches (Creswell, 2007), and I used visual and textual material (collected through my discourse analysis) in some of the interviews. Photovoice (also called photo elicitation), is simply

the act of incorporating visual materials into interviews (Harper, 2002). This is most commonly done through the use of photographs, but it is also possible to do photovoice with paintings, cartoons, and advertisements as the visual material (Harper, 2002). The meaning of specific images is constructed by the people who take them and the people who view them (Harrison, 2002). According to Schwartz (1989), the photograph “becomes a receptacle from which individual viewers withdraw meaning” (pp. 120). Viewing photographs is a dynamic process that entails interaction between the photographer, the spectator, and the image; as a research tool, photographs can act as raw materials that trigger meaning (Byers, 1966, as cited in Schwartz 1989). In this sense, photographs can be used to stimulate participants to discuss areas that they are aware of but may not have tried to put into words before.

Combining photovoice with participant interviews helps counter the danger of the researcher assuming how people define and interpret visual images (Harper, 2002): participants can explain in their own words what they think a particular image signifies. Interviews are also a useful tool to overcome the researcher’s potential biases and focus on what the participant thinks is important (Wang & Pies, 2008). Two additional benefits of incorporating visual material are that it helps build rapport by stimulating conversation between two people who do not know each other and may not share taken-for-granted knowledge (Harper, 2002) and also that visual materials are accessible to anyone, regardless of whether they can read or write (Wang & Pies, 2008).

It is not necessary for participants to take a photo themselves in order for them to be able to talk about what they think the image means (Harrison, 2002; Harper, 2002). This means that when people look at an image they themselves did not create, they are

nonetheless able to talk about what it symbolizes to them. In order to understand how informal caregivers interpret and make sense of the health-promotion discourse, I showed them an image from a health-promotion brochure targeting informal caregivers and asked them to tell me the story of the image. Instead of showing all participants the same image, I selected images from the brochures that most closely matched each individual's situation. I asked the caregivers how they are similar to and different from the person in the photograph. Depending on the depth of information these questions elicited, I asked some participants to talk about key messages in the brochures. For example, HealthLinkBC tells caregivers to first "take care of yourself" (Davis & Poore, 2009, np), and the *Information Package for Family Caregivers* offers "Ten Timely Tips for Caregivers," including "get regular physical check-ups, eat a balanced diet and try to take time out to express sadness, anger and helplessness" (Family Caregivers' Network Society, nd, pp. 1). Asking caregivers to talk about how they interpret suggestions from health promotion brochures aids my exploration of how they engage with the health promotion discourse.

Sampling, sample size & recruitment: caregivers

It would be possible to randomly select participants for the study (e.g., through random digit dialling). However, obtaining a representative sample is expensive and time consuming (Palys & Atchison, 2008) and I am able to answer my research questions by purposively selecting participants who have experience caring for someone else while also experiencing pressure to be healthy themselves (Creswell, 2007). I do not make claims about the statistical significance of my results or how my sample is representative of the population of caregivers as a whole. Instead, I describe in rich detail how

caregivers experience the ideological imperative to be healthy. Therefore, my use of non-probability, purposive sampling allows me to deliberately select informal caregivers who are interested in speaking with me about their experiences (Ritchie, Lewis & Elam, 2003). My sample size is small (N=11) because I am interested in gaining extensive detail from each participant rather than trying to generalize my findings to the wider population (Creswell, 2007). My eligibility criteria for participants are as follows:

- The participant is the primary caregiver for an older family member or close friend
 - The care recipient is at least 65 years old
 - There are no specific criteria for the type of illness the care recipient has. Care recipient needs can be physical, cognitive, or both.
 - Caregivers who employ others to help with care (including live-in assistance) will be included as long as the caregiver has primary responsibility for the care recipient (e.g., self-defines as the person who is “responsible” for the care recipient, or makes the important decisions – whether financial, emotional, or physical – regarding the care recipient’s overall wellbeing)
- The participant does not necessarily co-habit with the care recipient, but they should be providing at least three hours of in-person care per week (caregivers who provide more than three hours of assistance per week are significantly different on cultural and structural levels than those who provide less than three hours of assistance per week (Keefe, Rosenthal & Beland, 2000)).
 - Although McConaghy and Callabriano (2005) found that neither

caregiver burden nor physical health is associated with time spent providing care, I sampled for caregivers who have been providing at least three hours of care per week for at least three months. This ensured that the consequences of caregiving and the need to look after their own health were evident to caregivers.

- The caregiver may be any age (as long as they are older than 18), but must be able to communicate in English and live in the Greater Victoria area (including Sooke and Sidney, but not North of the Malahat).

One challenge in recruiting caregivers is that many people do not self-identify with this role. Self-identification as a caregiver is a complex transition that involves a change in self-perception, perception of the care recipient, and in daily activities and obligations (Dobrof & Ebenstien, 2003). As many as one half of spousal caregivers do not identify with the label “caregiver,” even though by objective standards they perform the duties associated with the role (O’Connor, 1999). In addition, some people report that their responsibilities as a caregiver began five or more years before the care recipient was formally diagnosed with health problems (Molloy, Lever, Bedard, Buyatt & Butt, 1996). Including broad information about who caregivers are and the types of responsibilities that caregivers assume is an important part of reaching the target audience of all caregivers, not just those who are comfortable with the label of “caregiver.” If I was to have used the term “caregiver” in my recruitment process, it is possible that I would have had difficulty finding people who were willing to participate. Instead, I focused on the tasks that people do (e.g., providing support to an older family member) rather than the label they identify with to aid my recruitment process.

Initially, I attempted to recruit participants through posters at local agencies (e.g., the Family Caregivers' Network Society), local rec centres (e.g., Oak Bay Rec Centre), libraries (e.g., the central library), and community centres (e.g., the Blanshard Community Centre). Although I was able to recruit one pilot participant through these posters (the second pilot participant was a friend who met the minimum eligibility criteria), the posters did not yield any other interview participants. I changed recruitment strategies (and amended my ethics application) and put advertisements for participants in the Epilepsy and Parkinson's Society's electronic newsletter and the Family Caregiver Network Society's print and electronic newsletter. I selected these two organizations because they both offered the opportunity to use their newsletters for recruitment when I stopped by to put up my recruitment posters.

Once a few participants were recruited through the newsletters, I used snowball sampling by asking interview participants to pass my contact information on to other acquaintances who they thought may be interested in participating. Snowball sampling is a useful technique for small populations who may not widely disclose the selection criteria (such as caregivers), but it can lead to a homogenous sample (Ritchie, Lewis & Elam, 2007). To mitigate this potential form of bias, I did not allow other family members or close friends to participate. For example, the caregiver with myesthenia gravis said that her husband was also her caregiver, and although he also met my participant criteria, I did not interview him because his views may have been very similar to his wife's. I also ensured that all participants were screened and met my eligibility criteria, regardless of how they found out about my research.

The combination of advertisements in newsletters and snowball sampling

produced a sufficiently diverse sample of caregivers to reach theoretical saturation - the point where no new insights were emerging from the data (Creswell, 2007).

Demonstration of theoretical saturation is incorporated into Chapter 4.

Interviews with producers

Critical discourse analysis is a valuable tool to help understand how language is used to exercise power and control (Jager & Maier, 2009); however, this methodology is not without critique. Critical discourse analysis can lead to simplified explanations of social structures and relationships (e.g., “executives always manipulate employees for their own benefit”) when ideas about power relationships are pre-defined and then “confirmed” by the discourse analyst (Blommaert, 2001). In order to avoid this type of bias, I include the voices of people who are involved in generating the discursive imperative for caregivers to be healthy. Interviews with people involved in discourse-creation (the “producers”) provide context (e.g., why the brochures were created, what their aim is, how they are consistent with agency policy) that would not be evident if I did not include these interviews. Including interviews with producers also counters the tendency to dichotomize discourse as structure and caregivers as agents constrained by structure. Instead, including data from three sources (producers, caregivers, and health-promotion brochures) illuminates the iterative ways in which individuals influence and are influenced by societal structures.

As in my interviews with caregivers, I do not make claims about the statistical significance of the data from my interviews with producers. Therefore, I also used purposive sampling to select participants in this group. I selected seven of the twelve organizations whose brochures I analyzed from which to recruit producers. My analysis

of the health-promotion documents produced by each of these seven agencies yielded rich results; I excluded the other five organizations from my producer recruitment strategy because their brochures were simpler, more generalized than the others, or because they rephrased and recontextualized information included in the others. Interviews with producers in the seven selected agencies add perspective as to why the agencies think caregiver health is important, challenge my interpretation of the health promotion brochures, and validate my understanding of how the imperative for caregivers to “be healthy” is connected to neoliberal ideology. Due to the small sample size I recruited, I will not identify which organizations I approached in order to help protect participant confidentiality.

The interviews with producers focus on the producers’ perceptions of why it is important for caregivers to be healthy and the barriers they believe caregivers face to being healthy. Similar to the caregiver interviews, the interviews with producers centre on the following two questions:

- “What are your experiences of the process of encouraging caregivers to be healthy?” and,
- “What contexts or situations have typically influenced or affected policy directions regarding health promotion efforts targeting caregivers?”

I also asked the producers to comment on the caregiver-targeted health promotion brochure produced by their agency using the same photovoice approach as in the caregiver interviews. I asked each producer to comment on photographs and text from the brochure produced by their agency (the interview schedule is included as Appendix III). As I already knew the producers’ occupational statuses (a principal indicator of socio-

economic status), I limited my questions about producers' backgrounds to a few questions about how long they have been in their position and how they chose their particular career. This both saved time and made it easier to maintain confidentiality.

Sampling, sample size & recruitment: producers

My recruitment strategy was to send emails to each organization that I wished to recruit from explaining who I am, what my research is about, what participation would entail, and what the benefits of participating would be. Email addresses for each organization were available on their websites. Where possible, I emailed the person or department responsible for communications for the organization. In cases where this contact information was not available on the website, I emailed the address given on the website and asked to be connected with the person or department responsible for producing and updating their brochures. In my emails, I explained that I would maintain their confidentiality as much as possible; however, this would be somewhat limited due to their positions within the agencies (recruitment instruments are included as Appendix I). For example, I let potential participants know that I would identify the agencies included in the discourse analysis by name, but not attribute the interview data to a particular organization. For those who were hesitant to participate, I offered the option to review my use of their data before it was submitted for review by my committee.

Although I had originally intended to interview four to six producers, this proved difficult. Repeated emails and phone calls to various organizations yielded either no reply or replies from people who did not meet my eligibility criteria. Eventually I was able to recruit two eligible producers. The inclusion of only two producer interviews is justifiable for a few reasons. This is a small qualitative study and I am not making claims

about the statistical significance of this research. More interviews with producers would be needed in order to validate my findings about how producers conceptualize the imperative for caregivers to be healthy. However, this is not the primary focus of my thesis. The two interviews with producers are included, nonetheless, because they challenge the results of my critical discourse analysis and add depth to my findings about the means by which caregivers experience the imperative to be healthy. I expand on these ideas in Chapter 4.

Data analysis: Critical discourse analysis

There are multiple approaches that fall under the umbrella of methods of discourse analysis. In general, a discourse analyst looks beyond what a particular text (whether written or spoken words, non-verbal communication, or semiotics) is about and tries to understand what the discourse actually does. Wood and Kroger state that the discourse analyst assumes that phenomena of interest are “constituted in and through discourse” (2000: 4). Discourse analysis is traditionally rooted in constructionist ontology and relies on inductive approaches to data collection and analysis. For example, Wood and Kroger describe the task of discourse analysis as “[identifying] the ways in which participants themselves actively construct and employ categories in their talk” (2000: 29), instead of stating a hypothesis and looking to see if there is evidence in the discourse to support it. Constructivist discourse analysis emphasizes that individuals develop and relate to socially-constructed discourse. This discourse can be pre-existing because we are born into pre-constructed social worlds (Berger & Luckman, 1967). Nonetheless, discourse is seen as a product of human behaviour; we engage with ideology in an ongoing manner through discourse. In constructivist approaches to discourse analysis,

meaning is not imposed on discourse but is created through interaction between individuals. Therefore, constructivist discourse analysis rejects the idea of one “true” interpretation of the discourse (Wood & Kroger, 2000).

Critical discourse analysis, on the other hand, is predicated on the belief that structures, institutions, and especially power influence both the creation and effect of discourse (Jager & Maier, 2009). Critical discourse analysis is critical in that it explicitly aims at “revealing how language is used for the exercise of socio-political control” (Widdowson, 2004: 89). This method critiques statements that seem “common sense” in an attempt to illustrate the impact of background value judgments. Researchers using critical discourse analysis begin from a moderately deductive approach because they believe that discourses have been influenced by structural forces (this underlying hypothesis lends critical discourse analysis its deductive start, though it does not preclude the inclusion of inductive orientation as analysis unfolds). In fact, one critique of critical discourse analysis is that it imposes a priori categories and assumes a taken-for-granted approach to power and social reality (Wood and Kroger, 2000).

From a critical point of view, the purpose of discourse is to produce particular types of meaning or action. This is part of an exercise of power, wherein structures or groups that have power attempt to exercise their power over others. Power relationships may not act directly and immediately on others, but instead indirectly through their actions (Foucault, 1982). Additionally, the power effects of discourse are not necessarily due to manipulative effects of groups or individuals but should be interpreted in light of their relationship to structural and ideological forces (Jager & Maier, 2009). Arguably, the organizations and agencies that authored the brochures analyzed in this thesis have

caregivers' best interests at heart. However, their good intentions may not prevent deeply-seated – and sometimes unconscious – ideological beliefs from influencing how self-care advice is framed. Indeed I show this to be the case in Part 2 of Chapter 4.

Again from a critical perspective, it is a mistake to analyze discourse as if it was simply culturally co-constructed, as interpretivists advocate. Instead, the aim of critical discourse analysis is to explore how power and structure influence the cultural co-construction of discourse. The approach to discourse analysis I adopt in this paper is primarily qualitative because I seek to explain how meaning is generated and perpetuated through discourse. This methodology can also be quantitative, for example by counting how many times particular statements or themes are used. Jager and Maier (2009) suggest that a critical discourse analysis should fully capture the qualitative range of what can be said and how it is said, and so sampling is done until theoretical saturation is reached and no new analyses emerge. Wodak and Meyer (2009) discuss six different versions of critical discourse analysis; I briefly outline two (Dispositive Analysis and Dialectical-Relational) that are incorporated into my own critical discourse analysis.

Dispositive Analysis is based on Foucault's discursive theory (Jager & Maier, 2009) and is more deductive than inductive. Dispositive Analysis also takes a mid-range position between the importance of structure and agency (Wodak & Meyer, 2009). Dispositive Analysis is positioned as a materialist, rather than idealist, theory. According to Jager and Maier, "without discourses, there would be no (social) reality...discourses are fully valid material realities" (2009: 36). Jager and Maier leave room for constrained individual agency: they say that social actors intervene as "co-producers and co-agents of discourse" (2009: 37). On one hand is the "power of discourse" – discourse limits what is

sayable. On the other hand, individuals and groups also have “power over discourse” to the extent that they have differential power over what is said.

In analyzing the power of/power over effects of discourse, the researcher must distinguish texts from discourses. Simply put, a discourse develops through the accumulation of many individual texts when these texts together present a comprehensible message (the texts themselves may be written documents, but they may also be conversations). The effects of individual texts on people are difficult to observe. For example, it is difficult to measure the effect that reading a particular book has on an individual person. Discourse, because it is made up of recurring themes and symbols that reach wider audiences and have greater impact, lends itself to an analysis of effects. I incorporate the dispositive analysis method of critical discourse analysis by identifying recurring themes and symbols in the health-promotion brochures. By identifying recurring themes in the discourse, I am able to comment on the extent to which the neoliberal ideology of individual responsibility for health is evident in the health-promotion discourse targeting informal caregivers.

The second version of critical discourse analysis that is incorporated in this thesis uses the Dialectical-Relational methods described by Norman Fairclough, one of the dominant voices of critical discourse analysis. The Dialectical-Relational strand of critical discourse analysis focuses on how practices (i.e., institutions and organizations) mediate the relationship between the abstract (structures) and the concrete (events) (Fairclough, 2009). Dialectical-Relational methods privilege the role of structure over that of agency and are the most strongly deductive of all six versions of critical discourse analysis reviewed by Wodak and Meyer. Dialectical-Relational methodology has

theoretical roots in Marx, Foucault, and Halliday (Wodak & Meyer, 2009). It stresses that the dialectical relationship between semiosis and other social elements is what research should focus on, rather than semiosis as such (Fairclough, 2009). Although the focus on dialectics rather than the material reality of discourse could indicate a constructionist approach, Fairclough states that his approach comes from a “critical realist position which is moderately socially constructivist” (2005: 916). Fairclough (2005) is critical of versions of critical discourse analysis that see social phenomena as solely socially constructed in discourse. Instead, he focuses on the relationship between social and cultural structures and discursive events, with a particular aim at illuminating the sometimes-opaque power relationship within discourse (Fairclough, 1993).

Incorporating moderately critical realist Dialectical-Relational methods is useful in order to contextualize the analysis in this paper. From a critical realist standpoint, reality exists independently from our knowledge of it (Danermark, 2002). The objects studied in the social sciences are socially produced, but nevertheless real. Reality is not transparent, and in order to unearth the generative mechanisms that affect reality, we need to go beyond peoples’ explanations of the social world: critical discourse analysis is a method that embraces this type of analysis. Social systems are inherently open: outcomes in the social world always entail interplay between structure and agency, which are temporally distinguishable and analytically separable. Structure and agency are intertwined in reality, but by analytically separating them we are able to identify emergent structures, differentiate between the causal powers of structures and agency, and explain outcomes (Archer, 2003). Although my discourse analysis focuses on the structural contexts in which the health-promotion discourse is situated, in reality the

structural contexts are also influenced by individual people. People wrote the documents, and it is people who read them. Even though the documents may present a certain ideology, it cannot be assumed that the readers and writers share this ideology or incorporate it into their own lives.

