Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Primary Caregivers of Children with Disabilities

by

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Abstract

Background: Primary caregivers of children with disabilities are at risk for poor health; rural caregivers may be especially at risk. Engagement in health promoting behaviors can improve the health of these caregivers but few studies have described these behaviors or outlined the facilitators and barriers to health promoting behaviors that they experience. The Integrated Social Ecology Model guided this study.

Purpose: To describe and compare the health status, health promoting behaviors, and facilitators and barriers to health promoting behaviors of urban versus rural primary caregivers of children with disabilities living in Central Alberta.

Method: A sequential explanatory mixed methods design was used. Phase 1 was a quantitative study using mailed surveys to measure health status and health promoting behaviors. Phase 2 was a qualitative study using telephone interviews to assess facilitators and barriers to health promoting behaviors.

Participants: Eighty-nine urban and 105 rural primary caregivers of children with disabilities responded to the survey. Ten urban and ten rural caregivers participated in the telephone interviews.

Findings: Quantitative findings revealed many similarities and few differences between the urban and rural samples. Most caregivers reported their health as good to excellent. More urban than rural caregivers had given up paid employment because of their child's care needs. Rural caregivers traveled further to access their physicians and were more likely to be overweight or obese. For both groups, the most common facilitator of health promoting behaviors was the need for caregivers to stay healthy so that they could continue to meet the long-term care needs of their child. The most common barrier was lack of time due to the numerous appointments, therapies, programs, and care needs of their children with disabilities. The availability of health promoting services and programs was a facilitator unique to urban caregivers and a barrier unique to some rural caregivers.

Implications: Urban and rural primary caregivers of children with disabilities experience complex and multifaceted facilitators and barriers to health promoting behaviors that need to be considered when planning programs to improve their health.

Key words: primary caregivers, parents, children with disabilities, children with special health care needs, health status, health promoting behaviors, facilitators, barriers, mixed methods, sequential explanatory, social ecology theory

Preface

This thesis is an original work by Brenda Anne Query. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Primary Caregivers of Children with Disabilities", No. Pro00029753, July 26, 2012.

Dedication

This dissertation is dedicated to my son Jason. Even though he was severely multiply disabled, he always lived life to the fullest and with a flourish that exemplified his abilities. During his short life he taught me how to love, laugh, and persevere in the face of adversity with dignity and grace. Memories of his beautiful smile, laugh, and happy dance will live in my heart forever.

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Table of Contents

Chapter

List of Tables

List of Figures

Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Primary Caregivers of Children with Disabilities

Chapter 1: INTRODUCTION

The majority of caregivers of children with disabilities obtain rewards and satisfaction from caregiving and the presence of the child with a disability has a positive impact on the family (Corman, 2007; Cummins, 2001; Davis et al., 2010; Grant, Ramcharan, McGrath, Nolan, & Keady, 1998; Hastings, Beck, & Hill, 2005; Trute, Benzies, Worthington, Reddon, & Moore, 2010). However, the work required to raise a child with a disability is above and beyond that of raising a typically developing child (Burkhard, 2013; Ray, 2002). Little is known about the health promoting behaviors of their caregivers. This chapter provides an overview of primary caregivers' role in caring for a child with a disability and the potential health effects of providing this care. The importance of health promotion and the effect of selected facilitators and barriers on caregivers' health promoting behaviors are outlined. This is followed by a discussion of the conceptual framework that guided the study and the questions to be addressed.

Background of the Study

Findings from the Statistics Canada (2006b) 2006 Participation and Activity Limitation Survey (PALS) indicated that 298,410 persons with disabilities aged 0 to 19 years were living in Canada. Findings from the 2012 General Social Survey on Caregiving and Care Receiving (GSSCCR) indicate that there are an estimated 400,000 Canadians providing care to a child with a long-term health condition or disability (Turcotte, 2013). More children with disabilities are surviving longer due to advances in medicine and technology (Burke, Taylor, Urbano, & Hodapp, 2012). The Family Support for Children with Disabilities (FSCD) program defines disability as:

> A chronic developmental, physical, sensory, mental or neurological condition or impairment but does not include a condition for which the primary need is for medical care or health services to treat or manage the condition unless it is a chronic condition that significantly limits a child's ability to function in normal living. (Government of Alberta, 2003, p. 2)

Most of these children are cared for at home and many parents assume complex and long-term caregiving responsibilities (Anderson, Dumont, Jacobs, & Azzaria, 2007; Armstrong, 2007; Fast, Keating, & Yacyshyn, 2008; Hanvey, 2002; Prince, 2006; Wuest, Merritt-Gray, Berman, & Ford-Gilboe, 2002).

Demands faced by primary caregivers of children with disabilities may include exceptional daily caregiving activities and financial costs, uncertainty about their child's future, an ongoing need to interface with a myriad of health and service agencies, and a lifetime of caring for their child (Burton & Phipps, 2009; Ray, 2002; Wiart et al., 2010). Additionally, the informal support networks that are present for many caregivers (such as extended family, friends, respite, and community groups) may not be available or sufficient to assist with their child's complex care (Bruns, 2000; Corman, 2013; Kuster & Merkle, 2004; Neufeld, 1997; Statistics Canada, 2008). Some Canadian caregivers have experienced negative psychological and health effects, as well as financial issues as a result of their caregiving and these problems can persist for many years (Brehaut et al., 2011; Sinha, 2013; Turcotte, 2013).

In Canada, findings from the PALS 2006 indicated that 45.5% of parents of children with disabilities reported their daily stress as 'quite a bit' to 'extremely stressful' (Statistics Canada, 2008), which is twice the rate of the 22.7% of Canadians aged 15 or older who reported in 2012 that most days were 'quite a bit' to 'extremely' stressful (Statistics Canada, 2013b). Feelings of stress increased with the severity of the child's disability. Sources of stress included family, work, finances, and the child's health needs (Statistics Canada, 2008).

Given the extra demands that are placed on caregivers of children with disabilities, the stress that they may incur, and the impact that stress has on decreasing the effectiveness of the immune system and in increasing cellular aging (Ader & Cohen, 1995; Cohen & Herbert, 1996; Daruna, 2004; Epel, 2009; Epel et al., 2004; 2006; Kiecolt-Glaser, 1999; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Selye, 1950; 1976; Tsigos, Kyrou, & Chrousos, 2005), one could postulate that their health may be compromised as well. Unlike children without disabilities, some children with disabilities are dependent on their caregivers throughout their lifetime and their care needs may increase as they age and become taller and heavier (Murphy, Christian, Caplin, &

Young, 2006). This responsibility may negatively affect the health of a caregiver who is also experiencing the normal degenerative effects of aging (Cairns, Tolson, Brown, & Darbyshire, 2013; Fast et al., 2008; Kuster & Merkle, 2004). However, there are inconsistent findings regarding caregiver health status. Burton, Lethbridge, and Phipps (2008a) analyzed data from the 1994 to 2000 National Longitudinal Study of Children and Youth and found that Canadian mothers of children with disabilities aged 6 to 15 years were twice as likely to report being in poor or fair health compared to mothers of children without disabilities. Conversely, the 2006 PALS (Statistics Canada, 2008) reported that 64.8% of the 8945 parents or guardians of children with disabilities reported their health as being good to excellent.

Theoretically, the health of rural caregivers of children with disabilities may be compromised more than their urban counterparts. While there are a number of benefits associated with living in rural communities, which may include having less stress and a stronger sense of community (Hoogsteen & Woodgate, 2013; Statistics Canada, 2010a), the health and life expectancy of rural Canadians is worse than their urban counterparts (Canadian Institute for Health Information [CIHI], 2006a; Greenberg & Normandin, 2011; Ministerial Advisory Council on Rural Health [MACRH], 2002; Population Health, 2007). Similarities and differences in the health of urban and rural caregivers of children with disabilities remain unknown.

One way to decrease the potentially negative impact of caregiving and stress on health is to engage in health promoting behaviors to maintain or improve health. No studies have compared the health promoting behaviors of urban and rural primary caregivers of children with disabilities and the effectiveness of health promotion strategies targeting urban populations in rural settings is unknown (Kulig, MacLeod, Stewart, & Pitblado, 2008).

While individuals are responsible for the decisions that they make regarding their health promoting behaviors, other factors that have the potential to influence these behaviors need to be considered. One could assume that, with the time constraints, fatigue, economic challenges, increased demands, and decreased support experienced by some caregivers of children with disabilities (Anderson et al., 2007; Baker et al., 2003; Burton & Phipps, 2009; Butcher, Wind, & Bouma, 2008; Glenn, Cunningham, Poole, Reeves, & Weindling, 2009; Kelso, French, &

Fernandez, 2005; Leiter, Krauss, Anderson, & Wells, 2004; Statistics Canada, 2008), finding time to engage in health promoting behaviors may be difficult. Rural caregivers may be particularly vulnerable because they do not have the same access to resources and facilities as urban caregivers (CIHI, 2006a; Pong et al., 2011). It is important to explore and to compare the facilitators and barriers to health promoting behaviors of urban and rural caregivers.

The viewpoint that individuals are not solely responsible for their health promoting behaviors is supported by proponents of social ecology models. They contend that other family, social, organizational, environmental, economic, and policy factors act as facilitators and barriers to health promoting behaviors (McLeroy, Bibeau, Steckler, & Glanz, 1988; Sallis, Owen, & Fisher, 2008; Stokols, 1996).

Conceptual Framework: Social Ecology Model

Social ecological models argue for the need to go beyond an individualistic perspective to include the social and environmental conditions that contribute to health promoting behaviors (Green, Richard, & Potvin, 1996; Raphael, 2008; Sallis et al., 2008; Stokols, 1996). An individual's desire to modify his or her behavior may be facilitated or impeded by economic, social, and environmental constraints (Breslow, 1996; Robertson, 1998). These models offer a way to explicate the multiple determinants of health promoting behaviors and can guide multi-level assessments and interventions.

History

Modern ecological perspectives on health promotion were evident in several earlier theories and models. The key premise was that understanding an individual's perception of their environmental constraints and opportunities was key to understanding their behaviors (Lewin, 1936, as cited in McLaren & Hawe, 2005). Social ecological perspectives evolved with the increased prevalence of chronic diseases and the need to consider the influence of sociocultural and environmental contexts on health behaviors (Stokols, 1992). The roots of social ecological models can be traced back to Bronfenbrenner (1979); his ecological theory of development drew attention to the fact that multiple environments affect a child's development. While children have inherent psychological and physiological traits, Bronfenbrenner's theory posits that children are surrounded by four systems that exert a collective influence on their development and behavior. The microsystem is most proximal to the child and is composed of the interactions with persons such as family or peers in settings such as the home, school, and playground. The mesosystem is comprised of the interrelations among two or more settings in which the child participates, such as family and school. The exosystem refers to one or more settings in which the child is not an active participant, but in which events affect or are affected by what happens in those settings containing the child. This may include parents' place of work or activities of the local school board. A macrosystem contains all of the previous systems, in addition to the belief systems, values, and ideologies within the subculture, such as gendered values and beliefs. Each of these systems is nested inside the other, with the individual at the center.

McLeroy and colleagues (1988) looked at various levels of influences on individual behavior. They built on Bronfenbrenner's (1979) ecological theory and proposed an ecological model to explain individual health promoting behaviors that was more specific in identifying resources and constraints. Their model focused on patterned behavior as the outcome of interest; they proposed that behavior is influenced by five levels of factors. These include intrapersonal (e.g. knowledge, skills, attitudes), interpersonal (e.g. family, colleagues, neighbors, or friends), organizational (e.g. work or school), community (e. g. churches or neighborhoods), and policy (e.g. local, provincial, or national policies, procedures, and laws) factors. Targets for program outcomes include individuals, small groups or other persons affecting individuals, organizations, communities, and political systems (Novilla, Barnes, De La Cruz, Williams, & Rogers, 2006).

Sallis, Bauman, and Pratt (1998) presented a simplified ecological model for examining physical activity related outcomes that introduced additional concepts to factors similar to those used by McLeroy and colleagues (1988). Their four domains included: (a) intrapersonal factors such as self motivation, perceived competence, and values; (b) social variables such as formal and informal support networks, including family, colleagues, and friends; (c) physical environmental variables, such as availability of recreational facilities in the community, community safety, and weather conditions; and (d) policies such as when and where physical activity can occur and local government regulations regarding allocation of parks and recreational centers.

Assumptions and Principles

While social ecology models vary, Stokols (1992) proposed four core assumptions in relation to health promoting behaviors that apply across all models. First, the healthfulness of a situation and the health of its participants are influenced by multiple facets of the social (culture, economics, and politics) and physical (e.g. geography, architecture, and technology) environments. Second, analyses of health and health promotion should consider and address the multidimensional and complex nature of human environments. Third, behavior should be studied at multiple levels of analysis using methods appropriate to each level (e.g. interviews with individuals or small groups and questionnaires for populations). Fourth, a social ecological perspective of health promotion incorporates a variety of concepts from systems theory, including homeostasis and feedback. As such, efforts to improve health promoting behaviors need to consider the interdependencies that exist among various environments.

Similarly, Sallis and colleagues (2008) proposed that ecological perspectives on health behavior change have four core principles that apply across models. First, health behaviors are influenced by multiple levels of factors, including intrapersonal, interpersonal, organizational, community, and public policy factors. Second, these influences on behavior are reciprocal and interact across levels. Third, multi-level interventions are most effective in achieving sustainable behavior changes; this includes individual efforts at modifying behavior combined with changes to the physical and social environment. Finally, ecological models are most powerful when they are specific to certain behaviors (e.g. laws preventing public smoking may not promote exercise).

Strengths and Limitations

Ecological models of health behavior have been central to health promotion for several years and there is an increasing reliance on multi-level interventions. For example, the decrease in smoking rates in recent years is partially attributable to messages on cigarette packages describing the deleterious effects of smoking (intrapersonal), banning smoking in workplaces (organizational), and increasing taxes on cigarettes (policy) (Sallis et al., 2008). A key strength of these multi-level interventions is that they move beyond explanations that hold individuals solely responsible for harmful behaviors (Baum & Fisher, 2014; Sallis et al., 2008). Instead, they provide a broader understanding of the multiple factors that facilitate or impede individuals' efforts to engage in healthy behaviors (Stokols, 1996). A pragmatic limitation of ecological models is that multiple theoretical levels of influence means collecting data, intervening, and analyzing data regarding these multi-level influences; this places significant demands on the time and resources of researchers. Multi-level influences also make it more challenging to isolate an intervention from its context (Sallis et al., 2008). Nevertheless, with attention to both the individual and their environment, social ecological models have the potential to increase understanding of facilitators and barriers to health promoting behaviors.

Integrated Social Ecology Model

McLeroy and colleagues' (1988) social ecology model of factors that affect health behaviors was a good fit for this study as it was likely that multiple individual and environmental factors are affecting the health and health promoting behaviors of urban and rural caregivers of children with disabilities. Furthermore, ecological models account for the influence of differential access to resources that may exist in urban and rural communities (Thurston & Blundell-Gosselin, 2005). Spence and Lee (2003) argue that the McLeroy model is more of an environmental model since it does not situate the individual at the center. This study followed Bronfenbrenner's (1979) and Flack's (2009) approaches that placed the individual (caregiver) at the center of the model. Flack's nomenclature, an "Integrated Social Ecology Model" (ISEM) was used to denote this adaptation of McLeroy et al.'s model. This model integrates the multiple levels of influence on health promoting behaviors of urban and rural caregivers of children with disabilities. As shown in Figure 1, the ISEM is a series of nested, concentric circles of environmental influence with the caregivers whose health promoting behaviors are of interest at the center. Each level of factors interacts with the other as shown by the bidirectional arrows.

Intrapersonal factors include individual factors, such as knowledge, skills, motivation, values, and attitudes. Interpersonal factors include formal and informal social support systems, such as family, children, colleagues, and friends. Organizational factors include formal and informal rules and regulations in institutions such as work and school. Community factors include factors such as presence or absence of recreational facilities, grocery stores with affordable healthy food, the presence or absence of public transportation, neighborhood safety, and weather conditions (Sallis et al., 1998). Finally, policy factors include relevant municipal, provincial, and national government policies, rules, and regulations.

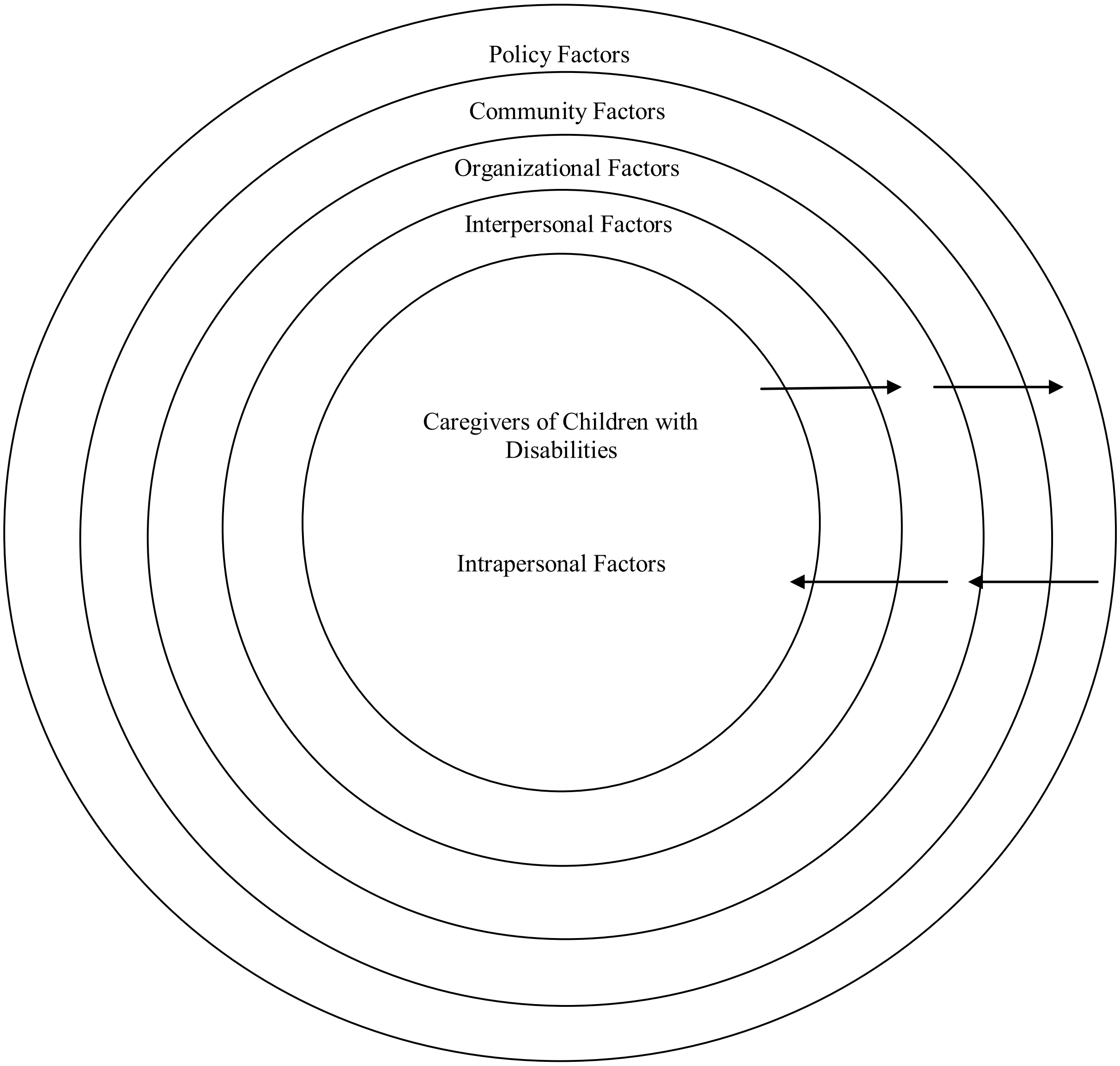

Figure 1. Integrated Social Ecology Model

Summary

Knowledge and theories developed from a social ecological perspective provide a way to comprehensively assess the multiple factors that affect the health promoting behaviors of urban and rural caregivers of children with disabilities. This knowledge can then be used with input from key stakeholders to develop appropriate and relevant interventions. Ecological models suggest that providing caregivers with motivation and skills to change their health promoting behaviors will be ineffective if their environment makes it difficult or impossible to engage in these behaviors. Conversely, health promoting behaviors are maximized with environments and policies that support healthy and informed choices. An ISEM was proposed to facilitate understanding of the interrelated effects of multiple influences within the individual and their environment on the health promoting behaviors of urban and rural caregivers of children with disabilities.

Purpose of the Study

The purpose of this “sequential explanatory” (Creswell, 2009, p. 211) mixed methods study was to describe and to compare the self-reported health status, health promoting behaviors, and facilitators and barriers to health promoting behaviors of urban and rural primary caregivers of children with disabilities living in Central Alberta. In the first phase, caregivers were surveyed to identify and to compare urban and rural caregiver health status and health promoting behaviors. To further comprehend and explain the quantitative results, a second qualitative phase was done to explore and compare the facilitators and barriers to health promoting behaviors of urban and rural caregivers.

Research Questions

1. What are the similarities and differences in the health status of urban and rural primary caregivers of children with disabilities who live in Central Alberta?
2. What are the similarities and differences in the health promoting behaviors of urban and rural primary caregivers of children with disabilities who live in Central Alberta?
3. What are the similarities and differences in the facilitators and barriers to health promoting behaviors experienced by urban and rural primary caregivers of children with disabilities who live in Central Alberta?

Relevance of the Study

Children with disabilities need an environment that is organized, appropriately stimulating, and responsive to facilitate their physical, mental, social, and cognitive development; primary caregivers are better able to provide this environment when they are healthy. Poor primary caregiver health has negative consequences for the family and may result in increased healthcare costs for the caregiver, as well as increased respite costs for the child with the disability. Serious caregiver illness and the resulting inability to fulfill their caregiving roles may result in placement of the child with a disability outside of the home, breaking up the family unit and incurring significant costs for both health and social services. Potential benefits of health promoting efforts include improving caregiver health and decreasing their risk for compromised health and chronic diseases. Health promoting behaviors may also improve the health of other members of the family, including the child with a disability. More important, improved caregiver health means that caregivers can continue to care for their child with a disability within the supportive environment of the family unit.

Health promotion is widely accepted as a key nursing role. An understanding of the health and health promoting behaviors of these caregivers is needed to develop and implement appropriate programs and policies to assist them in adopting a healthy lifestyle. It is also important to determine what facilitators and barriers to health promoting behaviors are experienced by this vulnerable population so that strategies can be developed to ameliorate the facilitators and to overcome the barriers.

Chapter 2: LITERATURE REVIEW

This chapter includes a summary of research related to the health, health promoting behaviors, and facilitators and barriers to health promoting behaviors of urban and rural caregivers of children with disabilities. Medline, CINAHL, Psychology and Behavioral Sciences Collection, and Social Sciences Citation Index databases were searched using the following key terms: child, caregiver, mother, father, parent, disability, handicap, chronic, special needs, health, health promotion, rural, smoking, obesity, healthy eating, physical activity, stress management, heavy drinking, checkups, and facilitators and barriers to health promoting behaviors. The quality of the studies was not assessed in-depth, though efforts were made to indicate when studies had small sample sizes that limited the generalizability of the results. Several topics that were assessed had a limited evidence base, so all available literature was included irrespective of quality. Trends, gaps, contradictions, and areas needing further study in the literature are identified.

Health

While health is seen as a central construct of interest in nursing (Fawcett, 1995), there is debate about what it is and how it can be achieved (Saylor, 2004; Winstead-Fry, 1980); conflicting definitions of health are a major source of this confusion (Couper, 2003; Reynolds, 1988). In this section, definitions of health and self-reported health are briefly reviewed, followed by a discussion of the health of caregivers of children with disabilities.

Definitions of Health

The medical definition of health as the absence of disease has dominated our culture for the past three centuries and prevails in many Western societies (Smith, 1981; Young & Higgins, 2005). The World Health Organization (WHO, 1948) offered a broader and more positive view of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease of infirmity" (para. 1). This definition was expanded on in the WHO's (1986) *Ottawa Charter for Health Promotion* where health was "seen as a resource for everyday life, not the object of living" (para. 3). A similar approach was taken in Canada by Lalonde (1974) and Epp (1986) when they identified health as not merely the absence of disease or infirmity, but as a positive state for which individuals could strive.

The concept of health in the nursing literature has its roots in the mid-1800s when Nightingale (1859) defined nursing as the science of health; however, definitions of health vary within the discipline. Various nurse theorists have discussed the concept of health and there are as many definitions as there are theorists (Carper, 1975; Smith, 1981; Tripp-Reimer, 1984). Tripp-Reimer (1984) states that definitions of health can be categorized in three major ways: a) a dichotomous variable; b) a continuum, and c) a more inclusive holistic state. As an example of a more abstract perspective on health, Newman (2003) claims that health falls into two paradigms – the wellness-illness continuum and unitary patterning of the person-environment. While the specific definition of health varies according to the philosophic perspective, there is agreement that health is a multidimensional construct; one such construct is self-reported health.

Self-reported health. Leninger (1978) noted that the individual and the health professional may perceive health differently. The lay definition of health ranges from the traditional Western view of health as absence from disease to the Eastern view of health as mind-body balance and harmony (Jensen & Allen, 1993; Saylor, 2004). Tripp-Reimer (1984) discussed this when describing etic and emic approaches to defining health. The conceptualization of health, without understanding the viewpoint of the individual, is the etic approach. Alternatively, the emic approach describes a phenomenon from the perspective of the client and is advocated by Leninger (1978) because it can enhance culturally congruent care.

Krause and Jay (1994) found that, when participants rated their health, they used more than one criterion and the criteria were complex and multilayered. Participants considered their general physical functioning, psychological well-being, specific health problems, presence of positive and negative health behaviors, and made comparisons to individuals similar in age. Idler, Hudson, and Leventhal (1999) found that the criteria that respondents used to rate their health included physical, psychological, emotional, and spiritual health; ability to function; ability to engage in social activities; cultural context; family history; health risk behaviors; and social relationships. In Kaplan and Baron-Epel's (2003) study, subjects considered general well-being, pain, difficulty in performing activities, diseases identified by their physician, medications, and treatments when describing their health status.

Given the range of definitional criteria that scholars use, a comprehensive approach to health must acknowledge the variety of physical, mental, personal, social, environmental, behavioral, functional, cultural, psychological, and other factors that shape self-reported health. For this study, self-reported health (SRH) is defined as an individual's judgment regarding his or her own level of health using the dimensions of health that are relevant to that individual. This definition is viewed as a multi-dimensional phenomenon with multiple determinants.

Health of Caregivers of Children with Disabilities

This section reviews studies of the health of caregivers raising children with disabilities. Inclusion criteria for articles were that the study: a) primarily targeted caregivers of children as participants, b) included caregivers residing with children, c) was reported in English, and d) assessed multidimensional aspects of health. Studies must have included either a multidimensional global rating of SRH or a physical or physiological assessment, in addition to a mental or psychological assessment of health. Studies on caregiving for only adult children and the elderly were excluded, as were any studies that reported on family health versus individual caregiver health. Individual summaries of studies are in Table 1, Appendix A. The most commonly studied domains were general, physical, mental, social, and financial health; factors associated with caregiver health are also outlined.

General health. Of the seventeen studies that reported on and compared the general health of caregivers of children with disabilities to a control group or to population norms, fourteen found that caregivers of children with disabilities had poorer general health (Bella, Garcia, & Spadari-Bratfisch, 2011; Benjak, Mavrinac, & Simetin, 2009; Brehaut et al., 2009; Burton et al., 2008a; Byrne, Hurley, Daly, & Cunningaham, 2010; De Andres-Garcia, Moya-Albiol, & Gonzalez-Bono, 2012; Eisenhower, Baker, & Blacher, 2009; Eker & Tuzan, 2004; Flom-Meland, 2004; Kaya et al., 2010; Kuhlthau, Kahn, Hill, Gnanasekaran, & Ettner, 2010; Lach et al., 2009; Thyen, Terres, Yazdgerdi, & Oerrun, 1998; Tuna, Unalan, Tuna, & Kokino, 2004). Two studies found that the majority of caregivers of children with disabilities reported that their health was good to excellent (Kuster, 2002; Neufeld, 1997); one study reported no difference between caregivers of children with disabilities and a control group (Seltzer, Greenberg, Floyd, Pettee, & Hong , 2001). The 2006 PALS (Statistics Canada, 2008) reported that 64.8% of the 8945 parents or guardians of children with disabilities aged from birth to 14 years reported their health as being good to excellent. This is similar to the national average; in 2012, 65% of Canadians aged 35 to 44 reported their health as being very good to excellent (Statistics Canada, 2013b).

When exploring possible explanations for contradictory findings, one must consider indicators of the quality of the study, including sample size and the representativeness of the sample. For example, the PALS study (Statistics Canada, 2008) had a large, representative sample compared to many of the other studies; in the next largest study, Brehaut et al. (2009) included 2495 mothers. The severity of the child's condition may also influence study results; greater severity is assumed to be associated with greater demands on caregivers. While the PALS data (Statistics Canada, 2007b) did not include the proportion of children included in the mild, moderate, severe, or very severe categories of disability, sample stratification was based on census data. Census data from 2006 found that 58.3% of children with disabilities were in the mild to moderate category and 41.6% were in the severe to very severe category (Statistics Canada, 2007a). The PALS study reported that health decreased as severity of the child's disability increased; almost twice as many parents of children with severe to very severe disabilities reported being in fair or poor health (22.8%) versus parents of children with mild to moderate disabilities (11.9%) (Statistics Canada, 2008). Controlling for severity of disability may be important in explaining variations across studies.

Physical and physiological health. To provide care to their child with a disability, caregivers need to be physically healthy. Compared to caregivers of healthy children or children without a physical disability, eleven studies found that caregivers of children with disabilities had poorer physical health (Bella et al., 2011; Brehaut et al., 2004; Byrne et al., 2010; Cairns, 1992; Eisenhower et al., 2009; Flom-Meland, 2004; Kaya et al., 2010; Kuhlthau et al., 2010; Ones, Yilmaz, Cetinkaya, & Caglar, 2005; Tong et al., 2002; Tuna et al., 2004). In six studies, caregivers of children with disabilities experienced more pain than caregivers of typically developing children (Bella et al., 2011; Benjak et al., 2009; Eker & Tuzan, 2004; Kaya et al., 2010; McConnell & Llewellyn, 2006; Thyen et al., 1998). Nine studies found that caregivers had less vitality and energy or more fatigue than controls (Benjak et al., 2009; De Andres-Garcia et al., 2012; Eker & Tuzan, 2004; Flom-Meland, 2004; Hedov, Anneren, & Wikblad, 2000; McConnell & Llewellyn, 2006; Ones et al., 2005; Thyen et al., 1998; Tuna et al., 2004).

Caregivers of children with disabilities also had a greater likelihood of experiencing a variety of physical problems or chronic conditions than controls (Benjak et al., 2009; Brehaut et al., 2004; Brehaut et al., 2009; De Andres-Garcia et al., 2012; Kuster, 2002; Lach et al., 2009; Ray, Croen, & Habel, 2009; Wallander et al., 1989; Wyatt, 1991). Their health problems included back problems, asthma, migraine headaches, ulcers, arthritis, high blood pressure, trouble sleeping, sleep deprivation, chronic fatigue, pain, and impaired immunity (Gallagher, Phillips, Drayson, & Carroll, 2009; Kaya et al., 2010; Kuster, 2002; Leonard, Johnson, & Brust, 1993; Morelius & Hemmingsson, 2013; Murphy et al., 2006; Neufeld, 1997; Tong et al., 2003).

Numerous studies have used the physical health composite score of the Medical Outcomes Study Short Form Health Survey (MOS SF-36) or the shorter item MOS SF-12 which provides a broad index of functional health. Several studies found no difference between caregivers of children with disabilities and controls in the physical health composite score of the SF-36 and the SF-12 (Bourke et al., 2008; Flom-Meland, 2004; McConnell & Llewellyn, 2006; Thyen et al., 1998) or in the physical functioning domain of the SF-36 (Benjak et al., 2009; Eker & Tuzan, 2004; Hedov et al., 2000; Holm, 2004; McConnell & Llewellyn, 2006; Thyen et al., 1998). It is not known whether the lack of difference was real or whether the measure (Ware, 2000) lacked the sensitivity to detect the health status changes expected among otherwise healthy young adults aged 26 to 44 years.

Mental and psychological health. Eighteen studies found that caregivers of children with disabilities had poorer mental or psychological health than their comparative group of caregivers of children without disabilities (Benjak et al., 2009; Brehaut et al., 2004; Brehaut et al., 2009; De Andres-Garcia et al., 2012; Eisenhower et al., 2009; Eker & Tuzan, 2004; Flom-Meland, 2004; Gallagher et al., 2009; Hedov et al., 2000; Kaya et al., 2010; Kuhlthau et al., 2010; Kuster, 2002; Lach et al., 2009; McConnell & Llewellyn, 2006; Ones et al., 2005; Pariante et al., 1997; Ray et al., 2009; Thyen et al., 1998). Five studies found no difference between the two groups on mental health scores (Allik, Larsson, & Smedje, 2006; Bella et al., 2011; Seltzer et al., 2001; Tuna et al., 2004) or depression (Pariante et al., 1997).

Caregivers of children with disabilities have high levels of stress significantly more frequently than parents of typically developing children or population norms (Baker et al., 2003; Brehaut et al., 2004; Buelow, McNelis, Shore, & Austin, 2006; Butcher et al., 2008; Epel et al., 2004; Esdaile & Greenwood, 2003; Flom-Meland, 2004; Gallagher et al., 2009; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Oelofsen & Richardson, 2006; Parkes, McCullough, Madden, & McCahey, 2009; Roach, Orsmond, & Barratt, 1999). Sources of stress include child behavior difficulties, increased financial strain, negative impact of the child's health care needs on employment, extra caregiving demands, less time for spouse and siblings, uncertainty about the future, social isolation, lack of resources, lack of support, fatigue, and worry about their child's health (Anderson et al., 2007; Baker et al., 2003; Butcher et al., 2008; Denham & Looman, 2010; Glenn et al., 2009; Kelso et al., 2005; Ketelaar, Volman, Gorter, & Vermeer, 2008; Krulik et al., 1999; Leiter et al., 2004).

The 2006 PALS (Statistics Canada, 2008) reported that 45.5% of parents and guardians of children with disabilities rated their daily lives as quite a bit to extremely stressful and 61.4% were sometimes or always stressed from balancing daily life with responsibilities related to the child's condition. Of the 50.1% of parents and guardians reporting problems related to the child's condition in their marital or common-law relationship, 85.4% reported stress or depression as the source of the problem. Therefore, even though there are some inconsistent findings, the majority of studies appear to indicate that the mental health of caregivers of children with disabilities may be at risk.

Social health. Given the extra demands of caring for a child with a disability, some caregivers may have fewer opportunities to engage in social activities. Ten studies found that the social functioning of caregivers of children with disabilities was worse than the social functioning of caregivers of children without disabilities or population norms (Benjak et al., 2009; Eker & Tuzan, 2004; Flom-Meland, 2004; Kuhlthau et al., 2010; Kuster, 2002; McConnell & Llewellyn, 2006; Ones et al., 2005; Pariante et al., 1997; Seltzer et al., 2001; Thyen et al., 1998). Two studies found that caregivers of children with disabilities had lower levels of social support than caregivers of children without disabilities (Kuster, 2002; Lach et al., 2009). Only four studies found no difference in social functioning (Kaya et al., 2010; Tuna, et al., 2004) or social support (Brehaut et al., 2004; Gallagher et al., 2009). Others have also found that the informal support networks that are present for many caregivers (such as extended family, friends, respite, and community groups) may not be available or be able to assist with the child's complex care (Kuster & Merkle, 2004; Neufeld, 1997; Statistics Canada, 2008).

Results from the 2006 PALS found that 51.6% of parents and guardians reported having less personal time due to responsibilities related to the child's disability (Statistics Canada 2008). Similar findings were reported in the 2012 GSSCCR (Turcotte, 2013); 65% of partnered caregivers reported spending less time with their partner/spouse due to caregiving responsibilities. Caregivers also reported that time spent on social activities (51%), with friends (46%), and relaxing or taking care of oneself (54%) was affected.

One way to expand social activities is to use respite. However, participants in the PALS study (Statistics Canada, 2008) reported barriers to having help with childcare, including cost, lack of local resources, and a lack of knowledge of where to find help. Furthermore, 21.5% of parents and guardians stated that childcare services and caregivers in a home other than the child's had refused to provide care for their child with a disability. The incidence of refusal increased to 31.7% for children with severe or very severe disabilities. Issues with respite have been found in other studies, especially if the child has behavior problems or requires complex care (Neufeld, 1997; Yantzi, 2005). Therefore, it appears that some caregivers of children with disabilities are at risk for poorer social health than caregivers of children with typical development.

Financial health. Several studies included some component of income or employment. Caregivers of children with disabilities had lower incomes (Brehaut et al., 2004; Thyen et al., 1998) and higher out of pocket expenses or financial difficulties than controls (Kuhlthau et al., 2010; Pariante et al., 1997; Thyen et al., 1998). Conversely, Brehaut and colleagues (2009) found that their sample of 2495 primary caregivers of children with health problems had higher incomes than national norms. This may have been due to the fact that their sample had higher rates of education and two parent households than population norms. However, differences in sample characteristics make it difficult to draw general conclusions.

Lower household incomes may be due to the fact that caregivers of children with disabilities were less likely to work full time (Brehaut et al., 2004; Kuhlthau et al., 2010; Svedberg, Englund, Malker, & Stener-Victorin, 2010) and were more likely to be unemployed or full time caregivers (Gallagher et al., 2009; Kuhlthau et al., 2010; Murphy et al., 2006; Seltzer et al., 2001; Shearn & Todd, 2000; Svedberg et al., 2010; Thyen et al., 1998). Statistics Canada (2008) also reported that, in 2005, 19.1% of children with disabilities lived in a household below the Low Income Cut-off (LICO), compared to 13.4% of households with a non-disabled child. Employability of caregivers was also affected; however, more mothers (64.1%) were affected than fathers (8.3%). Furthermore, 63.3% of mothers worked fewer hours and 55.6% adjusted their work hours. Similarly, studies have found that mothers of children with health problems were less likely to engage in paid work and worked fewer hours than mothers of typically developing children (Burton, Lethbridge, & Phipps, 2007) and that the effect of childhood activity limitations on employment was stronger among mothers than fathers (Kuhlthau et al., 2010).

Other researchers have found no difference between the employment status of caregivers of children with and without disabilities (Flom-Meland, 2004; Hedov et al., 2000). In the PALS (Statistics Canada, 2008), 81.8% of parents and guardians reported no financial problems due to the child's disability even though 38.4% of parents and guardians worked fewer hours and 38.5% adjusted their work hours due to the child's disability. Regarding out of pocket expenses, 29.7% of parents and guardians reported extra costs for transportation and 36.7% reported extra costs for the help that they received. Of those parents reporting problems in their marital or common-law relationship resulting from the child's disability, 45.8% were due to financial problems and 32.1% were due to problems at work. Only 18.2% of parents and guardians reported financial difficulties; however, parents of children with severe to very severe disabilities were three times more likely to report financial difficulties than parents of children with less severe disabilities.

Caregivers of children with a long-term care health condition or disability reported issues with extra costs related to the care needs of their child in the 2012 GSSCCR (Turcotte, 2013).

Nearly half reported that they had spent $2000 or more on out of pocket expenses, including medications and professional services. Nearly 28% of these caregivers reported financial hardship because of their caregiving responsibilities. Thirty-four percent of caregivers reported that their caregiving responsibilities had prevented them from holding a job. Of those who were employed, 45% had to take a leave from their job and 25% had reduced their hours of work due to caregiving responsibilities. Hence, it appears that some caregivers of children with disabilities do experience financial and employment issues, with mother's employment being most affected.

Factors associated with caregiver health. A number of interpersonal factors have been significantly associated with caregiver health. Child behavior difficulties were significantly associated with poorer caregiver health (Bourke et al., 2008; Eisenhower et al., 2009; Gallagher et al., 2009; Lach et al., 2009; Laurvick et al., 2006; Raina et al., 2005; Zhu, Walter, Rosenbaum, Russell, & Raina, 2006). Poorer health was associated with longer duration of caregiving (Burton et al., 2008a; 2008b; Byrne et al., 2010; Davis et al., 2010; Epel et al., 2004; Kaya et al., 2010; Pariante et al., 1997), children with more functional limitations (Bourke et al., 2008; Eker & Tuzan, 2004; Kuhlthau et al., 2010; Kuster, Badr, Chang, Wuerker, & Benjamin, 2004; Svedberg et al., 2010; Tong et al., 2002; 2003), poorer child health (Bourke et al., 2008), greater caregiving demands (Kuster, 2002; Pariante et al., 1997; Raina et al., 2005; Wyatt, 1991; Zhu et al., 2006), and worse scores on assessments of family function (Raina at al., 2005; Zhu et al., 2006). Three studies reported contradictory results (Flom-Meland, 2004; Ones et al., 2005; Pariante et al., 1997); however, Flom-Meland lacked information on type and severity of the child's condition and Pariante and colleagues had small samples.

Severity of disability was significantly related to health in the 2006 PALS (Statistics Canada, 2008). Parents and guardians of children with severe to very severe disabilities were less likely to rate their health as good to excellent; had higher levels of stress; and were more likely to indicate that the child's disability affected employment, finances, leisure, personal time, and ability to find childcare than parents and guardians of children with mild to moderate disabilities.

Summary

Most nurse theorists agree that health is a multidimensional construct. Self-reported health incorporates the viewpoint of the individual and considers the multitude of factors that affect health. Studies of the health of caregivers of children with disabilities were primarily comparative and descriptive designs. The preponderance of evidence suggests that a subset of caregivers of children with disabilities may be at risk for poorer general, physical, mental, social, and financial health. Caregivers of children with severe disabilities and mothers of children with disabilities appear to be at the most risk. However, these results contradict findings from the PALS 2006 by Statistics Canada (2008) which found that the majority of caregivers of children with disabilities rated their health as being good to excellent. While this contradiction may be explained by the breadth of conditions included, future studies need to clearly identify the characteristics of the population and to examine subgroup differences, such as urban versus rural residency.

Rural Health

Results from the 2006 census indicated that an estimated 19% of Canadians (and 17% of Albertans) live in rural areas (Statistics Canada, 2011c). There are a number of benefits associated with living in a rural community. Rural residents are thought to have a strong sense of community; to believe that rural areas are a safe and clean place to raise their children; and to find rural living less stressful due to the slower place, diminished noise, and reduced traffic congestion (Catholic Family Counseling Centre, 2005). Other benefits of rural living include having more privacy, access to more affordable housing, lower taxes, living in more open spaces, and a lower cost of living (Centre for Rural and Northern Health Research, 2001; Environmental Protection Agency, 2010).

Although most individuals have a general idea about what 'rural' means, a universally accepted definition has been difficult to establish (Bosak & Perlman, 1982; Hanvey, 2005; Minore, Hill, Pugliese, & Gauld, 2008). Nevertheless, the current literature suggests that rural residence does affect the health of some Canadians (CIHI, 2006a; Mitura & Bollman, 2003). The following sections discuss definitions of rural, health of rural Canadians, possible reasons for the health issues of some rural Canadians, and the effect of rural residence on caregivers of children with disabilities.

Definitions of Rural

Defining what constitutes rural residency is a complex process that changes according to the purpose for which the definition is intended (Racher, Vollman, & Annis, 2004). In Canada, many definitions of 'rural' are used, depending on the level of analysis, methodology, and criteria being assessed (CIHI, 2006a; MACRH, 2002). du Plessis, Beshiri, Bollman, and Clemenson (2002) reviewed Statistics Canada databases and found six different definitions of rural. They recommend that, if one definition must be used, 'rural and small town' be defined as populations living in towns and municipalities outside the commuting zone of larger urban centers with a population of 10,000 or more.

For Canadian research, several authors (du Plessis et al., 2002; Minore et al., 2008; Racher et al., 2004) recommend that investigators select the definition of ‘rural’ best suited to their research and this is reflected in the array of definitions across studies. For the purpose of this literature review, no attempt was made to standardize rural criteria for study inclusion.

Health of Rural Canadians

Living in rural and remote Canada has a positive effect on the health status of some Canadians, including lower rates of 'high' life stress and stronger social support networks (CIHI, 2006a; MACRH, 2002). However, there are some negative effects; while Canadians are considered to be among the healthiest people in the world with an average life expectancy of 81.1 years (Statistics Canada, 2012), rural Canadians have shorter life expectancies by up to 3 years when compared to their urban counterparts (CIHI, 2006a; Greenberg & Normandin, 2011; MACRH, 2002; Population Health, 2007). Reduced life expectancies are due, in part, to a higher risk of dying prematurely from diabetes, injuries, suicide, and respiratory and circulatory diseases. A decreased life expectancy is also not surprising given that health status declines as one moves further away from urban centers (CIHI, 2006a; Hanvey, 2005; Kirby & LeBreton, 2002; Romanow, 2002).

In a pan-Canadian study, the CIHI (2006a) analyzed data from the Canadian Community Health Survey (CCHS) cycle 1.1 (2000-2001), the Canadian Cancer Registry, and the Canadian annual mortality database in their report on the health of rural Canadians. Rural Canadians had higher rates of obesity, diabetes, hypertension, and arthritis/rheumatism than urban residents, but they were similar in their self-reported health, disability days, pain severity, stress, activity limitations, and scores on the Health Utility Index. Rural residents had a lower or similar incidence of lung cancer and lower incidences of colon, breast, and prostate cancer, as well as all-cancer mortality rates. However, they had higher incidences of cervical and lip cancer and were more likely to die from respiratory disease. Mortality rates from all injuries (including motor vehicle accidents) and poisoning increased as rurality increased.

Statistics Canada (2010b) published health fact sheets comparing the health of urban and rural Canadians aged 12 and over based on the 2008 CCHS of health status, health care utilization, and health determinants. Rural residents had higher rates of arthritis (rural 18.1% vs. urban 14.7%), obesity (rural 20.9% vs. urban 16.4%), diabetes (rural 6.4% vs. urban 5.8%), and high blood pressure (rural 19.1% vs. urban 15.8%). However, levels of significance were not reported, making the numbers hard to interpret. Asthma rates (8.4%) and diagnosed mood disorders (6.8%) were similar. The number of residents who described their days as being quite a bit or extremely stressful was higher in urban residents (rural 20.5% vs. urban 22.7%). Bivariate analysis found that rural Canadians reported a stronger sense of community belonging (rural 76.8% vs. urban 56.2%).

Other authors have found similar results regarding the health of rural Canadians when compared to their urban counterparts. These include a decreased life expectancy (MACRH, 2002; Shields & Tremblay, 2002), an increased prevalence of obesity (Chen, Rennie, & Dosman, 2009; MACRH, 2002; Reeder, Chen, Macdonald, Angel, & Sweet, 1997; Shields & Tjepkema, 2006a; 2006b), an increased incidence of injury (MACRH, 2002; Pong, DesMeules, & Lagace, 2009), and lower incomes and decreased access to employment opportunities (Burns, Bruce, & Marlin, 2007; Keefe, Hawkins, & Fancey, 2006; Leipert, 2006; 2008a; MACRH, 2002; Singh, 2004; Sutherns, McPhedran, & Haworth-Brockman, 2004). Mortality due to circulatory diseases and motor vehicle accidents was also higher in rural residents (Pong et al., 2009). However, mortality rates due to all cancers were slightly lower in rural areas than in urban areas (MACRH, 2002; Pong et al., 2009). Several authors have postulated reasons for these differences.

Reasons for health issues of rural Canadians. Several community and policy factors may contribute to the health issues of some rural Canadians. Health care reform in Canada has resulted in the downsizing and closure of rural hospitals; these hospitals were major employers and many rural health professionals and other individuals lost their jobs (Leipert, 2005; MACRH, 2002). As a result, there are fewer registered nurses and physicians working in rural and small town Canada, so rural residents have decreased access to health care, health information, and lifestyle advice (CIHI, 2000; 2008; Hanvey, 2005; Kirby & LeBreton, 2002; Premier's Advisory Council on Health for Alberta, 2001; Scott, 1999). Rural health care providers also have complex and expanded roles, which are often accompanied by fewer clinical support services; therefore, they are also less likely to move to or stay in these rural areas (CIHI, 2005; Hanvey, 2005; MacLeod, Kulig, Stewart, & Pitblado, 2004; Minore et al., 2008). The majority of medical specialists, physicians, nurses, and other health care providers live in urban areas, where Canadians with the longest life expectancy live (CIHI, 2008; Greenberg & Normandin, 2011; Romanow, 2002; Troughton, 1999). There can also be a lack of continuity of care when residents are transferred from local rural hospitals to urban hospitals, then back to their rural hospital (Bowie, 2006). Limited broadband internet services in some rural communities also limits access to health information (Canadian Radio-television and Telecommunications Commission [CRTC], 2012; Leipert, 2006; McKeown, Noce, & Czerny, 2007; Wathen & Harris, 2007). Other deficits in rural health care services include fewer diagnostic services, health promotion programs, and rehabilitation programs, as well as under-servicing of specific populations, such as seniors and people with disabilities (Leipert, 2005; Lombardo et al., 2014; MACRH, 2002).

Decreased access to health care services means traveling longer distances to reach health services; this further imposes financial burdens on a population already affected by lower incomes. Road hazards and inclement weather increase the likelihood that rural residents will decide not to travel for health services (Bowie, 2006; Kirby & LeBreton, 2002). The high incidence of mortality from motor vehicle accidents in rural areas may be attributed to poorer roads, winter driving hazards, and greater distances traveled (CIHI, 2006a; MACRH, 2002). Higher mortality rates from injuries may be due to longer delays in discovery and longer response times from emergency services (CIHI, 2006a; Leipert, 2005). Addresses in rural parts of the province are harder to find, which, when combined with greater distances to travel, may result in delays in providing emergency services. As a result, rural residents are more likely to transport victims themselves, potentially resulting in delayed interventions (Bowie, 2006). Drug and alcohol abuse are high in some rural areas, increasing the likelihood of injury (Leipert, 2008b; MACRH, 2002; Population Health, 2007).

Lower socioeconomic status has been associated with worse health in Canadians (Phipps, 2003; Raphael, 2001; Reutter, 2000; Reutter & Kushner, 2009; Yu & Raphael, 2004) and rural Canada has a higher proportion of individuals with less formal education and lower incomes than urban Canada (CIHI, 2006a; Kulig, Edge, & Joyce, 2008; Leipert, 2008a). Many farmers also lack supplementary health insurance, making some drug therapies cost prohibitive (Leipert, 2006).

Organizational factors also play a role; rural Canadians are more likely to be involved in occupations with higher physical risks, such as farming, fishing, mining, and logging (CIHI, 2006a; Leipert, 2005; MACRH, 2002; Troughton, 1999). Rural Alberta is comprised of a number of farms and farming activities can contribute to a higher rate of injury (Thurston & Blundell-Gosselin, 2005; Thurston, Blundell-Gosselin, & Vollman, 2003). Primary operators of farms with older equipment with fewer safety features and those specializing in farm animals with an unpredictable nature, including horses, cattle, and sheep, are especially at risk (Maltais, 2007). The seasonally long hours that farmers work have also been associated with increased injury as a result of fatigue, stress, and a decrease in physical and cognitive performance (Heather, Skillen, Cross, Vladicka, 2012; Pickett et al., 2011). Other hazards associated with farming include handling pesticides and fertilizers, which can increase risks for respiratory diseases and cancer (Masley et al., 2000; Thurston & Blundell-Gosselin, 2005). These risks are not limited to male farmers; Young (1997) studied the risks to health experienced by farm-women living in rural Central Alberta. The farm women experienced musculoskeletal and soft tissue disorders from hauling heavy equipment and handling heavy animals, chemical exposure to pesticides and fertilizers, hearing loss from the loud noise associated with farm animals and equipment, and exposure to toxic gases from animal waste in confined farm buildings.

Health of Rural Caregivers of Children with Disabilities

Few studies have examined the health of rural caregivers of children with disabilities; a summary of findings regarding the mental, social, and financial health of these caregivers are presented. Three studies comparing urban and rural caregivers' health are also summarized.

Mental health. In a rural Australian study, Mackey and Goddard (2006) found that, due to the need to be constantly vigilant to the health status of their child, the five mothers experienced considerable stress and were not alert to changes in their own health status. In two US studies, Halls (2008) and Brasfield (2008) found that rural caregivers of children with disabilities reported stress due to the time and effort required to locate services for their child, as well as the cost of lengthy travel to access emergency care, hospitals, physicians, and interventions outside of their community. Conversely, Brasfield found that benefits of rural residence included less stress due to worry about their children because the community was safer and had less traffic.

Transportation and distance issues unique to rural caregivers were additional sources of stress. All ten of the mothers of children with disabilities in Brasfield's (2008) study spoke of the extra effort of transporting their child. Transportation was an issue for other caregivers of children with disabilities, especially if the child with a disability was more severely disabled and was in a wheelchair or was assisted by technology. While many cities provide wheelchair accessible public transportation, this may not be provided in many rural communities (Hanvey, 2002; Statistics Canada, 2008). Lauver (2010) reported that foster mothers in the Northeastern United States typically had to travel long distances to get the expert care required by their child with special health care needs. Many of these children required the care of pediatric specialists, which meant traveling anywhere from 30 minutes to three hours.

Social health. Rural Canadian caregivers of children with autism have reported that, while access to respite was limited, families in their small communities were a source of support for themselves and their children (Hoogsteen & Woodgate, 2013). Conversely, Mackey and

Goddard (2006) found that all five caregivers reported a lack of social support; partners worked long hours or worked far away from home and family was either geographically distant or too busy to provide assistance and support. Brasfield's (2008) study in the rural Southeastern United States found that mothers spoke of social isolation due to geographic separation from others. All ten mothers noted the absence of sufficient family support services in the area, including support groups. Lauver (2010) found that most of the ten rural foster mothers of children with special health care needs in the Northeastern US spoke of unremitting social isolation. The lack of access to social activities and social isolation may also be due, in part, to more limited access to affordable and qualified respite in rural areas (Hanvey, 2001; 2002; Powell & Bauer, 2010; Valentine, 2001; Yantzi, 2005; Yantzi, Rosenberg, & McKeever, 2006).

Hospitalizations of the child with a disability in distant urban centers also contribute to isolation due to the lack of pediatric specialists in rural areas (CIHI, 2008; Halls, 2008; Yantzi, Rosenberg, Burke, & Harrison, 2001). The primary caregiver frequently stays with the hospitalized child while partners, friends, and family remain at home to work and care for other children. Travel costs, work obligations, and driving conditions also contribute to isolation during hospitalization (Beagan et al., 2005; DiFazio & Vessey, 2013; Yantzi et al., 2001).

Financial health. Caregivers of children with disabilities experience a number of financial challenges (Bourke-Taylor, Cotter, & Stephan, 2013a; Burton & Phipps, 2009; Statistics Canada, 2008). Yantzi (1998) studied families of repeatedly hospitalized children with chronic conditions in Ontario and looked at the impact of distance on families. Wear and tear on vehicles, as well as expenditures for fuel, phone calls, meals, and accommodations increased the further away one was from the hospital and other services (Brasfield, 2008; Burton et al., 2007).

Limited opportunities for employment are also a factor; Halls (2008) found that most of the mothers in her study of caregivers in rural Montana were unable to work outside of the home after the birth of their child with special health care needs. This was a result of both increased demands in caring for their child and unavailability of adequately trained respite providers.

Urban vs. rural caregivers. Leonard and colleagues (1993) asked urban and rural parents how they were managing. They found that more rural than urban mothers were managing

‘OK’ versus those who reported that they were managing ‘Not OK’ , which was defined as needing more help or not being able to manage much longer. The authors suggest that this may be due to the stronger social networks typically found in rural communities. Conversely, Murphy and colleagues (2006) found that rural caregivers of children with developmental disabilities reported less peer support than their urban and suburban counterparts.

One study in the United States used the MOS SF-36 to compare the health of urban and rural caregivers; Flom-Meland (2004) studied 55 female and four male urban and rural caregivers (age 30 to 61 years, mean 42 years) of children with special needs. She found that the health of caregivers of children with special needs was worse than the health of caregivers of children without special needs and worse than instrument norms, but there was no difference in the health of urban and rural caregivers of children with special needs.

Summary

A review of the literature found no consistent operational definition of rural residency. The majority of studies found that some rural Canadians experience worse health and have shorter life expectancies than their urban counterparts, although the quality of the evidence was not assessed in this review. Reasons for differences may include fewer employment opportunities, lower incomes, decreased access to health services and personnel, and longer distances to access health services on poor roads. The health of some rural caregivers of children with disabilities was also affected by these factors; however, their health may be at further risk since research suggests that their health may already be affected by their caregiving responsibilities. Few studies compared the effect of urban and rural residence on the caregiver, the sample sizes were small, and the findings were contradictory. Therefore, it would seem prudent to determine what, if anything, these urban and rural caregivers of children with disabilities are doing to promote and maintain their health.

Health Promotion

The Canadian Community Health Survey found that 33% of Canadians aged 12 years and older reported at least one chronic health condition, including arthritis, cancer, chronic obstructive pulmonary disease, diabetes, heart disease, high blood pressure, and mood disorders (Health

Council of Canada, 2007). The increasing prevalence of these diseases is a major concern as they are the leading cause of disability and death in Canada (Butler-Jones, 2008; Canadian Nurses Association [CNA], 2005a; Ford et al., 2007; Minister of Health, 2005; Orpana, Lemyre, & Kelly, 2007). However, the development of these chronic conditions is not inevitable; while genetic predisposition plays a role, modifiable risk factors within an individual's control can both prevent and limit the severity of these chronic conditions (Chronic Disease Prevention Alliance of Canada [CDPAC], 2007; Ramage-Morin, Shields, & Martel, 2010). Physical activity, healthy eating, maintaining a healthy weight, managing stress, and avoiding tobacco exposure all decrease the risk of cancer, premature heart disease, stroke, Type 2 diabetes, and chronic obstructive respiratory diseases (CDPAC, 2007; Ford et al., 2007; Warburton, Nicol, & Bredin, 2006; WHO, 2005). It is estimated that “90% of type 2 diabetes and 80% of coronary heart disease could be avoided or postponed with good nutrition, regular physical activity, the elimination of smoking, and effective stress management” (Minister of Health, 2005, p. 1).

While the current focus of Canada’s and Alberta's health care systems is on treating illness, there is a need for a paradigm shift to support upstream activities such as health promotion (CNA, 2009; Minke et al., 2007). Participation in health promoting behaviors can help to improve and maintain an individual's health, as well as prevent and decrease the morbidity and mortality associated with chronic diseases. Health promotion is widely accepted as a key nursing role; early nursing activities in health promotion were primarily health education and nurses used more of a traditional approach to nurse driven information giving (Benson & Latter, 1998; Cohen, 2005; Donaldson & Crowley, 1978; Smith, 1990; Whitehead, 2009). This practice has changed as social determinants of health became more widely recognized (Federal, Provincial, and Territorial Advisory Committee on Population Health, 1994; Hamilton & Bhatti, 1996; Raphael, 2008). Nurses now take on the more complex task of a client- or community-centered collaborative approach to health promotion that includes both health education and intervening on social, economic, political, and other determinants of health and health promoting behaviors (Benson & Latter, 1998; Caelli, Downie, & Caelli, 2003; CNA, 2005b; Green & Kreuter, 2005; Maben & Clark, 1995; Norton, 1998; Whitehead, 2004).

Definitions of Health Promotion and Health Promoting Behaviors

Health promotion. Health promotion is complex and multi-faceted; there are numerous definitions in the nursing literature (Caelli et al., 2003; Maben & Clark, 1995; Smith, 1990). Smith found common themes evident in these definitions; these included that they were holistic, promoted the potential for health, included modifying the environment, involved a nurse-client interrelationship and partnership, and that the outcomes were client defined.

The most widely used definition of health promotion is from the *Ottawa Charter for the Promotion of Health* (WHO, 1986): "health promotion is the process of enabling people to increase control over, and to improve, their health" (p. 4). This definition was used in this study. Health promotion includes actions that strengthen the skills and capabilities of individuals and that change social, economic, and environmental conditions of individuals, groups, and communities (Baum, 2008; Benson & Latter, 1998; Pender, Murdaugh, & Parsons, 2011; WHO, 1998).

Health promoting behaviors. For this study, health promoting behaviors are defined as those behaviors that individuals engage in to maintain and/or improve their health. These behaviors are determined "by the interplay between an individual's personal characteristics, social interactions, and socioeconomic and environmental living conditions" (WHO, 1998, p. 16). Health promoting behaviors include being physically active (Canadian Society for Exercise Physiology, 2013; Fox, 1999) and eating a diet according to the Canada Food Guide (Health Canada, 2007), both of which contribute to attaining and maintaining a healthy weight (Keith et al., 2006; Obesity Canada, 2006; Orpana, Tremblay, & Fines, 2007; Shields & Tremblay, 2008b). Health Canada (2007) recommends that the daily diet of adults include 7-10 servings of fruits and vegetables, 6-8 servings of grain products, 2 servings of milk and alternatives, and 2-3 servings of meat and alternatives. New physical activity guidelines for Canadian adults aged 18 to 64 years are at least 150 minutes of moderate to vigorous intensity aerobic physical activity a week, in bouts of 10 minutes or more (Canadian Society for Exercise Physiology, 2013; Statistics Canada, 2011a). Engaging in this level of activity can help reduce the risk of premature death, coronary heart disease, stroke, hypertension, colon cancer, breast cancer, type 2 diabetes, and osteoporosis (Canadian Society for Exercise Physiology, 2013). Other health promoting behaviors include abstaining from smoking (Canadian Lung Association [CLA], 2008) and limiting alcohol consumption (Centre for Addiction and Mental Health, 2010).