Data analysis: interviews

Everyone I interviewed consented to have their interview digitally recorded. I used Dragon NaturallySpeaking 11.0¹ to transcribe the interviews. I used qualitative software (QRS NVivo 9) to code the transcripts. Interview data analysis was an iterative process; it was both inductive and deductive. To begin, I highlighted significant statements in each interview, categorizing each statement into broad themes. Creswell (2007) refers to this process as “horizontalization.” It both creates a horizon of significant statements that encompasses the broad range of relevant data and helps manage the copious amount of data that is generated by in-depth interviews. During this stage, I used both themes identified in my literature review as potentially significant (i.e., deduction) and new themes that emerged from the data analysis (i.e., induction). For example, I knew from my literature review that it was important to understand why caregivers felt that it was important to be healthy themselves, so I coded statements relating to this theme as “why I should be healthy.” During data analysis, I discovered that several caregivers talked about how, for them, the process of learning how to be healthy while being a caregiver was an important part of experiential learning. This is not a theme that I had anticipated ahead of time. I coded statements that related to this experience as “it is learnt by doing.”

¹ Dragon NatruallySpeaking is voice recognition software. Once the user “teaches” the software her own voice, the software is able to translate the user’s voice into text. In order to transcribe the interviews, I listened to the interview through headphones and spoke both parts into a microphone. This process is significantly faster than typing the transcription).

During subsequent iterations of data analysis, I continued to categorize the data into themes with specific excerpts from the interviews to illustrate the themes (Creswell, 2007; Aubeeluck & Buchanan, 2006). I began data analysis by separately analyzing each group of data in order to establish what being healthy means to caregivers, how being healthy is represented in discourse, and how producers frame the importance of caregiver responsibility to be healthy. Each facet of data analysis gives a different perspective on the ideological imperative for caregivers to be healthy, although there are also surprising ways in which the perspectives overlap. After analyzing each group separately, I compared and contrasted what caregivers and producers say about being healthy with my findings from the critical discourse analysis. This is how I have been able to bridge caregivers' personal experience of being healthy with the structural conditions that create an ideological imperative to be healthy.

Operationalization of neoliberalism

In the context of this thesis, I have conceptualized neoliberalism as, in particular, a cultural tendency towards individual responsibility. Ilcan (2009) identifies three themes which help operationalize the shift towards individual (or private) responsibility which characterizes neoliberalism. First, there is a shift from social to private responsibility. This does not necessarily correspond with a complete withdrawal of the State, but state apparatuses may be reconfigured. In particular, this shift is seen as individuals become responsible for monitoring and paying for their own health. For example, caregivers who opt for private home care over subsidized home care demonstrate this shift from social to private responsibility. Changes to eligibility requirements for home and community further necessitate this shift. Second, Ilcan (2009) describes a responsible citizenry that

becomes more flexible yet at the same time subject to the rhetoric of responsible living and caring. The flexibility is seen in the assumption of multiple roles, for example working, parenting, and caregiving for older adults at the same time. Caregiving has traditionally been associated with familial responsibility. It enters the realm of neoliberalism when caregivers are not just caregivers, but also responsible for integrating other cultural roles. Finally, Ilcan (2009) argues that neoliberal governments encourage citizens to manage their own social and economic development. This is exemplified by caregivers who become active advocates for their care recipients. Advocacy can take multiple forms, from joining a family council to talking to the care recipient's doctor in order to advocate for better care. What distinguishes this third theme as neoliberal is that individuals and their families are required to take on this role in order to ensure appropriate care. Caregivers cannot count on the State to ensure the social and economic wellbeing of the care recipient. They must take active roles.

In the context of a neoliberal imperative to be healthy, neoliberalism values are related to healthist values. Healthism situates the problem of health and illness with the individual, and solutions are formulated at the individual level (Crawford, 1980). Individual action is considered the most important factor in preventing physical decline and disability (Clarke, Griffin & The PACC Research Team, 2008). Many Canadians prescribe to healthist beliefs to some degree, so it is not a matter of identifying whether or not interviewees express healthist beliefs, but to what extent they do and whether they also incorporate conflicting discourses. The following list developed by Greenhalgh and Wessely (2004) outlines how healthism is operationalized. People who demonstrate healthist beliefs are:

- Keen to exercise patients' rights
- Enthusiastic about seeking information about how to be healthy
- Trying to make healthy lifestyle choices (e.g., exercise, little use of alcohol or tobacco)
- Using alternative medications with holistic properties (e.g., vitamins, supplements, herbs)
- Concerned about "unnatural" health risks (e.g., chemicals, additives)
- Exercising consumer choice in how the medical system is accessed and used

Validity, representativeness, and transferability

The quality of my research can be gauged by standards appropriate for qualitative research. I ensure the validity of my results by focusing on four criteria outlined by Creswell (2007):

- the results are a credible interpretation of what participants meant. To assure this, I include quotes and excerpts from transcripts that illustrate the interpretations that I have developed,
- the research is authentic and different voices are heard. To assure this, I ensure that my analysis reflects the broad range of my participants' experiences, not just those that I think support my findings,
- there is a critical appraisal of the research. This will include exploring both opinions that recur in the data as well as deviant cases,
- and the investigator is reflexive and self-critical. This includes being self-

aware of the understanding that I bring to the research and how it may be different from the understanding I derive from the research. I ensured that I remained reflexive by writing memos and keeping a journal throughout the data collection and analysis phases about my experience, my own thoughts about the research and my reactions.

All of these steps together ensure that my findings are accurate and reflective of the experiences of the people I interviewed.

There are also several steps I took to ensure the representativeness of my research. I was able to digitally record each interview; verbatim transcriptions provide a reliable representation of the interviews I conducted. Although I was the only person coding the transcripts (making it difficult to check inter-coder reliability), I maintained a clear record of how codes were developed and how codes were grouped into themes. Including perspectives from producers ensures a fair representation of the motivations for publishing health promotion brochures targeting caregivers, rather than assuming that neoliberal ideology predominates these decisions.

Ethics

My research proposal received ethics approval (protocol number 10-478) from the UVic Human Research Ethics Board on December 23, 2010. I subsequently amended my caregiver recruitment strategy; approval of the amendments was received on February 18, 2011. All research participants reviewed the informed consent form and were given the opportunity to ask questions. The caregiver and producer informed consent forms are included as Appendix II.

Chapter 4: Results and Discussion

Overview

In this chapter, I present and discuss my research results. The results and discussion are separated into two main parts: what being healthy means to caregivers and the means by which caregivers can be healthy. I begin by providing an overview of the characteristics of the people I interviewed, both caregivers and producers. I describe the aggregate participant groups and introduce the reader to their stories. Descriptions are aggregated in order to protect participant confidentiality.

In Part 1 of this chapter, I describe what being healthy means to caregivers by exploring their viewpoints in relationship to the concepts of agency and structure. Part 1 is divided into sub-sections based on key themes. To begin, only data from caregiver interviews is presented and discussed. The way that caregivers talk about what being healthy means is divided into sub-themes in order to capture the breadth of experience and provide rich description of what being healthy means for caregivers. In this way, I describe how caregivers use their agency to develop ownership of individual definitions of what being healthy means. In recognition that viewpoints of what being healthy means are also influenced by structure, I describe how the meaning of being healthy for caregivers both changes as the caregiving experience unfolds and is influenced by personal biography and history. As could be expected, Part 1 reflects previous research on what being healthy means while also reflecting known challenges caregivers face. Even though the results are not unexpected, they form an important part of this research because they validate previous research and form the groundwork for Part 2 of this chapter.

Part 1 concludes with a discussion of how the three data sources (caregivers, producers, and critical discourse analysis) describe why it is important to for caregivers to be healthy. Examining why it is important for caregivers to be healthy leads into Part 2, which explores the means by which caregivers can be healthy. This section uses the sociological concepts of individual, familial, and collective (and communal) responsibility as a framework to demonstrate how the means caregivers can use to be healthy either resonate with or challenge neoliberal ideology. Part 2 incorporates the critical discourse analysis findings, which suggest that caregivers are encouraged to primarily take individual responsibility for their own health, consistent with neoliberal values. I show that although caregivers describe individual actions when they talk about what being healthy means (Part 1), suggestions and advice from others along these lines can be problematic. Most interestingly, interviews with producers suggest that the motivation in creating health promotion brochures may be twofold: to encourage caregivers to be healthy, but also to encourage caregivers to reach out to the organization that produces the brochure for additional information and support. Interviews with producers challenge the idea that health promotion brochures are created by people who demonstrate neoliberal values.

My critical discourse analysis suggests that health promotion brochures are used to encourage caregivers to take individual responsibility, consistent with neoliberal ideology. Of note, I show that both caregivers and producers challenge neoliberal ideology by offering diverse suggestions about the means caregivers can use to be healthy. Being healthy, in the end, results from actions that individuals take. However, the ability to take individual action is predicated on having the necessary supports in

place to do so. I conclude that the producers I interviewed demonstrate a desire to enable caregivers to be healthy by encouraging them to reach out for support both from formal and informal resources.

Participant characteristics: Caregivers, care recipients, and producers

I conducted two pilot interviews in order to test my interview guide and refine my interviewing skills. Both pilot participants were active caregivers, although their caregiving responsibilities were slightly lighter than my eligibility criteria's threshold. This reinforced for me the importance of screening: although both pilot interviewees had much to say about being healthy, it is difficult to describe the additional challenge that caregiving places on their responsibility for being healthy because they did not experience the same competing pressures as more active caregivers.

During the pilot interviews, I noticed that the participants were not as engaged in the questions during the photovoice component of the interview as I had anticipated. For example, participants would only say a sentence or two when I asked them to tell me the story of the photograph. Additionally, when I asked the pilot participants how they were like or not like the people in the photographs, they focused on obvious physical traits (e.g., hair colour, age). Although these responses led me to suspect that the photovoice component may not add the depth of detail and link between advice people receive from brochures and their own viewpoints that I had initially expected, I decided to continue using the photovoice component for a few interviews to see if it could still provide me with useful and insightful data. In the end, I only used photovoice in some of the interviews. I found that asking people about the advice they receive about being healthy

and probing specifically about media, organizations, or professionals yielded rich responses about the external pressures people feel to be healthy. In some interviews where it was more challenging to engage the participant, I found that the photographs were a useful tool to stimulate conversation, so I continued to use photovoice when it encouraged the participant to talk more about being healthy.

After completing the pilot interviews, I conducted 11 interviews with caregivers between February 13 and June 1, 2011. The interviews were conducted at caregivers' homes, my office at UVic, and coffee shops. The interviews took between 1:08 and 1:53 to complete, with an average interview length of 1:29. I interviewed nine women and two men. The average age of the caregivers is 58, and the caregivers' ages range from early thirties to mid-seventies (exact age range is not reported to help preserve participant confidentiality). Five caregivers are employed, five are retired, and one is a mature student. One caregiver rates her health as fair and the others rate their health as either excellent, very good or good (on a five-point self-rated health scale ranging from poor to excellent). None of the caregivers rate their health as poor, even though three have significant health issues of their own (Parkinson's disease, clinical depression, and a neuromuscular disease called myasthenia gravis).

All of the caregiver-care recipient dyad relationships are familial: the caregivers I interviewed are caring for spouses, parents, and siblings. Three of the caregivers currently cohabitate with the care recipient - in these cases, the care recipient is either a spouse or parent of the caregiver. Five of the caregivers have other family members living in their households (non-care recipient spouses and children), while five of the caregivers live alone. Four of the caregivers have previously been a caregiver for

someone else in their family.

The average care recipient's age is 83, and care recipient ages range from late sixties to centenarians. Care recipients have a variety of living arrangements. Of those not living with their caregiver, two care recipients live in independent living and five live in institutions (residential and palliative care). One care recipient had been living alone at home, but at the time of the interview was hospitalized for a fall. This care recipient is in transition - after hospitalization, it was not clear if she would return home or move into a residential care facility.

Care recipients require support because of a variety of acute and chronic conditions. In most cases, they have multiple chronic conditions; where acute conditions occur, these are fall-related and in addition to pre-existing chronic conditions. Chronic health conditions include the following: dementia (including Alzheimer's disease), cancer, stroke, Parkinson's disease, heart disease, Multiple Sclerosis, diabetes, depression, anxiety, and blindness. Most care recipients have been receiving support from their caregiver for between half a year and six years, although in one case the care recipient has required increasing support for 30 years.

Caregivers provide diverse types of support to their care recipients. Some of the care provided is with activities of daily living, such as helping the care recipient eat, bathe, and dress. Caregivers also provide support with instrumental activities of daily living, for example by helping the care recipient with cooking, cleaning, shopping and banking. Several caregivers list companionship or social stimulation as an important part of the care they provide. Most caregivers provide more than one type of support. In fact, only one caregiver says that she provides just one type of support (in this case,

companionship). Two caregivers are not accessing subsidized or private supplemental support. The others are using a variety of supports ranging from laundry and housekeeping provided by the Department of Veterans Affairs, to public and private home support, respite, live-in caregivers, and full-time residential and palliative care.

I conducted two interviews with producers. Both are female and work for non-profit organizations that produce health promotion brochures targeting caregivers. The interviews with producers took on average 40 minutes to complete, and in both cases were conducted by telephone. Both interviews were digitally recorded and transcribed verbatim. Because the sample size is so small, additional participant characteristics are not presented in order to preserve participant confidentiality.

Part 1: What being healthy means for caregivers

In my review of the literature, I show how previous research has demonstrated that the meaning of being healthy is subjective, fluid, and made up of multiple components. My interviews with caregivers echo this research. What caregivers say being healthy means is much as would be expected. Some caregivers talk about being healthy in a holistic sense, similar to people in other studies about being healthy (after all, caregivers are people too, they are not just caregivers!). Others discuss their own physical health conditions, or how the stress of being a caregiver makes it difficult to be healthy.

At some point during the interviews, all of the caregivers describe the ideal state of being healthy as the successful incorporation of multiple elements. These include regular physical exercise, a balanced diet, rest, relaxation, and socializing. As Jean notes, “Well, I think, there's several levels, there's physical health, and for me that entails some physical exercise, and on a regular basis...and eating properly...I think I eat you know a

fairly decent diet...I try to get sufficient rest.” James summarizes that for him, “being balanced physically, emotionally...being social, whether that's with friends or family, eating properly, and sleeping enough hours in the day, nutrition, and rest, and exercise” are all components of being healthy. Jessica says that overall she is a healthy person: she does not have physical ailments that affect her abilities to accomplish day-to-day activities. Nonetheless, she feels that she should be doing more to be healthy, such as exercise, weight control, eating more consistently, and managing her stress. Meghan too describes health in holistic terms; she feels that having a healthy mind and body helps her prepare for the unexpected.

Although the caregivers share similar, holistic definitions of what being healthy means, it cannot be stated that this is because they share similar life experiences. The people I interviewed encompass a wide range of ages, backgrounds, and experience as caregivers. The similarities that they describe, when I first asked about what being healthy means, reflect broad cultural experiences of the imperative to be healthy. It would have been surprising had I NOT found that people talk about being healthy as a holistic combination of mental, physical, and social components.

Variation emerges in the lived experience of being healthy. Three of the caregivers have or expect to have serious health concerns of their own. For them, the lived experience of being healthy centres around being healthy in spite of their own physical challenges. For example, Olive, who is diagnosed with Parkinson’s disease, says that “even if you may have some disability, to be able to keep functioning, in as normal a way as possible” is what being healthy is about. Bev’s beliefs are similar: she states that

“to be at peace, I think, in your mind, and spirit, and then to be able to cope or find solutions...the running of your body, the day-to-day in and out, and that has really

changed for me over the years. I thought being healthy met just getting up and going.”

As her health changed, and as she began to come to terms with the limitations of her illness, Bev’s previous definition of being healthy as being physically fit became replaced with a view of being healthy as being able to cope with life, no matter what physical condition her body is in. In a similar vein, Evelyn feels that it is important to be healthy by remaining physically active in order to prevent the physical ailments that she had witnessed among other, older, family members. Evelyn feels that although some changes in health are out of her control, there are things that she can and should be doing now to prevent negative outcomes as much as possible.

When faced with their own physical illnesses or potential physical illnesses, these three caregivers each share a similar viewpoint: the meaning of being healthy is closely linked to individual actions. These caregivers discuss how the meaning of being healthy has changed as their illnesses have progressed and they have aged, yet the coping strategies they discuss are related to changes they as individuals can exert control over.

Three interviewees are currently sandwiched between caring for their care recipient and younger dependents (children and grandchildren). For these caregivers, the lived experience of being healthy emerges as being able to have a little mental space for themselves. Rebecca feels that, overall, her health is quite good, but that she would be better at being healthy if she could have “some kind of mental space for myself... it's something I've been trying to carve out for myself, I think it's the, the mental space that I need a little bit better for myself.” This mental space could take different forms, from being able to walk the dog alone in the morning to having the time sit down and write letters, but the key element is that this time be free from the demands that her mother,

husband, daughter and granddaughter all create.