Health Promoting Behaviors of Urban and Rural Canadians

The importance of health promotion in preventing and decreasing the effect of chronic diseases is well recognized. Similar to health, the health promoting behaviors of some rural Canadians differed from urban Canadians in many areas. The Ministerial Advisory Council on Rural Health (2002) reported that health promotion and education services are underdeveloped in most rural communities in Canada. A pan-Canadian study by the CIHI (2006a) using data from the CCHS 2000/2001 cycle 1.1 found that rural Canadians were less likely than urban Canadians to engage in several health promoting behaviors (level of significance $p < .05$). Significantly more rural Canadians were smokers (32.4% rural vs. 24.9% urban) or were exposed to second hand smoke (34.2% rural vs. 27% urban). Significantly fewer proportions of rural residents reported eating the then recommended five servings of fruit and vegetables each day (rural 31.1% vs. urban 38.2%). Rural residents were more likely to be overweight (rural 57.2% vs. urban 46.9%) but there was no significant difference in leisure time physical activity (rural 22.4% vs. 23.1% urban). The incidence of consuming more than two drinks of alcohol per day was similar in rural (4.8%) and urban (4.1%) residents.

Statistics Canada (2010b) recently compared the health promoting behaviors of urban and rural Canadians using data from the 2008 CCHS; levels of significance and *p* values were not reported. The study found that rural residents had higher incidences than urban residents of unhealthy behaviors such as smoking (rural 22.7% vs. urban 21.1%), exposure of non-smokers to second hand smoke (rural 9.3% vs. urban 6.1%), and heavy drinking (rural 18.0% vs. urban 16.7%). There was no difference between urban and rural Canadians in the consumption of fruit and vegetables five or more times a day (43.7%). Rural residents were more likely than urban residents to be satisfied or very satisfied with life (rural 94.0% vs. urban 90.8%). Shields and Tremblay (2008a; 2008b) used data from the 2007 Canadian Community Health Survey and found that rural residents (31%) were more likely to be frequent television viewers than urban residents in centers with a population of 500,000 or more (26%) but significantly less than residents of urban areas with a population of 30,000 to 99,999 (35%).

Health promoting behaviors of rural western Canadians. Johnson, Ratner, and Bottorff (1995) compared the health promoting behaviors of urban and rural Albertans. They found that individuals living outside of Edmonton and Calgary were more likely to have a body mass index (BMI) greater than 27 kg/m^2 and rural residents were significantly more likely to consume fried and fatty foods; no differences were noted in smoking or in frequency of exercise. A normal adult BMI is between 18.5 and 24.9 kg/m^2 (Orpana , Tremblay, et al., 2007; WHO, 2013). Thurston and colleagues (2003) studied the health concerns and practices of 332 male (mean age 49.9 years) and 231 female (mean age 45.8 years) farmers in rural Southern Alberta. Only 13.6% of men and 14.4% of women smoked, which was less than the Alberta rate of 29.6%. While exercise patterns varied, the majority of farmers were infrequent exercisers.

Paluck, Allerdings, Kealy, and Dorgan (2006) used focus groups to study the health promotion of 44 rural women living in Saskatchewan. The participants were divided into three groups: ages 18-44 years (younger age, n=16), 45 - 64 years (middle age, n=16), and ≥ 65 years (older age, n=12). Participants described over 70 different health practices that they engaged in to maintain and improve their health. These behaviors fell into two general categories: (a) activities to improve physical health, such as exercise and nutrition; and (b) mental activities to improve or maintain a healthy mind or well-being, such as stress reduction, social support, and intellectual stimulation. Older women tended to have a balance of physical and mental behaviors, while women in the middle and younger age groups were more focused on behaviors that improved their physical health and put less emphasis on their mental health. Quitting smoking and drinking in moderation were only reported by middle and older aged women.

Health Promoting Behaviors of Urban and Rural Caregivers of Children with Disabilities

Studies suggest that the health of some caregivers of children with disabilities is at risk and that some give priority to the health of their child over their own health needs. No studies to date have compared the health promoting behaviors of urban and rural caregivers of children with disabilities. Few studies have examined the health promoting behaviors of caregivers of children with disabilities and none of the studies were Canadian. Wyatt (1991) assessed the health and health promoting behaviors of 40 mothers and 40 fathers of technology assisted homebound children with respiratory illnesses living in the United States. Both mothers’ and fathers’ health promotion scores were significantly lower than those for other healthy adults. As health promotion scores improved, parents reported fewer health symptoms. As family integration and social support scores improved, mothers' health promotion behavior scores also improved.

Kuster (2002) studied the health promoting behaviors of 38 female caregivers of ventilator-assisted children living in California using a questionnaire and open-ended questions. The majority of mothers had 'never' smoked (89.5%) and 'never' drank more than two alcoholic beverages daily (84.2%). More than half (55.3%) ‘frequently’ to ‘almost always’ saw a health care provider every year. They ‘frequently’ or ‘almost always’ ate at regular times during the day (65.8%) and ate foods from each of the food groups daily (71%). There were areas that were challenging. Most (82%) ‘never’ or ‘only occasionally’ had a planned exercise program and 81.6% ‘never’ to ‘only occasionally’ participated in physical activity three times a week. More than half (60.5%) ‘never’ or ‘occasionally’ received adequate sleep, took time to relax 15-20 minutes a day (57.9%), or were able to get together with friends (73.7%). As perceived impact on the family increased, mothers participated less in wellness behaviors. Mothers who participated in a greater number of wellness behaviors had better perceived general health and less depressive mood symptoms. Regression analysis found that mothers of higher functioning children participated in a greater number of wellness behaviors.

Magana and Smith (2008) used the 1999-2001 National Health Interview Survey in the United States to compare the health behaviors of 162 older (mean age 50.61 years) Latina (n=83) and Black American (n=79) mothers who co-resided with children (mean age 17.9 years) with developmental disabilities with 2,754 age related and similar ethnicity peers who did not co-reside with a child with a developmental disability. The groups were also split into midlife (40 to 54 years) and older (55 + years) caregivers. Both the co-residing and control groups had high rates of obesity and low levels of exercise. Black American mothers of children with disabilities were significantly less likely to exercise than their comparison group, but there were no differences in incidences of smoking, drinking, or obesity. Midlife Latina caregiving mothers were two times more likely to smoke than their comparison group; no older Latina mothers smoked. There were no significant differences between Latina mothers of children with disabilities and their comparison group in exercise, drinking, or obesity.

Other authors have commented on the health promotion of caregivers of children with disabilities. In a Canadian study, Ray (2002) studied 30 mothers and 13 fathers of 34 children aged 15 months to 16 years with chronic health conditions and found that only a few parents exercised and most parents did not care for their physical health as they should. Mackey and Goddard (2006) studied five mothers of children with intellectual disabilities aged from birth to 5 years living in a rural Australian city. While the mothers were promoting the health of their child, they were not engaging in health promoting behaviors for themselves. All of the mothers put their own health needs into the background since most of their energy was directed toward the health and needs of the child with a disability. Murphy and colleagues (2006) studied 40 caregivers of children with disabilities living in Utah and found that, although parents acknowledged the importance of maintaining their own health, most had little energy left at the end of the day and so they frequently decided to forego their own healthcare needs.

Summary

A review of the health promoting behaviors of rural Canadians found that many engaged in fewer health promoting behaviors than their urban counterparts. The few existing studies also suggest that some caregivers of children with disabilities are engaging in few health promoting behaviors; no studies were found comparing the health promoting behaviors of urban and rural caregivers of children with disabilities. However, as proponents of social ecology models suggest, one also needs to look beyond individuals to consider other factors that may be affecting their ability to engage in health promoting behaviors.

Facilitators and Barriers to Health Promoting Behaviors

One of the challenges of looking at individual behavior is the tendency for a victim blaming approach (Norton, 1998; Robertson, 1998). While it is important to assess individual health promoting behaviors of urban and rural caregivers of children with disabilities, one also needs to acknowledge the numerous factors outside of the caregiver that may be contributing to engagement in health promoting behaviors (Alvaro et al., 2010; Baum & Fisher, 2014).

The following section presents studies of facilitators and barriers to health promoting behaviors of adults in the general population, rural residents, and urban and rural caregivers of children with disabilities. Facilitators make it easier or more likely that an individual will engage in health promoting behaviors and barriers inhibit or prevent an individual from engaging in health promoting behaviors. Facilitators and barriers are categorized according to the intrapersonal, interpersonal, organizational, community, and policy factors of the ISEM (Bronfenbrenner, 1979; Flack, 2009; McLeroy et al., 1988; Sallis et al., 1998).

Facilitators and Barriers to Health Promoting Behaviors of the General Population

Not all factors that affect health and health promoting behaviors are within the control of the individual; these include factors in one's environment (Frohlich & Potvin, 1999; Hamilton & Bhatti, 1996; Raeburn & Rootman, 2007; Stokols, 1996). Facilitators and barriers to physical activity, healthy eating, maintaining a healthy weight, mental health, smoking cessation, limiting alcohol consumption, and social support in the general population are summarized.

Physical activity. The 2011 CCHS (Statistics Canada, 2013c) found that only 53.9% of Canadians age 12 and older were moderately active in their leisure time. Findings from the 2007 to 2009 Canadian Health Measures Survey indicate that only 15% of adults engage in the required 150 minutes per week of moderate to vigorous physical activity (Colley et al., 2011; Garriguet & Colley, 2012).

Intrapersonal facilitators of physical activity included making exercise a priority; scheduling physical activity (Alberta Centre for Active Living [ACAL], 2011; Tavares & Plotnikoff, 2008); and the belief that exercise prevents heart disease, decreases stress, and helps with tasks in older age (Canadian Fitness and Lifestyle Research Institute [CFLRI], 2007; Gillis, 1993). Interpersonal facilitators included exercising with a partner (CFLRI, 2007; Kowal & Fortier, 2007; Tavares & Plotnikoff, 2008) and social support (Dishman, Sallis, & Orenstein, 1985; Duffy, 1986; Frohlich & Potvin, 1999; Gillis, 1993; Timmerman, 1999). Organizational facilitators included implementing policies that allow employees time and opportunities for physical activity during work hours (Shill et al., 2012). Community facilitators included more favorable weather (Chan, Ryan, & Tudor-Locke, 2006; Tavares & Plotnikoff, 2008), affordable facilities or programs (CFLRI, 2007; Tavares & Plotnikoff, 2008), convenient public transportation and parking, affordable child care, specific instruction or coaching (CFLRI, 2007), and safe environments or neighborhoods (Kowal & Fortier, 2007). Policy facilitators included improved urban planning and provision of infrastructure to promote walking and cycling, discouraging use of private motorized vehicles, mandating that school physical activity facilities be available to the public outside of school hours, and subsidizing the price of commuter bicycles (Shill et al., 2012).

The most common intrapersonal barriers to physical activity were lack of motivation, feeling lazy, and fatigue (Adachi-Mejia et al., 2010; Burke et al., 1999; CFLRI, 2007; Duffy, 1986; Kowal & Fortier, 2007; Tavares & Plotnikoff, 2008; Timmerman, 1999). Other intrapersonal barriers were illness or injury (CFLRI, 2007; Kowal & Fortier, 2007; Stenberg, Fjellman-Wiklund, & Ahlgren, 2014; Tavares & Plotnikoff, 2008), lack of discipline (Burke et al., 1999; Tavares & Plotnikoff, 2008), needing more information (Burke et al., 1999), lack of interest (Adachi-Mejia et al., 2010), fear of injury, feeling uncomfortable (CFLRI, 2007), and stress (Tavares & Plotnikoff, 2008). An interpersonal barrier was lack of an exercise partner (Burke et al., 1999; Kowal & Fortier, 2007). Lack of time, being busy with other obligations (Adachi-Mejia et al., 2010; Burke et al., 1999; CFLRI, 2007; Dishman et al., 1985; Duffy, 1986; Kowal & Fortier, 2007; Ottenbacher, 2001; Tavares & Plotnikoff, 2008; Timmerman, 1999; van Zandvoort, Irwin, & Morrow, 2009), and lack of money or high cost of programs (CFLRI, 2007; Salmon, Owen, Crawford, Bauman, & Sallis, 2003; Tavares & Plotnikoff, 2008) are both interpersonal and organizational barriers. Poor or limited access to facilities (CFLRI, 2007; Kowal & Fortier, 2007; Tavares & Plotnikoff, 2008), inclement weather (Chan et al., 2006; Salmon et al., 2003, Timmerman, 1999), unsafe neighborhoods (Kowal & Fortier, 2007), and lack of child care (CFLRI, 2007; Duffy, 1986) are community barriers. Policy barriers included car industry and automotive associations blocking regulations to promote bicycling/walking, lack of a clear definition of ‘walkability’, cost, lack of evidence to support policy interventions, and lack of collaboration across sectors (Barnidge et al., 2013; Shill et al., 2012).

Healthy eating. In 2011, 39.6% of Canadians aged 12 and older were consuming five servings of fruits and vegetables a day (Statistics Canada, 2013c). Intrapersonal facilitators of healthy eating were knowledge of the benefits of fruits and vegetables, concern over their children’s health (Yeh et al., 2008), cooking extra portions of healthy meals to have on hand, having nutrition knowledge (Garcia, Sykes, Matthews, Martin, & Leipert, 2010), and having high levels of self-efficacy (Tudoran, Scholderer, & Brunso, 2012). An interpersonal facilitator was social support (Yeh et al., 2008). Community facilitators included getting information from physicians (Yeh et al., 2008), having healthy and affordable options at the supermarket and fast food places, and having access to public transportation to get to supermarkets (Garcia et al., 2010). Easy access to nutrition information on food labels was a policy facilitator (Garcia et al., 2010). Other policy facilitators included providing vouchers to reduce price barriers, promoting healthy menu options, limiting the density of fast food restaurants, providing subsidies for farmers’ markets, mandating a minimum percentage of locally produced fruits and vegetables in supermarkets, improved labeling of healthy food products, providing incentives for change to food manufacturers, and establishing a food policy council to examine ways to reduce barriers to healthy eating (Baum & Fisher, 2014; Hood, Martinez-Donate, & Meinen, 2012; Shill et al., 2011).

Intrapersonal barriers to healthy eating included a lack of knowledge about the content of food labels and about what a healthy diet should include (Burke et al., 1999; Garcia et al., 2010; Sullivan, 2003), buying unhealthy foods, disliking the taste of healthy food, having difficulty eating healthy when eating out (Burke et al., 1999), the convenience of prepackaged food (Garcia et al., 2010; Yeh et al., 2008), and fear of contamination from pesticides (Yeh et al., 2008). Interpersonal and organizational barriers included lack of time to plan and prepare healthy foods (Burke et al., 1999; Garcia et al., 2010; Ottenbacher, 2001; van Zandvoort et al., 2009) and exposure to unhealthy food cues by family, friends, and colleagues (Timmerman, 1999). Community factors included the lack of access to grocery stores, the high cost of fruits and vegetables, the convenience of prepackaged and fast food (Garcia et al., 2010; Yeh et al., 2008), the low cost of unhealthy food (Garcia et al., 2010), and the poor quality of available produce (Yeh et al., 2008). Policy barriers included the influence of the food industry on government and lobbyists, perceived conflicts between policies and departmental agendas that promote industrial innovation, difficulty enforcing regulations, cost of implementing regulations, and lack of evidence to support policy interventions (Shill et al., 2011).

Low-income Canadians have additional barriers to overcome. Tarasuk (2010) analyzed data from the 2004 CCHS cycle 2.2 and found that 9.2% of Canadians experienced income-related barriers to accessing healthy food and 'food insecurity'. Participants of all ages in food-insecure households consumed fewer servings of fruits, vegetables, and milk products. Smoyer-Tomic and colleagues (2008) examined whether exposure to supermarkets and fast food outlets varied with neighborhood socioeconomic status in Edmonton, Alberta. While access to supermarkets was similar among all areas, fast food outlets were more prevalent in areas with more Aboriginals, renters, lone parents, low-income households, and public transportation commuters.

Maintaining a healthy weight. Findings from the Canadian Community Health Survey 2011/2012 (Statistics Canada, 2013c) indicate that 18.3% of Canadians are considered obese. When those who are overweight are added, 60.1% of men and 44.5% of women in Canada have increased health risks due to excess weight. Intrapersonal facilitators to maintaining a healthy weight included tracking nutritional intake and calories (Corbalan et al., 2009; Kruger, 2009), planning meals, daily weights, measuring the amount of food on their plate, and eating smaller portions (Cometto, 2011; Kruger, 2009). Organizational facilitators included weight gain prevention counseling with occupational health professionals (Verweij et al., 2012). Attending programs or group therapy sessions in their community was a community facilitator (Corbalan et al., 2009).

The most common intrapersonal barrier to maintaining a healthy weight was lack of motivation (Cometto, 2011; Corbalan et al., 2009; Kruger, 2009). Other intrapersonal barriers included eating when bored (Corbalan et al., 2009), eating away from home, liking to eat junk food, using over the counter diet products, not being satisfied after eating diet foods (Kruger, 2009), placing one's needs after others in the family (Ottenbacher, 2001), fatigue, being frustrated with their lack of progress in weight loss (van Zandvoort et al., 2009), and eating in front of the television (Cometto, 2011). An interpersonal barrier was pressure from family members to buy less than nutritious foods (Ottenbacher, 2001). An organizational barrier was lack of motivation by employers to implement programs to prevent obesity (Verweij et al., 2012).

Mental health. The percentage of Canadians diagnosed with a mood disorder rose from 5.3% in 2003 to 7.2% in 2011. In 2011, 23.9% of Canadians aged 15 and older reported that most of their days were ‘quite a bit’ or ‘extremely’ stressful; women (24.6%) reported more stress than men (21.7%) (Statistics Canada, 2013c). Intrapersonal facilitators of mental health help-seeking included positive past experiences with help-seeking, confidence in the health care professional, education and awareness, perceiving the problem as serious, being able to easily express emotion and openness, and positive attitudes toward seeking help. Interpersonal facilitators included social support and encouragement from others (Gulliver, Griffiths, & Christensen, 2010).

Intrapersonal barriers included reluctance to accept mental health services (Nelson & Park, 2006), fear of stigma, difficulty identifying symptoms of mental illness, concern about the health professional, reliance on self, unwillingness to express emotion, not wanting to burden someone, preferring other sources of help, and worry about effect on career (Gulliver et al., 2010). Interpersonal barriers included a lack of child care and difficulty scheduling appointments due to family responsibilities. Organizational barriers included difficulty scheduling appointments due to work commitments, having insufficient income to afford the costs of getting help (Nelson & Park, 2006), and lack of health care coverage (Gulliver et al., 2010). Community barriers included a lack of access to professionals, long wait times, and no transportation (Gulliver et al., 2010; Nelson & Park, 2006).

Smoking cessation. In 2012, 19.9% of Canadians aged 12 and older smoked daily or occasionally (Janz, 2012; Statistics Canada, 2013b). Intrapersonal facilitators of smoking cessation included setting a quit date (Balmford, Borland, & Burney, 2010), knowing that smoking was harmful to one’s health, having future health concerns (CLA, 2008; Jones et al., 2011; Whiton, 1997), knowledge that smoking harmed other family members, being motivated to quit smoking

(Whiton, 1997), not wanting their house to smell of cigarette smoke (Jones et al., 2011), and quitting ‘cold turkey’ (CLA, 2008). An interpersonal facilitator to smoking cessation was pressure and support from family and friends (CLA, 2008; Jones et al., 2011; Whiton, 1997) and worry about exposing newborn babies to second hand smoke (Jones et al., 2011). Community facilitators included cessation advice from health professionals (CLA, 2008) and access to pharmacological alternatives that eased symptoms of nicotine withdrawal (Bullen et al., 2013; Gorin & Schnoll, 2006). Policy facilitators were the high cost of cigarettes (CLA, 2008) and public smoking bans (Lemstra, Neudorf, & Opondo, 2008; WHO, 2007).

Intrapersonal barriers to smoking cessation included misperceptions about smokeless tobacco and nicotine replacement products (Hammond, McDonald, Fong, & Borland, 2004; Heavner, Rosenberg, & Phillips, 2009; McIvor, 2009), fear of gaining weight (Burke et al., 1999; CLA, 2008; Whiton, 1997), lack of motivation or willpower (Burke et al., 1999; CLA, 2008; Jones et al, 2011), cravings and concern about withdrawal symptoms (CLA, 2008; Whiton, 1997), and that smoking was a part of their daily routine (CLA, 2008; Jones et al., 2011). Stress relief is also an intrapersonal barrier to smoking cessation (Burke et al., 1999; CLA, 2008; Jones et al., 2011; Whiton, 1997); however, Siahpush, Borland, and Scollo (2003) found in their sample of 6892 Australians that the odds of experiencing financial stress were 1.3 to 1.5 times greater and the odds of experiencing severe financial stress were twice as large in smoking households compared to non-smoking households. An interpersonal barrier to smoking cessation was being around family and friends who smoked and who applied pressure to continue smoking (Burke et al., 1999; CLA, 2008; Timmerman, 1999; Whiton, 1997). Lack of coverage of the cost of prescription medications and the high cost of nicotine replacement products were organizational and policy barriers. Knowing few health professionals trained in tobacco cessation (CLA, 2008) and the lack of access to prescription medications were community barriers (CLA, 2008).

Limiting alcohol consumption. In 2011 25.5% of males and 11% of females in Canada engaged in heavy drinking, which is 5 or more drinks per day (Statistics Canada, 2013c). Intrapersonal facilitators of limiting alcohol consumption included personal motivation and having knowledge about treatment (Cooksey, 2006). The only interpersonal facilitator was social support.

Intrapersonal barriers included fear of withdrawal when alcohol consumption was discontinued (Faltz & Wing, 2005), using alcohol to get close to someone, using alcohol to relax, guilt/shame in seeking treatment (Burke et al., 1999), and lack of knowledge about treatment locations (Cooksey, 2006). Interpersonal barriers included being exposed to alcohol in their social environments and peer pressure at social activities (Burke et al., 1999). A community barrier was waiting lists for treatment (Cooksey, 2006).

Social support. Social network members can provide information, act as role models, provide encouragement to comply with regimens, and constrain people from inappropriate health behaviors (Stewart & Langille, 2000). Intrapersonal facilitators of social support included being willing to acknowledge that support was needed and allowing others to provide support. An interpersonal facilitator was having friends and family offer support (Neufeld & Harrison, 2010).

Intrapersonal barriers to social support were concern about burdening the supporter (Harrison, Neufeld, & Kushner, 1995; Neufeld & Harrison, 2010), being reluctant to ask for support (Harrison et al., 1995), feeling a sense of obligation to provide care, and fear of refusal (Harrison & Neufeld, 1997). Interpersonal barriers included being unable to reciprocate support due to caregiving demands (Harrison & Neufeld, 1997; Harrison et al., 1995; Offer, 2010), non-supportive messages included with supportive actions from others (Harrison et al., 1995), and the time and effort needed to coach others to provide effective support (Harrison & Neufeld, 1997). A community barrier was lack of availability of competent help (Harrison & Neufeld, 1997).

Facilitators and Barriers to Health Promoting Behaviors of Rural Canadians

The health of some rural Canadians may be worse than their urban counterparts; recent studies suggest that rural Canadians were more likely to be overweight or obese and to smoke or have non-smokers be exposed to second hand smoke (CIHI, 2006a; Statistics Canada, 2010b). One reason for this difference in health promoting behaviors may be due to the unique facilitators and barriers to health promotion that some rural Canadians experience. A review of the literature found facilitators and barriers to physical activity, healthy eating, mental health, and smoking cessation of rural Canadians.

Physical activity. Intrapersonal facilitators to increasing physical activity included the perception that the activity was fun and owning a dog since it encouraged frequent walking (ACAL, 2008). Interpersonal facilitators were socializing while being active (ACAL, 2008; Paluck et al., 2006), and having family and friends who supported and encouraged them (ACAL, 2008). Community facilitators included quick and easy access to parks, low cost recreational facilities, safe neighborhoods, proximity to places such as the post office and the grocery store that promoted walking (Sutherns et al., 2004), and having child care available during fitness program times (ACAL, 2008).

Intrapersonal barriers were fear of injury, lack of personal motivation, lack of awareness about physical activity options, lack of awareness about the health benefits of being active, feeling uncomfortable while exercising, and lack of knowledge about how to do the physical activity (ACAL, 2008; CFLRI, 2007). Interpersonal barriers were a lack of social support (CFLRI, 2007; Paluck et al., 2006; Sutherns et al., 2004) and lack of time due to family commitments (ACAL, 2008; Paluck et al., 2006). An organizational barrier was lack of money to engage in activities due to the sporadic nature of income from farming due to factors such as inclement weather (e.g. drought, floods, hail) (ACAL, 2008; Sutherns et al., 2004). Community barriers included poor weather conditions that limited or prevented activities (ACAL, 2008; Sutherns et al., 2004), poor lighting on roads (Sutherns et al., 2004), a lack of facilities and resources (including trained personnel), discontinuation of previously offered programs and services, travel distance to events and facilities (CFLRI, 2007; Paluck et al., 2006), few sidewalks and bike paths in their communities, a lack of transportation (CFLRI, 2007), and cost of transportation to get to the activity/program (ACAL, 2008).

Healthy eating. Community facilitators included flexible grocers, a variety of food choices at restaurants, access to health professionals (Paluck et al., 2006), and having gardens where they could grow their own fruits and vegetables (Sutherns et al., 2004). Community barriers were a lack of variety of healthy foods at the grocery store, poor selection of healthy choices at restaurants (Paluck et al., 2006), the high cost of quality food, limited access to food banks, and a lack of public transportation to affordable grocery stores (Sutherns et al., 2004).

Mental health. Intrapersonal facilitators of stress resiliency included being positive and open-minded, being flexible, building and maintaining healthy relationships, controlling the pace of life, learning from difficult experiences to generate a positive meaning from the experience, making goals, setting personal boundaries, and controlling worry. Interpersonal facilitators were communicating with family about problems and support from family, friends, and the community. Community facilitators were getting advice and support from clergy and health professionals who knew about rural life, accessing education regarding farm finances and ways to manage farm stress, and retaining youth in the community to help revitalize the community (Gerard, Kulig, & Nowatzki, 2004)

Intrapersonal barriers to addressing mental health issues included fear of stigma, fears of loss of anonymity and confidentiality as a result of being seen accessing services (Gerard et al., 2004; Roberta & Falk, 2000), lack of knowledge about resources, and being resistant to change (Gerard et al., 2004). Interpersonal barriers included family demands and expectations that were exacerbated by the depopulation of rural communities and having less people to fulfil responsibilities (Gerard et al., 2004). Organizational barriers were low incomes that were insufficient to cover the cost of services due to the high cost of farming (Gerard et al., 2004; Roberta & Falk, 2000), the sporadic nature of farm work, and off-farm employment that required travel (Gerard et al., 2004). Community barriers included a lack of information about available services in their community, being reluctant to bring up concerns due to fear of overworking physicians and ultimately losing their services, long distances to access services, and lack of transportation to access services outside of their communities (Roberta & Falk, 2000). Policy barriers included difficulty in retaining physicians due to hospital closures resulting in inadequate or overloaded mental health services.

Smoking cessation. The Canadian Lung Association (2008) studied 2002 smokers; a community barrier to cessation for smokers living in remote and rural areas of Canada was limited access to online supports, help lines, or counseling. Regarding internet use, when income and level of education are controlled, individuals living in urban areas of Canada are 1.48 times more likely to use the internet for help with quitting smoking than those from small towns or rural areas

(McKeown et al., 2007). Part of this may be due to the decreased availability of high-speed broadband services in some areas of rural and remote Canada. The CRTC (2012) found that 20% of rural and remote Canadian communities did not have broadband access.

Facilitators and Barriers to Health Promoting Behaviors of Urban and Rural Caregivers of Children with Disabilities

While they are likely to be experiencing facilitators and barriers similar to those of both urban and rural residents, one could postulate that some caregivers of children with disabilities may be experiencing additional facilitators and barriers to health promoting behaviors due to factors related to caring for their child with a disability. However, few studies have examined this phenomenon. As such, only facilitators and barriers to a health promoting lifestyle, to maintaining a healthy weight, and to respite care are discussed.

Factors associated with a health promoting lifestyle. Tucker, Butler, Loyuk, Desmond, and Surrency (2009) used multiple regression to determine predictors of an overall health promoting lifestyle in 96 low-income African American and Caucasian mothers of chronically ill children. Behaviors were assessed using variables from the Health Self-Empowerment Theory (HSE) and four subscales of the HPLP II. They found that health self-efficacy, active coping, health motivation, and health self-praise were intrapersonal facilitators that accounted for 67% of the variance in eating a healthy diet, exercising consistently, stress management, and health responsibility behaviors. Lower depression scores (Kuster, 2002) and better perceived health (Kuster, 2002; Wyatt, 1991) were also associated with more health promoting behaviors. Interpersonal facilitators included higher child functioning (Kuster, 2002) and having social support (Wyatt, 1991).

Interpersonal barriers to a health promoting lifestyle were prioritizing their child's health over their own health needs (Kuster, 2002; Mackey & Goddard, 2006; Murphy et al., 2006) and having little energy left at the end of the day to invest in themselves after providing care for their child with a disability (Kuster, 2002; Murphy et al., 2006; Wyatt, 1991). Community barriers included a lack of respite and a lack of qualified alternative care providers (Murphy et al., 2006).

Maintaining a healthy weight. Lack of sleep due to stress and demands of caring for their child was an interpersonal barrier for many caregivers of children with disabilities (Hemmingsson, Stenhammar, & Paulsson, 2008; Morelius & Hemmingsson, 2013; Robinson & Richdale, 2004; Statistics Canada, 2008). Individuals who sleep less tend to have higher body mass indexes due to increased production of ghrelin (hormone that increases hunger) and lower amounts of leptin (hormone that decreases hunger) (Boutcher & Dunn, 2009; Elder et al., 2012; Nielsen et al., 2011; van Zandvoort et al., 2009). Sleep deprivation has also been associated with increased resting cortisol levels, which have been shown to encourage fat storage (Talbott, 2007). Stress also increases cortisol production (Heim, Ehlert, & Hellhammer, 2000; Kuster & Merkle, 2004); caregivers of children with disabilities have been shown to have higher amounts of stress than parents of typically developing children (Brehaut et al., 2004; Epel et al., 2004; Gallagher et al., 2009; Hamlyn-Wright et al., 2007; Oelofsen & Richardson, 2006; Parkes et al., 2009; Roach et al., 1999; Statistics Canada, 2008).

Respite care. Respite is intended to reduce stress and fatigue while increasing opportunities for social interaction in caregivers of children with disabilities (Doig, McLennan, & Urichuk, 2009). Several authors have studied barriers to respite for Canadian caregivers of children with disabilities. Community barriers reported by Neufeld, Query, and Drummond (2001) included a lack of people or agencies to provide care and a lack of qualified caregivers; similar findings were reported by Hoogsteen and Woodgate (2013). Lack of knowledge about available services was both an intrapersonal and policy barrier. Other policy barriers included a lack of funding and the inability to accommodate children's behavioral or physical needs (Statistics Canada, 2008). Additional policy barriers included that services were often difficult to arrange (Damiani, Rosenbaum, Swinton, & Russell, 2004), waitlists, home visits and needs assessments that needed to be completed, obtaining and coordinating funding, age restrictions, behavioral requirements, lack of flexibility, and the amount of paperwork required (Canadian Healthcare Association, 2012; Doig et al., 2009; Simpson, 2009).

Urban vs. rural caregivers. Yantzi and colleagues (2006) studied the challenges in getting out of the house and leaving the child with an alternative caregiver for 8 urban and 3 rural mothers of children with disabilities living in Ontario. Similarities included that interpersonal barriers were the work and planning required in moving the child's equipment and supplies and meticulous planning of the outing within the child's daily schedule. The lack of people within their formal and informal networks with the knowledge, skills, and expertise to care for the child was both an interpersonal and community barrier. Another community barrier was navigating physical barriers within the environment. Policy barriers were a result of the conditions that needed to be met for them to be able or willing to leave the house and the gap between the policies and practice of paid respite. The only difference reported was that mothers in urban communities had greater access to out of home respite care than rural mothers. Community barriers to accessing respite for rural mothers were lack of availability of out of home respite options and a greater distance required to travel to access respite, which was sometimes more than an hour away.

Summary

A review of the literature supported the notion of social ecologists that there are a number of facilitators and barriers affecting individual health promoting behaviors that are both within and beyond an individual's control. While personal motivation may be within an individual’s purview, factors such as the availability of social support, available time after completing family and work responsibilities, the availability of resources in the community, weather, and government policies are not always within the control of the individual. While few studies have been done, some rural residents and caregivers of children with disabilities experienced additional barriers to engaging in health promoting behaviors. Some rural residents experienced a number of community barriers due to limited access to services and resources, as well as the long distances required to travel to access programs. Several of the barriers encountered by caregivers were a result of caring for their child with a disability or government policy factors. Given the barriers experienced by rural residents and caregivers of children with disabilities, some rural caregivers may be facing significant obstacles to participating in health promoting behaviors. However, few studies have examined this phenomenon and only one study compared urban and rural caregiver's access to respite.

Need for the Study

There is a need for more studies to compare the health of urban and rural caregivers of children with disabilities. Most Canadian studies have been conducted in Ontario and four of the nine Canadian studies on the health of caregivers only included children with cerebral palsy and other neurodevelopmental disorders. Therefore, it would seem prudent for further studies to include caregivers of children with a full range of disabilities.

Much of the research to date has focused on the health problems experienced by caregivers of children with disabilities and many have used stress as their conceptual approach. There is a need for research to go beyond the negative effects of caregiving to focus on capacity development that builds skills and a research basis for health promotion practice since health promoting behaviors prevent and limit the severity of a number of chronic diseases. However, those few studies that have been done found that caregivers were engaging in few health promoting behaviors and no studies have compared the health promoting behaviors of urban and rural caregivers of children with disabilities.

There is a paucity of research examining the similarities and differences in facilitators and barriers to health promoting behaviors of urban and rural caregivers of children with disabilities. A mixed methods study that combines quantitative data that captures trends about the health status and health promoting behaviors of these urban and rural caregivers with qualitative data that reflects the local context regarding facilitators and barriers to health promoting behaviors is a method of inquiry that provides more insight than using either method on its own.

Chapter 3: RESEARCH METHODS

A sequential explanatory mixed methods research design (Creswell & Plano Clark, 2011; Creswell, Plano Clark, Gutmann, & Hanson, 2008; Kroll & Neri, 2009) was used to answer the questions in the study. In Phase 1 quantitative data were collected via mailed surveys to assess and describe the health and health promoting behaviors of urban and rural caregivers of children with disabilities. In Phase 2 a qualitative approach was used to determine the facilitators and barriers to health promoting behaviors experienced by urban and rural caregivers to enable a more in-depth interpretation of the survey findings. Phase 2 of the study used semi-structured telephone interviews with purposively selected volunteers from the survey respondents. A visual diagram of the sequencing of the study (Creswell & Plano Clark, 2011; Ivankova & Stick, 2007) is in Figure 2 in Appendix B. A description of mixed methods, the study sample, and the two phases of the study are outlined. The ethical considerations of each of the phases of the study are described separately for clarity but they received concurrent ethical review and approval (Appendix C).

Mixed Methods

Mixed methods research is defined as research "in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry" (Tashakkori & Creswell, 2007, p. 4). There are many reasons to use mixed methods designs (Bryman, 2006; Greene, Caracelli, & Graham, 1989; Morse & Niehaus, 2009; Sandelowski, 2014). In a sequential explanatory mixed methods research design, data are first collected quantitatively; this is followed by a second qualitative phase in which the researcher follows up on specific results from the first phase. The purpose of the second qualitative phase is to explain some of the results of the first quantitative phase (Caracelli & Greene, 1993; Creswell & Plano Clark, 2011; Kroll & Neri, 2009). Strengths of the sequential explanatory mixed methods design are its ease of implementation and its capacity for furthering inquiry beyond that of cross sectional quantitative data (Wilkins & Woodgate, 2008). The main challenge is the extended study duration (Creswell & Plano Clark, 2011). In weighing these features, the interpretive gains realized through the qualitative interviews justify the two-phase approach (Creswell et al., 2008; Thomas, 2003).

In this study, findings from the surveys were used to determine the similarities and differences between the health and health promoting behaviors of urban and rural caregivers of children with disabilities. Survey findings were also used to purposively select participants for the interviews and the interviews focused on facilitators and barriers to the top three health promoting behaviors that were identified in the surveys. Findings from the interviews helped to explain some of the similarities and differences between the health status and health promoting behaviors of urban and rural caregivers of children with disabilities found in the survey.

Several authors contend that a mixed methods approach is appropriate for families with a child with a chronic condition due to the complexity of their circumstances (Shepard, Orsi, Mahon, & Carroll, 2002; Wilkins & Woodgate, 2008). While a number of studies have been done on the health of caregivers of children with disabilities, few studies have examined what might be helping and preventing them from implementing strategies to improve or maintain their health. Therefore, a mixed methods approach also served the purpose of confirming and elaborating on current and previous research findings (Sosu, McWilliam, & Gray, 2008).

Sample

The convenience (Phase 1) and purposive (Phase 2) sample included urban and rural primary caregivers of children with disabilities living in Central Alberta. The primary caregiver was the person who identified him or herself as being the individual who provided the majority of care for their child with a disability. Caregivers who were accessing the FSCD program from the Central Alberta Child and Family Services Authority (CFSA) comprised the target population for both phases of the study. The Central Alberta CFSA serves individuals in the city of Red Deer and surrounding communities (see Figure 3 in Appendix D, Permission Letter Appendix E). Staff at the Central Alberta office indicated that there were approximately 530 families with children with disabilities living in Central Alberta. Inclusion criteria were that: (a) the respondent identified him or herself as the primary caregiver of a child (or children) with a disability, (b) the child (or children) resided with the caregiver and met the definition of disability (p. 1) used by FSCD (Government of Alberta, 2003) for admission to their program, (c) the child (or children) with a disability was less than 18 years old, and (d) the respondent was able to read and write English.

Caregivers who said that they were experiencing a family crisis at the time of recruitment for the interview or at the time of the scheduled interview were excluded. Two caregivers were excluded – one had a child who had recently passed away and the other's child without a disability had been diagnosed with cancer.

FSCD is a community-based program that serves children with a variety of diagnoses and their families (Government of Alberta, 2007). Findings from the literature review suggest that the health of some caregivers may be compromised regardless of the child's diagnosis, although the health of caregivers of children with more severe disabilities may be at greater risk. For these reasons, caregivers of children with a variety of types and levels of severity of disabilities were included. This non-categorical approach emphasized the similarities in life experiences of caregivers across a variety of childhood disabilities and recognized that the effects on the parent or caregiver are independent of the child's specific condition (Stein & Jessop, 1982). Furthermore, this approach facilitates the development of interventions appropriate for caregivers of children with a variety of disabilities, which is congruent with community-based service delivery (Stein & Jessop, 1982; 1989).

Within the Central Alberta CFSA, rural was defined as those small cities, towns, villages, and municipalities in Central Alberta outside the commuting zone of larger urban cities with a population of 10,000 or more (du Plessis et al., 2002). Red Deer (population 97,109 [Government of Alberta, 2013]) is the major service center for children with disabilities in Central Alberta; services include pediatricians, pediatric rehabilitation services, pediatric emergency care, and other specialized services for children with disabilities.

The two phases of the study were conducted sequentially; the data collection and procedures are described separately – one outlining the quantitative phase (Phase 1) and the second outlining the qualitative phase (Phase 2). The findings from each phase are presented separately in the results chapter and then synthesized in both the results and discussion chapters.

Phase 1: Quantitative Study

The following research questions were addressed in Phase 1 of the study:

1. What are the similarities and differences in the health status of urban and rural primary caregivers of children with disabilities who live in Central Alberta?
2. What are the similarities and differences in the health promoting behaviors of urban and rural primary caregivers of children with disabilities who live in Central Alberta?

Self-administered surveys were mailed to the total population of caregivers receiving services through the FSCD program in Central Alberta. A mailed survey was used rather than an online version because some rural residents in Canada have less access to broadband internet services than urban residents (CRTC, 2012). Mail surveys are also a convenient, efficient, and economical means of collecting information across a large geographic area (Dillman, Smyth, & Christian, 2009; Green, 1996; Shuy, 2003). The convenience sample was composed of those caregivers who chose to respond to the survey.

Survey

The survey (Appendix F) was designed specifically for this study and was based on the literature review, the investigator's experience as a parent of a child with a disability and as a pediatric nurse, and consultation with the core dissertation committee who have expertise with families and their children with disabilities. The survey elicited information about the caregiver's demographic characteristics, health, and health promoting behaviors. Additional descriptive information was collected about the child with a disability and urban versus rural residency. The survey was primarily composed of closed-ended questions in which the respondent was asked to choose one (or more) of the given alternatives.

Demographics. Demographic questions were based on the literature review, standard demographic questions from the PALS (Statistics Canada, 2006a) and the CCHS (Statistics Canada, 2010a), and questions used in prior studies (Ray, 2002). Child characteristics that were assessed included age, gender, diagnoses, and severity of disability. A second demographic form was included in the package in case the caregiver had more than one child with a disability (Appendix G). In such cases, the child with the most impairments was used for describing the sample and for any comparative analyses.

Caregiver characteristics included relationship to the child with a disability, age, gender, number of children, marital status, level of education, employment status, income, and extended health insurance coverage. Determination of urban or rural residency was critical for the results of this study, so a number of indicators were used in the survey to measure this variable; they included questions about place of residence. Internet access and the distance to health care services were also determined.

Measurement of health. Questions about caregiver health were derived from a variety of sources. The items regarding caregiver sleep, stress management, and support were successfully used in previous studies (Ray, 2002). Questions about caregiver stress, body mass index, smoking, alcohol use, and medical problems were derived from the CCHS (Statistics Canada, 2010a). All items represent salient concepts identified in the literature review. Face and content validity were assessed in the pilot of this survey.

A single item measure from the PALS (Statistics Canada, 2008) was used to assess caregiver self-reported health (SRH). Caregivers were asked: 'Compared to other people your age, how would you rate your usual state of health?' Possible responses included excellent, very good, good, fair, and poor. SRH is the judgment of an individual regarding his or her own level of health. This definition is viewed as a multidimensional measure with multiple determinants that goes beyond the medical definition of health and decreases the burden on the respondent, thus increasing the likelihood of a higher response rate (Cott, Gignac, & Bradley, 1999; McDowell, 2006). While multidimensional measures of health exist, the measures may not address what the respondent considers crucial in determining their level of health (Krause & Jay, 1994). SRH reflects incipient disease, aspects of positive health, psychological and physiological reserves, and social and mental function (Statistics Canada, 2013c).

The single item measure of SRH was used in recent Statistics Canada surveys, including the PALS (2006a) and CCHS (2010a). In reviewing the predictive validity of SRH, Idler and Benyamini (1997) and Benyamini and Idler (1999) found that, in 40 of 46 longitudinal studies reviewed, 'poor' self-rated health in adults was associated with a higher risk of mortality. Other studies have also found self evaluations of health to be significant predictors of mortality

(Benjamins, Hummer, Eberstein, & Nam, 2004; Mossey & Shapiro, 1982; Perruccio, 2009) and morbidity (Cott et al., 1999; Mantyselka, Turunen, Ahonen, & Kumpusalo, 2003; Perruccio, 2009; Perruccio, Power, & Badley, 2007; Reyes-Gibby, Aday, & Cleeland, 2002).

For evidence of construct validity, significant associations have been found between SRH and other indices of physical health. Poor/fair SRH has been significantly positively associated with the presence of pain (Mantyselka et al., 2003; Reyes-Gibby et al., 2002), fatigue (Kaplan & Baron-Opel, 2003; Singh-Manoux et al., 2006), work limitations (Benyamini, Idler, Leventhal, & Leventhal, 2000; Denton & Walters, 1999; Finnegan, Marion, & Cox, 2005), obesity (Ferraro & Yu, 1995; Finnegan et al., 2005; Goldman, Glei, & Chang, 2004; Haddock et al., 2006; Prosper, Moczulski, & Qureshji, 2009), a larger number of physical symptoms (Perruccio et al., 2007; Singh-Manoux et al., 2006), a larger number of prescription medications (Singh-Manoux et al., 2006), and decreased functional performance (Kaplan & Baron-Epel, 2003; Reyes-Gibby et al., 2002).

Poor/fair self-rated health in individuals 18 years of age and over has also been significantly positively associated with factors related to mental health. These include a greater likelihood of depression and depressive symptoms (Bailis, Segall, Mahon, Chipperfield, & Dunn, 2001; Haddock et al., 2006; Schnittker, 2005), higher levels of distress and anxiety (Cockerham, Kunz, & Lueschen, 1988; Shields & Shooshtari, 2001), reduced social functioning (Perruccio, 2009), and financial worries (Mellner, Krantz, & Lundberg, 2006).

Several studies have found better SRH to be significantly positively associated with the presence of certain lifestyle and social factors. These include being positively associated with health promoting behaviors (Bailis, Segall, & Chipperfield, 2003; Leinonen, Heikken, & Jylha, 2001; Shields & Shooshtari, 2001), engagement in more social activities (Zunzunegui et al., 2004), having a strong sense of community belonging (Shields, 2008), and having higher levels of social support (Benyamini, Leventhal, & Leventhal, 1999; Hyppa & Maki, 2001).

Measurement of health promoting behaviors. Questions about the health promoting behaviors of caregivers were developed based on the literature review and items from the CCHS (Statistics Canada, 2010a). Behaviors assessed included: getting regular checkups, physical activity, eating habits, maintaining a positive attitude, support from family and friends, stress management, sleep, weight loss, smoking, and alcohol consumption. To determine which behaviors were most meaningful to discuss in the qualitative phase, caregivers were asked to rank the top three health promoting behaviors that they thought were most important to work on to improve or maintain their health in the next 12 months. Face and content validity of the questions were assessed in the pilot of the survey.

Health promoting behaviors were also assessed using the Health-Promoting Lifestyle Profile (HPLP) II (Walker, Sechrist, & Pender, 1995). The instrument is included in the survey in Appendix F. Permission to use the instrument (Walker, 2011a) and scoring instructions for the instrument (Walker, 2011b) are included in Appendix H and I respectively. The 52 item self-report instrument assesses the frequency with which respondents currently engage in health promoting behaviors; participants are asked to indicate on a 4-point likert scale [(1 = never (N), 2 = sometimes (S), 3 = often (O), 4 = routinely (R)] the frequency with which they engage in the behavior indicated. The scale consists of six subscales: (a) health responsibility—accountability for one's own health, (b) physical activity—engagement in regular physical activity, (c) nutrition—making appropriate food choices, (d) spiritual growth—development of inner resources, (e) interpersonal relations—using communication to achieve meaningful relationships, and (f) stress management—controlling or reducing stress (Walker & Hill-Polerecky, 1996). A score for overall health promoting lifestyle is obtained by calculating the mean of the responses to the 52 items; means are also used to calculate the six subscale scores (Walker, 2011b). "The use of means rather than sums of scale items is recommended to retain the 1 to 4 metric of item responses and to allow meaningful comparisons of scores across subscales" (Walker, 2011b, para. 2). Higher scores indicate more frequent engagement in health promoting behaviors.

The development and initial psychometric evaluation of the original 48-item HPLP were described by Walker, Sechrist, and Pender (1987). Content and construct validity supported six subscales: Self-actualization, Health Responsibility, Exercise, Interpersonal Support, and Stress Management (Pender, Walker, Sechrist, & Frank-Stromborg, 1990). The original HPLP was revised to generate the HPLP II in 1995 (Walker & Hill-Polerecky, 1996). The names of three dimensions were changed to more accurately reflect their nature and content; Self-actualization became Spiritual Growth, Exercise was renamed Physical Activity, and Interpersonal Support became Interpersonal Relations. The HPLP II was then used with 712 adults aged 18 to 92 years; construct validity was supported by a factor analysis supporting the six dimensions. Convergent validity was supported with correlations with results from the Personal Lifestyle Questionnaire (r = .68). Criterion validity was supported by significant correlations with concurrent measures of perceived health status and quality of life (reliability coefficients ranged from .27 to .49). Internal consistency estimates were .94 for the entire scale and subscales estimates ranged from .79 to .89. Test-retest reliability was assessed over a three week interval; the internal consistency reliability coefficient for the total scale was .89. Reliability coefficients higher than .70 are considered satisfactory; however, coefficients of .80 to .95 are preferable (Nunnally & Bernstein, 1994; Polit & Beck, 2012).

Both the HPLP and the HPLP II have been widely used to assess the health promoting behaviors of adolescents, adults, and the elderly (Walker, 2011c). In the one study with caregivers of children with disabilities, Wyatt (1991) assessed the health promoting behaviors of 40 mothers and 40 fathers of technology assisted homebound children using the original HPLP. She reported an overall reliability coefficient of .94 for the entire scale and reliability coefficients for the subscales ranging from a low of .72 for Stress Management to a high of .92 for Self-actualization. In this study, the Cronbach’s alpha coefficient for the total HPLP II was .92. Cronbach’s alpha coefficients for the subscales were .80 (Health Responsibility), .82 (Physical Activity), .76 (Nutrition), .86 (Spiritual Growth), .81 (Interpersonal Relations), and .73 (Stress Management).

A limitation of the HPLP II was that it did not reflect current Canadian recommendations for adults regarding physical activity and consumption of grain products. Since the comparative data and existing psychometric properties would be lost through item revision, two additional questions were added at the end of the survey to reflect current recommendations for physical activity (Canadian Society for Exercise Physiology, 2013) and diet using the Canada Food Guide (Health Canada, 2007). One additional question was used to assess the incidence of eating fruits and vegetables five or more times a day based on how frequency of consumption is currently reported by Statistics Canada (2010b; 2011b; 2013c).

Ethical Considerations

Ethical approval for Phase 1 was obtained from the Research Ethics Board at the University of Alberta. In addition, administrative support was obtained from the Collaborative Policy and Analysis branch of the Child and Family Services Authority in Alberta.

Informed consent. An information letter (Appendix J) outlining the background, purpose, procedures, potential risks and benefits, methods for maintaining confidentiality, voluntariness of participation, reimbursement of expenses, and compensation for the study was included with all of the survey packages. The information letter was at a Grade 9 or less reading level according to the Flesch-Kincaid readability test. It stated that participants were free to decide whether or not to complete and return the survey and that returning the survey constituted their informed consent to participate in this phase of the study.

Benefits and risks. There were no direct benefits to the caregiver in completing the survey; however, the study may help health professionals understand the health and health promoting behaviors of caregivers of children with disabilities. There were no direct risks in completing the survey; however, it may have alerted the caregiver to health concerns. Therefore, the investigator identified a social worker who was willing to speak with the caregiver and either arrange a meeting or a referral to someone in their nearby community to discuss their concerns.

Confidentiality. Staff from the FSCD program in Red Deer affixed the mailing labels on the survey packages and reminder letters so the investigator did not know the identity of any of the families at the time of mailing. Anonymity was not possible when caregivers chose to provide their name and contact information on the contact information sheet when they returned their survey. Confidentiality was protected by using identifying codes on all pages of the survey. Reports have been and will be worded so that individual participants are not recognizable; they contain no identifying information about the participants, their child, or the city/town/village in which they live. Data were pooled and comparisons were at an aggregate level.

Compensation. For recognition of their time in completing the survey, respondents were offered the opportunity to win one of six cheques for $50. This incentive amount achieved a balance between appropriate recognition and undue pressure to participate. A cheque was mailed to all winners after they answered a simple skill-testing question according to ethics protocol (Research Ethics Office, 2009).

Data Collection Procedures

Pilot. A pilot of the survey was conducted with five caregivers of children with disabilities known to the supervisory committee. Pilot caregivers were contacted to determine if they wished to complete the survey and participate in a telephone interview. An information letter (Appendix K) and the survey were mailed to the five caregivers. Caregivers were asked to document the exact time that it took them to fill out the survey. All five caregivers received $20 for their time.

Five caregivers of children with disabilities living in Edmonton, Alberta and the surrounding area completed the survey. Following completion of the survey, participants were asked to comment on the clarity, purpose, content, ordering, and layout of questions. Piloting the survey helped decrease the risk of measurement error that occurs when questions are poorly worded (Dillman et al., 2009). They found that the survey took approximately 12 to 20 minutes to complete. Two questions about frequency of smoking and alcohol use were changed and the preface to the question regarding average amount of time spent awake caring for the child was revised to include both typical parenting and care related to the disability. Changes to improve the wording of the question regarding the top three choices for improving or maintaining their health in the next 12 months were made to enhance clarity.

Final survey. Sealed survey packages containing the information letter, finalized survey, form for a second child with a disability, and a self-addressed stamped return envelope were provided to the FSCD office in Red Deer. Staff at the FSCD office affixed address labels to the envelopes and mailed the surveys to all families currently receiving services from the FSCD program in Central Alberta. A reminder letter (Appendix L) was mailed to caregivers ten days after the initial survey was sent (Dillman et al., 2009; Harvey, 1987). Potential respondents were asked to return their surveys within three weeks. Participants had the option of providing contact information to enter their name into a draw for a prize, receive a summary of results of the study, and/or to participate in an interview regarding facilitators and barriers to health promoting behaviors that they experience.

Data Analysis

Data from the surveys were analyzed using the SPSS 18.0 program; the quantitative data were coded and checked for accuracy. The descriptive statistics include frequencies and – where applicable – percentages of the sample, as well as ranges, medians, and means with standard deviations (SD). Chi square (χ^2 nominal), Mann Whitney *U* (ordinal), and independent *t* tests (interval, ratio) were used to assess for significant differences between characteristics of urban and rural caregivers and their children. The independent samples median test was used to compare medians and some of the ordinal data were broken down into proportions to further elucidate differences (Bencivenga, 2012; Corty, 2007). Means (with standard deviations) were used to determine the top three ranked health promoting behaviors that urban and rural caregivers intended to do to improve or maintain their health in the next 12 months.

To reduce the risk of committing a Type I error due to the number of comparisons, the significance level was adjusted (Klockars & Sax, 1986; Munro, 2005). Due to the exploratory nature of the study and to decrease the risk of making a Type II error, a significance level of .01 was used in this study. Post hoc power analyses were done using both Cohen (1988) and the G*Power 3 program (Faul, Endfelder, Land, and Buchner, 2007). Using n = 194, two tailed test, $p = .01$, and a medium effect size (estimated), a power of .803 was calculated for the *t* tests and a power of .87 was calculated for the proportions (df = 1).

Phase 2: Qualitative Study

Phase 2 of the study was used to answer the following research question:

3. What are the similarities and differences in the facilitators and barriers to health promoting behaviors experienced by urban and rural primary caregivers of children with disabilities who live in Central Alberta?

Phase 2 of the study consisted of semi-structured qualitative telephone interviews. Descriptions of the purposive sample selection, telephone interviews, ethical considerations, data collection procedures, and data analysis for Phase 2 of the study are summarized.

Purposive Sample Selection

Potential Phase 2 participants were purposively selected from the Phase 1 respondents who indicated on the survey that they were willing to be contacted for a follow up interview. One goal of the purposive sampling was that there be an equal number of urban and rural caregivers. While the final approach to sampling was determined by the investigator and her supervisor, caregivers who picked the three top ranked health promoting behaviors from Phase 1 were selected so that more could be learned about these three behaviors. Existing literature suggests that caregivers do not make their own health a priority; therefore, the health promoting behavior related to getting regular checkups was also discussed. Maximal variation strategies were used so that the viewpoints of individuals with different perspectives were considered (Creswell & Plano Clark, 2011). Due to the exploratory nature of this phase of the study, time constraints, and the fact that the investigator was unable to predict who would agree to participate in the study, it was not anticipated that complete data saturation or thematic redundancy would be achieved for all themes.

Telephone Interviews

Data were collected through semi-structured telephone interviews. Telephone interviews placed the burden of recording answers on the interviewer and not the survey respondent, which was important given the time constraints of this population. A telephone interview was also reasonable given the large geographic size of the Central Alberta CFSA region (Dillman et al., 2009).

Participants were initially asked what factors they considered when they rated their health since there is a paucity of literature on this topic. The interviewer then asked about facilitators and barriers to the top three most important health promoting behaviors as determined by the survey results and a question about their behaviors regarding getting regular checkups. The exact number of behaviors assessed was restricted to what could be discussed within a 60 minute interview and depended on how much detail was provided by the respondent. Semi-structured guiding questions regarding the facilitators and barriers to health promoting behaviors of urban and rural primary caregivers are included in the script for the telephone interview in Appendix M. Initially, open-ended questions about the facilitators and barriers to health promoting behaviors were asked. These were followed by targeted probes that addressed concepts from the Integrated Social Ecology Model (Bronfenbrenner, 1979; Flack, 2009; McLeroy et al., 1988; Sallis et al., 1998) regarding intrapersonal, interpersonal, organizational, community, and policy factors that acted as facilitators and barriers to health promoting behaviors experienced by the caregivers.

Ethical Considerations

Ethical approval for Phase 2 was obtained from the Research Ethics Board at the University of Alberta. Support for this phase of the study was also obtained from the Collaborative Policy and Analysis branch of the Child and Family Services Authority in Alberta.

Informed consent. An information letter (Appendix N) outlining the background, purpose, procedures, potential risks and benefits, methods for maintaining confidentiality, voluntariness of participation, compensation, and contact information for the investigator and her supervisor was mailed out to prospective informants at least one week prior to the interviews. At the start of the telephone interview rapport was established with the caregiver. The caregiver was asked if they had any questions about the study as a result of reading the information letter; all questions were answered in lay terms. The consent form for the telephone interview (Appendix O) was read to the caregiver and was completed by the investigator with the respondent's name and the date of the consent. All caregivers agreed to have the interview recorded and their consent was recorded with the interview.

Caregivers could withdraw from the study at any time prior to or during data collection simply by telling the researcher. If they changed their mind prior to the actual interview, they were told that they could contact the researcher or refuse to participate at the time of the scheduled telephone interview. During the interview, caregivers were informed that they could stop the interview at any time and request that the tape recorder be turned off without consequence. Similarly, they could choose not to answer any specific questions.

Benefits and risks. While there were no direct benefits for the caregiver in participating in the interview, prior studies have found that caregivers appreciated the opportunity to explain their circumstances and were highly motivated to contribute so that other families might benefit in the future (Ray, 2002; Wiart et al., 2010). There were no risks to the caregiver in completing the interview; however, it was possible that the caregiver could experience an emotional response when discussing barriers to their health promoting behaviors. While such discussions are typically experienced as cathartic, arrangements were made for a social worker to be available to take or make referrals.

Confidentiality. Various methods were used to ensure caregiver confidentiality. The interview transcript, audio tape, and field notes were coded and kept separately from the contact information sheet and consent. All files are only accessible by the investigator and her supervisor. All interview transcripts, audio tapes, and field notes will be kept in a separate locked file apart from the consents in a locked room for a minimum of five years, at which time they will be destroyed. Only the investigator, her supervisor, and the transcribers read the typed interviews. The transcribers signed a confidentiality agreement before transcribing the interviews (Appendix P). Only code numbers were used for the recordings that were given to the transcribers. All computers used in analyzing the data were password protected and any files stored were encrypted. Publications and presentations resulting from the study will not contain any identifying information. All informants and family members were assigned pseudonyms and names of place of residence were changed. When examples or quotes from the interviews are used in future published documents and presentations, care will be taken to remove or change any other identifying information.

Compensation. For recognition of the time that they took to complete the telephone interview, those informants who were selected and who gave oral consent for the telephone interview were mailed a cheque for $20.

Data Collection Procedures

Analysis of data from Phase 1 of the study occurred before the interviews commenced; this analysis took approximately two months. As a retention strategy, telephone contact was established with all caregivers who were interested in participating in a telephone interview immediately after their survey was received. It was explained that they might be contacted in the near future to participate in a telephone interview.

The investigator and her supervisor reviewed the analysis of the survey responses to determine potential informants for the interviews. Potential informants were contacted by telephone to determine if they were still interested in participating in the interview. If so, they were sent an information letter about the telephone interview. One week after the letter was mailed, all caregivers were called again by the investigator to determine if they had reviewed the letter and if they were still willing to do the interview. A suitable time for the interview was then established.

All participants agreed to record the interviews; notes were also taken in case the audio recording failed. The interview began with a tone designed to establish rapport (Seidman, 2006), confirmation that this was still a convenient time for the interview, and a brief explanation of the process. The findings of the Phase 1 survey were briefly described so that the caregiver understood the purpose of exploring the top three health promoting behaviors and the reason for asking about getting regular checkups. The investigator then proceeded with the interview; the caregiver was asked to elaborate on what helped and what hindered their ability to engage in the three highest ranked health promoting behaviors and to getting regular checkups.

A timer was used to alert the investigator that 60 minutes had elapsed; at that point informants were given the choice of concluding the interview or continuing until all four topics were discussed. At the end of the interview a brief summary of the caregiver's responses was done to allow for confirmation of their responses and/or additional information to be given (Kvale & Brinkmann, 2009). Permission was also sought to call the caregiver for further clarification of their responses in case questions arose during the interpretation of the results. After the interview was completed, personal impressions and reflections of the interview were documented in field notes (Byrne, 2001).