Eileen is also sandwiched between the responsibility for her mom and her family (husband and son) at home. The first thing that came to mind for her when I asked about being healthy was walking the dog in the morning. She says:

“I like to walk the dog in the morning, early in the morning when there's nobody else around, because I just really love the peace and quiet, I'm outside, I'm getting exercise and fresh air, and listening to the birds, like it's all one big picture, it's not just one little bit of that scenario, it's the whole picture combined. So if I have lots of time, that if I do that, I feel like I'm more well-balanced.”

For the three “sandwich generation” caregivers, taking time to be alone is essential to be healthy. The activities they enjoy, coincidentally, are quite similar. Although these caregivers discuss actions that are similar to those discussed in previous sections, what differentiates this group is that being healthy is closely tied to being able to ask for and receive time alone.

Two of the caregivers I interviewed say that being healthy is simply not possible for them. However, they come to this conclusion for very different reasons. Beth is very cognizant of our cultural standard of a holistic definition of health, and for her this standard simply does not fit. Her response to my questions about what being healthy means is “Well I know I'm not, because to me being healthy means you have some kind of balance in your life. And I've never had any balance in my life.” That said, Beth goes on to describe how being out of balance, or living with a different definition of balance in which passions cycle from one healthy passion to another, is what feels healthy to her. Nonetheless, she is aware that what she feels she needs to do to be healthy is at odds with our cultural standard of what health and being healthy look like.

Dave, on the other hand, feels that life circumstances, and the combination of his own depression and his wife's long battle with Multiple Sclerosis, have created a

situation where being healthy is “something that I can't seem to get.” By objective standards, Dave is healthy: he has no major physical ailments and has been given a clean bill of health by his doctor on several different occasions. Nonetheless, Dave does not consider himself healthy because he is not happy. He says:

“I'm not healthy, I don't think...Being healthy? I wish. Like I said, there's not much wrong with me physically...they don't ask about what goes on up here. I haven't been happy for a long, long time. I can't even remember the last time I felt happy. And I don't know how to attain that, if I'll ever get back to feeling happy...Feeling joyful, you know I thought about it from time to time, you know it would be nice if something would happen that I could just jump up and hey! Isn't it great or something! Nothing like that ever happens to me, or with me. And I don't think it will. Well, because of the situation, but also because of my depression. Depression is the thing that is the biggest problem I've got healthwise.”

The combination of his depression and his wife's steadily worsening health make Dave feel that being healthy is impossible. He is not able to be healthy “in spite of” it all, as are some other people. He is living through exceptionally difficult life circumstances, and having a hard time coming to terms with it. Interestingly, he is also the caregiver who describes spending the most time and effort searching for help from a variety of other sources. Other caregivers talked about seeing a counsellor a few times, or asking a doctor a few questions, but Dave has sought help - with limited success - from a variety of private and public sources.

These two caregivers feel disconnected from the idea of being healthy because they recognize that there is a cultural standard for this concept that they are unable to achieve. Although being healthy means different things to different people, there are still dominant themes within this spectrum of difference. Caregivers who feel different from the culturally-accepted definitions of being healthy may feel alienated from the concept and have difficulties relating to health-promotion efforts.

Summary

All of the caregivers I interviewed describe being healthy as multidimensional when they considered what being healthy means in the ideal sense. Whether or not they see themselves as healthy, all of the caregivers that I interviewed see health as multifaceted. The combination of factors that make up health vary, but no one defines health in purely physical terms. Interestingly, of the two who focus more on single factors, both emphasize mental – not physical – health as the key component of being healthy.

Another key theme that ties caregiver's initial responses together is their discussion about who is responsible for maintaining their own health. All of the caregivers mentioned things that are their own responsibility to do. Whether it is an imperative to exercise more, eat healthier, rest more - or even in Dave's case, be happier - no one mentions that they think someone else is involved in their efforts to be healthy. The people I interviewed believe that being healthy, at first glance, is their own individual responsibility.

The meaning of being healthy changes as the caregiving experience unfolds

People become caregivers when they already have an idea about what being healthy means: each individual's understanding of the meaning of being healthy develops over the course of their lives. Some of the caregivers began by describing the meaning of being healthy purely in the context of their own lives; others focused from the start on the meaning of being healthy in the context of caregiving. In this section, I explore how the meaning of being healthy changes as the caregiving experience unfolds. Some of the

caregivers I interviewed focus on one aspect of being healthy rather than multiple aspects. Some emphasize that being healthy is important in order to be a good caregiver. And for some caregivers, what emerges is that it is more important to be a good caregiver than to be healthy yourself.

As caregiving responsibilities intensify, the caregiver's experience of the imperative to be healthy may also change. For two interviewees, the change was that one facet of being healthy emerges as very important while other facets diminish. Being a caregiver for a mom with Alzheimer's disease and a son with autism has influenced Beth's viewpoint on what being healthy means. Beth feels that the stereotypical vision of health (as physical fitness) never really fit for her. Even more so because of the experience she has gained as a caregiver, Beth has come to feel that being healthy is more connected to overall wellness, especially mental wellness, than physical fitness. Over the course of her caregiving experiences, she has come to realize that

“health is actually a lot bigger than that, that health has more to do with relationships, and with, um, with fuelling passions...probably has more to do with mental health than it has to do with physical health, in terms of your own satisfaction with your own life.”

The things that Beth does now to be healthy are likely to encompass an evening out at a bookstore with her husband or a planning session about a support group she organizes with a friend. When Beth feels that she is able to direct her energy towards projects she is passionate about, she feels she is being healthy. At times, caregiving makes this more difficult and as a result, Beth feels that her health suffers.

When Eileen's mom was in the hospital, Eileen's belief about what was important for her to do to be healthy changed dramatically. Typically, Eileen considers herself a very health-conscious person. She eats well, exercises regularly, and makes sure

to incorporate healthy socializing into her life. All of this changed when her mom's health became precarious. Eileen says that

“if you asked me at that time what it meant to be healthy during that period...it was doing everything I could to not catch a cold or the flu, so that I would always be available for my mom, and so I took the, you know the handwashing and hand sanitizer, and you know wearing a mask, and you know just doing everything I could so that I could stay disease-free.”

Eileen wanted to be healthy in order to be available at all times for her mom, and this meant being extremely careful not to catch any infectious diseases that she could potentially transfer to her mom while mom's health was vulnerable.

At this stage in the caregiving process, being healthy was closely tied to physical health. Eileen needed to be healthy so that she would not make her mom sick. However, all the other activities that Eileen typically does to be healthy when she is not a caregiver suffered as a result. For example, she would drive to the hospital instead of riding her bicycle because it saved time. Her attitude adjusted; Eileen compensated for the change in activities by looking for ways in which the new activities help her be healthy instead of allowing herself to be frustrated. She says that

“I was having to drive up to the [Victoria General Hospital], I hated it, I hated being in a car I hated being in traffic, I was just like grrrr, and then when I realized that if I looked at it differently, that 20 min. or 30 min. that I had in the car was actually a really nice time to listen to the radio, which I never got to do because when you ride your bike you never hear the radio, so it turned out to be that time in the car, I really, really liked it.”

As the caregiving experience unfolds, Eileen finds that she consistently needs to adapt what being healthy means in order to reconcile her daily life with what being healthy means because it is very important to her.

Evelyn's attitude about the importance of being healthy has also changed as a result of caregiving, but this is because she is concerned about her own risk of developing

Alzheimer's disease when she is older. She has added healthy brain activities such as Sudoku and crossword puzzles to her regular routine. She is determined to include activities in her lifestyle that keep her brain active and challenged, in the hopes that this will lower her own risk of dementia. For Evelyn, seeing the effects of dementia first-hand opened her eyes to her own risk. Now, part of being healthy is risk mitigation.

Each of these three caregivers has been affected by her experience as a caregiver. The caregiving experience can challenge people to rethink their own values, priorities, and expectations when it comes to being healthy.

Six interviewees have already lived through experiences of high caregivers stress and burden, including care recipient hospitalization for chronic, life-threatening illness and transitions to residential and palliative care. During these times, the practical realities of being a caregiver make incorporating time for self-care extremely difficult. It can be difficult to take even short breaks. This was Jean's experience as her husband's health deteriorated. Even when she was accessing supplemental support from a variety of other people, Jean still felt that she was not able to cope. She knew that she was not being healthy, but was unable to find a way to separate herself from the stress. Having gone through such a stressful experience as a caregiver to her husband has impacted her current role as a caregiver to her sister. Now, Jean feels it is vitally important to maintain her own boundaries and not end up in that type of situation again. Indeed, Jean stresses that the really difficult decisions about her sister's care need to be made by her sister's daughters, not by her. She sees herself more in the role of facilitator and companion. She is not willing to be the same type of caregiver to her sister that she was to her husband.

Evelyn, too, remembers how hard it was to be healthy when things were really

intense with her mom. She remembers that “time gets gobbled up, you can feel really, powerless, right, it's like I can't solve any problems, I can't even keep myself, and you just get, you feel really, like I remember just feeling like, just so worn out.” Caregivers who are in the midst of a stressful caregiving time have a hard time focusing on their own health because so much of their time and attention is being directed towards the care recipient. Looking back once the difficult time has ebbed, caregivers openly acknowledge that being healthy can feel extremely difficult. They also speak candidly about the supports that were useful (as I will describe in Part 2).

Three people describe how sometimes being a good caregiver is more important than being healthy themselves. This can feel like a choice they have made, and in many cases would make again. At other times it feels outside of their control, and they struggle to come to terms with the desire to be healthy and be a good caregiver. For Dave, the challenge to being healthy while being a caregiver to his wife with Multiple Sclerosis is closely tied to feelings of guilt that he has not come to terms with. He grieves over the changes to their relationship, and over transitioning from husband to caregiver. He is upset about the loss of all the things they had planned to do during their retirement. But mostly, he feels guilty when he goes out to do something he enjoys because he knows that his wife is at home, possibly bored, and unable to take part in many of the activities that she enjoys. It seems that he would rather be miserable together than happy while she is not. He admits that he struggles on the losing side of coming to terms with the feelings of guilt for wanting to go out and take part in social activities (the key activity that he feels would help him be more healthy). I asked him what he currently does to support himself, and he candidly replied

Bugger all. That's being frank! I've realized in the last few weeks, that I do have to get out and do some things on my own. But I don't know anybody I can go and do anything with! I don't! Because I've been isolated for so long.

Dave is caught in a cycle of wanting to do more but feeling guilty when he does. Doing things for himself in order to be healthy is incredibly difficult at this time.

At the time of our interview, James's dad was in palliative care with cancer that had spread to his bones. He says

in one sense, I think, yes I have to help myself to help others, and I know all those things...but then there's also the underlying fear, I guess, of am I not doing enough, and will I regret, looking, you know 10 years from now looking back and saying I could've done a bit more...because I know every time I go there, I'm completely done, so I can say I've done as much as possible.

James knows that being healthy is important, but when he imagines looking back on his time as a caregiver, he feels that it will have been more important to have done everything humanly possible to help his dad than to have focused on trying to maintain his own health at the same time.

Jessica feels similarly to James, although because she has been a caregiver for so much longer, she has had to come to terms with the fact that she now has to take some time for herself. Similar to Dave, she feels somewhat guilty for going out and enjoying herself while her husband is in a residential care home. Indeed, he sometimes makes this feeling worse by asking her "what about me? When do I get to enjoy myself?" Jessica knows that he does engage in regular activities at the residential care home, but because of his short-term memory problems he does not always re

member these activities. Knowing that the way he feels is not necessarily based on facts helps, but Jessica still feels the sting when he accuses her of having fun while he is not able to. Nonetheless, she has had to strike a balance between spending time with him and time at home.

Jessica's current balance feels healthy for her, yet it struck me that she has come to this balance based on his needs more than her own. She would rather ensure that all of his needs are met than put some of her own first (although she is learning that every now and then she needs to step away for a few days or weeks). She says

“I think, I think I've found a pretty good balance now, for balancing things, the fact that if I don't go in until four in the afternoon, that gives me two thirds of the day to do stuff, so I have gotten back involved in some of the activities that I was doing before, outside, volunteering, seeing some friends, or just being here. But it's just, you still feel like you're on the treadmill.”

She still goes to visit her husband every evening, and does not have much time for herself. Although she is beginning to take more time for herself, Jessica prioritizes being a good caregiver and wife over being a good individual.

However, it should not be assumed that all caregivers are so willing to sacrifice their own health in order to be a “good caregiver.” Meghan says that when things become too intense and she feels competing pressures to balance her mom's needs and her own health concerns, she has to step back from caregiving and let the formal healthcare system take over for a little while. In the past, she says she stepped back and “just said enough is enough, I just can't take it anymore. I said because I had issues with my own health, I've got to take care of myself.” Meghan is not willing to compromise her own health in order to help enhance her mothers. Not all caregivers are willing to put the care recipient's welfare above their own, and it is not easy to generalize what type of caregiver will. Megan's experience illustrates that not all caregivers react the same way to the pressure of being a caregiver. It is important to bear in mind that caregiving is a highly individualized experience.

A brochure produced by the Parkinson Society of BC begins with the question “What has happened to my life? I am now a caregiver.” This quote implies that there is

no way for personal life and caregiving to coexist. The individual becomes a caregiver. Nonetheless, the brochure counsels that you can cope successfully as a caregiver “through lifestyle and important self-care choices.” As I demonstrate in Part 2, there is a predominant emphasis in brochures such as this one on the caregiver’s responsibility for controlling their own individual lifestyle choices and self-managing their stress. In the following paragraphs, I explore what being healthy during the tough times - times of high caregiver stress and burden - feels like for caregivers. Most of the people I interviewed discussed beliefs about being healthy that are consistent with individual responsibility when I first asked them what being healthy means. However, a different picture emerges when they are in the thick of things.

Sometimes when people are highly involved as caregivers, even taking the time to think about their own health is a daunting task. Jean remembers what it was like to be a caregiver to her husband while he required intense support. I asked her what she would have said if I asked her during that time what being healthy means, and she replied

“well I think when you're in the midst of that sort of thing, it's really hard to be detached, and be able to sort of look at yourself, I just knew that I felt awful, and very, very stressed all of the time, despite the fact that there other people were helping me, so I think I could've said that, that I was feeling awful, and that I wasn't terribly healthy on many levels, yeah.”

Jean knew she did not feel healthy, and even with supports in place was unable to imagine how things could be different. Rebecca, who is currently actively caring for her mother, says that when she doesn’t feel healthy, it feels like “cement block boots” are attached to her feet. When she feels she’s not coping, she can sense the work and responsibility piling up around her.

James describes how sometimes taking a break, even a short one, becomes critical. It is less about doing something to be healthy and more about doing something to

avoid becoming too unhealthy. For him, this short break can come when he steps out of the room to talk with his siblings, read the paper, or listen to some of his favourite music. James's experience suggests that being healthy when the caregiving becomes really difficult is not about incorporating multiple dimensions of health: it is about knowing what the few things are that you can spend the least amount of time on and derive the most recuperative benefit from. However short these breaks are, they nonetheless become critical. James says that

“when I reach the limit, I try to do something about it quickly, because I know if I don't it'll become a problem... physically through high blood pressure and stomach pains, or you know emotionally.”

Yet James struggles even with taking these short breaks. He notes that

“something that hinders caregivers from, from being more healthy in the end... is just their, I guess the expectations they put on themselves, to be there all the time, it's like the advice I've given to my sisters tonnes of times, it's been like you can't help dad unless you help yourself, if you don't help yourself, you're not going to be able to help him, and you won't be able to help anyone, but whether it's them or myself, I know I'm just as bad as them, and you feel a certain moral responsibility, like it's built into your fibres that you have to help us much as you can... well it's kind of an eye-opener here, I guess I've been helping other people a lot and not myself.”

Because of this feeling, James struggles with the idea of taking any time for himself if it means taking time away from the people who need him. James feels that there are excellent resources for people like his dad who need intense care. However, he notes that “people don't focus enough time on the caregivers.” Especially when it is emphasized that the care recipient relies so heavily of the caregiver, James feels that there is not enough support available for the caregivers themselves.

Yet discovering what it is that will actually help caregivers is no small feat. This is in part because many caregivers know theoretically what they should be doing to be healthy, but can have an extremely difficult time putting this into practice. Jessica says

“no, you're absolutely right, on one hand it's easy to say, I know this is what I should do, this is what I would like to do, but to actually do it, and I know I'm guilty of, but maybe not taking you know enough time for myself, of having got into the routine-slash-rut of yeah, being sort of involved in [my husband's] care, because that's really what the point of all this is, even though he is in a place.”

Even though her husband lives in a long-term care facility, Jessica has difficulty distancing herself and taking time for herself. She puts him first, but through a process of coming to terms with the fact that he has a long-term chronic condition from which he will not recover, she has started trying to reclaim some of the parts of her life that make her feel healthy. She notes that she has returned to singing in a choir once a week, a practice that she had given up when her husband first became ill.

Nonetheless, Jessica is still cognizant of the pressure to do more for herself to be healthy. She struggles to balance what - to her - has become a healthy-enough balance between her own health and her husband's care with how she feels she “should” be acting. She notes that

“in many ways I made the decision that my priority is going to be [my husband], and doing what I can for him, and also maintaining the lifestyle that I have as long as I can afford to do that...and there's times when I think that maybe, not that it's the wrong choice, but that maybe I'm waiting too much, for him, and not doing enough for me. But it does seem to be working for me, I do feel that I've got a much better balance now than I did before, and it does seem to be working now... Maybe I should just accept that if that's what I'm comfortable doing, and I feel that I do have control, then that's what it is.”