Data Analysis

Interviews were transcribed into Microsoft Word 10 files; the transcription was reviewed along with the tape by the investigator to ensure that no errors in transcribing had occurred (Poland, 2003). Data analysis of the transcripts of the interviews was done using the NVivo 10 program. The method used was content analysis; the purpose of content analysis is to classify large amounts of text into an efficient number of categories or subcategories through the process of coding and identifying themes or patterns (Hsieh & Shannon, 2005; Morse, 1991; Vaismoradi, Turunen, & Bondas, 2013; Weber, 1990). Data collection and analysis occurred simultaneously so the iterative process of data analysis started at the initiation of data collection (Field & Morse, 1985); as a result, follow-up questions and probes evolved as the interviews progressed. Transcription, analysis, and coding of the first interview were done by the investigator in consultation with her supervisor.

Content analysis was done both deductively and inductively. Deductive analysis was done first; this approach was appropriate because interview questions and the analysis of the data were guided by the ISEM (Hsieh & Shannon, 2005). The initial themes were the four health promoting behaviors; within these themes were the subthemes of facilitators and barriers to health promoting behaviors. These subthemes were then broken down into the categories of intrapersonal, interpersonal, organizational, community, and policy factors.

The investigator read and reread the transcripts to achieve immersion in the data (Burnard, 1991). Coding began by identifying and highlighting all instances of facilitators and barriers to health promoting behaviors experienced; notes about first impressions were made in the margins (Miles & Huberman, 1994). After that, each of the highlighted passages was coded according to whether it was an intrapersonal, interpersonal, organizational, community, or policy facilitator or barrier. Any text that did not fit into one of these categories was noted; this allowed for the emergence of concepts that were not anticipated prior to the analysis (Hsieh & Shannon, 2005). In this study, use of technology was a concept that had not been identified in previous ecological models of factors that influence health promoting behaviors.

Inductive analysis took place within the categories. Open coding of the manifest content under each of the categories was done using a line-by-line analysis process. Key content was highlighted and coded; text was broken into manageable segments and one or more words were attached to the text segment that condensed the meaning of the text (Kvale & Brinkmann, 2009; Seidman, 2006). Once codes were identified a list was created and similar codes were clustered into mutually exclusive subcategories (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). Throughout this process, definitions of each of the codes and subcategories were also documented (Miles & Huberman, 1994; Ryan & Bernard, 2000). Discussion with the investigator's supervisor was also done to illuminate the findings and to achieve consensus on the coding and identification of the subcategories. As the data were coded and subcategories emerged, they were compared within and across interviews. Memo-writing, diagrams, and discussion were used by the investigator to support the comparative analysis (Miles & Huberman, 1994).

As the study progressed and subcategories began to emerge from the data, later interviews were used to seek expansion and clarification of the various subcategories. In this way, data from previous interviews directed selection of informants who could provide clarification and validation of the emerging subcategories (Field & Morse, 1985). Once codes and subcategories were generated, the facilitators and barriers to health promoting behaviors of urban and rural caregivers were compared to determine similarities and differences.

Rigor

Rigor was established through a number of strategies; Caelli, Ray, and Mill (2003) note that it is important to select an approach to rigor that is congruent with the method being used. Credibility was accomplished through peer debriefing with the investigator’s supervisor about the codes during the analysis of the interviews; any disagreement was resolved through discussion until consensus was reached. At the end of each interview, the investigator briefly summarized with the caregiver the results of the interview and asked if the summary was correct. Credibility was also supported with prolonged engagement with the subject matter; data collection and analysis occurred over a period of nine months (Lincoln & Guba, 1985; Streubert & Carpenter, 2011). Dependability was enhanced through investigator triangulation; the investigator's supervisor and committee reviewed and discussed the investigator's analysis and interpretation. Confirmability was achieved through development of a decision trail during the data analysis phase of the interviews that would allow other researchers to follow the decisions made by the investigator of the study (Sandelowski, 1986). Finally, transferability was enhanced through thick descriptions of the setting and the caregivers included in the study (Lincoln & Guba, 1990).

Bias was also considered during the interviews and in the analysis of the data. Given the literature review of the issues faced by rural Canadians, it was important to stay open to both the positive aspects of rural living and of caring for a child with a disability within a rural context. Furthermore, it was important to consider that rural living may offer equal or more positive living options. The summary of the results of each interview were reviewed with caregivers and they were asked if the summary was correct. This was also addressed by having the supervisory committee review both the summary of the results from the interviews and the discussion.

Legitimation Issues

Validity issues regarding the quality of inferences that arise from combining quantitative and qualitative research (Teddlie & Tashakkori, 2009) have been termed legitimation issues by Onwuegbuzie and Johnson (2006). Sample integration legitimation was addressed by not making statistical generalizations based on findings from the smaller purposeful qualitative sample to the larger sample derived from the survey. Inside-outside legitimation was addressed by having the investigator's supervisory committee review data integration and conclusions derived from mixing the data. Multiple validities legitimation was addressed by choosing survey questions with demonstrated face, content, and construct validity; validity was addressed in the qualitative phase through the processes outlined under the section on rigor (Kvale & Brinkmann, 2009; Miles & Huberman, 1994; O'Cathain, 2010). Paradigmatic mixing legitimation was addressed by using different viewpoints during the two phases of the study: postpositivism during the quantitative phase of the study and constructivism during the qualitative phase of the study (Creswell & Plano Clark, 2011). When the findings from each phase were integrated, commensurability legitimation was addressed in that the concept of incommensurability of worldviews was rejected (Howe, 1988). Instead, a third and more pragmatic viewpoint was used that places primary importance on the use of multiple methods of data collection to answer research questions in a study and that believes that knowledge can be both constructed and result from empirical discovery (Johnson & Onwuegbuzie, 2004; Morgan, 2007).

Chapter 4: RESULTS

This chapter contains a summary of the findings from the surveys (Phase 1) and telephone interviews (Phase 2) with urban and rural caregivers of children with disabilities in Central Alberta. The results of the following research questions are addressed:

1. What are the similarities and differences in the health status of urban and rural primary caregivers of children with disabilities who live in Central Alberta?
2. What are the similarities and differences in the health promoting behaviors of urban and rural primary caregivers of children with disabilities who live in Central Alberta?
3. What are the similarities and differences in the facilitators and barriers to health promoting behaviors experienced by urban and rural primary caregivers of children with disabilities who live in Central Alberta?

Phase 1: Quantitative Study

The results of the quantitative phase of the study included comparisons between urban and rural respondents of caregiver characteristics, caregiver health status, and caregiver health promoting behaviors. Caregivers' top three ranked health promoting behaviors were also compared.

Caregiver Characteristics

A total of 194 out of 530 caregivers in Central Alberta responded to the survey and met the inclusion criteria for a response rate of 36.6%. Eighty-nine (46%) urban and 105 (54%) rural caregivers comprised the sample. Comparisons were made to ensure sample equivalence; all comparisons satisfied Levene's Test for Equality of Variances with the exception of the following: number of kilometers one way to caregiver's and child's doctor, and number of child diagnoses. In each case, appropriate *t* and *p* values are reported, as are degrees of freedom.

Urban and rural living. Of the 105 caregivers who lived in rural communities, 37 (35%) lived on a farm or ranch. The remainder lived in or adjacent to small towns, villages, and municipalities. For this study, rural was defined as populations living in towns, villages, and municipalities outside the commuting zone of larger urban centers with a population of 10,000 or more (du Plessis et al., 2002). Other characteristics of urban and rural living are described in Table

2. As expected, there were significant differences between urban and rural caregivers in distance to the caregiver’s doctor and their child with a disability’s doctor or specialists.

Table 2

Urban and Rural Living

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Internet access (Q5)				$\chi^2 = .071$
Yes	189 (97.5%)	87 (98%)	102 (97%)	df = 1
No	5 (2.5%)	2 (2%)	3 (3%)	*p* = .789
Type of internet access (Q6)				
Broadband	154 (79.5%)	79 (89%)	75 (71.5%)	
Dial-up	5 (2.5%)	1 (1%)	4 (3.5%)	
Other	23 (12%)	3 (3.5%)	20 (19%)	
None	5 (2.5)	2 (2%)	3 (3%)	
Missing	7 (3.5%)	4 (4.5%)	3 (3%)	
Mean (SD) number of kilometers one way to caregiver's doctor (Q7)	21.6 (34.3)	9.9 (20.5)	31.9 (40.4)	*t* = -4.797 df = 150.65
Range	1 - 300	1 - 180	1 - 200	$p \leq .001$*
Mean (SD) number of kilometers one way to child with a disability's doctor or specialist (Q8)	114.7 (69.9)	101 (73)	126.8 (65.1)	*t* = -2.563 df = 177.93
Range	3 - 300	3 - 250	12 - 300	*p* = .01*

*$p \leq .01$

Child with a disability. The age, gender, and severity of disability of the children are summarized in Table 3. There were no significant differences between the urban and rural samples. The children’s reported diagnoses are presented in Table 4; the median number of diagnoses reported for each child was two.

Table 3

Characteristics of the Child with a Disability

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test For Difference
Mean (SD) Child age (Q1)	10.2 (4.2)	9.8 (4.4)	10.5 (4.1)	*t* = -1.158
	4 months - 17	4 months - 17	10 months - 17	df = 191
				p = .248
Child gender (Q2)				$\chi^2 = 2.255$
Boy	138 (71%)	68 (76.5%)	70 (67%)	df = 1
Girl	56 (29%)	21 (23.5%)	35 (33%)	*p* = .136
Severity of the disability (Q4)				
Mild to moderate	93 (48%)	40 (45%)	53 (50.5%)	$\chi^2 = .684$
Severe to very severe	98 (50.5%)	48 (54%)	50 (47.5%)	df = 1
Missing	3 (1.5%)	1 (1%)	2 (2%)	*p* = .408

Table 4

Child`s Reported Diagnoses

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105
Diagnosis (Q3)			
ADHD or ADD	38 (19.5%)	19 (21.5%)	19 (18%)
Autism Spectrum Disorder	71 (36.5%)	38 (42.5%)	33 (31.5%)
Behavior problems	25 (13%)	12 (13.5%)	13 (12.5%)
Bladder/Bowel Problems	3 (1.5%)	2 (2%)	1 (1%)
Cardiac/Lung Disorder	17 (9%)	10 (11%)	7 (6.5%)
Cerebral Palsy	20 (10%)	7 (8%)	13 (12.5%)
Developmental disability	47 (24%)	23 (26%)	24 (23%)
Down Syndrome	13 (6.5%)	4 (4.5%)	9 (8.5%)
Emotional difficulties	4 (2%)	1 (1%)	3 (3%)
Epilepsy	16 (8%)	7 (8%)	9 (8.5%)
Fetal Alcohol Spectrum Disorder	15 (8%)	8 (9%)	7 (6.5%)
Other Genetic Disorder	26 (13.5%)	13 (14.5%)	13 (12.5%)
Other Motor Impairment	17 (9%)	9 (10%)	8 (7.5%)
Hearing impairment	8 (4%)	3 (3%)	5 (5%)
Leukemia	3 (1.5%)	2 (2%)	1 (1%)
Muscular Dystrophy	3 (1.5%)	1 (1%)	2 (2%)
Psychological difficulties	21 (11%)	9 (10%)	11 (10.5%)
Sensory Impairment	7 (3.5%)	3 (3%)	4 (4%)
Speech disorder	10 (5%)	5 (5.5%)	5 (5%)
Spina Bifida	4 (2%)	2 (2%)	2 (2%)
Tourette Syndrome	3 (1.5%)	2 (2%)	1 (1%)
Visual impairment	10 (5%)	4 (4.5%)	6 (6%)
Other	5 (2.5%)	3 (3%)	2(2%)
Median Number of Diagnoses per child (Q3)	2	2	2
Range	1 - 6	1 - 6	1 - 6

Demographics. Demographic characteristics of the caregivers are presented in Table 5. The majority of the caregivers were female; 86% were mothers. All eight male respondents were fathers. Caregivers ranged in age from 20 to 67 years, with a mean age of 41.3 years. The majority (79%, n = 153) of caregivers cared for one child with a disability; 18% (n = 35) cared for two, and 3% (n = 6) cared for three children with disabilities. Seventy-nine percent of caregivers were living with a spouse or partner. The majority of caregivers were well educated, with 75% indicating that they had completed some post-secondary education. There were no significant differences in the demographics of the urban and rural samples.

Employment. Employment status and whether or not family members had given up employment because of their child's care needs are reported in Table 6. Most caregivers were employed; however, 53% of the study participants and/or their partners had given up employment at some point in time because of their child's care needs. More females than males had given up employment. Significantly more urban than rural caregivers and/or their partners had given up paid employment to care for their child's care needs.

Table 5

Caregiver Characteristics

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Relationship to Child with a Disability (Q1)				
Mother	167 (86%)	79 (89%)	88 (84%)	
Stepmother	1 (.5%)	0 (0%)	1 (.5%)	
Foster mother	1 (.5%)	0 (0%)	1 (.5%)	
Adopted mother	9 (5%)	4 (5%)	5 (5%)	
Grandmother	8 (4%)	3 (3%)	5 (5%)	
Father	8 (4%)	3 (3%)	5 (5%)	
Gender (Q2)				$\chi^2 = .236$
Male	8 (4%)	3 (3%)	5 (5%)	df = 1
Female	186 (96%)	86 (97%)	100 (95%)	$p = .627$
Ethnicity (Q3)				
White	182 (94%)	82 (92%)	100 (95%)	
Chinese	3 (1.5%)	3 (4%)	0 (0%)	
Metis	3 (1.5%)	1 (1%)	2 (2%)	
North American Indian	3 (1.5%)	1 (1%)	2 (2%)	
West Asian	1 (.5%)	1 (1%)	0 (0%)	
Missing	2 (1%)	1 (1%)	1 (1%)	
Mean (SD) Age (Q4)	41.3 (8.5)	40.3 (8.4)	42.2 (8.5)	$t = -1.575$
Range	20 - 67	20 - 67	26 - 67	df = 192
				$p = .117$
Median number of children living with caregiver (Q5)	2	2	2	
Median number of children with a disability living with caregiver (Q6)	1	1	1	
Partner status (Q7)				$\chi^2 = 2.187$
Married/Common Law/Partner	153 (79%)	66 (74%)	87 (83%)	df = 1
Divorced/Separated/Single/Widowed	41 (21%)	23 (26%)	18 (17%)	$p = .139$
Education (Q8)				$\chi^2 = 1.363$
High school or less	50 (25%)	26 (29%)	24 (23%)	df = 1
More than high school	144 (75%)	63 (71%)	81 (77%)	$p = .243$

Income and health insurance. Family income and presence of additional health insurance are presented in Table 7. Family income was high for most participants. The median family income for urban caregivers was \$70,000 - \$79,000 and for rural caregivers was \$80,000 - \$89,000; there was no significant difference between the medians (*p* = .283, df = 1). Using the Low Income Cut-off from 2011-2012 for a family of four (sample median two children), the majority of the 183 participants who reported family income were above the \$30,945 cut-off (Statistics Canada, 2013d). The majority of caregivers had additional health insurance with no significant difference between the urban and rural samples.

Table 6

Caregiver Employment Status

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Employment status (Q9)				
Employed full time	56 (29%)	22 (25%)	34 (32%)	
Employed part time	42 (21.5%)	20 (22.5%)	22 (21%)	
Self-employed	31 (16%)	12 (13.5%)	19 (18%)	
Unemployed and looking for work	8 (4%)	5 (5.5%)	3 (3%)	
Full time caregiver	49 (25%)	26 (29%)	23 (22%)	
Full time student	1 (.5%)	0 (0%)	1 (1%)	
Retired	1 (.5%)	0 (0%)	1 (1%)	
Other	6 (3%)	4 (4.5%)	2 (2%)	
Employment status (Q9)				$\chi^2 = 1.517$
Employed	135 (69.5%)	58 (65%)	77 (73%)	df = 1
Unemployed/Not employed	59 (30.5%)	31 (35%)	28 (27%)	*p* = .218
Given up employment to care for child (Q10)				
No	91 (47%)	32 (36%)	59 (56%)	
Mother/female partner	94 (48%)	52 (58.5%)	42 (40%)	
Father/male partner	4 (2%)	2 (2%)	2 (2%)	
Both parents/partners	5 (3%)	3 (3.5%)	2 (2%)	
Given up employment to care for child (Q10)				$\chi^2 = 7.920$
Yes	103 (53%)	57 (64%)	46 (44%)	df = 1
No	91 (47%)	32 (36%)	59 (56%)	*p* = .005*

$^*p \leq .01$

Table 7

Caregiver Income and Health Insurance

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Yearly family income (Q11)				
Low Income Cut-off or less	40 (20.5%)	19 (21%)	21 (20%)	$\chi^2 = .005$
Greater than Low Income Cut-off	143 (74%)	67 (75.5%)	76 (72.5%)	df = 1
Missing	11 (5.5%)	3 (3.5%)	8 (7.5%)	*p* = .942
Additional health insurance (Q13)				$\chi^2 = .630$
Yes	152 (78.5%)	72 (81%)	80 (76%)	df = 1
No	42 (21.5%)	17 (19%)	25 (24%)	*p* = .428

Caregiver Health (Research Question 1)

Caregiving, sleep, stress, and support. No significant differences were found on these variables between urban and rural samples (Table 8). In a 24-hour period, caregivers spent an average of 10.8 hours caring for their child with a disability on weekdays and 13.9 hours on weekends. About half (52.5%) of caregivers indicated that their daily stress was ‘quite a bit’ to ‘extremely’ stressful. On average, urban and rural caregivers had two supports to help them with their child with a disability. ‘Other’ supports included a nanny/babysitter, counsellor, and service dog.

Table 8

Caregiver Caregiving, Sleep, Stress, and Support

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Mean (SD) awake hours per 24 hours caring for child (Q2)				
Weekdays	10.8 (4.8)	11.2 (5)	10.4 (4.6)	$t = 1.217$
Range	1 – 20	1 – 20	1 – 19.5	df = 179
				$p = .225$
Weekends	13.9 (3.5)	13.8 (3.5)	13.9 (3.5)	$t = -.160$
Range	1 - 20	3 - 20	1 – 19.5	df = 175
				$p = .873$
Mean (SD) nights of adequate sleep per week (Q3)	3.6 (2.4)	3.5 (2.4)	3.7 (2.4)	$t = -.810$ df = 188
Range	0 - 7	0 - 7	0 - 7	$p = .419$
Mean (SD) hours of sleep each night (Q4)	6.5 (1.1)	6.5 (1)	6.6 (1.1)	$t = -.088$ df = 191
Range	3 – 8.5	3 – 8.5	4 – 8.5	$p = .930$
Stress on most days (Q5)				
Not at all, not very, or a bit stressful	92 (47.5%)	39 (44%)	53 (50.5%)	$\chi^2 = .856$ df = 1
Quite a bit or extremely stressful	102 (52.5%)	50 (56%)	52 (49.5%)	$p = .355$
Ability to manage stress (Q6)				$\chi^2 = 1.896$
Managing stress	117 (60%)	49 (55%)	68 (65%)	df = 1
Difficulty managing stress	77 (40%)	40 (45%)	37 (35%)	$p = .169$
Help with child when needed (Q7)				
Spouse/Partner	137 (71%)	61 (68.5%)	76 (72.5%)	
Other family members	121 (62.5%)	52 (58.5%)	69 (68%)	
Friends	84 (43%)	44 (49.5%)	40 (38%)	
Neighbors	24 (12.5%)	12 (13.5%)	12 (11.5%)	
Community resources	90 (46.5%)	50 (56%)	40 (38%)	
Other	5 (3%)	4 (4.5%)	1 (1%)	
No one available to help	9 (4.5%)	5 (5.5%)	4 (4%)	
Mean (SD) total Number of Supports (Q7)	2.4 (1.1)	2.5 (1.2)	2.3 (1.1)	$t = 1.519$ df = 192
Range	0 - 5	0 - 5	0 - 5	$p = .130$

BMI, smoking, and alcohol use. Caregiver BMI, smoking, and alcohol use are summarized in Table 9. The mean BMI for the sample was 27.8, which is considered to be overweight (WHO, 2013). Significantly more rural than urban caregivers were overweight or obese. The majority of caregivers did not smoke and most caregivers did not drink more than five drinks of alcohol on one occasion.

Table 9

Caregiver BMI, Smoking, and Alcohol Use

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
BMI Classification (Q8)				
Normal or underweight	68 (35%)	41 (46%)	27 (26%)	$\chi^2 = 8.24$
Overweight or obese	117 (60.5%)	45 (50.5%)	72 (68.5%)	df = 1
Missing	9 (4.5%)	3 (3.5%)	6 (5.5%)	$p = .004$*
Cigarette smoking (Q9)				$\chi^2 = .134$
Yes	34 (17.5%)	17 (19%)	17 (16%)	df = 1
No	160 (82.5%)	72 (81%)	88 (84%)	$p = .714$
Alcohol consumption (Q10)				
Not at all	62 (32%)	23 (26%)	39 (37%)	$U = 4011.5$
Occasionally	126 (65%)	61 (68.5%)	65 (62%)	$z = -1.754$
Daily	6 (3%)	5 (5.5%)	1 (1%)	$p = .079$
5 or more drinks of alcohol on one occasion (Q 11)				$\chi^2 = .728$
Yes	78 (40%)	39 (44%)	39 (37%)	df = 1
No	116 (60%)	50 (56%)	66 (63%)	$p = .393$

*$p \leq .01$

Self-reported health. Caregiver self-reported health is presented in Table 10. The majority (75%) of caregivers reported their health as good to excellent. There was no significant difference between urban and rural caregivers in self-reported health.

Table 10

Caregiver Self-reported Health

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Self-reported health (Q1)				
Excellent	18 (9.5%)	8 (9%)	10 (9.5%)	$U = 4385$
Very good	51 (26%)	26 (29%)	25 (24%)	$z = -.771$
Good	76 (39.5%)	35 (39.5%)	41 (38.5%)	$p = .440$
Fair	40 (20.5%)	16 (18%)	24 (23%)	
Poor	9 (4.5%)	4 (4.5%)	5 (5%)	

Medical problems. The frequency and percentages of medical problems experienced by caregivers for at least six months are reported in Table 11. Twenty-two caregivers (11%) reported no medical problems, while 25 (13%) reported one, 23 (12%) reported two, 23 (12%) reported three, 28 (14.5%) reported four, and the remaining 73 (37.5%) identified five or more medical problems; the mean was four medical problems. The most common problem identified was being overly tired, followed by trouble sleeping, back pain, depression, headaches, and anxiety. Medical problems reported under ‘Other’ categories are summarized in Appendix Q, Table 12.

Table 11

Caregiver Medical Problems Expected to Last Six Months or More

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Medical Problems (Q12)				
Allergies	45 (23%)	21 (23.5%)	24 (23%)	
Anxiety	57 (29.5%)	31 (35%)	26 (25%)	
Arthritis or rheumatism	21 (11%)	8 (9%)	13 (12.5%)	
Asthma	6 (3%)	3 (3.5%)	3 (3%)	
Back pain	80 (41%)	34 (38%)	46 (44%)	
Bronchitis	10 (5%)	3 (3.5%)	7 (6.5%)	
Cancer	5 (2.5%)	2 (2%)	3 (3%)	
Crohn's disease	1 (.5%)	1 (1%)	0 (0%)	
Depression	65 (33.5%)	32 (36%)	33 (31.5%)	
Diabetes	6 (3%)	2 (2%)	4 (4%)	
Epilepsy	6 (3%)	2 (2%)	4 (4%)	
Frequent colds/flu	13 (7%)	5 (5.5%)	8 (7.5%)	
Headaches (not migraines)	64 (33%)	34 (38%)	30 (28.5%)	
Heart disease	2 (1%)	1 (1%)	1 (1%)	
High blood pressure	16 (8%)	5 (5.5%)	11 (10.5%)	
High cholesterol	10 (5%)	3 (3.5%)	7 (6.5%)	
Migraine headaches	40 (20.5%)	17 (19%)	23 (22%)	
Osteoporosis	3 (1.5%)	1 (1%)	2 (2%)	
Other mental health issues	2 (1%)	1 (1%)	1 (1%)	
Overly tired/lack of energy	93 (48%)	45 (50.5%)	48 (45.5%)	
Pain (not back pain)	43 (22%)	23 (26%)	20 (19%)	
Sinusitis	19 (10%)	6 (6.5%)	13 (12.5%)	
Stomach problems (not IBD/ulcers)	27 (14%)	12 (13.5%)	15 (14.3%)	
Thyroid condition	25 (13%)	9 (10%)	16 (15%)	
Trouble sleeping	82 (42%)	42 (47%)	40 (38%)	
Ulcerative colitis	2 (1%)	0 (0%)	2 (2%)	
Ulcers	6 (3%)	3 (3.5%)	3 (3%)	
Other	28 (14.5%)	17 (19%)	11 (10.5%)	
No medical problems	22 (11%)	9 (10%)	14 (13%)	
Mean (SD) Number of medical problems (Q12)	4 (3)	4.2 (3)	3.9 (3)	t = .514 df = 192
Range	0 - 15	0 - 15	0 - 15	p = .608

Caregiver Health Promoting Behaviors (Research Question 2)

Several questions on the survey were used to compare the health promoting behaviors of urban and rural caregivers. All but seven caregivers felt that there was something that they could to do improve/maintain their health. On average, caregivers intended to do four things to improve their health in the next 12 months. Approximately 34.5% of caregivers were doing more to improve/maintain their health since their child had been diagnosed with a disability while 42.5% were doing less (Table 13).

Table 13

Caregiver Health Improvement/Maintenance

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Anything can do to improve/maintain health (Q1)				$\chi^2 = 5.19$
Yes	187 (96.5%)	88 (99%)	99 (94.5%)	df = 1
No	7 (3.5%)	1 (1%)	6 (5.5%)	$p = .023$
Health promoting behaviors changed since child diagnosed with disability (Q4)				
Now do a lot more	23 (12%)	15 (17%)	8 (7.5%)	
Now do a bit more	43 (22.5%)	21 (23.5%)	22 (21%)	$U = 4162.5$
Did not change	45 (23%)	17 (19%)	28 (26.5%)	$z = -1.339$
Now do a bit less	45 (23%)	19 (21.5%)	26 (25%)	$p = .180$
Now do a lot less	38 (19.5%)	17 (19%)	21 (20%)	

Health Promoting Lifestyle Profile. Independent *t* tests were used to test for differences between urban and rural caregivers in the HPLP II. There was no significant difference found in the total scale scores. For exploratory reasons, the means of the subscales were also compared. All comparisons satisfied Levene's Test for Equality of Variances except for the Physical Activity subscale; appropriate *t* and *p* values, as well degrees of freedom, are reported. Urban caregivers' scores were significantly higher than rural caregivers only in the Health Responsibility subscale. Means (standard deviations) and confidence intervals set at 99% are reported in Table 14.

Table 14

Health Promoting Lifestyle Profile II Scores [a]

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Health-Promoting Lifestyle Scale (Total scale)	2.39 (.4) [2.3, 2.5]	2.45 (.4) [2.3, 2.6]	2.35 (.4) [2.3, 2.4]	$t = 1.796$ df = 192 $p = .074$
Health responsibility subscale	2.24 (.6) [2.1, 2.3]	2.36 (.5) [2.2, 2.5]	2.13 (.5) [2, 2.3]	$t = 2.874$ df = 192 $p = .005$*
Physical activity subscale	1.97 (.6) [1.9, 2.1]	2.05 (.7) [1.9, 2.2]	1.9 (.5) [1.8, 2]	$t = 1.678$ df = 163.6 $p = .095$
Nutrition subscale	2.6 (.5) [2.5, 2.7]	2.64 (.6) [2.5, 2.8]	2.57 (.5) [2.4, 2.7]	$t = 1.000$ df = 192 $p = .319$
Spiritual growth subscale	2.68 (.6) [2.6, 2.8]	2.69 (.6) [2.5, 2.9]	2.65 (.6) [2.5, 2.8]	$t = .495$ df = 192 $p = .621$
Interpersonal relations subscale	2.68 (.5) [2.6, 2.8]	2.71 (.5) [2.6, 2.9]	2.65 (.5) [2.5, 2.8]	$t = .883$ df = 192 $p = .378$
Stress management subscale	2.14 (.5) [2, 2.2]	2.16 (.5) [2, 2.3]	2.12 (.5) [2, 2.2]	$t = .557$ df = 192 $p = .578$

*$p \leq .01$

[a] Scores range from 1 to 4 as means are divided by the number of items.

Canadian recommendations. A limitation of the HPLP II is that it does not reflect current Canadian recommendations for adults regarding physical activity, as well as consumption of grain products and fruits and vegetables. These results are presented in Table 15. Results indicate that, overall, the majority of urban and rural caregivers 'never' or 'only sometimes' engaged in 150 minutes of vigorous activity each week (84%), ate 6-8 servings of grain products daily (78%), or ate 5 or more servings of fruits and vegetables daily (56.5%). There were no significant differences between the urban and rural samples.

Table 15

Current Canadian Recommendations for Adults

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Engage in at least 150 minutes of moderate to vigorous intensity aerobic activity a week, in bouts of 10 minutes or more (Q1)				
Never	110 (57%)	45 (50.5%)	65 (62%)	$U = 3935$
Sometimes	53 (27%)	23 (26%)	30 (28%)	$z = -2.12$
Often	14 (7%)	9 (10%)	5 (5%)	$p = .030$
Routinely	17 (9%)	12 (13.5%)	5 (5%)	
Eat 6-8 servings of grain products daily (Q2)				
Never	56 (29%)	29 (32.5%)	27 (25.5%)	$U = 4283$
Sometimes	95 (49%)	42 (47%)	53 (50.5%)	$z = -1.08$
Often	24 (12%)	11 (12.5%)	13 (12.5%)	$p = .28$
Routinely	19 (10%)	7 (8%)	12 (11.5%)	
Eat 5 or more servings of fruits and vegetables daily (Q3)				
Never	34 (17.5%)	14 (16%)	20 (19%)	$U = 4566.5$
Sometimes	75 (39%)	34 (38%)	41 (39%)	$z = -.284$
Often	47 (24%)	26 (29%)	21 (20%)	$p = .776$
Routinely	38 (19.5%)	15 (17%)	23 (22%)	

Top Three Ranked Health Promoting Behaviors

Caregivers were asked to identify health promoting behaviors that they intended to do in the next 12 months to improve or maintain their health (Table 16); they were then asked to rank their top three health promoting behaviors. Responses were coded as 0 = not ranked, 1 = checked but not ranked, 2 = ranked #3, 3 = ranked #2, and 4 = ranked #1. Means (standard deviations) were used to determine the top three ranked health promoting behaviors. Overall, participants ranked increasing physical activity, improving eating habits, and losing weight as their top three most important health promoting behaviors. However, findings differed between the two groups. Urban

Table 16

Health Promoting Behaviors that Caregivers Intend to do in the Next 12 Months

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105
Intend to do to improve/maintain health (Q2)			
Increase physical activity	153 (79%)	71 (80%)	82 (78%)
Improve eating habits	123 (63.5%)	64 (72%)	59 (56%)
Lose weight	113 (58%)	41 (46%)	72 (68.5%)
Get more sleep	96 (49.5%)	54 (61%)	42 (40%)
Engage in activities that enhance personal growth	85 (44%)	43 (48%)	42 (40%)
Reduce stress levels	84 (43%)	43 (48%)	41 (39%)
Strive for a positive attitude	84 (43%)	42 (47%)	42 (40%)
Get regular checkups	77 (40%)	39 (44%)	38 (36%)
Increase support from family, friends, neighbors	31 (16%)	20 (22.5%)	11 (10.5%)
Quit smoking/reduce amount smoked	20 (10%)	12 (13.5%)	8 (7.5%)
Other	9 (4.5%)	5 (5.5%)	4 (4%)
Drink less alcohol	4 (2%)	3 (3.5%)	1 (1%)

caregivers prioritized increasing physical activity, improving eating habits, and getting more sleep. Similar to overall results, rural caregivers prioritized increasing physical activity, losing weight, and improving eating habits. Independent *t* tests indicated that there were no significant differences in the ranking of activities by urban and rural caregivers (Table 17). Comparisons satisfied Levene's Test for Equality of Variances with the exception of improving eating habits; appropriate *t* and *p* values are reported, as are degrees of freedom. The results of this analysis identified behaviors to assess in the qualitative interviews, along with getting regular checkups.

Table 17

Ranking of Most Important Health Promoting Behaviors

Variable	Total Sample n = 194	Urban n = 89	Rural n = 105	Test for Difference
Increase physical activity	1.91 (1.7)	1.74 (1.7)	2.05 (1.6)	*t* = -1.276 df = 192 *p* = .203
Improve eating habits	1.24 (1.5)	1.12 (1.4)	1.33 (1.6)	*t* = -.983 df = 191.6 *p* = .322
Lose weight	1.12 (1.5)	.88 (1.4)	1.32 (1.5)	*t* = -2.098 df = 192 *p* = .037
Get more sleep	1.08 (1.5)	1.17 (1.6)	1.01 (1.5)	*t* = .718 df = 192 *p* = .474
Reduce stress levels	.72 (1.4)	.66 (1.4)	.76 (1.4)	*t* = -.504 df = 192 *p* = .149
Get regular checkups	.41 (1)	.44 (1.1)	.38 (1)	*t* = .378 df = 192 *p* = .706

Summary

Overall, the urban and rural samples were very similar in their demographic characteristics. As expected, rural caregivers drove significantly further to see their doctor and their child with a disability's doctor/specialists than did urban caregivers. Significantly more urban caregivers and/or their partners had given up paid employment at some point in time because of their child's care needs; more females than males had given up employment. Most participants were living with a spouse or partner, were well educated, had incomes well above the LICO, and had additional health insurance.

Over half of participants rated their daily stress as 'quite a bit' to 'extremely' stressful; however, most caregivers reported that they were able to manage their stress on 'some' or 'most' days. Participants had a broad range of medical issues; on average, caregivers reported four medical problems. More than half of caregivers were overweight or obese; significantly more rural than urban caregiver were either overweight or obese. The majority of caregivers did not smoke or drink five or more drinks of alcohol on one occasion. The majority of caregivers reported their health as good to excellent; there was no significant difference in their self-reported health.

Almost all caregivers reported that they could do something to improve/maintain their health. The majority of responders 'never' or 'sometimes' engaged in 150 minutes of vigorous activity each week, ate 6 – 8 servings of grain products daily, and ate 5 or more servings of fruits and vegetables daily. Urban and rural caregivers did not differ on the HPLP II total score. An exploratory analysis of the subscales indicated that rural caregivers' scores were significantly lower than urban caregivers only in the Health Responsibility subscale of the HPLP II. Overall, the top three ranked health promoting behaviors that urban and rural caregivers intended to do in the next 12 months to improve or maintain their health were increasing physical activity, improving eating habits, and losing weight. Getting more sleep was also frequently mentioned. However, there was no indication of the underlying facilitators and barriers to the health promoting behaviors most important to these caregivers. These facilitators and barriers are critical to one's understanding if programs are to be developed to help improve caregiver health.

Phase 2: Qualitative Study

In Phase 1, respondents to the survey were asked to rank their top three most important health promoting behaviors. These were increasing physical activity, eating a healthy diet, and achieving a healthy weight. An additional question was asked about getting regular checkups. Phase 2 of the study was used to answer what caregivers considered when rating their health and to answer the third research question about similarities and differences in the facilitators and barriers to health promoting behaviors experienced by urban and rural primary caregivers of children with disabilities who live in Central Alberta.

Results from each stage of the study were first analyzed separately; the two sets of results were then integrated into a matrix (Table 18, Appendix R) that contains both the quantitative and qualitative results (Creswell & Plano Clark, 2011; Dickinson, 2010; Miles & Huberman, 1994). Facilitators and barriers to the top three ranked health promoting behaviors and getting regular checkups were merged together to form the matrix. Also addressed in the matrix are the categories of factors unique to caregivers living in urban and rural communities, as well as factors related to caring for a child with a disability. The factors that caregivers emphasized the most in their discussion are presented.

Participants

Of the 69 survey respondents from Phase 1 who agreed to a telephone interview (29 urban and 40 rural), ten urban and ten rural primary caregivers of children with disabilities were selected to participate in Phase 2. The goal of informant selection was to maximize diversity – caregivers were selected to ensure variation in their child's severity of disability and to ensure representation of both physical disability and behavior problems. Caregiver factors that were considered included gender, ethnicity, employment, income, marital status, BMI, health status, number of kilometers driven to see their physician, and those with high and low scores in the HPLP II categories of Physical Activity, Nutrition, and Health Responsibility. Caregiver characteristics are presented in Table 19; scoring of the HPLP II is outlined in Appendix I. Characteristics of their children with disabilities are outlined in Table 20.

Table 19

Characteristics of Caregivers – Phase 2

Variable	Urban n = 10	Rural n = 10
Relationship to the Child with a Disability		
Mother	10 (100%)	9 (90%)
Father	0 (0%)	1 (10%)
Ethnicity		
White	8 (80%)	9 (90%)
Métis	2 (20%)	1 (10%)
Mean (SD) Age	40 (5.74)	42.7 (6.83)
Range	31 - 49	34 - 52
Marital status		
Married/Common Law/ Partner	6 (60%)	6 (60%)
Divorced/Separated/Single	4 (40%)	4 (40%)
Education		
High school or less	3 (30%)	0 (0%)
More than high school	7 (70%)	10 (100%)
Employment status		
Employed full time	2 (20%)	4 (40%)
Employed part time	4 (40%)	2 (20%)
Self-employed	1 (10%)	0 (0%)
Full time caregiver	3 (30%)	3 (30%)
Full time student	0 (0%)	1 (10%)
Yearly family income		
Low Income Cut-off or less	2 (20%)	2 (20%)
Greater than Low Income Cut-off	7 (70%)	7 (70%)
Missing	1 (10%)	1 (10%)
Mean (SD) Number of kilometers one way to caregiver's doctor	4.35 (3.39)	47.4 (64.99)
Range	1 - 10	4 - 200
Self-reported health		
Excellent	1 (10%)	2 (20%)
Very good	2 (20%)	1 (10%)
Good	5 (50%)	4 (40%)
Fair	1 (10%)	3 (30%)
Poor	1 (10%)	0 (0%)
Stress on most days		
Not at all stressful	0 (0%)	0 (0%)
Not very stressful	0 (0%)	1 (10%)
A bit stressful	4 (40%)	3 (30%)
Quite a bit stressful	4 (40%)	6 (60%)
Extremely stressful	2 (20%)	0 (0%)
BMI	26.06 (5.32)	25.67 (6.15)
	19.5 – 36.8	18.3 – 35.4
HPLP Overall Score	2.36 (.38)	2.39 (.43)
	1.81 – 3.06	1.67 – 3.04
HPLP Health Responsibility Subscale	2.19 (.4)	2.33 (.59)
	1.56 – 2.78	1.44 – 3.11
HPLP Physical Activity Subscale	2.00 (.68)	1.94 (.68)
	1.13 – 3.13	1.13 – 3.38
HPLP Nutrition Subscale	2.52 (.6)	2.76 (.53)
	1.56 – 3.44	2.11 – 3.56

Table 20

Characteristics of the Child with a Disability – Phase 2

Variable	Urban n = 10	Rural n = 10
Mean (SD) child age	10.65 (3.87)	10 (2.3)
Range	6-17	8 – 15
Child gender		
Boy	8 (80%)	6 (60%)
Girl	2 (20%)	4 (40%)
Mean (SD) number of Diagnoses	2.7 (1.49)	2.3 (1.64)
Range	1 – 5	1 – 6
Severity of the disability		
Mild	1 (10%)	1 (10%)
Moderate	1 (10%)	2 (20%)
Severe	7 (70%)	6 (60%)
Very severe	1 (10%)	1 (10%)

Factors Considered When Asked to Rate Their Health

When caregivers rated their overall health, they primarily considered physical health and participation in health promoting behaviors, with few taking mental health into account.

Physical health. All 20 caregivers considered their physical health; specifically the presence or absence of pain, whether or not they were on medications, how frequently they were ill, and how often they had to take time off work due to illness. Nine caregivers mentioned the presence or absence of chronic illnesses:

> P076 I am 46 years old, I've never been on any medication; I don't have any allergies whatsoever, no arthritis, no high blood pressure, no … nothing.

Four caregivers also considered their physical functioning, claiming that their health was poor if they got little sleep or were unable to do all of their daily activities or if they were experiencing pain. If caregivers had "good" energy and were able to do all of the things that they needed to do during the day, then they rated their health higher:

> P025 I don't have any problems with mobility, I am able to function in daily activities, I don't have any concerns or anything with that.

Six caregivers considered themselves overweight; as a result, they felt that this had a negative effect on their health, even if they did not have any major health problems.

Participation in health promoting behaviors. Twelve caregivers considered their participation in health promoting behaviors when rating their health. One caregiver attributed an improvement in health to reprioritizing healthy behaviors:

> P038 … I think that both my husband and I… I'd say in the last two years, have put our health on a much more … importance. Health has sort of been down near the bottom, because we just felt like we were running ragged. So I kind of started it two years ago, and I've been exercising and trying to eat really healthy … very few carbs, and if they are, they are whole grain type things. And we both have just felt so much better.

Not being able to exercise regularly was also a factor when four caregivers rated their health:

> P101 I don't get out and exercise regularly, but I am run around on my feet all day at my job. So you know I could do more and I know that just as I age, there are things that I really should take care of that I haven't.

Mental health. Only five of the 20 caregivers considered mental health when rating their health; one caregiver experienced anxiety on a regular basis. The role of mental health varied among these five caregivers from being a positive asset, to a holistic health goal, to a detriment. One of these caregivers felt there was a need to consider all aspects of health when rating their health and that striving for health was an ongoing process:

> P038 …. I …look at health as the whole, not just physical – but also your mental, emotional, spiritual … for me it's a whole package. There's always areas that suffer when you focus on one … it's hard to find balance.

Facilitators and Barriers to Health Promoting Behaviors (Research Question 3)

The interviews provided the opportunity to explore caregivers' reasoning and contextualized explanations of facilitators and barriers to the four health promoting behaviors of increasing physical activity, eating a healthy diet, achieving a healthy weight, and getting regular checkups. These questions were guided by the Integrated Social Ecology Model (Bronfenbrenner, 1979; Flack, 2009; McLeroy et al., 1988; Sallis et al., 1998); intrapersonal, interpersonal, organizational, community, and policy factors were discussed. An illustration of the facilitators and barriers to health promoting behaviors of primary caregivers are summarized in Figure 4.

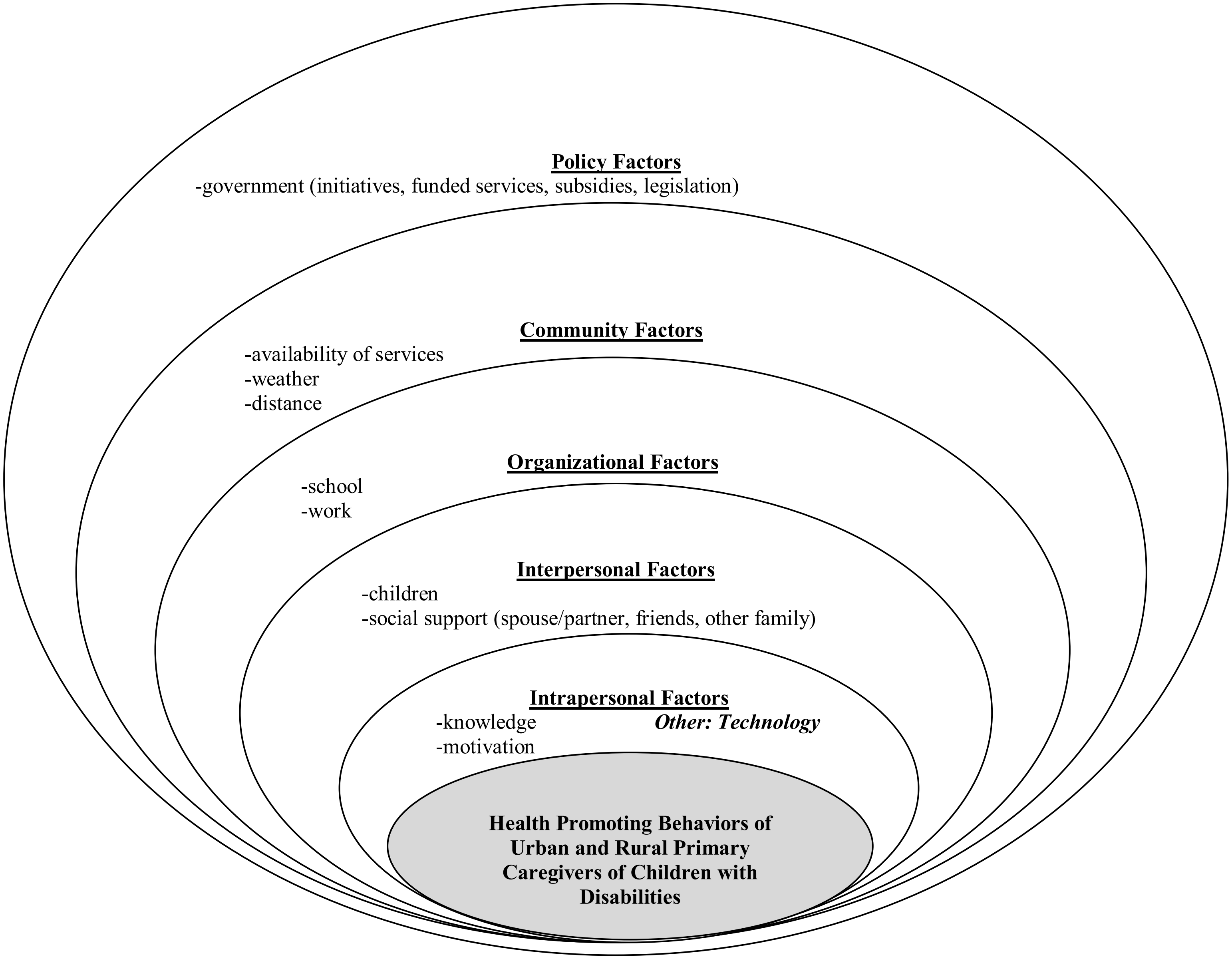

Figure 4. Overview of Facilitators and Barriers to Health Promoting Behaviors of Primary Caregivers

Intrapersonal factors.

Knowledge. All 20 caregivers were knowledgeable about the health benefits of increasing their physical activity, eating a healthy diet, being a healthy weight, and getting regular checkups. Sources of this knowledge included family, friends, school, and media (television, radio, and the internet). The use of technology, while not identified as a specific factor in previous social ecology models, is also included as it provided caregivers with the knowledge to make healthy choices.

Increasing physical activity. Three caregivers learned about ways to increase physical activity from fitness trainers, but 17 caregivers said that they lacked knowledge about the specific amount of exercise recommended to decrease their risk for chronic illnesses. They could not estimate the duration or intensity of recommended physical activity needed to minimize disease risks.

Healthy eating. Caregivers identified various ways of eating healthy, including knowing how to check the nutritional content of food, how to harvest and store/preserve food from their gardens or farmer's markets, how to avoid processed food, how to make food from scratch, how to pre-plan meals, how to find cookbooks with healthy recipes, and how to determine what constituted a healthy snack. One caregiver illustrated the need to be a discretionary consumer of various sources of information:

> P169 If I hear something I'll go on the internet and see if there's been any [negative reviews] about it, because often [television] shows only tell you the upside. I have [learned to] … make proper changes as opposed to going on any one specific juice or no sugar fad diet. As a result, I have cut back on whites, starches, and carbohydrates and changed to browns and other healthier choices.

Two caregivers used applications (apps) on their phones to help them eat healthy. One caregiver used an app to determine an appropriate portion size depending on what she was eating. Another caregiver used an app to help her determine the calorie count of various foods, enabling her to make healthy food choices:

> P101 [The app] has made me pick a salad instead of a burger or something, because of

> the calorie count. I mean, you can only have so many calories in one day.

Not all caregivers had this comfort level in interpreting and recording nutritional information. One explained that she was unable to read and understand food labels; she did not know about the Canada Food Guide and she felt that looking at food labels was trying to read "Greek." Another caregiver had grown up in a family that ate primarily meat and potatoes – she had never been taught how to incorporate fruits and vegetables into her diet.

Healthy weight. Caregivers spoke of different strategies to help them maintain/attain a healthy weight. Three caregivers believed that weighing themselves daily was an effective way to determine when they should implement strategies to try and lose weight. Six spoke of using the fit of their clothes as a guide:

> P038 We don't own a scale … so I go by my clothes and how they fit. And if I notice that things are getting tight, it's okay well, one less glass of wine on the weekend.

Motivation. Caregivers varied considerably in their motivation. Motivation was highest among caregivers who capitalized on facilitators and incorporated healthy strategies into daily routines. Reasons offered for lack of motivation varied with the health promoting behavior.

Increasing physical activity. Six caregivers prioritized physical activity; generally, they felt better when they exercised. A strategy that one caregiver used was to put appointments into her calendar – others simply tried to fit in some type of daily exercise:

> P044 I make it a priority for me to do something every day…definitely, incorporate something for at least 30 minutes every day. If it's the fast walk … or if it's a short jog …it could be yoga – I do that too. That's part of my … my mental health maintenance.

Another caregiver employed a variety of strategies to incorporate activity into daily life:

> P085 I bought an elliptical, so that helps if it is too cold. We also have a long driveway, so I walk the kids to the bus every morning and walk and pick them up if I'm home. We all just try to take the stairs and I don't park close to the entrance ways at Wal-Mart.

Three caregivers purposefully brought dogs into their homes as a way to increase their physical activity. They were aware that the dogs would need to be walked regardless of the weather, so they would get more exercise in their day as a result.

Nine caregivers were not willing, not motivated, or too tired to exercise. Two additional caregivers preferred to spend free moments with their children:

> P134 At some point in time you think okay, do I spend a little time with [my daughter] reading a story or do I go and exercise. So, 99% of the time, [exercise] gets pushed off.

Six caregivers were experiencing health issues that made them reluctant to exercise; issues included neck injuries, fibromyalgia, and insomnia. Two additional caregivers were afraid of being injured while doing structured exercise so they avoided it; one of these caregivers had a physically active job and her family depended on her income.

Healthy eating. Caregivers experienced a mix of motivation and degree of success with various strategies. Six caregivers were motivated to make healthy eating a priority because they felt unwell after eating unhealthy food; eating healthy gave them more energy and helped them to feel better. Planning helped these caregivers stick to a healthy diet:

> P134 Having the ingredients…and so that means shopping lists. And not having junk food available helps a lot too. I mean just have a pop free zone. I feel like chips or prepared foods would be a special occasion type thing only.

Eight caregivers were unmotivated or unwilling to stick to a healthy diet, citing cost, cravings, a desire for treats, or preparation time as rationale:

> P167 It's just more convenience food like boxed food or … not choosing the healthiest thing, you know? We had enchiladas tonight [laughs]. Or we didn't throw a salad with it or … you know, there are certain things I could do. I just don't make the time to do it.

Four of these caregivers made sure that their children ate healthy diets, but were not motivated to eat healthy themselves – they simply grabbed whatever was convenient, which was often pre-packaged foods high in salt and fat content.

Healthy weight. Caregivers who were motivated to maintain/attain a healthy weight incorporated different strategies. Four caregivers ate frequent small meals to help curb their appetite and nine caregivers limited their portion sizes to help decrease their caloric intake.

Four caregivers said that the effort needed to diet was "too much work" to track calories, points, and weigh food. Another four caregivers said that they became frustrated when their attempts to lose weight were unsuccessful and three became frustrated with their diets because they were always hungry:

> P049 They say there's a lot of fiber and stuff in broccoli and rice and stuff, but, I'm still hungry after eating. Sometimes, I'm almost like 'get out of my way' and go for the fridge because I am so hungry.

Two other caregivers became depressed when their attempts to lose weight were unsuccessful and ate more as a result; this caused them to gain even more weight:

> P102 It wouldn't come off, no matter what they did [at Herbal Magic], it's just … my body stopped. You're not hitting your goal [and] I got upset and kind of depressed. Then I started eating again. So there went another twenty pounds back on.

Regular checkups. Four caregivers who were motivated to get regular checkups used the date of their birthdays as a reminder. Five caregivers booked a checkup when they had to visit their physician for other health concerns:

> P102 I'm on birth control so I have to go every year to get it refilled. And so, you know, in order to do that you have to have a physical, so I just do that yearly.

Four caregivers who did not get regular checkups said that they felt healthy and really had no need to go to for a checkup – there were no issues. Two caregivers had been to physicians a lot as a child and were now afraid of going to the doctor. One of these caregivers had additional health issues as an adult:

> P169 Every time I go there is something they have got to check, something new to have to think about. When I have gone, I have had a couple of scares – well, we need to do some more testing again, because they'll have the signs of ovarian cancer. So they'll say – well we have to test you again in six months. Then you get the clean bill of health … and then you'll avoid the doctors for a few years, because you don't want to deal with it.

Interpersonal factors.

Children. Children both helped and hindered caregivers' health promoting behaviors. The most frequently mentioned facilitators were that caregivers wanted to engage in all four health promoting behaviors in order to be able to provide care for their child with a disability over the long-term and that they wanted to role model healthy behaviors for their children. The most frequently mentioned barrier was lack of time due to the care needs of their child with a disability; time constraints due to the needs of their children without disabilities were also mentioned.

Increasing physical activity. By engaging in activities with their children, six caregivers were able to increase their activity levels. Another caregiver's child with a disability was involved in special activities that required participation from the caregiver:

> P169 Last year we went skiing with the disability program. And we also have him out to a ranch on Fridays, and so he is riding and I'm walking with him. So we are tacking up, we are grooming, we are doing stuff.

Children also encouraged their caregivers to engage in exercise:

> P038 If [my son's] not at a hockey practice, he has dry land training, or he'll be working out in his room. And so he'll say mom, have you done this exercise, and so we sort of motivate each other too, and he'll sometimes come out for a run with me too.

Four caregivers used exercise to decrease the stress that was a result of factors related to caring for their child with a disability as evidenced by this caregiver:

> P044 [My son] not being able to speak … there's lots of stress there … trying to find out what he needs and what he wants … because he's not very good at communicating. I've had many years to accept his condition but it still pains me every once in a while when I sit down and think about it. What it would be like to hear him say 'I love you'. Stuff like that will really bother me. So I make [exercise] a priority. I have to do something every day, that's the only way I can take care of the stress.

One of these caregivers exercised as a way to stay fit so that she would be able to continue to provide the physical care required by her child with a severe physical disability – it was a way to "maintain my back." For three other caregivers of children with physical disabilities, pushing their child's wheelchair and caring for their child (therapies, feeding, toileting, bathing) was a way to be physically active.

Ten caregivers were too busy to exercise because they were driving/supervising their children without disabilities in after-school activities:

> P065 My kids are in things, right. I have one in karate, one that works part time, one in music, one in gymnastics, one in pony club. I mean, my gosh, it is so busy.

Sixteen caregivers had little or no time to increase their physical activity due to the special care that they needed to provide for their child with disabilities. Six caregivers had extensive therapies (speech, physical, behavioral, etc.) that they did after school; three of these caregivers also had to provide for their child's physical needs (feeding, toileting, bathing). Five of the sixteen caregivers discussed the need to help their child with homework after school; while many parents do this with their children, some caregivers of children with disabilities have additional responsibilities:

> P022 He's got the typical homework; he's in grade one so you're learning to read. But he's having trouble with some memory issues, symbol recognition, and as well as some sensory issues. So, we're supposed to work on all of this for three hours at night. By the time you put him to bed at seven thirty – I just want to relax, not exercise.

Another caregiver described the fatigue that she experienced from the extensive routine that her teenager with ADHD and autism required:

> P038 Our other two children are quite independent, but [child] just requires a lot of … coaching and guidance to get from point A to B. So in the morning … his medications have not kicked in yet either, because he takes his meds with breakfast. Reminding about hygiene things, reminding him to put his deodorant on. And then it's constant coaching – so just to get him out the door on time every day is a constant battle – and it does drain me – I feel like I've been through ten rounds in the ring. It's hard mentally and it's hard physically – I just get exhausted so exercise is the last thing that I want to do.

Four caregivers of children with autism did not exercise because their children became distressed when they varied from their typical routine.

Eight employed caregivers were unable to leave their child with a disability after school to exercise because of difficulty finding respite. Three of these caregivers sometimes used their children without disabilities to provide respite; however, all three reported that they only rarely did this as these children also had lives and responsibilities. Therefore, they did not feel comfortable asking their child to care for their child with a disability while they went to exercise:

> P035 You know, I just can't leave [my son] with just anybody. He's got ADHD too, so I mean, he gets very distracted and very tired, and very frustrated, very easily. I don't like leaving him with [his sister]. She is now in high school and she's got quite a heavy homework load, she's got extracurricular stuff that she wants to do, and you know, she's in guitar lessons and whatnot. So I don't want to deny her that so that I can go workout.

Two other caregivers spoke of the inability to bring their child with a disability to the gym with them; while both gyms had child care available, the services were only for "normal" children. Due to the lack of respite, three caregivers reported having to bring their child with them when they engaged in physical activities. However, this did not always work; one caregiver attempted to bring her ten year old child with behavioral issues to aquacize with her, but his behaviors were so disruptive that she had to stop attending.

Frequent calls from school about their child with a disability were a barrier for six caregivers. They had tried attending exercise classes, but interruptions from phone calls from school to help manage their child's behaviors prevented them from continuing with the class. One mother of a child with autism described her experience:

> P169 That is one of the toughest parts, is that full dependency and … those phone calls from school, because they can't handle him and you've got to pick him up. [They would call and say] can you come pick him up, he's hitting people. Years ago when I first started trying to work out they'd phone me every ten minutes; they couldn't get through a day without phoning me. So you never knew, you'd always listen for that ring, and you would be into your workout and you'd have that phone right in front of you, and as soon as it went off you knew – I had to stop. So what was the point in even going?

Caregivers who could not participate in paid employment because of their child's care needs found the fees for organized activities prohibitive:

> P054 So the problem with [joining those exercise classes] is money, right. I am really struggling financially because I cannot keep a full time job. I have another full time job

> with [my daughter] – the organization of all of the doctors' appointments, the going in for the hospital stays, all the therapists' appointments, all the getting the wheelchair fixed, it just goes on and on. And so I cannot work full time and I can also only work certain jobs because I'm also a very unreliable person now. If my daughter is sick, I don't go to work. If my daughter's caregiver is sick I don't go to work. My caregiver got stuck on the highway the other morning, so I don't go to work. It's impossible to have a job.

Healthy eating. Having their children eat healthy reminded five caregivers that they needed to eat healthy as well:

> P101 Yeah, otherwise I probably wouldn't bother with breakfast. So you know, when you get up, I have got to get him [ready to go] to school, so it's, okay, let's have breakfast … oh, I better have breakfast myself. You know, like you just start to fall into that, right.

One caregiver's child with cerebral palsy was on a low sodium diet because of his medications. As a result, the whole family ate few processed foods and more fruits and vegetables. For five caregivers of children with autism, having their child on a special diet to help reduce autism symptoms also helped them to eat healthy:

> P044 We make everything from scratch at home. Our son's on a gluten-free, casein-free diet. So the whole family is just eating that way because it simplifies things, to not have to make more than one meal. So we eat very, very clean food … in its natural state. We barely touch processed food, ever.

Children were barriers for two reasons; picky eaters and after school activities. Two caregivers had children who would only eat certain pre-packaged or processed foods (chicken fingers were mentioned frequently) and they could not afford to cook different meals for themselves and their children. Four caregivers had children who were involved in activities after school; because they spent so much time driving back and forth to these activities, it was easier to eat at fast food restaurants or to buy pre-packaged convenience foods:

> P167 I would say Monday to Thursday we have things going on, every day of the week. I work until 4:00 pm – then right after is somebody's practice. Picking one kid up, dropping him off. I find it really hard to maintain trying to make a meal. It's just that

> nobody's in the same area at one time to make a meal. Same with my husband. He's running with one, or I'm running with the other. And you're not sitting down as a family at suppertime because there's always someone gone. And trying to fit in grocery shopping … I'm just finding convenience wins over most of the time.

Six caregivers reported eating "comfort foods" such as chips and chocolate as a way to deal with the stress of caring for their child with a disability. One caregiver was stressed due to worry about what others thought of her child with autism and the fact that other children did not include him in activities. One of these caregivers with a child with ADHD often made "bad choices" with her food because of stress:

> P101 I get stressed because he isn't able to focus on any one thing. I have to be right beside him even to take his medication, brush his teeth, get dressed, or it just is not happening … he just will wander off somewhere else … so he takes a lot of time. A lot of days we're late for school.

Two caregivers wanted to have a garden, but there was no time due to the care requirements of their children with disabilities. Three caregivers reported being so busy meeting their children's needs before, during, and after meals that they frequently had no time to eat themselves. Weekends were particularly difficult for one caregiver of a child with a severe physical disability:

> P054 My routine really revolves around my daughter because … when I'm in my home she's the only thing that I think about. She's the first thing on my mind so that's very distracting for me. There are so many details to looking after her – feeding, bathing, therapies ... so before you know it my whole weekend is gone and I haven't gotten to my meals. That's what ends up being one of the last things I look at – myself.