An important part of the whole experience, for Jessica, has been learning for herself how to come to terms with the changes she has experienced. Although she knows intellectually what being healthy means, she values that her experiential understanding of being healthy as a caregiver has come from within.

The ability to re-incorporate healthy behaviours varies widely among caregivers experiencing high levels of stress and burden. For example, Jessica and James have a

good understanding of the one or two key things that they can do - even if these things are small - to make themselves feel healthy. James listens to music or jokes with his siblings. Jessica rejoins her choir. On the other hand, Dave finds reclaiming past activities that made him feel healthy a daunting task. For him, it has been quite a while since he has been able to do things for himself for the sake of health. He says

“I guess that's probably why my health, overall health has dropped down to the level that it is that, because I haven't been proactive for myself. I haven't taken the initiative. And like, but just recently when I have thought about doing something, I can't think of what to do! To be proactive, you know? Nothing, nothing comes to my mind, what the hell can I do, where can I go, I can go to the pub by myself, you know that's not gonna help.”

Even knowing one thing to do to be healthy can be difficult, let alone being able to incorporate this activity into one's lifestyle.

Even though the stress of caregiving often ebbs, Meghan sees no way around a return to stress should conditions change for her mom. Meghan knows that if her mom's health deteriorates again, she is “just gonna be stressed out again, that's exactly what's gonna happen again.” Meghan is the person that her mom calls on in emergencies. She knows that if her mom is released from hospital back to her home, it is only a matter of time until she is back into a stress-heavy crisis-management role. When the time comes and they are needed, caregivers like Meghan will drop whatever they can possibly drop in order to help support someone they love. If being healthy is the thing they drop, some caregivers see it as a worthwhile sacrifice.

Although the majority of caregivers I interviewed note that caregiving changes their understanding of what being healthy means, it is a mistake to assume that caregiving necessarily causes a negative impact on the caregiver's ability to be healthy. Even though she does notice that some days she feels more tired because of her caregiving

responsibilities, Olive has not noticed that her responsibility as a caregiver is negatively impacting her health. Bev, too, feels that being a caregiver has not had a negative impact on her health. She feels well informed about what to expect, and therefore feels that declines in her mom's health have not been "a dreadful shock." Instead, she worries that her own poor health is making it more challenging to provide the level of care to her mother that she wishes she could. She feels that her body limits the care she can provide to her mom, and sometimes wishes she could do more.

To summarize, the meaning of being healthy often changes as the caregiving experience unfolds. What's more, these changes are not always perceived in a negative light. Caregivers may find that their previous understandings of what being healthy means change as they become more involved as caregivers. This can include an intensification of previously-held beliefs or a complete change to a new definition of what being healthy is. Most caregivers value the experience of re-defining what being healthy means and coming to terms with being healthy in the context of being a caregiver. Yet for a few the process is a struggle. It is clear that the experience of intensifying caregiving demands affects caregivers' beliefs about what being healthy means. This meaning is also influenced by the caregivers' life experiences.

The meaning of being healthy is influenced by the caregiver's personal biography

In this section, I apply a lifecourse perspective to caregivers' beliefs about what being healthy means. The life course perspective, as a social theory, encompasses four main points: individual lives are shaped by history and geography; the effects of life events depend on when they occur during a person's life course; individuals exert agency

(constrained by their social and historical circumstances); and, lives are lived interdependently with others (Glen Elder, 2000, as cited in Chappell, McDonald & Stone, 2007). The meaning of being healthy for caregivers is shaped by these factors. Looking at how caregivers' beliefs about being healthy have changed and other factors that influence their experience of trying to be healthy while caregiving helps illuminate the variation in what caregivers think being healthy means. It also provides historical context. In the following paragraphs, I use the four key points of lifecourse theory to frame my discussion.

Caregivers' current viewpoints about what being healthy means do not spontaneously arise: they are rooted in prior experience. Jean feels that her own viewpoint about what being healthy means has not changed much over the course of her life. As a child, her family did not have much money. She grew up during World War II, and her family subsisted on their own gardening and the meat they raised. Her mother prioritized nutritious food over new clothes or fancy houses. Jean was the same with her own children: both her upbringing and her training as a nurse taught her the importance of prioritizing nutritious food over material possessions. To this day, it is important to her to eat healthily, grow her own food as much as possible, and avoid over-processed foods. For Jean, this aspect of being healthy is not changed by her experience as a caregiver.

Changes in beliefs about being healthy can also be linked to the aging process. For example, Eileen says that when she was younger, being healthy was synonymous with being physically fit, and that it was important that her exercise included cardiovascular training. Now, she says, "maybe it's just an age thing, you get to that point in your life where you're not as hard on yourself." She still likes to be physically fit, but

she feels that it is also important to enjoy herself, slow down and listen to the birds, and let go of some of her expectations.

How the caregiving role impacts individuals depends partly on the quality of their relationship with the care recipient (Yates, Tennstedt & Chang, 1999). Similarly, for some caregivers, the quality of relationship affects how they interpret the health effects of being a caregiver. Meghan feels that she has never been very close with her mom. Her mom is “very independent and strong-willed.” Meghan spent a lot of time travelling and living away from her parents when she was younger. She struggles now with her mom’s expectation that she will be there whenever needed. In light of this pressure, Meghan firmly believes that the “overwhelming” stress of caregiving negatively affects her health. In contrast, Eileen describes her relationship with her mom throughout her life as excellent: they have always “just been super close.” Before her mom got sick, they regularly spoke on the phone at least once a day. Now, she continues to telephone her mom regularly to check on her, but in the context of a lifetime spent connecting this way it does not feel like a change. Eileen acknowledges that the extra burden of being a caregiver is stressful and makes it hard to maintain some of the activities she likes to do to be healthy. She also feels that

“in the whole scheme of our whole lives together, this is a very small part of it!
And so it's okay to focus this much time, on this right now, because the more time
I spend now, the better it'll be the long run.”

Accordingly, Eileen focuses more on the positive experience of caregiving than on the negative impact it has on her life.

Part of the lifecourse perspective, as mentioned above, is that the impact of life events - such as becoming a caregiver - depend on when they occur during a person’s life course. The stage during the life course in which someone becomes a caregiver impacts

how they interpret the way caregiving impacts their responsibility to be healthy. Olive is retired and has adult children “scattered across the country.” As her mom’s care needs grow, Olive does not feel that it impacts her own ability to be healthy because “it became part of my daily activity, and so was absorbed into a normal routine, so life went on being quite normal, so there's no reason really for its impact on my health.” In contrast, James is young, does not yet have a family, and works full time. He travels regularly to Alberta to care for his dad and give his sisters a break. When he is in Alberta, James often sleeps poorly and says of his stress level (on a scale of 1 = no stress to 10 = extreme stress): “it's an instant 10 the day I'm going there, and it's going to be 10 until I leave.” As his dad’s health worsened and James wanted to be able to spend more time with him, he began sacrificing his extra-curricular activities such as biking in order to be able to work longer hours to compensate for the time spent away from his job. As a consequence, now it is difficult for him to have the time to be physically healthy. His ability to do the things that keep him physically healthy has “slipped quite a lot,” and although he does other things to try to maintain his overall wellbeing, these things “help compensate for the loss, but it doesn't make up entirely for it.”

Four of the caregivers have been caregivers before, and this impacts how they approach their current caregiving role and how they prioritize their own health now. Previous caregiving experience can teach people the importance of setting boundaries. Although Jean is geographically closest to her sister, she sees her caregiving role as primarily supportive. She is reluctant to be too involved for two reasons. First, she believes that her sister’s daughters are the ones who should be responsible for making the difficult decisions. Second, Jean was a caregiver for her own husband, and found the

experience stressful and overwhelming. She is reluctant to become involved again to that same extent. Jean says

“I think the past experience really helps, just because I know how awful I felt before, and I don't want to go there again, so I'm able to kind of distance myself, sort of mentally I guess, and not allow myself to get too wound up, and just do what I know I can do, and then stop at that point.”

This time around, her own health is more important than being a caregiver. She has learned how to set boundaries, rely on other family members, and trust that the healthcare system will take good care of her sister.

Caregivers also contemplate what they would do differently to be healthy, were they to become caregivers again in the future, or if they had the chance to do it all over again. Eileen isn't sure how she would react if she had to go through the whole experience again. On one hand, she thinks she might “go 110%, just like I did before.” On the other hand, she adds that “maybe it's important right now, when things are good, to say, to have a plan in place, so that if something happens in the future, I've set my limits.” For her, limits would include setting aside time to be with her husband and son, as well as time to just be by herself. She thinks that it would be hard to maintain these limits, but that by setting them for herself ahead of time, she would be less inclined to feel distressed in the future if other people told her to take a break.

Men are under-represented in my sample, making it difficult to discuss gendered differences in caregiver experiences of the imperative to be healthy. Of note, though, is that both male caregivers in my sample are experiencing high levels of caregiver stress and burden. They are experiencing the same challenges to being healthy as their female counterparts. For the people I interviewed, gender does not appear to have a significant impact on the meaning of or challenges to being healthy.

Forty years separate the oldest and youngest caregivers in my sample, yet as with gender, age does not appear to impact the meaning of being healthy as a caregiver. For example, both James and Dave (the youngest and oldest people in my sample, respectively) consider themselves in good health. Both consider physical fitness and socializing key components of being healthy. Although the physical activities they take part in differ (James enjoys playing hockey and mountain biking; Dave hikes), they both make it a priority to maintain at least some physical fitness in their routines, even as their caregiver responsibilities intensify.

Occupation per se does not appear to impact the meaning of being healthy, but caregivers who are retired or have flexible work schedules appear to have an easier time maintaining the activities that help them be healthy than caregivers with full-time employment. For example, Olive, who is retired, feels that caregiving has not changed her experience of being healthy at all because she has been able to incorporate it into her day-to-day activities. Bev, also retired, mentions that visiting her mom is actually something she does to relax. Evelyn is self-employed and had the freedom to work less when her mom needed more support. She too does not feel that caregiving has changed what being healthy means to her. On the other hand, employed caregivers such as James and Eileen tend to have a harder time maintaining all of the activities that help them be healthy when caregiving intensifies. They also tend to be the ones who focus on one particular area of health at a time when life becomes very busy (James socializes with his family and Eileen tries to not become sick). The meaning of being healthy changes much more for employed caregivers than non-working caregivers as the experience evolves.

Caregivers' lives are shaped by history and geography, by the people they are

surrounded by and the resources they have access to. Caregivers who have always felt close to their care recipient may interpret the health impact of being a caregiver less negatively than those who do not feel as close to the care recipient. Being healthy is less challenging for caregivers who consider the act of providing care to be something that helps them be healthy or easily assimilated into daily routine. For this reason, employed caregivers may find that being healthy becomes increasingly challenging because they have less time overall. Previous stressful caregiving experience can be protective against future caregiver burden.

Why the caregiver's health is important: caregiver perspective

Caregivers readily spoke about what being healthy means to them. In the next few sections, I explore why it is important for caregivers to be healthy, from caregivers' and producers' points of view as well as from the perspective of the critical discourse analysis. In some cases, caregivers believe they should be healthy because this is a general cultural requirement. In other cases, the importance of being healthy extends beyond health for health's sake: some caregivers believe they should be healthy because it will help them fulfill their roles as caregivers. This second viewpoint is echoed by producers and the critical discourse analysis. This section begins with description of caregivers' viewpoints and is followed by results from interviews with producers and the critical discourse analysis.

About half of the caregivers discuss the importance of being healthy for health's sake. For example, Olive said that it is important for her to be healthy because "It's not much fun not being healthy. If you observe people who are not healthy, it does not look like they're enjoying themselves." This is an uncomplicated viewpoint of why you should

be healthy: being healthy means not being unhealthy, and no one wants to be unhealthy. In a similar vein, Evelyn says that she feels that it is good to have some pressure put on her to be healthy. This pressure to be healthy makes her be active, whether by biking, walking, going to the gym, or engaging in other favourite activities. Nonetheless, she acknowledges that sometimes she “makes herself” engage in physical activity because she knows that it is good for her, if not always enjoyable.

For James, being healthy is part of what makes us human. He says that

“it's essential to live a proper life. If you're not healthy, you know you're gonna lose your the health of your body, and your mind, and kind of your spirit, if you don't actually invest into yourself as well as others, then you're going to, I think you pay for it, in your life, in the end. Like you don't, if you don't get enough sleep, you're gonna be more tired, if you don't eat properly your body is going to pay, and you're going to pay mentally, you aren't going to have to energy. And if you don't take time...social interaction, that's what humans have been doing forever, and if they don't spend the time to do that, and continue to maintain those relationships, you're not going to have to same standard of living, really.”

For James, being healthy is important because it is a core part of who he is. It is what he believes makes him human. Being healthy is closely tied to his perception of his standard of living. At the same time, James sees his responsibility towards his dad as a core part of who he is. He feels that the responsibility to care for others is built into his moral fibres. Although seemingly contradictory, James is able to negotiate the responsibility he feels towards himself and his father.

Bev and her husband have previously heard the message that a care recipient's health is influenced by the caregiver's. When we were talking about what being healthy means in the context of caregiving, Bev's husband said that “your health becomes critical when you're a primary caregiver.” Bev agrees with this statement, but adds that “it shouldn't be just because you're a caregiver. It does, as you age, you're more susceptible to things...you think more clearly and more cautiously, I think.” Bev recognizes that

being healthy is essential to being a good caregiver, but she rebels against the notion that this is why you should be healthy.

In general, the caregivers I interviewed feel that health is important for multiple reasons. Most note that being healthy has always been an important part of their lives. However, they primarily want to be healthy for themselves, not because it makes them a better caregiver.

Why the caregiver's health is important: CDA and producers' perspective

The challenge of caregiving is often used in the brochures I analyzed to transition from definitions of caregiving into descriptions of why it is important for the caregiver to stay healthy. The challenges of caregiving are described as contributing to ill health through physical stress, emotional stress, and burnout. Only three of the 12 documents do not tell caregivers that it is important to maintain their own health: the Veterans Affairs *Protect Yourself Against Caregiver Burnout (VA – Protect Yourself)* focuses on formal resources caregivers can use to help with burnout; 50Plus.com gives symptoms and advice about burnout; and VIHA's *Wellness is Within Reach* does not say why health is important, just how to achieve wellbeing. These three documents take for granted that the reader thinks health is important. The rest of the documents describe why the caregiver's health is important.

There are two themes present in the documents that define why caregiver health is important. The first is simply that health and self-care are important in their own right. The WHN says that “while it may seem like the last thing you have time to do, it's very important to maintain your own health while you are caring for someone else.”

HealthLinkBC notes that taking care of health is important because not doing so puts caregivers at higher risk for “colds and the flu and also chronic illness, such as heart disease, diabetes, and cancer.” HealthLinkBC also notes that when caregivers take care of themselves, “good things usually happen: they stay healthier, they feel better about themselves, they have more energy and enthusiasm and can keep giving care.” In both of these examples, the implication is that there is a connection between individual action and long-term health conditions; social determinants of health or factors outside of individual control are not addressed in either case.

The second theme, which appears more frequently than the first, is that being healthy is an important part of being a successful caregiver. According to Caregiving and Parkinson’s and Caregiver Connect, caring for oneself is essential in order to be able to provide care over the long term. The Cancer Society document says that self-care is not “selfish” and is necessary in order to be able to cope with the many responsibilities of caring for someone with cancer. The *Information Package for Family Caregivers* goes a step further and states that “the welfare of another person depends on you. If you are not in good health, that other person also may suffer.” The Alzheimer Society’s *Reducing Caregiver Stress* brochure echoes this statement by saying “you may well be the most important person in the life of someone with Alzheimer’s disease.” The Caregiver Connect document also adds that a caregiver’s ability to provide care improves when they are physically, mentally, emotionally, spiritually, and financially strong. Caregivers are encouraged to be healthy in order to provide care for as long as possible and keep the care recipient healthier for longer.

In all of the documents, health is conceptualized as the caregiver’s individual

responsibility. None of the documents mention the role that social determinants of health play in determining health outcomes. By focusing, instead, on individual action and individual responsibility, a neo-liberal message about individual responsibility for health is implicit. This focus on individual responsibility for health channels the discursive possibilities for how health is experienced and normalizes a focus on achieving health through individual action. Caregivers are told that they should be healthy as much as possible, and the implication is also that they will want to be a caregiver for as long as possible.

Both of the producers I interviewed are cognizant of the societal importance of caregiver health. They both describe how caregivers' involvement benefits the healthcare system (and society at large). In fact, it is estimated that caregivers save the Canadian healthcare system about \$25 billion annually in unpaid care (Hollander, Liu & Chappell, 2009). If caregivers were not able to perform even some of the tasks that they do, the healthcare system would be much more burdened, and therefore expensive for Canadians. Yet at the same time, one of the producers mentioned that health is important to caregivers as individuals. Producer 2 states that it is also important for caregivers to be healthy because this is what everyone needs in order to be a healthy citizen. In other words, caregivers have the same right to be healthy as any other Canadian. As demonstrated earlier, this is an idea that is not unfamiliar to caregivers. Caregivers too believe that being healthy is both personally important and part of their responsibility as a caregiver.

Part 1: summary

There are few surprises in my analysis of what being healthy means to caregivers

and why being healthy is important. Caregivers see being healthy as a multidimensional concept. Being healthy can become increasingly difficult as the caregiving role intensifies. During times of high stress or burden, caregivers will often focus on one or two key areas that help them be healthy, rather than on the multidimensional approach they prefer under ideal circumstances. Most caregivers are able to maintain a least one behaviour that helps them be healthy, but for a few caregivers it can feel practically impossible to focus on being healthy themselves while they are so focused on caring for someone else.

Being healthy is generally thought of in terms of the actions that caregivers are individually responsible for. For instance, caregivers talk about how being healthy includes a healthy diet, exercise, sleep, and making time to spend with friends and family. If my thesis had stopped here, I may have concluded that caregivers' beliefs about being healthy are consistent with a neoliberal imperative to be healthy. When I look a little deeper at how this state of being healthy can be achieved, it becomes clear that it involves more than just the actions that caregivers can individually take responsibility for. In order to take individual responsibility for being healthy, there are other components that need to be in place. Part 2 explores the means by which caregivers can be healthy, incorporating data from all three sources. I demonstrate that although individual actions are the key components of what being healthy means to caregivers, the ability to be healthy is supported in more diverse ways. In this light, it becomes clear that neoliberal values are not the only values at work.

Part 2: The means by which caregivers can be healthy

Overview

Caregivers take and are encouraged to take responsibility for their health in different ways. The means they use to be healthy can be classified as consistent with individual, collective, and familial responsibility. I begin with what my research shows about how discourse, caregivers, and producers conceptualize the means by which caregivers can be healthy in the sphere of individual responsibility. The subsequent section combines results from the three groups in terms of collective, familial, and communal responsibility for health. Although caregivers often talk about being healthy as the result of actions they are individually responsible for (as shown in part 1), when it comes to advising caregivers about how to be healthy, focusing on individual responsibility is shown to be problematic. As I demonstrate, helping caregivers connect with the healthcare system and with other people in their social networks may be a better way to encourage caregivers to be healthy. In many cases, this is already the way many caregivers access support. Furthermore, I demonstrate that although the critical discourse analysis suggests that caregivers primarily receive advice about taking individual responsibility for their own health, the reasons and hoped-for outcomes of this individual-focused advice is much more focused on encouraging caregivers to reach out to other people, organizations, and the healthcare system for help. There is a disconnect between the language of the brochures and the outcomes producers hope for. This disconnect suggests that the relationship between the advice that caregivers receive and neoliberal ideology is more complicated than expected

Individual responsibility for the means of being healthy

In part 1 I demonstrated that caregivers tend to think about the meaning of being healthy in terms of actions they take individual responsibility for. In the following sections, I demonstrate that health promotion brochures also tend to advise caregivers about how to be healthy in terms of actions they are individually responsible for. This is operationalized as advice to engage in self-care. I contrast this type of advice with caregiver reactions when asked about the information provided in health promotion brochures. Although caregivers often understand that the brochures offer good, well-intentioned advice, their reactions suggest that such advice may not be a very effective way of encouraging caregivers to be healthy. In this section I also describe the support and advice that doctors give caregivers. Finally, this section concludes with discussion about how and why producers include advice in the brochures about the importance of self-care.

Formal and informal resources

Each of the documents analyzed as part of the critical discourse analysis contains suggestions about how caregivers can maintain or improve their health. These suggestions can be divided into two categories: those involving formal resources and those involving informal resources. Formal resources are defined as those that involve official agencies (e.g., respite providers, hospitals, nursing homes, condition-specific agencies), professional services (e.g., doctors, counsellors, therapists) and support groups. Formal resources are organized or provided by someone other than the caregiver, and although the caregiver must take initiative to access formal resources, the services are generally designed to meet specific needs. The cost associated with formal services may

be covered by the healthcare system (or another government payer) or privately by the caregiver (e.g., some counselling is paid out-of-pocket). Informal resources, on the other hand, encompass activities and resources that are more clearly the individual caregiver's responsibility. Informal resources include lifestyle decisions (e.g., food, exercise, sleep), support from family and friends, and other things that caregivers can do without engaging with formal services.

Dividing self-care tips into those involving formal versus informal resources permits comparison of where the documents' authors believe caregivers should ask for help from. Documents that focus on reliance on formal resources tell the caregiver to rely on the social safety net and show an underlying ideology of collective responsibility for health. Documents that focus on reliance on informal resources show an underlying ideology of individual and familial responsibility for health. Overall, the majority of advice in the documents can be categorized as informal rather than formal resources. Out of a total of 13 suggestions, *WHN* only recommends one formal resource; *Wellness is Within Reach*, *50Plus.com*, *Information Package for Family Caregivers*, and *Caregiving and Parkinson's* each suggest two (out of a total of 12, 12, 30, and 16 suggestions, respectively). *HealthLinkBC* has a fairly equal balance between formal and informal resources (12 formal, 9 informal).

One notable exception is *VA Protect Yourself*, which includes one informal resource and nine formal ones. Since its inception in 1981, the Veterans Independence Program (administered by Veterans Affairs Canada) has provided formal services (ranging from counselling and help with housekeeping to medical supplies and equipment) to veterans and their caregivers (Struthers, 2007). This program aims to help

veterans age in place in recognition of a perceived right to care in return for service provided to Canada during wartime. At the same time, the program aims to reduce the costs of institutionalization by ensuring that caregivers can provide care at home for as long as possible. Relieving caregiver burden, in this case, is perceived as cost-efficient and in the long-term interest of Canadian policy makers. The Veterans Affairs Canada website provides an interesting contrast to the other documents included in this research: it places much more emphasis on the role of formal resources than any of the other documents.

As I demonstrated in Part 1, caregivers are very aware of the things they can do to be healthy. Additionally, most of the actions they mention can be considered actions that they are individually responsible for. However, they react quite strongly to hearing what they should do from other people. In order to gauge their reactions, I asked two caregivers to read the following excerpt from a health-promotion brochure and tell me how they react to the advice:

“Your health is important. Do not ignore it. Eat proper meals and exercise regularly. Find ways to relax and try to get the rest you need. Make regular appointments with your doctor for checkups. You also need to take regular breaks from caregiving. Do not wait until you are too exhausted to plan this. Take time to maintain interests and hobbies. Keep in touch with friends and family so you will not feel lonely and isolated. These things will give you strength to continue providing care.” (Alzheimer Society, *Reducing Caregiver Stress*)

This type of advice is typical of the self-care advice offered in health promotion brochures.

Rebecca quickly scanned the list and said “I'd say right, yep, ha ha yep, this is true, check check check, but dang! That's just not an easy thing to do...It feels like a to do list. But I'm probably not going to get a whole lot of it done.” She is aware of the different factors that contribute to an overall healthy lifestyle, yet seeing these factors laid

out as a list makes it seem like a daunting to-do list that she will not be able to accomplish. She feels that each item on the list would take time and energy, both of which are already in short supply in her life. Although she feels that this type of information is useful, she responds that she would file the information away in her mind until a time comes when she has the time and energy to think about it again.

Beth's reaction to the same task and question is similar to Rebecca's. She says

“we all know academically what we should do, you know? So, it's not, I don't think I would be, um, upset if somebody said that to me, because I think those kind of people do say those kind of things to you, I think it's an expression of their concern for you, so that's okay, um, it doesn't mean I'll listen!”

Beth feels we have a shared cultural knowledge about what it takes to be healthy, and that people say these things out of genuine concern. However, in the grand scheme of what is important in her life, suggestions like this rank lower than other actions - like her advocacy efforts - that are more important in order to be healthy.

Beth and Rebecca's reactions to the self-care advice suggest that although caregivers believe individual actions are an important part of being healthy, telling caregivers to do such things may be problematic. Busy caregivers may look at this type of self-care advice as well-intentioned but not practical. Without suggestions as to how to re-incorporate self-care into their lives (or maintain self-care), the advice can come across as useless.

Advice from doctors to look after yourself

In contradiction to what Castro et al. (2007) found, I did not find that the caregivers I interviewed tended to ask their doctors for advice about being healthy (those that did hear advice from doctors got the advice from the care recipient's doctor). In fact, of the six people I asked directly if they got advice from their doctors about being

healthy, none said that this is something that had happened to them. Granted, two people countered that it was not something they had ever asked about, either.

The caregivers I interviewed, in general, do not go to their doctors for advice about being healthy. This is probably indicative of a perception that caregivers can cope most of the time without having their own health adversely affected. When caregiving does become detrimental to health, it seems that mental health is what caregivers are concerned about: three have talked to counsellors or sought out support groups. The physical effects of caregiving are perhaps harder to notice, distinguish from stress, or separate from other life events that affect health. Nonetheless, the long-term negative health implications of living with stress and foregoing health-maintaining activities can accumulate, especially when we consider that some caregivers are in this role for years.

Although the caregivers I interviewed are not receiving advice from their own doctors about the importance of self care, some receive this advice from their care recipient's doctor. Their reactions are somewhat mixed, yet overall hearing this message from doctors does not appear to make much of an impression. Even early on, Jessica says that the medical team caring for her husband told her that it is important for her to take time to care for herself. She feels that intellectually she understood, but that emotionally it was very hard for her to accomplish. She remembers that she needed to reach the point where she discovered for herself the importance of taking time for self care. Jessica notes that throughout our lives people tell us what to do:

“but we don't listen to people like that, nobody changes their behaviour just because someone else says you should! You know, you have to, well there's gotta be a reason, you've got to understand, and maybe it's trial and error, and hopefully the consequences aren't so severe with what you're doing.”

Jessica values learning through experience. Unless she knows for herself why she should

change her behaviour, she is reluctant to heed such advice.

Nevertheless, Jessica feels the advice is rooted in a sincere desire to help. Evelyn's interpretation of this type of advice is different. She remembers that during her first meeting with her mom's doctor "the doctor saying something about, it was sort of 'how are you doing?'" and I thought that was really nice of him." Yet one year later, when the doctor asked Evelyn the very same question, her reaction was different: "maybe it was sort of like, just something that people say... maybe it makes them feel better, it makes them feel magnanimous." She felt that she was part of a stream of people flowing through the doctor's office, receiving the same treatment as everyone else, just like in a factory. The second time around, the doctor's inquiry into her wellbeing came across as scripted and insincere.

Just as advice from health promotion brochures does not seem to resonate with caregivers, being told by doctors to take care of themselves may not influence some caregivers to change their behaviour.

Producers' view on self-care for caregivers

Both of the producers recognize that the lists of self-care actions in health promotion brochures may not be a very efficient means of encouraging caregivers to engage in the type of actions that the brochures mention. Interestingly, it turns out that the motivation behind the production of these lists is different than it appears of the surface. In the critical discourse analysis, it seems that these lists are intended to encourage caregivers to take individual action to improve their health. This may in part be true. Producer 2 notes that "people will cherry-pick what works for them, and we want them to be proactive from the start". She feels that even though people will forget or

ignore most of what they read in a list like the one quoted earlier, it is possible that a little bit of the message will sink in and be incorporated as part of daily life, either now or at a later time.

A more important purpose of these health promotion brochures, from the point of view of both producers, is to entice caregivers to reach out to the authoring organization where they can receive more information, support, and connection with other people. Both producers stated that their goal with the health promotion brochures is to catch caregivers' attention and urge them to contact their organization. What's more, producer 2 feels that the brochure she is responsible for does a pretty good job of accomplishing this goal. She notes that the brochures are typically distributed to public places such as doctor's offices, where the target audience may pick them up by chance. The brochures are designed to be inviting. Producer 1 adds that the positive focus of the health promotion brochures is important because the organization does not want to start a relationship on a negative or depressing note. From the point of view of the producers, these health promotion brochures are considered a gateway to their organizations. They aim to normalize for caregivers that it is difficult to maintain self care. They want caregivers to know that there are organizations that exist to help them achieve this end. The producers do not expect that caregivers will be solely responsible for their own health: they hope that caregivers will reach out to them for help.

Rather than encouraging caregivers to take individual responsibility for being healthy, the producers hope that the brochures will encourage caregivers to reach out for help. This suggests that although the brochures' messages seem consistent with neoliberal values, the desired outcome of the brochures actually challenges these values.

Summary

Caregivers believe that being healthy results from actions that they are responsible for. Encouraging caregivers to take individual action is not easy. In particular, caregivers seem to respond more favourably to advice that is individualized rather than generic. The advice must be perceived as sincere if it is to be effective. From producers' perspectives, self-care may be seen as a safer topic to catch caregivers' attention than something such as how to access the healthcare system. As I showed in the previous section, caregivers are already aware of the need to be healthy. Information about accessing the formal system can be scary because it requires admitting that they have reached the place where the disease is serious enough to warrant help – realizing you have become a caregiver, not care partner anymore. Producers' goals are to encourage caregivers to access help through their organization. Using the rhetoric of self-care may be a means to this end.

Health promotion brochures are produced in order to elicit a reaction. The critical discourse analysis suggests that this reaction is to access informal resources. However, interviews with producers suggest a different viewpoint: the brochures are seen as a gateway to the authoring organization. The goal of the brochures is to help caregivers be healthy by helping them connect with a wider support network. More research is necessary in order to say whether this is an effective strategy.

Collective, communal, and familial means for caregivers to be healthy

How caregivers are supported by their families, communities, and the State is not overtly connected to caregivers' beliefs about being healthy. Nonetheless, caregivers – and producers – recognize that this support can have a profound effect on caregivers'

abilities to be healthy. Support from family, community and the State is vital because it can give caregivers the time and resources they need in order to do the things for themselves that help them be healthy.

Communal and familial support

Caregivers draw on support from their social networks, and they receive substantial amounts of practical information from these resources about how to be healthy: this information tends to encompass all spheres of things caregivers can do – individually, collectively, and with help from the State. In this section, I describe the advice that the caregivers I interviewed receive about being healthy from their friends, families, and communities. I also describe the ways that friends, families, and communities support caregivers' efforts to be healthy.

James sums up the support from his family members as “invaluable.” James's aunt invites him over for meals because she knows he tends to eat poorly on his own when he is stressed. She also encourages him to spend time fishing with his cousins, which provides him both a chance to be outdoors and socialize with people important to him, two activities that are key components of being healthy for James. His aunt steps in when she knows he needs help and takes the initiative to help James be healthy. In this case, familial responsibility is being extended towards the caregiver. James cares for his dad, and his extended family cares for him.

Eileen notes that some family members are better than others at helping her be healthy. She feels her sister does not understand the weight that caregiving places on her shoulders, but she has a cousin who “would phone me, and she would say I'm not asking how your mom is, I'm only asking how you are...That was great.” This cousin, who has

also been a caregiver, knows that from the caregiver's perspective it is important for people to check in on them personally. Producer 2 also knows how important this support is, and encourages caregivers to reach out to family.

The caregivers I interviewed are supported by their communities when they interact with peers and mentors. Informal peer support and support from mentors is important for caregivers who want to be healthy, especially when these people are deemed credible because they have personal experience as caregivers. Eileen says that these mentors are trustworthy because they have gone through the same thing before. The advice they provide about being healthy is deemed trustworthy. Peer caregivers also help each other by sharing information about facilities and in particular specific staff members within facilities. Indeed, some caregivers become informal mentors after being caregivers for a while because they know that their experience is important to share, that it is hard for new caregivers to navigate their role as caregiver without this type of advice. Jessica adds that when a caregiver takes time off for a break from visiting their families in residential care, other families will "check in." They will spend a little extra time having coffee with the absent caregivers' care recipient, or just make a point of stopping in for a quick chat while they know the caregiver is away. In this way, peer support makes it easier for some caregivers to take a break, because they know that their care recipient will still have companionship, even if it is not as much as they provide. Taking effective breaks is a key method for some caregivers to be healthy.

Although familial support and support from social networks is valuable, it can be difficult to attain. Dave notes that his responsibilities as a caregiver – even with support from two live-in caregivers – makes it difficult for him to re-establish his own social

network. The responsibility of co-ordinating his wife's care takes up a substantial amount of time. However, Dave admits that he has a hard time establishing a social network for himself because he feels guilty going out and having fun while his wife is at home and bored. Formal support groups help, because Dave can meet people who will not think he is crazy for feeling as he does, but Dave has not yet been able to balance his own needs for being healthy with his feelings of responsibility toward his wife. Producer 2 has heard this type of experience before, and adds that caregivers cannot perform their roles alone. Providing support groups is an important part of helping caregivers, which is something her organization does.

Families and communities support caregivers in a variety of ways. The support can be material (e.g., meals) or intangible (e.g., a phone call to check in), but this support can offer caregivers an important lifeline. The support from family and community is often readily accepted by caregivers. It is also frequently sought out. When it is missing – as in Dave's case – caregivers can feel quite lost and isolated. Although the caregivers I interviewed sometimes resist help from their family and community, they seem to accept it more readily than advice to take individual responsibility for being healthy. Help from family and community matters more and has more of an impact on overall caregiver health than simply telling caregivers what to do to be healthy.

Collective responsibility for caregivers' health

Being connected with the formal health care system is often seen as a way to help care recipients be healthy. However, helping care recipients helps caregivers too: lower levels of care recipient behaviour problems are correlated with better caregiver health (Pinquart & Sorensen, 2007). In this section I describe how support from the State – in

particular the healthcare system – helps caregivers be healthy. In the first section, I contrast how financial support for caregivers is viewed in the critical discourse analysis to producers’ perspective on the role of financial support. I focus on financial support because a key component of the welfare state is equitable access to services, regardless of ability to pay. In the second section, I describe caregivers’ experiences accessing formal supports available through the welfare state and the advice they receive about accessing such supports. Because the critical discourse analysis emphasizes reliance on informal over formal resources, it is somewhat surprising that the opposite happens when caregivers hear advice from people instead of brochures.