Four caregivers of children with autism frequently ate at fast food restaurants with their children due to ritualistic and other behaviors. One caregiver's child would have behaviors if they did not eat out at a particular McDonald's restaurant after every time that they went swimming; once there, she frequently made poor food choices due to stress. Another single parent on a limited income reported that her child would threaten self-injurious behaviors:

> P101 [My son has] OCD and he becomes obsessed … like toys, toys, toys. Last week we had a really bad week where he opened the car door driving, you know, threatening to hurt himself if I didn't take him to McDonalds. And sometimes he will get a cleaver out, and put it over his hand on the counter if I don't take him. …. I get scared, actually. And … just so that I don't have to deal with it, we go to McDonalds and he will take the toy over the food … he gives me all the food to eat, so he could just get the toy. And I don't want to waste it, so I end up eating the food.

Healthy weight. Two caregivers realized that they would need to achieve and maintain a healthy weight if they were to be there for their child in the future:

> P169 I need to extend my life as long as possible to make sure I can teach my kids as long as I can, to make sure that they have the skills and tools that they need when I eventually pass away. So, I have to be healthy, and that means having a healthy weight.

The other was a caregiver of a child with a physical disability; she felt that she would be unable to lift or care for her child if she was overweight.

Regular checkups. Eight caregivers were concerned about who would care for their children with disabilities if something happened to them. Therefore, they felt the need to get regular checkups to monitor their health. One of these caregivers had a child who saw multiple specialists:

> P102: I'll say to my husband – if something ever happened to me you would be in so much trouble. Because of his work he doesn't go to any of the doctors' appointments … I mean, we see specialists galore. We live at the children's hospital in Calgary. He couldn't tell you what doctors we go to, names of clinics, medications, anything. Even if I go out in the evening with a friend or something like that and its medication time for him, I have to have a list written on the fridge so he knows what medication to give at what time. There would be no way that my family would be able to survive without me, so I have to take care of me, which means regular checkups.

Nine caregivers spoke of the opposite effect – being so busy and worrying so much about their children's health and appointments and checkups that they spoke of "constantly forgetting about themselves." Four caregivers said that they had no time to go for checkups:

> P054 I don't have time to go for checkups because I've got so much stuff I'm organizing around [child]. I know I've got to do this for myself and that for myself, but it just keeps going to the bottom because she needs to go to that doctor, and she needs to go to this doctor. And she needs to go to this physiotherapist and it just goes on and on.

The need to attend numerous appointments for their child with a disability made some caregivers reluctant to take time off work so that they could get regular checkups. One caregiver was reluctant to take any time for herself to get a checkup because she had to take so much time off of work to facilitate her 17-year-old child's move from child to adult services. She needed to attend appointments about transitioning, guardianship, and trusteeship, among other things. In the week prior to the interview, she had taken time off work on three different days to see three different people. She felt that taking any additional time for herself would not "go over well" at work. Another caregiver of a child with multiple disabilities was unable to take time off of work for her own checkups because she had used up all of her sick days with her employer:

> P085 I really cannot take time off for myself. I usually use up my 12 days of sick time within the first three months of the year and then I'm in big trouble for the rest of the year because then I have to take it as non-paid days. And it's all kid related … we are guaranteed to have two appointments in Calgary a month. If [my son] has a severe seizure, then we're there for a couple of days. I'll just put me on the backburner, because that's just way too much running. I can for him, but I'll let my own appointments go.

Social support. The presence or absence of social support influenced caregivers' health promoting behaviors in various ways, depending on the health promoting behavior.

Increasing physical activity. Spouses/partners assisted five caregivers by caring for their children when the caregiver exercised; they also acted as workout partners:

> P049 Sometimes when I'm off work early I jog on my treadmill. I have two treadmills, one for my husband and [one for me] and I have two elliptical machines, so then we can work out together. And then so we'll watch … a movie while we work out together.

Family outings and activities that involved swimming, biking, hiking, kayaking, and other sports offered additional opportunities for exercise.

In Alberta, many families have a parent who works in the oil field; five of the 12 partnered caregivers who were interviewed had spouses who worked away from home for weeks at a time. Four of the eight caregivers without a partner reported that they had no one to give them a break when their spouse was away so that they could have some free time for them to be able to exercise.

Healthy eating. Five caregivers reported that having a spouse/partner helped in several ways; having a second income helped with the cost of purchasing healthy food and going out for supper with their spouse/partner was an opportunity for two caregivers to have a healthy, balanced meal. Another caregiver's husband had started to eat healthier, which made it easier for her to eat healthy:

> P038 I think now that my husband's onboard – he has battled some with his weight over the years. He would tend to go for the chips and well … if chips are in the house, then I want some too. It's a lot easier if you have somebody that's eating the same things as you. And you know, he would tease me when I'd have my steel cut oats in the morning, and go 'ooh that looks gross'. And now he likes it more than I do.

Being responsible for making healthy choices for the family helped one caregiver eat healthily:

> P065 I know that every meal should have fruits and vegetables and … your proteins and stuff like that. So I make myself make good healthy meals for my family and for myself.

One caregiver's mother had a garden that served as an affordable source of fresh fruits and vegetables. Two caregivers had friends who were interested in eating healthy; they served as sources of both information and support.

However, two caregivers had no partner and three of the five caregivers whose spouses worked away from home were lonely and ate unhealthy food as a way to "fill the emptiness." Six caregivers had spouses/partners who routinely ate unhealthy snacks; exposure to unhealthy food was a cue for them to eat that unhealthy food as well:

> P065 By the end of the day, after I have gotten all my kids to bed and my kitchen cleaned up, and you know and I take those few minutes, I usually get about two hours with my husband at the end of the day where we'll just sit and watch the news and talk about the day's events. My husband is a huge nighttime snacker … I'll sit down and eat potato chips or popcorn, or whatever he's eating. So that's bad, too.

In contrast to the aforementioned caregivers who ate healthy meals when their spouses returned, three of the five caregivers whose spouses worked away reported that their spouses' return triggered celebratory eating that included eating at fast food restaurants or going on dates that included drinking pop, as well as buttered popcorn or chocolate bars. Three others had spouses/partners who refused to eat healthy food; therefore, caregivers had to cook extra food at meals, which was also a barrier:

> P049 When I'll pick a healthy recipe, my husband turns up his nose. So I end up making him pork chops or a roast and buns and whipped potatoes, but I have to have [healthy] soup. And then I would want his food – having those cues makes you want to eat.

Socializing with friends was an opportunity to eat out and splurge on unhealthy food or high calorie foods for two caregivers. Another caregiver liked to have a treat when entertaining friends:

> P038 If we have friends over, we'll have popcorn, or nachos, or we'll have the occasional glass of wine. As a rule, we try to eat healthy, but we'll have the occasional treat.

Healthy weight. One caregiver's spouse was very encouraging when she tried to lose weight. For three caregivers, parents were either role models and/or sources of information:

> P038 My mom was always a healthy weight. If I'd complain – you know – in high school … I'm fat. And she'd say well just … cut back on the snacks a bit.

Regular checkups. Three caregivers had a family history of health issues that required routine screening from a physician:

> P025 My mother had early cervical cancer and so I was always aware of that. We are very aware of our family history and … early detection is the best detection. So I see my physician regularly.

Three caregivers had regular checkups as a result of prompting from family members. Two of these caregivers had checkups because their spouse/partner said that it was important. One caregiver went because her mother had instilled the importance of this at an early age.

For five caregivers, lack of social support affected their health monitoring. One rural caregiver was divorced and had not attended his eye exam because there was no one to provide transportation after his pupils were dilated. Three single parent caregivers reported that lack of respite prevented them from getting checkups:

> P022 You're managing a household with one person and you don't have that back up. You know, another parent would be able to take a child instead of me having to drag him to the doctor's office. And it's not like I can leave [him] with just anyone – he is too much work for a normal babysitter. I have tried in the past and it really doesn't work.

Another divorced caregiver of two children with disabilities could only go for checkups when her children were in school; one child had disruptive behaviors:

> P049 If I do go, I need to go before the kids get out of school, because I don't dare take them with me. [My son] gets restless. So, if I don't think ahead, bring say his Nintendo DS or something for him to do – it's trouble and I have to leave. He wants to run around and get in the way and look at all of the numbers on all of the doors and stuff.

Organizational factors.

School.

Increasing physical activity. Having their children in school provided caregivers with exercise when they walked to drop off and pick up their children from school. School newsletters facilitated awareness of the importance of physical activity. School also provided respite:

> P096 I think [school] gives me more time so that you can go to the gym. And to have that time when you're not lugging – three kids, in my situation – taking three kids to the gym and paying for daycare for all of them.

However, the varied schedules at their children's school were prohibitive for two caregivers. Having their children out of school for half days and/or days off prevented these caregivers from engaging in physical activity on those days, as did having to spend time supervising their child's class while on various field trips.

Healthy eating. For seven caregivers, their children were learning about healthy eating at school, so they discussed it as a family. The children also brought home resources, such as the Canada Food Guide and nutritional guidelines regarding what foods were appropriate to enhance healthy eating and prevent allergic reactions:

> P085 They also promote [healthy eating] through some of their meal deals that they offer at school. They do more Subway and … Extreme Pita, and places like that which are known to be healthier.

Preparing healthy food for their children to eat at school served as reminder for four caregivers that they needed to eat healthy as well. Two caregivers had children who lived close to their school, so they came home for lunch. Having their children home for lunch required caregivers to make their children a hot, healthy lunch – as a result, they ate a healthier lunch as well.

However, one caregiver was so busy with schoolwork that she wanted something quick and convenient when she sat down to eat; this frequently meant eating fast food. Another caregiver found that having her children away at school often resulted in her forgetting to eat – there was no one there stating that they were hungry or to remind her to make and eat lunch.

Regular checkups. Six caregivers reported that having their children in school gave them time to go to their physician for a checkup. One caregiver was enrolled in a post-secondary program that required a complete physical from a physician to get into the program and to transfer credits to a university.

Work. Paid employment was helpful if it ensured sufficient monetary resources to help caregivers engage in health promoting behaviors. However, work demands also inhibited or frequently left caregivers too tired to engage in health promoting behaviors.

Increasing physical activity. Paid employment helped six caregivers buy gym and recreational facility memberships. For six caregivers, the flexible employment of their spouses or partners enabled them to provide respite while the caregiver exercised.

Twelve caregivers had physically demanding jobs that provided them with several hours of high intensity physical activity during the day:

> P101 Most of the shifts I'm doing now with cooking – you kind of have to lift things above your head, and an oven [where] you're on your knees with this weight. And then you're unpacking orders and pallets of food, and yeah just go, go, race, race, race, all day.

Two of these 12 caregivers were fitness instructors; they engaged in several hours of aerobic activity each day both during work and outside of work as a way to stay fit. Two other caregivers accessed workplace wellness programs; they were reimbursed for things such as gym memberships, weight sets, kayaks, and hiking boots.

The type of physical work was different for six rural caregivers. Work on their property included milking cows, feeding cattle, mowing their acreage, chopping trees, and gardening:

> P076 Well, gardening, you're hoeing and … if I have to water the garden it's all by hand, so I haul pails. I mean, we picked and bagged 200 cups of peas. That's a lot of exercise!

Four of these six caregivers had to routinely check fence lines and other aspects of their land; they walked and biked long distances because of the size of their property.

For other caregivers, work prevented exercise; ten caregivers were too tired after work to engage in physical activities:

> P035 By the time I get home and the kids get home, and I can – you know, shower and call it a night and think about going to the gym, it's like ugh – [I am] tired. I need sleep.

One rural caregiver spent so much time sitting on a tractor cutting the grass on her small acreage that she had no time to exercise.

Seven caregivers and their families did not earn enough money to be able to afford organized or commercial physical activities:

> P085 If we ever wanted to really do any physical activity outside of the house, other than walking, I really don't know what we'd do, because we don't have the money after we

> pay for the basics to have swim passes or [to go to] a walking track that you can you use in the winter time. It's like $5.50 every time you go, and … we could never afford it.

Healthy eating. Four caregivers specifically mentioned that they earned enough to be able to afford healthy food. Six caregivers felt that packing a healthy lunch for work helped them to eat a healthy diet; otherwise they would go out for lunch with colleagues and there were not always healthy options to choose from. One caregiver finished work by 1600 each day, which provided enough time to prepare a healthy supper for the whole family. Three caregivers found that having scheduled breaks at work helped:

> P035 We have very set schedules at work for our breaks and everything; that allows me to eat smaller meals more frequently, which is healthier than eating three massive meals.

Conversely, unhealthy snacks were available at the workplace of four caregivers. Three caregivers found work stressful and stated that they did not make the best food choices when they were stressed. For seven caregivers, the cost of food was prohibitive – their family did not have enough income to afford healthy food and they felt that fruits and vegetables were much more expensive than convenience and fast food. Twelve caregivers were so busy with work that they frequently made unhealthy choices:

> P065 Sometimes my day ends up getting … too chaotic, those are the days that I haven't eaten. There's a little cappuccino coffee place, right in the same building as where I work. So she always has stuff out, like granola bars, and biscuits, and all kinds of really high sugar foods. To keep myself from actually starving to death, so that my brain continues to think, I'll go and eat one or two of those and then be done for the day.

Healthy weight. The employers of two caregivers had hired nurses who were available for counselling about ways to lose weight. Colleagues were also motivators for one caregiver:

> P134 I suppose there are examples at work of people who don't have a healthy weight and that's a very good motivator for me. When you see people who aren't taking good care of themselves, it shows. I mean there are some healthy people at work too. But when you look at some others who are really big …. It's like, ah man. You know you look at somebody and say – no, I'm not going there.

However, one caregiver did not have regular meal times and she was so busy that she would work for hours without eating. When she finally did have a chance to sit down and eat, she overate because she was so hungry. Three other caregivers reported that their family income from employment was not sufficient for them to be able to afford the food recommended for certain weight loss programs:

> P008 I have checked [those weight loss programs] out and no, because sometimes you have to buy certain kinds of food. There are three of us living here … I can't afford to be buying my food and then my kids' food too. I really have to watch my grocery budget.

Regular checkups. One caregiver needed an annual checkup from the physician as part of her employment; she booked other parts of the physical at the same time:

> P054 Well I have to because I have a class 2 driver's license so I have to go for a complete physical. They don't do the complete physical and stuff like that for the driver's license, but I book [the rest of it] all on the same day.

For another caregiver, having health care coverage at her place of employment helped her to afford to get the medications recommended after having regular medical checkups:

> P079 It was regular for me to leave [checkups] for one or two or three years. And, now that we have such good coverage at work, once a year I'm making sure that all three of us get in for a … check-up from the doctor. We also have a health spending account, so basically it's like getting reimbursed 100% for all medications.

However, two caregivers had physicians who only worked during the day when the caregiver also worked – they did not want to take time away from work to go to a physician's appointment due to a sense of responsibility to their employers:

> P035 I generally try not to book time off work to go see my doctor, unless I have to. I don't like doing that to work because I know how busy they are and that they need me.

Community factors. Factors affecting health promoting behaviors of caregivers were related to availability of services, weather, and distance. Factors similar for both urban and rural caregivers are initially presented; this is followed by factors unique to urban and rural residency.

All 20 caregivers were comfortable engaging in outside activities because they lived in safe neighborhoods.

Availability of services.

Healthy eating. For twelve caregivers healthy food was readily available. This occurred as a result of several factors, including having affordable grocery stores and farmer's markets in their communities, as well as having gardens. To save money, 13 caregivers discussed buying healthy food in bulk. One caregiver also belonged to a club:

> P054 I do try to support my local grocery store, but I have to buy most of my groceries in [city] and then I also belong to a whole foods club. To save money, I buy a lot of my food in bulk - I will buy 25 pounds of beans, but that will last me for about a year and a half.

Healthy weight. Two caregivers had bookstores in their community where they could go to get information about specific diets, such as the Atkins and the Dr. Dukan diet. Another caregiver sought help from a trainer at a gym in her community; he had given her tips on increasing her intake of fiber and water to help her feel full faster as a way to lose weight. Availability of weight loss programs where consultants were able to speak with caregivers about healthy eating, exercise, and portion control tips also helped. Five caregivers had gone to Herbal Magic, two caregivers were on Weight Watchers diets, and one caregiver had used Jenny Craig. Herbal Magic also included diet supplements and vitamins. One caregiver used shakes and other meal replacements from Herbal Life to decrease her caloric intake. Another caregiver used supplements from local stores:

> P169 I go into health food stores and homeopathic stores in my community and ask their opinion and ask if there are side effects. Supplements that I use include those that boost my energy and ones that metabolize fats faster - green tea, white tea, or using vitamin B.

Physicians in their community were sources of both information and medication for two caregivers. One caregiver had found information about what a healthy weight was for someone her height after seeing a poster in her physician's office – she then spoke to her physician about strategies to lose weight. Another caregiver's physician put her on a medication to lose weight:

> P102: I went to the gym, I watched what I ate. And it just would not come off. And so the doctor actually put me on Meridia, which was a weight loss pill. And it worked great. Of course it had the side effects. You know, may affect the heart, the liver, so I had to go in and get monitored. But it was the only thing that triggered my body back into doing what it needed to do. And so then I had lost sixty pounds and looked great for about six months – until they discontinued the medication.

Regular checkups. Four caregivers were sent reminders from their physician's offices that they needed to come in for their annual checkup. Sometimes this was a letter; other times it was a phone call – for one caregiver it was both.

A barrier for both urban and rural caregivers was that physicians were often too booked up to be able to make appointments at a convenient time. Five caregivers had to book well in advance for a checkup with their physician as illustrated by this caregiver:

> P038 You do have to book way ahead; for a physical you have to wait at least a month to get in. If it was just an appointment to see him about something small, it would maybe be a couple of weeks.

Weather.

Increasing physical activity. Four caregivers purposefully took advantage of the few months of warm weather in Alberta by doing outside activities such as walking, hiking, biking, golfing, horseback riding, swimming in outdoor pools, and playing baseball and soccer. However, the many months of winter in Alberta were a barrier for 13 caregivers. These caregivers did not like being cold so they did not engage in physical activities outdoors during cold weather. Three of these caregivers were also concerned about icy roads and sidewalks:

> P044 I wouldn't walk or run in the winter when it's icy because the roads don't get cleaned often. They're quite treacherous and dangerous. I only do those in the summer.

Weather conditions were a further deterrent for two caregivers of children in wheelchairs. They wanted to bring their children with disabilities when they went for walks in their community, but they were unable to do this in the winter because it was difficult to push the wheelchair in the snow. This was even more difficult if neighbors did not shovel their sidewalks. Another caregiver struggled with access due to ice and snow:

> P102 It's really honestly the weather. We have a toboggan that we have rigged up for him but it's still not fully safe out and about to get him places due to the ice – it is too slippery. We live just off a park, but we can't even get through to get to that area in the winter time with him because of all of the snow.

Unique to urban caregivers.

Increasing physical activity. All ten urban caregivers had convenient access to available services in their communities such as paths or trail systems that they could use for walking, jogging, and biking. They also had facilities with parking where they could go to increase their physical activity; most were within a ten minute walk or drive from their homes. Seven of these caregivers lived near multiplexes that offered gymnasiums, exercise facilities with trainers, and swimming pools:

> P169 Yes [the exercise facility] is right across the road from us. I have a trainer there who challenges me … I need that challenge so that I just don't walk in and do it half asleep.

Commuting distance and time on public transit limited availability of recreation for some caregivers. One caregiver did not drive or have a driver's license, so she used the bus system to travel within the city. However, bus transportation was too time consuming:

> P102 It takes me an hour to get to [the pool]…sometimes an hour and a half with transfers. But by the time I get there I have to ask - do I have enough time to make it for the bus for the kids? That's a problem.

Healthy eating. All ten urban caregivers had readily available services such as grocery stores with a good selection of affordable food. Seven caregivers lived in a community that had public transportation available to all grocery stores in their community, including bulk food stores. All caregivers had access to farmer's markets in the spring, summer, and fall where fresh produce was available. One caregiver got information about healthy food choices from her trainer at her local sports facility. However, four urban caregivers were forced to rely on family members who lived in rural communities for fresh fruit and vegetables because there was no room where they lived to have a garden. Three urban caregivers who lived outside of Red Deer still had to travel to get certain foods even though they lived in an urban community; some larger grocery store chains are only located in bigger urban communities:

> P038 Most of our groceries, we buy here in [city]. We've got three good grocery stores here … especially for the fresh things. And then some of the things that are a little more expensive and I can buy in bulk, we do Costco runs once or twice a month.

Urban communities were also sources of many fast food restaurants; as a result, two caregivers reported that readily available inexpensive, unhealthy food was a barrier to healthy eating. One caregiver felt that living away from the city would help:

> P079 If I was living on a farm or a ways out of town, I know that I would be more inclined to cook healthy meals and do more meal preparation, than living in a town, where there's fast food readily available on the spur of the moment. So I feel that if I lived in a rural area, we would probably be eating better.

Healthy weight. All 10 urban caregivers had easy access to a variety of weight loss programs and other services that were readily available in their communities. Programs mentioned included Weight Watchers, Jenny Craig, TOPS, Herbal Magic, Aesthetic Solutions, and U Weight Loss Clinic.

Regular checkups. For urban caregivers, walk-in clinics and public transportation to wherever they needed to go for their checkups was readily available. In one large urban community, three caregivers reported being able to go to a walk-in clinic to see a physician for checkups as needed. While they may have to wait an hour or more, they were able to see a physician on a day that was convenient for them.

Unique to rural caregivers.

Increasing physical activity. Seven rural caregivers had little to no services available in their community that would help them to increase their physical activity. Two other caregivers did have small gyms in their communities; however, they did not offer other services that they needed, including a trainer and day care. The only gym in one of these caregiver's village was so crowded that she was unable to use it at a time convenient for her. Another caregiver liked to go for walks on her property, but had to stop because of problems with a charging moose. One caregiver had also liked to go rollerblading before she moved to her rural community; this was virtually impossible to do now because none of the roads near her property were paved.

Lack of availability of services was further complicated by weather conditions for six caregivers. One of these caregivers liked to swim, but her small town only had an outdoor pool that was only open four months a year and could not operate during electrical storms or in winter. Four caregivers liked to go for walks – however, because there were no sidewalks or trails in their communities, they had to use the road. This was too hazardous to do in the winter due to risks from being hit by vehicles that slid on snow and ice. Another of these caregivers walked in the ditches along her country road – in the winter she was unable to do this because the ditches were filled with snow. Another caregiver experienced issues with having no street lights:

> P076 I try to get out and go for a walk. But, I usually like to go for a walk at five o'clock in the morning so that I am done by the time kids are awake and stuff. But, in the wintertime, of course, it's dark and I don't like to walk on the roads in the country when it's dark – I cannot see the ice and I am worried about being hit [by a vehicle].

Distance was a facilitator to increasing physical activity for two caregivers for different reasons. One caregiver worked in a small community where all of the businesses that she needed to work with during the day were within walking distance (one or two blocks). When she needed to speak with someone, she frequently walked to their business instead of using the telephone to increase her physical activity. The distance that another caregiver had to travel to take her children to activities was a facilitator to her planning to increase her physical activity:

> P167 What I'm planning to do in January … I would like to get a gym membership so I can work out when I drop off the boys to hockey. They have to be [at practice] at least 45 minutes and I live out of town, so it's not worth it for me to drive back and then drive back in and have to waste the gas and time.

However, distance was also a barrier; one caregiver's ex-husband was her main source of respite and he lived almost an hour away, so she felt that driving two hours to take a 45 minute aquacize class was not a good use of her time. Another caregiver drove long distances to take both herself and her children back and forth to school and to after school activities – this meant spending up to three hours each day in a vehicle; as a result, she had no time to exercise.

Healthy eating. Four caregivers had some grocery stores available in their communities. While their prices were a "bit" higher, if one also incorporated the cost of gas to drive into the city to buy food, the prices were considered to be comparable. One caregiver reported that her time was too valuable to "waste time driving into town to save a few cents." While five caregivers lived outside of their town or village, three only had a fifteen-minute drive to get to a grocery store or farmer's market. Six caregivers had large gardens on their property where they could grow a large variety of fruits and vegetables. Living in a farming community helped five caregivers obtain fresh eggs, chicken, and meat from their farming neighbors. The fact that their rural village did not have any fast food restaurants was a factor that helped two caregivers to eat healthy:

> P065 When we lived in [name of city] we ate out at fast food restaurants at least three times a week. We might eat out here in [name of village] once a month – we don't have the restaurants, so we can't go.

Four rural caregivers did not have any grocery stores in their communities. For four caregivers who did have grocery stores in their community, there were still several limitations. These included higher prices than big chain grocery stores, reduced selection, and produce that were not very fresh:

> P054 I do try to support my local grocery store, but …it's their variety that is one of the problems when it comes to fruits and vegetables. And then they tend to carry more processed food that will not go bad quickly.

Inclement weather presented challenges to healthy eating for seven of the ten rural caregivers. Many rural caregivers traveled outside of their communities to buy produce and food in bulk. Their rural roads were treacherous in the winter with snow and ice, and they often only had two lanes. So when winter storms occurred, these caregivers chose not to travel – they just made do with what was in their pantries, which was often processed food. There were other weather issues:

> P167 We live on a acreage, just west of [name of town] and I tried to grow a garden for four or five years. And we're just too close to the river and … I can't grow anything out here that, I get too much frost. We don't have the insulation that the town has … we are west of town in the flats. It's right along the river, so the frost comes in easier.

One caregiver was able to have healthy food on hand despite the weather:

> P171 I just time our visits [to town] with the good weather and the winter storms that we have don't usually last too long. I stock up in case we have to wait a week or so.

For six caregivers, having to travel long distances was a barrier to healthy eating. All six caregivers had children who were involved in activities after school and on weekends:

> P171 We live so far out of town that any trip we take with the kids is probably going to come in conflict with one of our meals. So, if they are getting hungry, then the easiest and cheapest way to feed them and us is fast food. Just because we are not home and the trips aren't quick enough – that is an obstacle.

Healthy weight. Three caregivers had no weight loss programs available in their communities. One other caregiver had been attending a Weight Watchers program in her community, but the one person who was running it had moved away. She had tried the online program, but found that she needed the personal contact to stay motivated. Distance and weather were an issue for another caregiver who had been driving 30 minutes to attend a weight loss program in another community. She was unable to attend during the winter months because of poor road conditions.

Regular checkups. Four caregivers were unable to see a physician because there were none available in their communities. Two caregivers had physicians nearer to their communities, but they were so busy that they were frequently unable to get in to see them:

> P076 I mean, he's been the only doctor around here now for about two years. So to get in to see him, [there is] a six month waiting list. And it is almost impossible to get [another physician] here ... just because it's in the middle of nowhere … not close to any major cities. When you're a rural doctor, you see everything, right? And some doctors just like to be specific in what they're dealing with.

One caregiver had recently moved to her rural community and was unable to see a physician:

> P079 There is a complete shortage of doctors in [town]. Doctors are completely overloaded and people that move to [town] now can't get a doctor and so people just end up going to emergency just to see a doctor.

Another caregiver lived in a small town that was using the Alberta rural physician initiative to try and bring in physicians, but they were having difficulty due to the lack of affordable housing:

> P167 Small towns are hard because we don't have a lot of apartment buildings for a lot of single people to move in. So we are having problems getting doctors to come here.

Distance and weather were an issue for one caregiver who had to drive several hours to see her physician; because this took much of her day, she had to plan several months in advance. If her appointment was in the winter and the roads were bad, she simply would not go; it was not worth the risk.

Policy factors. Policy factors were related to various government levels and ministries.

Increasing physical activity. Government initiatives encouraged caregivers to increase their physical activities. Eleven caregivers identified that they had seen ParticipACTION © commercials that reminded them to increase their physical activity. ParticipACTION © is a Canadian government (Minister of State – Sport) funded organization whose vision includes promoting healthy living and physical fitness. This organization has helped fund Body Break ©, which are 90 second television and radio segments about ways to keep fit (ParticipACTION, 2013):

> P169 [They just remind you] that it doesn't take much and that you don't have to have the big gym equipment, you don't have to have the trainer working with you, you know. Just being out, and moving around, just getting out playing with your kids is exercise.

Government funded (municipal, provincial, and/or national) recreational facilities, walking trails, biking trails, etc. that were easily accessible helped four caregivers to be physically active. Three caregivers' municipal governments subsidized various community activities, including yoga, aerobics, and services in a multiplex:

> P008 So [right now] we walk the malls and walk outside. But now with this [discount], I am definitely going to check it out because we can go use the gym and swimming pool during our family night. [Now] I can definitely afford it.

A policy barrier was related to the cost of exercising. Two of the seven caregivers who were unable to afford organized or commercial physical activities also talked about wanting to be able to claim their costs for exercise/activities on their income tax similar to what they were able to do for their children. One of these caregivers felt that it made no sense for the Canada Revenue Agency (2014) to encourage children to participate in physical activities by offering tax incentives; it was just as important for caregivers since they were their children's role models:

> P169 We need to be active to teach our kids to be active. We need to be healthy because [otherwise] there's nobody to look after our kids.

Healthy eating. Six caregivers were able to make healthy food choices because of Health Canada's (2014) regulations requiring standardized food labels on pre-packaged food. Caregivers were able to compare products to help them make healthy choices. While not required in Canada (Center for Science in the Public Interest, 2013), several restaurant chains posted nutritional information and/or calorie counts in their facilities or on their websites, which enabled four caregivers to make healthy choices when eating out:

> P044 I've done that with, for example, Tim Horton's on their website. If you go onto their website you can find out the nutritional breakdown of all of their products. It's fast food, but at least you can find out which things have the most salt in it, which things have the most fat in it, which things have the most sugar in it. And then make the [decision].

The Canada Food Guide (Health Canada, 2007) helped 12 caregivers with decisions about portion sizes and the number of servings recommended from each of the five food groups when planning meals for themselves and their families. Four caregivers also got ideas for healthy eating from Body Break © commercials on television – these include simple recipes that were easy for them to follow.

Lack of legislation from the Alberta Minister of Health requiring restaurants to list calories and nutrient content of food in their facilities was a policy barrier for nine caregivers.

Some restaurants did list calories, but lack of information about sodium, sugar, and fat content made it difficult to make healthy choices.

Regular checkups. A policy facilitator for six rural caregivers that improved availability of physicians was the Alberta Health funded Alberta Rural Physician Action Plan (RPAP, 2014). One caregiver indicated that six physicians were now practicing in her small town as a result of the initiative; she had no difficulty getting in to see a physician for a checkup because she could go to see one of the other physicians if her physician was not available. This had not been the case two years ago when there was only one physician. Another caregiver spoke of a local initiative to address the loss of her community's physicians:

> P167 Well they're trying to implement that here … a lot of our physicians are retiring and two of our physicians are leaving to go and work in New Zealand. So the town is using money from the initiative to bring new physicians in from New Zealand to cover while they're gone. So I hope we're having four to five new ones coming.