Financial support

As explained in my literature review, a key component of neoliberal ideology is that individuals, rather than the State, should be responsible for their wellbeing. In the following section, I describe the way that financial responsibility for self care is described in health promotion brochures. It is not surprising, given the previous discussion about the neoliberal orientation of many of the brochures, to find that in the health promotion brochures there is little advice about how to access financial support or services for which the caregiver is not financially responsible. If this were solely the case, this section would be housed under the section on results related to individual responsibility for health. However, it turns out that producers are acutely aware of the financial burden caregivers face. They justify the exclusion of financial advice in nationally-produced brochures because healthcare delivery is a provincial responsibility and varies from province to province. Additionally, they are keen to understand how they can better help caregivers access services and financial support. In the following paragraphs, I contrast the results

from my critical discourse analysis with interviews with producers.

Where financial issues are discussed in health promotion brochures, they fall into two themes: awareness about the financial burden of caregiving and suggestions about how to access financial help. The *Information Package for Family Caregivers* notes that “caring for an ill or disabled person can be costly for YOU.” The *WHN* stresses that caregiving is often unpaid work. *50Plus.com* contains anecdotes about the author’s colleagues who find the responsibility of caregiving frustrating because they still have to earn their living by working. *Caregiving and Parkinson’s*, *Cancer Society*, *HealthLinkBC*, *MDA Family Self-Care*, and *Wellness is Within Reach* (42% of the documents) do not discuss the financial commitments of being a caregiver.

Suggestions about how to utilize financial help and reduce the financial burden of being a caregiver cover a diverse range of topics. *VA Protect Yourself* suggests that family and friends can provide money. Other documents urge caregivers to plan their financial future early in the disease progression (especially in diseases with cognitive decline). For example, the *AS Reducing Caregiver Stress* tells caregivers to review the care recipient’s financial situation and discuss legal and estate planning while the person with Alzheimer’s is still capable of doing so. The *Information Package for Family Caregivers* urges caregivers to “seriously consider the financial consequences for you, your plans, your family or future” and notes that “[caregivers] may want to consult with financial or legal advisors before deciding to provide care.”

Caregiver Connect contains advice about how to reduce the costs associated with caregiving and maintaining the caregiver’s own health. The document tells caregivers that some in-home services may be available through the healthcare system and that

others can be purchased privately. This document also encourages caregivers to take advantage of volunteer services that are available in their communities. In terms of personal health, *Caregiver Connect* reminds caregivers that exercise does not need to be expensive: “there are many other inexpensive or free practical exercises that you can enjoy as well such as gentle stretching, walking, jogging, swimming or riding a bike.”

The *MS Guide for Caregivers* contains the most extensive information about financial burden and available financial services. This booklet urges caregivers to be proactive in their financial planning because “there is no way to predict who will develop severe disability” and require more substantial help in the future. The booklet recommends personal life and disability insurance as a way of ensuring future financial stability, but focuses primarily on how caregivers can find out about publicly-available financial support. For example, the document has suggestions about how to find out about employment, disability insurance, financial assistance and tax relief, as well as provincially-run programs. The *MS Guide for Caregivers* stresses the importance of understanding what is covered by medical insurance, including provincial health care and other benefits offered through Human Resources and Skills Development Canada (HRSDC). Additionally, the *MS Guide for Caregivers* advises readers that there are sections of the Canadian Human Rights Act that provide protection concerning housing, transportation, recreation and employment. The section on financial issues concludes with the following quote, which summarizes the issue raised by insufficient coverage of necessary services:

“people with disabilities need most help with daily care. Unfortunately, this kind of help is generally covered only to a certain extent, if at all, by provincial insurance plans. Unless one of the carepartners has a long-term care insurance policy with a home care provision, paid care will be limited to what the family can

afford.”

Finances are often conceptualized as primarily an individual’s (or potentially a family’s) responsibility.

The fact that nearly half of the documents do not even mention the financial impact of being a caregiver implies a viewpoint that money is not an issue or will not affect the caregiver’s ability to care for him- or herself. Where finances are discussed, they are often described as something under the control of caregivers (and care recipients until they lose this functional ability). Although the *Information Package for Family Caregivers* suggests that caregiving may not be financially feasible for all caregivers, it does not offer suggestions for caregivers who do not have the financial means to provide care. On the other hand, some documents do provide advice about resources available through the government as well as activities that can be done for very little money. However, even among activities that can be done for very little money, it is reasonable to expect that there will be differential abilities to engage in the activities along socioeconomic lines. Given that Raphael (2006) finds that income is a particularly important social determinant of health, the lack of focus on financial issues shows that the social determinants of health do not play a prominent role in the discourse about how to be healthy.

The health promotion brochures indicate a neoliberal viewpoint on the responsibility for health and healthcare, namely that individuals should rely first on their own resources, and only access State supports when absolutely necessary. However, the people responsible for these brochures have a very solid grasp on the financial barriers that caregivers face. Producer 1 notes that caregivers often face a double barrier: they do not know where to go for financial support and they do not know how to navigate the

healthcare system in order to access appropriate resources at the appropriate times. In terms of the cost barriers caregivers face, Producer 1 says “even if it's a minimum cost to have people, you know to come in, to keep them, in their communities a bit longer, they may not be able to afford that.” When I probed about why – if financial support can be such a barrier – it is not included in brochures about self care, both producers said that it is hard from a national level to address services that are covered by provincial jurisdiction. Nonetheless, Producer 2 said that her colleagues in provincial offices could provide this type of advice to caregivers, and reiterated that one of the aims of the brochures is to encourage caregivers to reach out to local organizations that can help.

Producer 2 notes that caregivers often ask for advice about taking breaks, exhaustion, and burnout. Given these questions from caregivers, she feels it is appropriate to offer psychosocial advice in healthy promotion brochures. But, as I probed about barriers to care, she observed that

“what's interesting about your questions, and it's making me think, we've gone with what the priorities seem to be, but we haven't addressed the, perhaps the less dominant things that we hear about, like the more practical tax break kind of question.”

She adds that

“we've taken a very sort of psychosocial approach in this brochure, very much focusing on the emotions, reactions, attitudes, values, beliefs that a caregiver may have. Of course there's a very practical physical toll the caregiving can take, so we've taken that kind of an approach to this brochure. I'm not sure it does a great job other than saying basically there's a whole lot that you're gonna need help with, and here's where you can go.”

She concludes that in terms of the financial barriers that caregivers face, the brochures “could probably do a better job” of helping caregiver overcome financial barriers.

The experience of accessing formal resources

The transition to residential care can be a time of intense stress. The events

leading up to a move to residential care can create a time in caregivers' lives where maintaining their own health is particularly challenging. Indeed, it is often the care recipient's needs, not the caregiver's, that determines service eligibility (Guberman, 2006) even though high caregiver stress is a predictor of entrance into long-term care (Spillman & Long, 2009). For the person moving into care, the transition can mean the end of a long-established way of life and coming to terms with a downward trajectory into old age (Aminzadeh, Dalziel, Molnar & Garcia, 2009). A few of the caregivers I interviewed have experienced this transition with the person they care for. Here, I describe some of the advice they received from other people about being healthy themselves during this very difficult period.

Research done by Mead, Eckert, Zimmerman and Schumacher (2005) finds that facility managers and administrators often play pivotal roles in determining the timing of transitions from one level of care to another. In the time leading up to her husband's move into residential care, Jean remembers feeling that the pressure of coordinating her husband's complex care needs was "burying [her] alive." When she reached the point where she could not do it anymore, she got support from a VIHA staff member as well as a coordinator of community care. She remembers that

"it was good to hear from an outsider, who wasn't emotionally involved with the situation, that it wasn't working anymore, you know that something needed to be done, and they made me feel, not that it was my fault, but that if I wanted to survive, changes had to be made. So they focused on me, getting me healthy again."

Jean felt that the VIHA and community care staff understood that moving her husband into residential care was not only for his health: it was necessary in order for her to be able to be healthy too.

Meghan is currently going through a similar experience: at the time of our

interview, her mom was in acute care, and she wasn't sure if her mom would be released back home or have to transition to residential care. Meghan feels that the stress of being a caregiver to her mom has a significantly negative impact on her own health. She also feels that her friends and colleagues understand this pressure: they encourage her "to step back, and not say anything, and let the system take over. Because it's just too much on me. And I've got my own, you know health issues I have to deal with too." Meghan's friends, colleagues, and her counsellor advise her to rely on the formal healthcare system. She is receptive to this advice, and appreciates that it is seen by others as a necessary part of helping her be healthy.

In contrast, Evelyn got similar advice – to let the formal healthcare system take responsibility for her mom – but she struggled to accept this advice. Her mom has always been an independent woman, and she did not want to give up her independence. Evelyn wanted to support her mom's independence by providing the support and resources her mom needed in order to live safely at home, yet she found that her friends were shocked that she would allow her mom with dementia to walk home by herself from the mall. She says she "got these feelings about people not approving of what you're doing, you know like you're thinking, they are thinking you've got to get your mom into a home, that's the impression that you get from people." Rather than feeling that her friends supported her desire to facilitate her mom's independence, she felt that they were pushing her to access formal resources. Nonetheless, accessing the formal healthcare system is not always an easy process. For example, Evelyn felt that "they wait until you're ready for care yourself" to allocate residential care beds. Even though caregivers are advised by other people to rely on the formal healthcare system, doing so does not always go as smoothly

as would be hoped for.

Accessing the formal healthcare system can also be difficult for caregivers because it involves admitting that things have progressed to the point where you need external help. Dave acknowledges that he doesn't want to think too much about the future because it is depressing to think about the time when he will no longer be able to care for his wife at home.

Many caregivers stay very involved once their care recipient goes into care. At the same time, it appears that staff in residential care facilities can be very cognisant of the pressure this puts on caregivers and supportive of their need to take breaks and allow the formal system to do its job. Typically, Jessica visits her husband in residential care every day. She provides companionship, physical and social stimulation, and personal care to her husband. Occasionally, she will take a break for a week or two. She talks about one time when she returned early from a short vacation. She bumped into a staff member from her husband's care facility when she was downtown. The staff member was surprised to see her back early, and she asked the staff member to not tell her husband she was back yet, as she intended to take a few days off at home. She was pleasantly surprised at the reaction she got:

“they thought it was a great idea. A lot of the staff are very supportive, and would encourage me to stay home too. They do realize that you need that, and they said that's a great idea! Oh, he's fine. We're all there. So when I came back it was like ‘hi Jessica! Good to see you back!’”

Feeling that the staff support her need to stay away enables Jessica's use of effective respite.

Summary

Individual actions are the things that, at the end of the day, caregivers need to do

in order to be healthy. No one can go for a run on someone else's behalf. However, as the demands of caregiving increase, familial, communal and collective support become critically important: caregivers need this support to be in place in order to be able to do self-care. Support from families and communities makes a difference in helping caregivers be healthy. When families understand what helps a caregiver be healthy, they can encourage him or her to maintain these behaviours. The sincere concern for a caregiver's wellbeing that friends and family express is invaluable. In addition, peer caregivers are deemed trustworthy: when one caregiver encourages another to be healthy, the advice may be considered more valid than advice coming from someone who has never been a caregiver before. When familial and communal support is lacking, caregivers can feel isolated.

Encouraging caregivers to access the formal healthcare system is not an easy task. When the advice comes at the right time, caregivers can feel relieved to find out that someone else notices how hard they are working and the impact that caregiving has on their health. Yet when the advice comes at the wrong time, caregivers may struggle to accept the advice, or – worse – assume that it is insincere. Knowing when the right time to address this transition is not easy or straightforward, but my research suggests that when the discussion is based on an in-depth understanding of the caregiver's situation it is more likely that the caregiver will heed the advice to accept support.

Even with the supports available through the healthcare system, caregivers can face significant financial burden. This burden is understood by producers, yet it is poorly addressed in health promotion brochures. Producers argue that this is reasonable because financial supports vary from province to province. Yet at the same time, health promotion

brochures often encourage caregivers to use the healthcare system – also an area of national jurisdiction. Producers hope that the health promotion brochures will encourage caregivers to seek out more information about financial support, but how to do so is missing from the brochures.

Chapter 5: Conclusions and recommendations

In this thesis, I have explored the ways in which caregivers' beliefs about being healthy are consistent with or a challenge to the values present in health promotion discourse. The health promotion brochures I analyzed as part of a critical discourse analysis tend to encourage caregivers to take individual responsibility for being healthy. The brochures emphasize reliance on informal over formal resources, and focus on self-care as the means by which caregivers should be healthy. Although these health promotion brochures do not exclusively present neoliberal values, these values dominate. As such, the brochures serve to normalize the imperative to take individual responsibility for being healthy.

Caregivers echo these values when they discuss what being healthy means and why they believe they should be healthy. Caregivers often conceptualize being healthy as the result of actions that they are individually responsible for: this is not surprising given the observable relationship between actions taken and health outcomes. Exercise leads to healthier bodies, and so does eating a healthy diet. During the interviews, all of the caregivers described the ideal state of being healthy as the successful incorporation of multiple elements, including a balanced diet, exercise, rest, relaxation, and socializing. The way caregivers enact the different components of being healthy varies. For example, many caregivers say that exercise is an important part of being healthy, but exercise means different things to different people. For some, exercise entails vigorous physical fitness that builds cardiovascular endurance; for other, exercise is a walk around a lake with a friend in order to relax and connect with nature. A balanced diet may mean eating food that you have grown yourself, or it may mean sharing a meal with close family members.

Therefore, telling caregivers to “exercise” or “eat a balanced diet” could be problematic if the manner in which these concepts are presented does not coincide with how the caregiver interprets the meaning of the word.

Life often gets in the way of living the ideal, multidimensional state of being healthy. This can occur when caregivers are overwhelmed with the caregiving role and feel they do not have time to pay attention to their own health. It can also be difficult for caregivers to prioritize their own health when they have made the conscious decision that their care recipient’s wellbeing is more important than their own. Under these circumstances, when caregivers decide to do something to be healthy, they tend to focus on one or two actions that they know through previous experience will quickly and efficiently make them feel better. This could be listening to music, going for a walk, or accepting a friend’s offer of a meal. Caregivers often know through their previous life experience what will work for them, and it will vary from person to person. When caregivers have their own health concerns, being healthy becomes focused on being well in spite of the illness. For caregivers sandwiched between the needs of their care recipient and their own children, being healthy often centres on the singular component of maintaining their mental health by creating a little space for themselves.

Being healthy often was described as non-static. Experiencing a change in beliefs about what is important in terms of being healthy can be a positive experience. For one caregiver, social connection emerged as more important than career development as the caregiving experience unfolded. He appreciated feeling the richness that social connections add to his life when he is not as busy with his career. Another caregiver discovered her ability to take what was originally a negative experience and focus on

turning it into a positive experience. She was delighted to realize that her definition of what being healthy means is malleable. These people allow the caregiving experience to shape their beliefs about being healthy and feel that doing so enhances their lives.

However, this is not the case for everyone. One of the women I interviewed shared that there is little positive to be learned from the experience of being a caregiver. She feels that it is extremely difficult to be healthy and be a caregiver, and say that the meaning of being healthy has not changed for her. Another feels that it is simply impossible for him to be healthy. Negative experiences of trying to combine being healthy and caregiving can make caregivers feel isolated, frustrated, and sad.

Times when being healthy becomes difficult tend to coincide with periods when the caregiving experience intensifies. As care recipients come to rely more on their caregivers, it makes sense that the caregivers will have less time available to do the things that help them be healthy. During these times, it is clear that there are some things that caregivers feel help them be healthy and some things that do not help. Almost half of the caregivers I interviewed say that they needed to learn for themselves how important it is to be healthy and how to combine being healthy with being a caregiver. Assistance from people who know the caregiver well enough to be able to help without asking what is needed can enhance the caregiver's wellbeing. Being told to do something to be healthy often has the opposite effect. When burdened caregivers hear that they should exercise more, take time for themselves, or relax, they often say that the advice comes across as condescending or impossible to heed. Although caregivers often trust that people give them this type of advice out of a sincere desire to help, the advice is not appreciated if it feels too difficult to incorporate into day-to-day life. Caregivers can be cynical and

question the motivations of the people who are giving them such advice.

There is consensus between all three data sources that caregiver health is important. In all three data sources I find that the discourse about why caregivers should be healthy can be categorized into two themes. First is the viewpoint that caregivers should be healthy for the sake of health. Health is seen as a universal goal, and thus as humans, caregivers should be healthy in the same way that anyone in society should be. Second is the viewpoint that the caregiver's health is important because it impacts the care recipient's health. Being healthy in this sense is important because it will ensure the care recipient receives the best possible care. Primarily, caregivers feel they should be healthy for the first reason: being healthy is a core value of who they are as individuals. Two caregivers mentioned hearing the second reason, but they both felt that although it is true that they will be better caregivers if they are healthy, this is not why they want to be healthy in the first place. On the other hand, the second viewpoint dominates the producer interviews and critical discourse analysis, although in some cases the first viewpoint is addressed to a lesser degree in these sources. Both producers that I interviewed are aware that fostering caregiver health is important because it saves the healthcare system money. Producers and the brochures approach the importance of caregiver health from a population health perspective, and perhaps for this reason do not align with why caregivers feel they should be healthy. They focus on the big picture of why caregiver health is important to society rather than on what being healthy means to individual caregivers.

Although caregivers believe that being healthy is composed of actions they are individually responsible for, helping caregivers access support from a broad range of

sources appears more effective than simply telling caregivers to do the things they already know they should be doing. Encouraging caregivers to access supports through the healthcare system is important because with this support in place, caregivers feel better able to take the time to do whatever it is that helps them be healthy. Facilitating caregivers' connections with members of their community is another effective way of supporting caregivers, especially when the people they connect with are perceived as trustworthy because they have been caregivers themselves. Informal connections with peers and mentors, as well as participation in caregiver support groups, all emerged as important ways that caregivers were able to focus on being healthy. They trust the advice from such community resources, and the act of connecting with others can fulfill the social element that is a key part of being healthy for many caregivers.

The brochures I analyzed focus on fostering caregiver health by encouraging caregivers to take individual action. Yet when I explored other information sources that caregivers use, I discovered that the means by which caregivers are encouraged to be healthy are much more complex than indicated in the critical discourse analysis. In retrospect, I should have expected this, as it seems common sense that caregivers would seek out information from a variety of sources. What is interesting is that the advice that caregivers receive from other people, contrary to what the critical discourse analysis led me to expect, centres on accessing support through means that fall into the spheres of familial, communal and collective responsibility. True, caregivers are told to take individual responsibility for being healthy by the health promotion brochures. But when they connect with other people, the advice they hear is to reach out to others and to the healthcare system.

The brochures resonate with neoliberal values of individual responsibility, but people – including producers – challenge these values in multiple ways. The critical discourse analysis shows that neoliberal values are strongly present in the discourse targeting caregivers. Caregivers are encouraged to take individual responsibility for their health, and generally speaking are encouraged to do so by engaging in activities that generate profit for private enterprises and are paid for by individuals. For example, joining a gym or even buying a yoga DVD – both activities that are described as worthwhile components of a healthy lifestyle – generate profit for private industries. However, the interviews with producers problematize the interpretation of health promotion brochures as vehicles of neoliberal ideology. Producers feel that the purpose of health promotion brochures is to help caregivers be healthy by encouraging them to reach out for support, and in particular to reach out to the organization that creates the brochure, where they can be connected with people, support, and more information.

Producers use the discourse on self-care because they hope it will be perceived as a safe topic. Indeed, there is congruence between what caregivers believe being healthy means (in the ideal sense) and what the brochures tell caregivers to do to be healthy. The idea of being healthy through self care is familiar to many caregivers, even if they do not rank it high among their caregiving responsibilities. By focusing on a safe and familiar topic, producers hope that caregivers will be enticed to pick up the brochures and then reach out for more support and information. Based on this, I conclude that there is a vast ideological difference between the explicit and implicit messages of the brochures. Explicitly, the brochures tell caregivers to take individual responsibility for being healthy, consistent with neoliberal values. But implicitly, the brochures challenge

neoliberal values by encouraging caregivers to reach out to their communities. However, I am unable to say how effective the implicit message is based on this research. None of the caregivers mentioned that health promotion brochures encourage them to connect with others, although I did not ask them to comment on what actions they believe the brochures encourage them to take.

Looking back, there are aspects of this research that may have unintentionally biased my results. When I sampled for health promotion brochures, I asked organizations what information they would give me if I was a caregiver asking what I could do to be healthy. They did not give me information about accessing the healthcare system or connecting with others because I did not ask for this information. In the same sense, caregivers discussed individual definitions of what being healthy means because this is what I asked them to do. If I had asked them what being healthy means for families or communities, I may well have heard very different responses. In this sense, my findings may be biased towards an overemphasis on individual responsibility for being healthy, both from the individuals and organizations that I included. That being said, my findings show that even when asked to talk about being healthy as an individual, caregivers and producers describe how health depends on more than just the individual. In light of this, I can confidently say that caregivers' and producers' beliefs about being healthy both resonate with and challenge neoliberal values. If anything, the bias included by my data collection strategies serves as a conservative test of the extent to which caregivers and producers challenge neoliberal ideology. If I had broadened my questioning, it is likely that this challenge would have emerged to an even greater extent.

My research may also be biased because both interview groups were homogenous

in some ways. Although the caregiver group was diverse in terms of caregiving experience, the caregivers themselves were fairly similar in terms of cultural and socioeconomic background. The majority of participants were white, middle-income Canadians. Therefore, care should be taken in applying my findings to other specific situations. It is possible that caregivers from lower socioeconomic backgrounds or different ethno cultural heritage have different experiences of the imperative to be healthy. All the more, it would be important to bear in mind that being healthy means different things to different people. It is also important to emphasize that this research is based on a small, select sample. My results provide rich detail about the lives of the caregivers I interviewed, but they cannot be generalized to caregivers as a whole.

My producer interview group was also homogeneous in the sense that both producers worked for non-profit organizations. Although I tried different methods to recruit producers from other types of organizations, I was unable to recruit suitable, willing participants. It is likely that other organizations view caregiver health differently from non-profit organizations, but more research would be needed to verify this. In light of the difficulties I had recruiting producers, I would recommend that future researchers interested in this group try multiple recruitment strategies and try engaging people higher up in the organization's hierarchy who have the power to promote the research to the group of interest.

After completing this research, I feel that I have raised more questions than I have answered. Future researchers could use my research in the following ways:

- to elaborate on what type of advice is useful for caregivers under what type of circumstances. For example, it may be possible to correlate established

caregiver burden scales with times when caregivers would be more or less receptive to advice about self-care. Caregivers experiencing high burden or stress, for example, seem to prefer practical support and connection with peers and mentors over suggestions to relax, rest, and exercise. More conclusively establishing this connection could help policy makers better target the support and advice they offer to caregivers in different circumstances.

- to explore in more depth the values conflict between the way health promotion brochures are written and the outcomes the producers hope to achieve. Self-care can be interpreted in two radically different ways: as a vehicle for neoliberal values which pushes caregivers to be responsible for themselves rather than relying on others, or as a touchstone of common cultural language which aims to help people connect. I feel I have only scratched the surface of this topic, and future research could explore why the brochures focus on individual action when their goal is much broader.
- A methodologically important aspect of this research emerged through the incorporation of methods and perspectives triangulation. Without the inclusion of interviews with producers, this would have been an entirely different thesis. I find it interesting that there is such a difference between the results of my critical discourse analysis and my interviews with producers. Future researchers interested in discourse analysis – and especially critical discourse analysis – would do well to bear this in mind. Including the voices of the people responsible for documents can show different motivations than the discourse analyst assumes.

My findings also have relevance for people who hope to support caregivers' desires to be healthy. Based on previous research on interventions targeting caregiver health, we know that best practices for improving caregiver health include programs that are individually tailored and provide options for multi-dimensional assistance (Chappell & Pridham, 2010). Based on my research, I contribute the following:

- Take into account that being healthy means different things to different people, and also that the meaning of being healthy changes for individuals over time.
- Recognize that although individuals take action to be healthy, they need to have supports and resources in place in order to be able to take action. The supports and resources will vary.
- Know that individual caregivers probably already are aware of what they want and need to do in order to be healthy. Instead of telling them what to do, support their efforts to do what they already know works.
- Many caregivers value support from other people, so policies and programs that aim to help caregivers connect – with each other, their families, and their communities – may turn out to be effective ways of helping caregivers be healthy.

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Appendix 1: Participant recruitment

Invitation to participate: producers**Email message:**

Dear NAME,

I am a Masters student at the University of Victoria. I am currently recruiting people to participate in my thesis research for a study about health, health promotion, and informal caregivers. My research has received ethics clearance through the UVic Human Research Ethics Board.

I would like to interview employees at ORGANIZATION who have been involved with developing or promoting health promotion materials such as BROCHURE NAME found WHERE I GOT THE DOCUMENT.

I would greatly appreciate it if you would forward this email (with attachment) to anyone at ORGANIZATION who you think would be suitable for this research.

Kind regards,

Emily Pridham
MA Candidate, UVic

Attachment with more information for potential producers:

Hello!

I would like to invite you to participate in research I am conducting for my master's thesis, titled "Informal caregivers and the ideological imperative to 'be healthy.'" In my research, I will explore what "being healthy" means to informal caregivers, and how their beliefs are similar to or different from the type of health we see in health promotion brochures. Informal caregivers are increasingly being encouraged to take responsibility for their own health, yet no research to date has explored what this means to caregivers.

As an employee at [ORGANIZATION] who has been involved with developing or promoting health promotion materials such as the [BROCHURE NAME] found [WHERE I FOUND IT], your participation would add invaluable perspective to this research. In particular, I would like to talk to you about why you think [ORGANIZATION] produces health promotion brochures for caregivers and how this fits with [ORGANIZATION]'s mission, values, and policy direction.

Comparing your perspective on caregiver health to caregivers' own perspectives will illuminate areas where these perspectives are similar and where they differ. The results of this research will be useful for improving policies and programs that aim to support caregiver health and wellbeing. If you or your colleagues at [ORGANIZATION] are interested in the results of this research, I will be happy to give you a summary or presentation of my thesis once it is complete.

Protecting your confidentiality is very important, particularly because it is possible that you will be the only person from your organization who is interviewed. Prior to the interview, I will explain how your confidentiality will be protected and you will have the opportunity to discuss any concerns. Your participation is completely voluntary.

Interviews will take about an hour and a half to complete. We can meet at a time and a place that is convenient for you. If you are interested in finding out more about this research, and if you would like to talk to me about scheduling an interview, please contact me directly by phone at [MY PHONE NUMBER] or by email at [MY EMAIL ADDRESS]. I look forward to hearing from you!

Sincerely,

Emily Pridham

MA Candidate, UVic

Recruitment poster: caregivers



Do you provide regular help or support to a family member or friend who is over the age of 65?



If so, you may be eligible to participate in a research study that will examine what “being healthy” means to people who care for older adults.

This study consists of a one-time interview which takes about two hours to complete.

The research is being conducted by Emily Pridham, who is a master’s student in UVic’s department of sociology. If you want more information or are interested in participating, please contact me at [REDACTED] or [REDACTED].

This study has been reviewed by, and received ethics clearance through UVic Human Research Ethics Board.

“Being healthy” study

“Being healthy” study

“Being healthy” study

“Being healthy” study

“Being healthy” study

“Being healthy” study

“Being healthy” study

“Being healthy” study

“Being healthy” study

“Being healthy” study

Eligibility interview: Caregivers

Thank you for getting in touch with me! I would like to tell you a little bit about my research, and then ask you a few short questions to see if you would be eligible to participate. If you are eligible for this study, I will then tell you what would be involved, and you can decide if you think it might be something you're interested in. This should take about ten minutes. Is that ok with you?

- *No* – Can I call you back at a time that is more convenient for you?
 - *No*: thank you for your time.
 - *Yes*: What phone number can I call you at? _____.
When is a good time to call you? (i.e. morning/afternoon/evening weekday/weekend) _____. What is your name?

- *Yes* – great!

In my research, I will be exploring what “being healthy” means to people who support an older adult. In my research I will be talking to people who help an older adult. I am interested in this group for two main reasons. First, more and more people are deciding to help older adults because more people are living into old age. Second, I am interested in those who support older adults because there is a lot of information in the media telling these people that they should lead healthy lifestyles, but no one has asked them what this means to them. In my research, I want to understand what “being healthy” means to you and people like you, so that I can recommend ways that policies and programs could be improved to better meet your needs.

Do you have any questions so far? (*yes* – answer them. *No* – ok, then I'd like to ask you a few questions to see if you would be a good candidate to participate in my research)

How old is ____ (the person you support) ?

Less than 65 = not eligible²

You could be helping ____ (care recipient) ____ with things like shopping, cooking, or help around the house, or with things like bathing, dressing, or going to the bathroom, or you could be providing emotional support and companionship. Thinking about all the things you do to help ____ (care recipient) ____ that he/she sometimes or often needs help with, about how many hours per day (per week) to you spend helping ____ (care recipient) ?

Less than 3 hrs / week = not eligible

In a regular week, can you tell me some of the things you typically do to help ____ (care recipient) ? (probe about instrumental activities of daily living, activities of daily living, emotional support)

If less than 3 hrs in person, not eligible

Thinking about the things you just told me you do to help ____ (care recipient) ____, about how many months would you say you have been helping ____ (care recipient) ____ for? You

² Note: if the potential participant was ineligible at any point during the interview, I asked if they knew anyone they'd like to pass the study information onto (they were to ask others to contact me), then I thanked them for their time and ended the call.

don't necessarily have to have been doing all of the things you mentioned the whole time.

Would you say it has been:

less than three months / more than three months? (circle)

Less than 3 months = not eligible

Are you older than 19? Yes / No (circle)

No = not eligible

Do you live in the Greater Victoria area?

_____ **Outside Greater Victoria = not eligible**

Ok, that's all the questions I have for you right now. It sounds like you'd be a great person to talk to for this research. Do you have any questions for me at this point?

If you think you would like to participate, I'd like to schedule an interview with you. The interview will take approximately an hour and a half to two hours to complete. During the interview I will ask you to talk about what "being healthy" means to you, and I will ask you some other questions about your experience providing support to an older adult. During the interview, you don't have to answer any questions that you don't want to answer and all of the information you provide is confidential. We can do the interview at a time and a place that is convenient for you. Would you like to participate in an interview?

No – ok, thank you for your time.

Yes:

Date of interview: _____

Time of interview: _____

Location of interview: _____

Finally, I need just a little information about you, in case I need to get in touch with you before our interview.

What is your name? _____

What is your phone number? _____

My name, again, is Emily Pridham. If you want to get in touch with me before the interview you can call me at [REDACTED].

Eligibility interview: Producers

Thank you for getting in touch with me! I would like to tell you a little bit about my research, and then ask you a few short questions to see if you would be eligible to participate. If you are eligible for this study, I will then tell you what would be involved, and you can decide if you think it might be something you're interested in. This should take about ten minutes. Is that ok with you?

- *No* – Can I call you back at a time that is more convenient for you?
 - *No*: thank you for your time.
 - *Yes*: What phone number can I call you at? _____
 When is a good time to call you? (i.e. morning/afternoon/evening
 weekday/weekend) _____. What is your name? (*FIRST
 NAME ONLY!!*) _____
- *Yes* – great!

In my research, I will be exploring what “being healthy” means to informal caregivers and how their beliefs compare to the way “being healthy” is presented in health promotion brochures. In one part of my research, I will be talking to people who help an older adult. I am interested in this group for two main reasons. First, more and more people are deciding to help older adults because more people are living into old age. Second, I am interested in those who support older adults because there is a lot of information in the media telling these people that they should lead healthy lifestyles, but no one has asked them what this means to them. In a second part of my research, I am interested in talking to people who work for government or non-government organizations who were involved in writing or developing specific health promotion material or are currently responsible for updating, distributing, or promoting this health promotion material.

Do you have any questions so far? (*yes* – answer them. *No* – ok, then I'd like to ask you a few questions to see if you would be a good candidate to participate in my research)

Great. So for ___(name of organization)___, I am interested in talking to people who have some experience with ___(name of brochure)___.

- a) Were you involved in writing or developing this brochure? Yes/No (circle)
- b) Are you currently involved in updating, distributing, or promoting this brochure? Yes/No (circle)

No to BOTH a) and b) = not eligible³

Are you currently an employee of ___(name of organization)___? Yes/No (circle)

No = not eligible

Are you older than 19? Yes / No (circle)

No = not eligible

Ok, that's all the questions I have for you right now. It sounds like you'd be a great person to talk to for this research. Do you have any questions for me at this point?

If you think you would like to participate, I'd like to schedule an interview with you. The interview will take approximately an hour and a half to complete. During the interview I

³ *Note: if the potential participant was ineligible at any point during the interview, I asked if they knew anyone they'd like to pass the study information onto (they were to ask others to contact me), then I thanked them for their time and ended the call.*

will ask you to discuss ___(*name of brochure*)___, and I will ask a few questions about you. During the interview, you don't have to answer any questions that you don't want to answer and all of the information you provide is confidential. We can do the interview at a time and a place that is convenient for you. Would you like to participate in an interview? (*If participant is outside of Victoria: Because you are not in Victoria, the interview will take place either by telephone or Skype.*)

No – ok, thank you for your time.

Yes:

Date of interview: _____

Time of interview: _____

Location of interview (place or number to be contacted):

Finally, I need just a little information about you, in case I need to get in touch with you before our interview.

What is your FIRST name? _____

What is your phone number? _____

My name, again, is Emily Pridham. If you want to get in touch with me before the interview you can call me at [REDACTED].

Appendix II: Participant consent forms



Participant Consent Form

You are invited you take part in a study that will examine what “being healthy” means to people who provide support to older adults and how these people’s beliefs are similar to or different from the type of “health” presented in health promotion brochures.

In this study, I will gather information about what people who provide support to older adults say “being healthy” means to them. I will also interview people who produce health promotion brochures. By comparing what the two groups say, I will be able to describe how the two groups are similar and how they differ. By doing so, I will be able to recommend ways in which health promotion can become more meaningful to people like you.

This study is important because no one so far has asked what “being healthy” means to people who support older adults. By talking to you and people like you about what “being healthy” means, I will be able to recommend improvements to health promotion policies and programs.

You have been invited to participate in this study because you provide support to an older adult in the Greater Victoria area.

You choose whether or not you would like to take part in this study.

Your participation is voluntary.

This study will be conducted by me, Emily Pridham. I am a graduate study in the department of sociology at the University of Victoria. I am conducting research as part of the requirements of my master's degree in sociology.

This research is being conducted under the supervision of Dr. Neena Chappell, who is a professor in the department of sociology and researcher at the Centre on Aging. She can be contacted by phone at [REDACTED], or by e-mail at [REDACTED].

If you choose take part in this study what will you do?

If you take part in this study, you will be invited to attend an interview where we will talk about what “being healthy” means to you. I will ask your permission to audio record the interview. It is up to you whether or not you would like the interview to be recorded. If you do not wish the interview to be recorded, I will take hand written notes while we talk.

How long will this take?

The interview will take about an hour and a half or two hours of your time.

The interview will take place somewhere that is convenient for you.

Are there any risks or benefits associated with taking part in this study?

You may benefit from the study through having an opportunity to have your voice heard about what it means for you to “be healthy.” In addition, the study may benefit you because the results may be used to improve the policies and programs that aim to support the health of people who support older adults.

If you take part in this study there is some chance that you might experience fatigue due to the length of the interview. If this happens, you are welcome to take a break from the interview and resume it at a time that is convenient to you.

Will you receive any payment for taking part in the study?

No payment will be made to people who take part in this study.

During the Study:

You will be asked questions about what “being healthy” means to you. You will be asked to look at a few photographs or text from a health promotion brochure and talk about what they mean to you. Additionally, you will be asked a few questions about your background, your experience supporting an older adult, your own health, and the person you care for.

- You do not have to answer any questions that make you feel uncomfortable.
- There are no right or wrong answers to any of the questions. I am interested in your opinion!
- Your responses are confidential, but please do not share any information you would prefer to keep private.
- When I analyze my results, I will be interested in findings at the aggregate (group) level. This means that I will describe participants as a group, rather than individuals. For example, I will give the average age of all participants rather than the age of each individual. Or, I could describe how several participants share certain viewpoints.
- I may select quotes from your interview to use in my thesis to illustrate certain ideas. In this case, you will not be identifiable because you will be given a pseudonym to help preserve anonymity.
- You may end the interview at any time, and you do not need to explain why you wish to end the interview.
- You may change your mind and withdraw from this study at any time, even after the interview is finished. There is no need to explain why you have changed your mind.

- If you change your mind, your contribution will not be used as long as you withdraw from the study before I submit the final draft of my thesis to my supervisor (approximately July, 2011).

After the study:

- I will know that you have taken part on this study. I will be the only person who will have access to the information you have shared.
- Your name will not be recorded on the transcripts of your interview
- I will ask your permission to contact you within the next four months. I may wish to ask you to discuss your interview, for example to clarify something you talked about or to make sure that I understand something you said in the interview. You choose whether or not you wish to continue participating, and I will not contact you for purposes other than this research.
- Each time you complete a research activity and meet with me, you will be reminded that your participation in the study is voluntary, asked if you wish to continue to take part, and, if you do, requested to initial your signed consent form to show that you have agreed to continue to take part in this study.
- Findings from this study will be reported in my thesis, possibly in journal articles, to other participants, and presented at workshops or conferences. Your name will not be used in these publications or presentations.

*Would you like to receive a summary of my findings? Yes ___ /
No ___*

- Your decision to take part in the study, or your decision to withdraw from the study, will not affect access to any services or medical care for you or the person you care for.

- Information collected during this study will be stored in a locked filing cabinet in my office and on a password protected computer for five years.
- At the end of this time all paper records will be shredded and all audiotapes and computer files will be deleted.

If you have any questions or if you would like to discuss this study further, please contact me by phone: [REDACTED] or e-mail:

[REDACTED]

Please remember that your participation in this study is voluntary

Consent:

I have read this consent letter Initials.....

I have had the opportunity to ask questions Initials

I understand that my participation in this study is voluntary Initials

I understand that I can withdraw my consent at any time Initials

I consent to interview being audio taped. Initials

I consent that Emily may contact me within the next four months to discuss my interview. I understand that even if I agree now, I may decline contact in the future and that I do not need to explain why I decline. Initials

I agree to take part in the study Initials

Name of Participant:

Signature:

Date:

A copy of this consent letter will be left with you and the researcher will take a copy.

The Human Research Ethics Board at the University of Victoria has approved the ethical conduct of this research. If you have any questions about the ethical conduct of this research, please contact the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca



Participant Consent Form

You are invited to participate in a study about informal caregivers and what it means for them to “be healthy” that is being conducted by Emily Pridham.

I am a graduate student in the department of sociology at the University of

Victoria and you may contact me if you have further questions by phone: [REDACTED]

[REDACTED] or email: [REDACTED]

As a graduate student, I am required to conduct research for my degree. It is being conducted under the supervision of Dr. Neena Chappell, who is a professor in the department of sociology and researcher at the Centre on Aging.

You may contact my supervisor at [REDACTED] or by email: [REDACTED]

Purpose and Objectives

The purpose of this research project is understand what “being healthy” means to informal caregivers and how their beliefs compare to the way “being healthy” is presented in health-promotion brochures.

Importance of this Research

Research of this type is important because to date, no research has investigated what “being healthy” means to caregivers. After my thesis is complete, I will be able to share the results with you and your organization, either as a presentation or a written summary. The results will be useful for understanding what “being healthy” means to caregivers and how this compares to the way they perceive health promotion brochures. You may find that the results can help your organization improve health promotion strategies or point to areas where more research is needed.

Would you like to receive a summary of my findings? Yes _____ No _____

Would you like me to contact you when my thesis is complete to discuss sharing my findings with your organization? Yes _____ No _____

Participants Selection

You are being asked to participate in this study because you were either involved in writing health promotion material for the organization you work for or are currently responsible for updating, distributing, or promoting this health promotion material. As such, you will be able to provide valuable insight as to how your organization conceptualizes the importance of caregiver health.

What is Involved

If you agree to voluntarily participate in this research, your participation will include a one-on-one interview with me. The interview will take about one and a half hours to complete. Where possible, the interview will take place in person at a location that is convenient for you. If you live outside of Victoria or the Lower Mainland, the interview will take place by telephone and/or Skype.

With your permission, audio recordings and written notes will be taken during the interview. I will transcribe the interview.

During the interview, I will ask you to discuss a health promotion brochure produced by your organization, and I will ask a few questions about you. As part of my research, I will also be interviewing informal caregivers. I will ask caregivers to discuss what “being healthy” means to them and how they interpret a selection of health promotion brochures that target caregivers.

Benefits

You could benefit from participating in this research because the results will point to ways in which health promotion efforts could be improved and areas where more research would be useful. Incorporating the findings into the way your organizations approaches health promotion may help you more effectively create programs that help caregivers in meaningful ways.

Risks

Participation may pose risks because as few as one person from each agency will be interviewed. In particular, it is possible that there could be social or economic risks to participants who are critical of their organization, such as unintended impacts on your status at work.

Several steps will be taken to minimize this risk, and this is covered in the sections on anonymity and confidentiality. However, please keep in mind that it is up to you how much information you decide to share with me. If you are concerned that disclosure of something you say in the interview could pose risk to you, PLEASE CONTACT ME. It will be possible to delete portions of your interview or the analysis based on your interview up until the final version of my thesis is submitted to my committee.

Inconvenience

Participation in this study may cause some inconvenience to you, including the time it takes to complete the interview. However, this inconvenience should be minimal because we will choose an interview time and setting that suits you.

Compensation

You will not receive any compensation for participating in this research.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study, your data will not be used as long as you withdraw from the study before I submit the final draft of my thesis to my supervisor (approximately July, 2011).

You do not have to answer any questions that make you feel uncomfortable.

Please do not share any information you would prefer to keep private.

On-going Consent

I will request permission to contact you within the next four months, in case I wish to have you expand or clarify statements you make during the interview. To make sure that you continue to consent to participate in this research, each time meet with me you will be reminded that your participation in the study is voluntary, asked if you wish to continue to take part, and, if you do, requested to initial your signed consent form to show that you have agreed to continue to take part in this study.

I do _____ / do not _____ consent that Emily may contact me within the next four months to discuss my interview. This includes permission to contact me to discuss how my interview is being used in order to minimize any potential

risk. I understand that even if I agree now, I may decline contact in the future and that I do not need to explain why I decline.

Anonymity

In terms of protecting your anonymity, I will be the only person who knows that you have participated in this research. I will only record your first name. At no time will your name be associated with your interview transcript or any notes made during the interview.

Confidentiality

Protecting your confidentiality is very important, particularly because it is possible that you will be the only person from your organization who is interviewed. Your confidentiality and the confidentiality of the data will be protected. You will be given a pseudonym. I am interested in results at the aggregate level. This means that I will describe the people who participate as a group, rather than as individuals. For example, I will describe the types of positions held by the people I interview, but I will not say what each individual's role within their organization is or how many people from the organization were interviewed.

The organization you work for could be identified in my thesis, for example in a listing of examples of the types of organizations included. In some cases, I may compare ideas you discuss in your interview to the health promotion brochure produced by your organization. This could include paraphrasing your interview or

using a direct quotation from the interview. The paraphrase or quote will be attributed to your pseudonym; it will not be linked to any characteristics that could identify you. You will be given the opportunity to review this use of your data before it is included in my thesis.

I will be the only person who knows your name and contact information. This information will be kept in a locked filing cabinet or on a password-protected computer, and destroyed after 5 years.

Dissemination of Results

In addition to sharing the results with you (if you request), I anticipate that the results of this study will be shared with others in the following ways: thesis, presentations to academic and/or community groups, and published article in an academic journal, and to other participants.

Disposal of Data

Data from this study will be disposed of five years after the research has concluded. Electronic files will be deleted and hard copies of files will be shredded.

Contacts

Individuals that may be contacted regarding this study include me (researcher) and Neena Chappell (supervisor). Our contact information is at the beginning of this consent form.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria ([REDACTED]).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix III: Interview schedules

Interview schedule: caregivers

Preamble and introduction:

Thank you for taking the time to participate in this interview today. As I told with you when we discussed the informed consent process, today I'll be asking you about your experience supporting _____ (care recipient) and what "being healthy" means to you. You don't have to answer any questions that you don't want to.

I'll be recording the interview (*only say if they have already consented*), and I'll also take notes during the interview. The notes are to remind me about things I'd like to ask you or things I want to remember about the interview. Sometimes I'll write more and sometimes I'll write less – this has nothing to do with how interested I am in what you're saying!

First, I'd like to start with a few questions about you and _____ (care recipient) so that I know a little bit more about you. Is that ok?

Background:

- What year were you born? And what year was (*name of care recipient*) born?
- What is your relationship with (*name of care recipient*)? (e.g., spouse, son, daughter, friend). How many people live in your household? What is your relation to them? (e.g., parent, child, spouse...)
- Do you work or are you retired?

- Work: tell me a bit about what you do for work (including how many hours per week, changes in work status since caregiving began)
- Retired: when did you retire? What was your job before you retired? Why did you decide to retire?
- How much education have you completed? (e.g., some high school, college) What did you study?
- What types of things do you do to help (*name of care recipient*)?
 - Probe about instrumental activities of daily living (IADLs) (e.g., cooking, shopping, finances, emotional support, companionship?) and activities of daily living (ADLs) (e.g., toileting, walking) if not mentioned
 - If not mentioned, probe about care recipient's behavioural problems, if applicable
- Who else helps care for (*name of care recipient*)? (How often, what do they do, do you have to pay them etc.) (list of formal services used by participant and care recipient)
- If you were to become ill (or be unavailable), who would help (*name of care recipient*)? (where do they live, would you have to pay them etc.) (if a family member, ask about relationship: how close they are)

Transition to body of interview :

Okay. So now that I understand a bit more about you and the support you provide to -
 _____ (care recipient) _____, I'd like to move on to some questions about you! For the next group of questions, I'll be asking you to explore the idea of what "being healthy" means to you. "Being healthy" means different things to different people, and I am interested in your opinion. There are no right or wrong answers.

Questions about health and being healthy:

- What does being healthy mean to you?

- Potential probes about experiences of being healthy:
 - Do you consider yourself a healthy person? How do you account for your healthiness?
 - What kinds of things do you do for the sake of health? (how often, who with, when started, why started and continues to do)
- What does “being unhealthy” mean to you?
 - Can you tell me what it feels like when you have a day where you feel unhealthy?
- “What contexts or situations have typically influenced or affected your experiences of being healthy?”
 - Potential probes:
 - Do you think things have changed over time? (when did things change? How did becoming a caregiver change things?)
 - What are the challenges/barriers/rewards of “being healthy”?
 - Why do you think it is important for you to be healthy?
 - What advice do you get from your Dr.? From other people?

Transition to talking about photographs:

Ok, we’ve been talking for a while about what “being healthy” means to you. Now I’d like to show you a few photos from some brochures and ask you to talk about them.

You’ve probably heard the saying “a picture is worth a thousand words.” Pictures are often used to help tell stories. Again, there are no right or wrong answers here because I’m interested in your opinion and what you imagine is going on in the pictures.

- Imagine that this picture was part of a short story. What do you think that story would be about?
 - Potential probes:
 - *If participant doesn’t talk about person in photo as a caregiver:* how would the story be different if I told you this person cares for her mother (or husband/wife/father) for 30 hours a week?
 - In what ways are you like the person in the photo?
 - In what ways are you unlike that person?
 - What do you think this person does to “be healthy”

- What do you imagine is challenging for this person when s/he tries to “be healthy”
- Who do you imagine helps this person “be healthy”

Transition to questions about health status:

Okay, that’s all the photos that I’m going to ask you to look at. For the final part of this interview I’d like to ask you some questions about your health.

- Note: there are many questionnaires that other researchers have used to gauge caregiver stress and burden; I will review the literature and select questions that are appropriate for my interview. The following are sample questions that I could use, but I will finalize this list based on my expanded literature review:
 - self-rated health: “compared to other people your age, would you say that your health is excellent, very good, good, fair, or poor?”
 - On a scale of 1 (no stress whatsoever) to 10 (extreme stress), how much stress do you say you have? What does this look like?
 - On a typical night, how many hours do you sleep? Is this too much/just right/not enough for you? (If “not enough,” what prevents you from getting enough sleep?)
 - In a regular week, about how many days a week do you exercise? How many minutes a day? What do you do? Who do you do it with?
 - What do you do to relax?
 - Do you drink alcohol? (if so, how many days per week on average; how many drinks per day on days that you drink)
 - Do you smoke cigarettes? (if so, how many cigarettes on average per day)

Conclusion:

Ok, that's all the questions I have for you. Now that we're about done, is there anything you would like to add to what you talked about today? Do you have any questions?

Thank you so much for taking the time to talk to me today. If you think of anyone else who may be interested in participating in this research, feel free to give them my phone number.

Interview schedule: producers

Preamble and introduction:

Thank you for taking the time to participate in this interview today. As I told with you when we discussed the informed consent process, today I'll be asking you about your experience working with _____ (*name of health promotion brochure*). You don't have to answer any questions that you don't want to.

I'll be recording the interview (*only say if they have already consented*), and I'll also take notes during the interview. The notes are to remind me about things I'd like to ask you or things I want to remember about the interview. Sometimes I'll write more and sometimes I'll write less – this has nothing to do with how interested I am in what you're saying!

I'd like to start with a few questions about you. Is that ok?

Background:

- How long have you worked at _____ (*name of organization*)?
- What is your current role with _____ (*name of organization*)? What do you do for _____ (*name of organization*)? (role, responsibilities, etc.)
- Where did you work before _____ (*name of organization*)?
- What is your educational background? (field and level of education)

Transition to in-depth questions:

Okay. Now I'd like to move on to some questions about your experience with this brochure, either with writing it or being involved with it in its current form. For these questions, what I'm interested in hearing about is your experience and your opinion. There are no right or wrong answers to the questions that I will be asking you.

- Tell me a little bit about what you know about why your organization decided to create this brochure.
- Before developing the brochure, what did your organization do to determine what should go into it?
 - (Probe about who decided on the content – what was included/excluded)
 - How did you decide about what photos to include? Why did you choose the ones that you did?
- What do you find challenging about working with this brochure?
- In terms of the advice (i.e. lists of things to do), how did you decide what to put first? Last?

Transition

Now I'd like to ask you a few questions about the brochure's target audience, caregivers.

- What do you think "being healthy" means to caregivers?
- Why do you think it is important for caregivers to "be healthy"?
- What barriers do you think caregivers face to "being healthy"? (and what should caregivers do when faced with these barriers?)

Transition

Now I'd like to ask you some questions about the contexts or situations that have typically influenced how health promotion is viewed by _____ (*name of organization*)_____.

- Why do you think _____ (*name of organization*)_____ thinks it is important for caregivers to “be healthy”? (probe about mission, values of organization)
- In what ways do you think _____ (*name of document*)_____ helps caregivers “be healthy”?
 - Do you think it addresses the barriers (mentioned by respondent in previous question)?
 - Do you think the brochure could be better? (what would you add/take out?)
- Did you ask caregivers for feedback about the brochure before it was published?
 - Why/why not?
 - If yes, what was their input?
 - Have you received any feedback from caregivers about _____ (*name of document*)_____ since it was published? (if so, what)

Transition to talking about photographs:

Ok, we've been talking for a while about what “being healthy” means to you. Now I'd like to show you a few photos from some brochures and ask you to talk about them.

You've probably heard the saying “a picture is worth a thousand words.” Pictures are

often used to help tell stories. Again, there are no right or wrong answers because I'm interested in your opinion and what you imagine is going on in the pictures.

- Imagine that this picture was part of a short story. What do you think that story would be about? *If participant doesn't talk about person in photo as a caregiver: how would the story be different if I told you this person cares for her mother (or husband/wife/father) for 30 hours a week?*
- What do you think this person does to "be healthy"
- What do you imagine is challenging for this person when s/he tries to "be healthy"
- Who do you imagine helps this person "be healthy"

Conclusion:

Ok, that's all the questions I have for you. Now that we're about done, is there anything you would like to add to what you talked about today? Do you have any questions?

Thank you so much for taking the time to talk to me today. *(If they said that they want to be contacted about the results, remind them that I'll be in touch when I've finished my thesis, give an approximate date).*