However, the length of contracts was an issue; while the rural physician initiative worked to bring more physicians in to some small towns, the ending of a contract for a physician meant that another physician had to take on their workload. One caregiver had to wait almost six months for an appointment for a checkup because the only physician near her community was overbooked:

> P076 At one time there were two doctors. I just went to the other one if he was booked. He wasn't my regular doctor but he was really good. He had just come to [name of town]; he signed a contract for two years and then he was gone again. So now I have to wait.

Summary

Urban and rural caregivers in this study reported a number of similar facilitators and barriers to increasing their physical activity, eating a healthy diet, achieving a healthy weight, and getting regular checkups. Facilitators included knowledge about how to increase their health promoting behaviors, role modeling health promoting behaviors, engaging in behaviors with their families, information from their children's schools, having the money to engage in health promoting activities, safe neighborhoods, and government initiatives that encouraged health promoting behaviors. Barriers included lack of knowledge and motivation, lack of time due to family and work demands, a lack of social support, being unable to afford to engage in health promoting behaviors, and a need for government policies that promoted healthy behaviors.

Similarities between urban and rural caregivers included factors related to caring for their child with a disability. The most common facilitator of health promoting behaviors was the need for caregivers to stay healthy so that they could continue to meet the long-term care needs of their child. The most common barrier to health promoting behaviors was lack of time due to the numerous appointments, therapies, and programs needed by their children. Lack of respite and child behaviors were also issues.

There were some differences between urban and rural caregivers. Readily available health promoting services and programs was a factor unique to urban caregivers; however, availability of many fast food restaurants was a barrier to healthy eating. Unique facilitators experienced by rural caregivers included the availability of gardens and livestock, as well as the Alberta Health facilitated rural physician initiative. The most commonly reported barriers for rural caregivers were lack of availability and distance hampered by inclement weather to health promoting programs and services.

Summary

In Phase 1 of this study, quantitative data were used to compare and describe the health and health promoting behaviors of caregivers of children with disabilities living in Central Alberta. Results indicated that there were more similarities than differences between the urban and rural samples. Four statistically significant differences were found: more urban caregivers had given up employment to care for their child; rural caregivers traveled further to access their own and their child with a disability's physicians and were more likely to be overweight or obese. An exploratory factor analysis found that rural caregivers had lower scores on the Health Responsibility subscale of the HPLP II.

Purposive selection using maximal variation strategies were used to select respondents from Phase 1 for the qualitative telephone interviews in Phase 2 of the study. The findings from these interviews provided an insight into what caregivers considered when rating their health;

similar to the literature, all caregivers considered their physical health. Unexpectedly, few caregivers considered their mental health.

There were more similarities than differences in what helped and what hindered these urban and rural caregivers to engage in health promoting behaviors. For all caregivers, raising a child with a disability and residential location offered a combination of both facilitators and barriers to health promoting activities. Implications of the quantitative and qualitative results will be integrated in the discussion chapter, along with methodological insights gained from employing a sequential explanatory mixed methods design.

Chapter 5: DISCUSSION

The purpose of this sequential explanatory mixed methods (Creswell, 2009) study was to describe and compare the health, health promoting behaviors, and facilitators and barriers to health promoting behaviors of urban versus rural primary caregivers of children with disabilities living in Central Alberta. Similarities and differences between urban and rural caregivers, implications of key findings from both phases of the study, strengths and limitations, reflections on the utility of the conceptual framework, and plans for dissemination of findings are presented in this chapter.

Urban-Rural Similarities and Differences

Overall, there were more similarities than differences evident in urban and rural caregiver characteristics, caregiver health, caregiver health promoting behaviors, and facilitators and barriers to health promoting behaviors. The most important similarities and differences are presented; where appropriate, citations for studies that reported similar results are included.

Similarities

Self-reported health. The majority of both urban and rural primary caregivers in this study reported their health as good to excellent, which is similar to results from the 2006 PALS (Statistics Canada, 2008) and other studies (Flom-Meland, 2004; Kuster, 2002; Neufeld, 1997). Both urban and rural samples were well educated; higher levels of education have been associated with higher levels of health literacy and increased reception to health prevention messages (Tjepkema, Wilkins, & Long, 2012). In contrast to national studies comparing the health of urban and rural Canadians, rural caregivers did not report poorer health (CIHI, 2006a; Hanvey, 2005; Lavergne & Kephart, 2012; MACRH, 2002).

This is the first study to determine what primary caregivers of children with disabilities considered when rating their health. Similar to other studies of adults (Idler et al., 1999; Kaplan & Baron-Epel, 2003; Krause & Jay, 1994), all caregivers primarily considered their physical health. The other most common aspect identified was their frequency of engagement in health promoting behaviors (Idler et al., 1999; Krause & Jay, 1994).

Obesity. The majority (60.5%) of both urban and rural primary caregivers in this study were overweight or obese, which is higher than the prevalence for both Albertans (52.7%) and

Canadians (52.3%) (Statistics Canada, 2013c). Being overweight or obese is associated with an increased risk for diabetes, hypertension, dyslipidemia, cardiovascular disease, osteoarthritis, and certain types of cancer; all of these increase morbidity and mortality (Health Canada, 2012; Luo et al., 2007; Maclagan et al., 2014; Obesity Canada, 2006; WHO, 2013). Facilitators to maintaining or achieving a healthy weight included cutting back on intake; limiting portion sizes; and eating frequent, small meals (Cometto, 2011; Corbalan et al., 2009; Webber & Loescher, 2013). Barriers included frustration with unsuccessful attempts at weight loss; reluctance to track calories, count points, and weigh food; and feeling hungry while dieting (Cometto, 2011; Corbalan et al., 2009; Kruger, 2009; van Zandvoort et al., 2009).

Causes of obesity are complex and multi-faceted (Mauro, Taylor, Wharton, & Sharma, 2008); sleep and stress are factors to consider. Urban and rural caregivers in this study reported getting adequate sleep 3.6 days per week; others have reported sleep issues in caregivers of children with disabilities (Bourke-Taylor, Pallant, Law, & Howie, 2013b; Hemmingsson et al., 2008; Morelius & Hemmingsson 2013; Robinson & Richdale, 2004; Statistics Canada, 2008). Lack of sleep can result in higher amounts of hormones that increase hunger and lower amounts of hormones that decrease hunger (Boutcher & Dunn, 2009; Elder et al., 2012; Nielsen et al., 2011; van Zandvoort et al., 2009). Sleep disruptions and stress also increase cortisol levels, which encourages fat storage (Talbott, 2007).

Stress. The majority (52.5%) of urban and rural primary caregivers rated their daily stress as ‘quite a bit’ to ‘extremely’ stressful. This is higher than findings in the 2006 PALS (45.5%) (Statistics Canada, 2008) and over twice the rate of Canadians (23.2%) and Albertans (23.9%) (Statistics Canada, 2013c). Contrary to other studies (Idler et al., 1999; Krause & Jay, 1994), only five of 20 caregivers considered their mental health when rating their health. This was surprising given the amount of stress reported by caregivers in this and other Canadian studies (Statistics Canada, 2008; Turcotte, 2013). Part of the reason for this finding in this study may be due to the fact that 60% of caregivers reported being able to manage their stress. Contrary to other Canadian findings (CIHI, 2006a), rural primary caregivers did not report less stress than their urban counterparts.

The stress incurred may be due to the number of hours that they provide care to their child with a disability – in a 24 hour period, urban and rural primary caregivers provided 10.8 hours of care on weekdays and 13.9 hours of care on weekends. Results from the 2012 GSSCCR found that 29% of caregivers of children with special health care needs provided 30 hours or more of care per week (Turcotte, 2013). Lack of time has also been shown to be a barrier to obesity management; time is needed to engage in physical activity, as well as to plan and prepare healthy meals (Mauro et al., 2008). About 82% of caregivers of children in the 2012 GSSCCR were worried or distressed because of their caregiving responsibilities and 51% of those who provided care to their child reported a number of symptoms of psychological distress (Turcotte, 2013; Woodman, 2014).

Rates of depression reported by both urban and rural primary caregivers in this study were 33.5% compared to 11.3% of Canadians aged 15 and older in the 2012 Community Health Survey – Mental Health (Pearson, Janz, & Ali, 2013). Several studies have found an association between stress and depression in caregivers of children with disabilities (Gallagher, Phillips, Oliver, & Carroll, 2008; Hamlyn-Wright et al., 2007; Ketelaar et al., 2008; Phetrasuwan & Miles, 2009). Depression among caregivers is especially concerning given that maternal depression has been associated with poor child outcomes due to the effect of depression on parenting qualities (Letourneau, Tramonte, & Willms, 2013).

Financial health. Caregivers who spend 20 hours or more a week on caregiving duties have reported a poor balance between life and work (Sinha, 2013). In this study 29% of caregivers were employed full time, which is similar to findings of other studies of caregivers of children with disabilities (Bourke-Taylor, Howie, & Law, 2011; Kuhlthau et al., 2010; Olsson & Hwang, 2006; Statistics Canada, 2008; Svedberg et al., 2010). In Canada in 2012, 79% of mothers with children aged 6 to 15 were part of the employed workforce (Statistics Canada, 2014), compared to 69.5% in this study. Forty-eight percent of caregivers had given up some employment at some point in time because of the care needs of their child with a disability. Similar results were found in the PALS (Statistics Canada, 2008), the 2012 GSSCCR (Turcotte, 2013), and other studies

(Bourke-Taylor et al., 2011; Burton et al., 2007; Fast, Dosman, Lero, & Lucas, 2013; Gallagher et al., 2009; Kuhlthau et al., 2010; Shearn & Todd, 2000; Svedberg et al., 2010).

The reduction in paid employment is concerning given that studies have found that working outside of the home is associated with better health in mothers of children with disabilities (Bourke-Taylor et al., 2011; Hunt, 2012; Morris, 2014; Olsson & Hwang, 2006) and in mothers of typically developing children (Frech & Damaske, 2012). A reduction in paid work hours caused 14% of caregivers in the 2012 GSSCCR to lose extended health benefits, dental benefits, life insurance, prescription drug coverage, and employer subsidized pensions (Sinha, 2013). These employment consequences and additional financial costs can continue even when these children with disabilities become adults (Keating, Lero, Fast, Lucas, & Eales, 2013); all of these may have a further negative impact on caregivers when they retire (Burton et al., 2007).

The median family income of caregivers in this study was $70,000 to $79,000, which is slightly lower than the median family income of the rest of Albertans in 2011 of $89,830 (Statistics Canada, 2013e). Contrary to other findings (Burns et al., 2007; Keefe et al., 2006; Leipert, 2006; 2008a; MACRH, 2002; Singh, 2004; Sutherns et al., 2004), the median family income of rural caregivers was $10,000 higher than urban caregivers. One possible reason for this was that significantly more urban than rural caregivers had given up employment at some point in time because of the care needs of their child with a disability. It may be that rural caregivers were more easily able to adjust their work routine on farms and acreages to accommodate their children's care. More than 75% of both urban and rural caregivers had additional health insurance, which is contrary to previous findings that rural Canadians are less likely to have supplemental health insurance (Leipert, 2006).

Health promoting behaviors. The majority of both urban and rural primary caregivers either did not change or were doing more to improve their health since their child's diagnosis with a disability. The Health Promoting Lifestyle Profile II (HPLP II) was used to assess engagement in health promoting behaviors. There was no significant difference between urban and rural primary caregivers in the total scale score or in any of the subscales, with the exception of the Health Responsibility subscale.

Regular checkups. Many urban and rural primary caregivers said that getting regular checkups was not a priority; they ranked it eighth overall when identifying health promoting behaviors that they intended to do in the next 12 months to improve or maintain their health. Facilitators included non-negotiable work and school requirements, as well as reminders from physician's offices about the need for annual physical exams (Everett et al., 2011). Barriers included that many physicians only worked during the day and that caregivers were reluctant to take time off work due to a sense of responsibility to their employers. Physicians were often too booked up to be able to make appointments at a convenient time; most complete physical checkups had to be booked months in advance. The CIHI (2012; 2013) reported that in 2010, 33% of Canadians reported waiting six days or more for an appointment with a doctor or nurse.

Some caregivers also reported that they were so busy taking their child with a disability to physician and other appointments that they often forgot about taking care of themselves (Kuster, 2002; Mackey & Goddard, 2006; Murphy et al., 2006; Ray, 2002). For some employed caregivers, the need to take time off for their child's numerous physician and therapy appointments made them reluctant to take time off to go to the doctor themselves. In 2012, caregivers of children with special needs in Canada were substantially more likely than other caregivers to have taken time away from their job three or more times in the last 12 months because of caring responsibilities (Turcotte, 2013).

Canadian recommendations for health promoting behaviors. Three additional health promoting behaviors that were based on current Canadian recommendations were also assessed – these included Canadian recommendations for engaging in physical activity to improve health, eating 5 or more servings of fruits and vegetables daily, and eating 6-8 servings of grain products daily according to the Canada Food Guide. There were no significant differences between urban and rural primary caregivers in any of these behaviors; nevertheless, there were some areas of concern.

Increasing physical activity. Only 16% of urban and rural primary caregivers met the Canadian recommendations for adults of engaging in at least 150 minutes of moderate to vigorous intensity aerobic activity a week, in bouts of 10 minutes or more. This is similar to the 15% of

Canadians who met these requirements in the 2007 to 2009 Canadian Health Measures Survey (Colley et al., 2011; Garriguet & Colley, 2012; Statistics Canada, 2013a). Facilitators included that all caregivers interviewed were knowledgeable about the health benefits of being physically active (ACAL, 2011; CFLRI, 2007; Tavares & Plotnikoff, 2008), lived in safe neighborhoods (Kowal & Fortier, 2007), and wanted to take advantage of warm weather (Chan et al., 2006). Government initiatives included Body Break © commercials (Bauman, Madill, Craig, & Salmon, 2004) and infrastructure such as multiplexes and walking/biking trails in some communities (Shill et al., 2012).

Barriers included a lack of knowledge about the amount of exercise needed to achieve health benefits, a lack of motivation, fatigue, other health issues, insufficient monetary resources to pay for the extra cost of physical activities (Adachi-Mejia et al., 2010; Burke et al., 1999; CFLRI, 2007; Kowal & Fortier, 2007; Tavares & Plotnikoff, 2008; Wuest et al., 2002), and fear of injury on ice and snow (Chan et al., 2006; Salmon et al., 2003). Both urban and rural caregivers reported being too fatigued and having no time to engage in physical activity due to the special care needs and therapies of their child with a disability (Kruijsen-Terpstra et al., 2013; Murphy et al., 2006; Wuest et al., 2002). Other barriers included disruptive child behaviors and a lack of respite; while many exercise facilities offered day care, they were unable to meet the needs of children with disabilities (Hoogsteen & Woodgate, 2013).

*Healthy eating***.** Only 22% of primary caregivers met the requirement of having six to eight servings of grain products daily. One reason for this may be that the majority of caregivers were overweight or obese and diets with reduced carbohydrates are helpful in reducing weight (Casazza et al., 2012; Haufe et al., 2012). Barriers to healthy eating were a lack of motivation and having insufficient income to afford healthy food (Burke et al., 1999). Spouses who ate unhealthy foods provided cues for caregivers to also eat unhealthy food (Schmied, Parada, Horton, Madanat, & Ayala, 2014; Timmerman, 1999). Lack of government legislation requiring all restaurants to list calories and nutritional content (e.g. sodium, fat, and sugar) of their food in their facilities was also a barrier to making healthy choices.

Barriers related to caring for their child with a disability included eating “comfort foods” as a way to cope with the stress of the demands of caring for their child (Butcher et al., 2008; Ketelaar et al., 2008). The care needs of their child also prohibited some caregivers from having the time to maintain a garden. Ritualistic behaviors of their children with autism resulted in several primary caregivers going to fast food restaurants after certain activities; failure to do so could result in disruptive behaviors. Behavior issues and food selectivity in children with autism spectrum disorders have been reported by others (Bandini et al., 2010; Emond, Emmett, Steer, & Golding, 2010; Kral, Eriksen, Souders, & Pinto-Martin, 2013; Kral et al., 2014; Rogers, Magill-Evans, & Rempel, 2012; Schmitt, Heiss, & Campbell, 2008).

There was no difference in urban and rural caregivers with reports on eating a healthy diet; 43.5% were either ‘often’ or ‘routinely’ eating five or more servings of fruits and vegetables daily, which is higher than both Albertans (39.6%) and Canadians (40.5%) (Statistics Canada, 2013c). Facilitators included knowledge of the health benefits of eating a healthy diet and planning meals in advance (Garcia et al., 2010; Yeh et al., 2008), wanting to role model healthy eating (Webber & Loescher, 2013), as well as having a spouse or partner who was interested in making good food choices and who provided a second income to be able to afford the cost of produce (Schmied et al., 2014; Yeh et al., 2008). Government initiatives that enhanced healthy food choices included food labels with nutritional information (Garcia et al., 2010), the Canada Food Guide (Health Canada, 2007), and Body Break © commercials that identified easy ways to incorporate fruit and vegetables into their diet (ParticipACTION, 2013). Facilitators related to caring for their child with a disability included the need to eat healthy as a way to maintain their health (Kuster, 2002; Murphy et al., 2006; Shuler, 2000) and having children on special diets, including gluten free (Pennesi & Klein, 2012) and low sodium diets that resulted in their caregivers also eating less processed foods.

Differences

As previously stated, there were more similarities than differences evident in urban and rural caregiver characteristics, caregiver health, caregiver health promoting behaviors, and facilitators and barriers to health promoting behaviors. As such, it would appear that place of residence is not a key factor in understanding the health and health promoting behaviors of most caregivers of children with disabilities. Those few differences that were found are now discussed.

Employment. While yearly family income was similar between urban and rural caregivers, significantly more urban than rural primary caregivers had given up some employment because of the care needs of their child. Possible reasons for this may be that a higher proportion of children with severe to very severe disabilities in this study lived in urban communities or that rural caregivers may have found it easier to continue farm-based work. Care needs have been shown to increase with severity of disability (Hauge et al., 2013; Kuo, Cohen, Agrawal, Berry, & Casey, 2011; Statistics Canada, 2008) and the PALS found that employment was most impacted in caregivers of children with severe to very severe disabilities (Statistics Canada, 2008).

Increasing physical activity. Although there was no significant difference found between urban and rural caregivers in the Physical Activity subscale of the HPLP II, urban and rural caregivers reported different ways of being physically active in the interviews. Rural caregivers were not homogenous in their activity levels; some were physically active working their farms and others had a more sedentary lifestyle (Chrisman, 2013; Frank, Andresen, & Schmid, 2004; Núñez-Córdoba et al., 2013; Olsen, 2013; Olson & Bove, 2006). Urban caregivers had convenient access to readily available sports facilities and paved trails for biking and walking (Shill et al., 2012). Some rural caregivers had limited access to recreational facilities and trainers (CFLRI, 2007), a lack of paved walking/biking trails, no street lights, and worries about being attacked by animals (ACAL, 2008; Chrisman, 2013; Olson & Bove, 2006; Sutherns et al., 2004). Distance to services also resulted in rural caregivers spending a large amount of their time in their vehicles, both for work and for taking children to appointments and other activities; this resulted in limited or no time to exercise (ACAL, 2008; Hoehner, Barlow, Allen, & Schootman, 2012; Núñez-Córdoba et al., 2013). Studies have found that each additional hour spent in a car was associated with an increased likelihood of obesity (Frank et al., 2004; Núñez-Córdoba et al., 2013).

Obesity. Significantly more rural than urban primary caregivers were overweight or obese (Chen et al., 2009; CIHI 2006a; 2006b; Shields & Tjepkema, 2006a; 2006b; Statistics

Canada, 2010b). Masters and colleagues (2013) found that obesity accounted for 18% of deaths between 1986 and 2006 in individuals aged 40 to 85; they suggest that life expectancy estimates need to be reduced due to the rising prevalence of obesity in younger cohorts. Given that being overweight or obese increases both morbidity and mortality, the life expectancy of some rural caregivers may be shorter than their urban counterparts (CIHI 2006a; Greenberg & Normandin, 2011). Higher rates of obesity are likely due to several reasons, but possibilities mentioned in the interviews include limited availability of trails and sports facilities, as well as limited to no availability of weight loss programs in their communities. Those few rural caregivers that did use weight loss programs often had to drive 30 or more minutes to access them; some chose not to attend in the winter when rural roads are treacherous with snow and ice.

Healthy eating. Although there was no significant difference found between urban and rural caregivers in the Nutrition subscale of the HPLP II, the primary difference between urban and rural caregivers who were interviewed was that the availability of healthy, fresh, affordable food was more limited for some rural caregivers. Many grocery stores in rural communities stocked limited fresh produce due to the lack of turnover in their small communities (CIHI, 2006a; Paluck et al., 2006; Sutherns et al., 2004). Access was also seasonal; rural caregivers often had to resort to processed foods in their pantries and local grocery stores due to treacherous rural roads in the winter. Time commuting to activities after school and on weekends was an issue for both urban and rural caregivers, but rural caregivers routinely traveled long distances to work and child activities that conflicted with meal times and fast food was easy and affordable.

Regular checkups. An exploratory analysis of the subscales of the HPLP II found that rural caregivers' scores were significantly lower than urban caregivers only in the Health Responsibility subscale, which includes reporting health issues to health care providers and asking health professionals about how to take better care of themselves. Lifestyle advice by health professionals has been found to be an important contributor to lifestyle change (Brobeck, Bergh, Odencrants, & Hildingh, 2014). Rural caregivers in this study had to drive significantly further to access their physicians (CIHI, 2005; 2006a; 2008); they also refused to drive long distances to see their physicians in inclement weather due to treacherous rural roads (Bowie, 2006; Kirby & LeBreton, 2002).

Lower scores on the HPLP II for some rural caregivers may also be due to the limited availability of health professionals; several rural caregivers reported that they had no physicians in their communities. There are fewer physicians and nurses working in rural and small town Canada (CIHI, 2000; 2005; 2008; Hanvey, 2005; Minore et al., 2008; Sibley & Weiner, 2011). Statistics Canada (2013c) reported that there were 92 physicians/100,000 population in the Central Zone of Alberta Health Services (AHS), which is lower than the number for Alberta (111) and Canada (106). Pong and colleagues (2011) reported that between 35% and 61% of rural residents in Canada had no family doctor compared to 13.2% of urban residents. These findings are not surprising given that this issue was the impetus for the Alberta Health funded Alberta Rural Physician Action Plan (2014).

Ranking of health promoting behaviors. Both urban and rural primary caregivers ranked increasing physical activity and improving eating habits in their top three things that they thought were important to do to improve/maintain their health in the next 12 months. The third most important behavior was different between the two groups; urban caregivers ranked getting more sleep in their top three while losing weight was fourth. One possible reason for this may be that a slightly higher proportion of urban caregivers had children with severe to very severe disabilities and studies have shown that caregivers of children with more complex health issues frequently experience sleep disruptions (Bourke-Taylor et al., 2013a; Hemmingsson et al., 2008). Conversely, rural caregivers ranked losing weight in their top three while getting more sleep was fourth; more rural than urban caregivers were likely to be overweight or obese (Chen et al., 2009; CIHI 2006a; Navaneelan & Janz, 2014; Shields & Tjepkema, 2006a; 2006b; Statistics Canada, 2010b) and had limited access to weight loss programs.

Strengths and Limitations of the Study

This study makes a unique contribution since few studies have compared the health and health promoting behaviors of urban and rural primary caregivers of children with disabilities and no studies have described the facilitators and barriers to health promoting behaviors that urban and rural primary caregivers experience. The results of this mixed method study are an important first step towards advancing the knowledge and understanding of the health and health promoting behaviors of this vulnerable population.

The use of a mixed methods design enabled the investigator to conduct more specifically focused interviews by using the survey findings to generate interview questions. This achieved both a deeper level of data, and demonstrated respect and understanding of the data that caregivers had already provided. Finally, using the Integrated Social Ecology Framework to guide the interviews resulted in a deeper and broader assessment of the complex and multifaceted nature of the facilitators and barriers to health promoting behaviors experienced by these caregivers.

Limitations of the study include that, overall, individuals who responded to the survey were highly educated and most had a spouse or partner – they may not resemble typical primary caregivers in Alberta or Canada. The majority of caregivers were Caucasian and respondents had to be able to read and write English, so findings may not apply to primary caregivers of other ethnicities or those with English as a second language. Caregivers who responded self-selected by responding to the survey and agreeing to an interview; it is possible that the sample might not include caregivers whose health and health promoting behaviors are most seriously affected. Therefore, generalizability and transferability are limited.

The feasible sample size for Phase 2 of the study precluded a full exploration of all themes for all levels of coding – future studies should include larger samples. At the request of the recruiting agency, a question was removed from the survey about whether or not the caregiver’s child had behavior problems. Future studies should include a question about behavioral issues and their impact. An additional limitation is that BMI and reports of healthy eating and physical activity were all based on self-reports, so it is possible that respondents under or over-estimated their behaviors. Finally, it was difficult to compare the ratings of health for these caregivers with national samples because most Canadian surveys include individuals over the age of 65 when summarizing findings, whereas the mean age of caregivers in this study was 41.3 years.

The inclusion criteria for the study were based on the population accessible through FSCD; those are children with “a chronic developmental, physical, sensory, mental or neurological condition or impairment but does not include a condition for which the primary need is for medical care or health services to treat or manage the condition unless it is a chronic condition that significantly limits a child's ability to function in normal living" (Government of Alberta, 2003). This is only a subset of children with disability and/or chronic illness and excludes children with chronic health conditions often included in studies such as the PALS (Statistics Canada, 2008). The PALS used the definition: "an activity limitation or participation restriction associated with a physical or mental condition or health problem" (Statistics Canada, 2007b, p. 8). The PALS definition was informed by WHO's (2001) framework of health and disability that considers disability more broadly, including the relationship between body functions, daily activities, and social participation, within the context of environmental factors. It is likely that caregivers of children with other special health care needs are also experiencing similar facilitators and barriers to health promoting behaviors; future research should include this population.

Implications

Although the complexities of primary caregiver health and health promoting behaviors may not be completely captured in this study, it still has some preliminary implications for practice, policy, program development, and research.

Practice Implications

Children with disabilities are cared for by nurses and other health professionals in a variety of health settings. Given the complexity of the facilitators and barriers encountered by urban and rural primary caregivers of children with disabilities, an interprofessional health care team approach is needed. Members of the team may include but are not limited to social workers, sports medicine specialists, recreational therapists, dieticians, physicians, nurse practitioners, registered nurses, physical and occupational therapists, and pharmacists.

In the context of a lengthening life expectancy for these children, family centered care needs to include attention to the health and health promoting behaviors of these primary caregivers. Individualized assessments of primary caregiver health need to include screening to address the increased prevalence of stress, depression, and obesity, which have all been shown to increase morbidity and mortality. Health professionals need to partner with these caregivers and their families to identify strategies to decrease stress, alleviate depression, and diminish barriers to weight loss that fit with their individual circumstances. Physical activity has been shown to help reduce the risk of these and other chronic diseases (CNA, 2011). In partnership with caregivers, health professionals can then provide health information and identify strategies to increase health promoting behaviors.

One also needs to be aware of the societal stigma of obesity and the unrealistic views that society has about body image (Puhl & Heuer, 2009). Health professionals need to screen caregivers by initially calculating their BMI; however, it is important to note that not every caregiver who is overweight may be experiencing health issues. Those caregivers whose BMI is greater than 25 (WHO, 2013) should be encouraged to have regular checkups and to have their blood pressure, glucose, lipid profile, and other bloodwork routinely monitored by a health professional due to their increased risk for hypertension, diabetes, dyslipidemia, cardiovascular disease, arthritis, and certain types of cancer (Health Canada, 2012; Luo et al., 2007; Maclagan et al., 2014; Obesity Canada, 2006; WHO, 2013). Furthermore, due to the multiple causes of obesity, telling caregivers to lose weight will not be effective unless other contextual factors are addressed. Given the findings from this study, teaching caregivers knowledge and skills regarding time and stress management are just as important as portion control, healthy eating, and exercise (Mauro et al., 2008). Health professionals also need to provide weight management interventions and support that are evidence-based, individually tailored, and implemented over the long-term (Kirk, Penney, McHugh, & Sharma, 2012).

While most caregivers were knowledgeable about the benefits of various health promoting behaviors, motivation was an issue for several caregivers regarding all four health promoting behaviors. Lack of motivation may be linked to the barriers that they experience to improving their health; health professionals need to assess the particular facilitators and barriers to health promoting behaviors experienced by each caregiver. Health professionals can incorporate strategies such as motivational interviewing that incorporates a client-centered approach to help break down behavioral change into manageable tasks. Once a health behavior change is identified, health professionals can provide caregivers with both the knowledge and skills needed to make the change (Dart, 2011; Hardcastle, Taylor, Bailey, Harley, & Hagger, 2013; Thompson et al., 2011). Other strategies include providing support to caregivers in rural communities with limited availability of services and programs. Since most caregivers had access to the internet, a website could be developed with links to relevant resources suggesting ways to improve health and to promote engagement in health promoting behaviors. Several weight loss programs also offer their services online; health professionals need to provide access to these services, while also developing support networks as resources to address lack of progress or other issues. For those caregivers not needing face to face support, other methods of dispersing education, skills, and support could include telehealth and video conferences. Caregivers can also be linked to social and other media sites where they can communicate with other caregivers for support and information about strategies to improve their health and to increase their engagement in health promoting behaviors.

As illustrated in this study, caregivers may be experiencing barriers to health promoting behaviors that are beyond their control. Given the complexity of these issues, health professionals caring for children with disabilities and their families will need to take on a more multifaceted approach to health promotion. For example, efforts towards health promotion need to be focused not only on the individual caregiver; family centered care that includes all members of the family when discussing the benefits of increasing physical activity, eating a healthy diet, achieving a healthy weight, and getting regular checkups is needed if interventions are to be successful. Health professionals also need to understand that some rural caregivers may have differing abilities to engage in health promoting behaviors due to the lack of services and programs in their communities. Therefore, community assessments and determination with and for rural caregivers of alternative resources is required. Doing an individualized assessment with each caregiver using a social ecology framework to assess facilitators and barriers to health promoting behaviors is needed if appropriate interventions are to be developed.

Caregivers also experienced a number of challenges to getting regular checkups; health professionals need to make primary caregivers aware of the importance of prioritizing their own health if they are to continue to care for their child with a disability over the long-term. Health professionals should lobby programs such as FSCD to fund respite so that caregivers can take the time to get checkups so that they can be made aware of and address health issues such as obesity, stress, and depression. Nurse practitioners practicing in rural communities can also be used to reduce wait times and to facilitate access and availability for caregivers to getting regular checkups. Leipert, Delaney, Forbes, and Forchuk (2011) found that rural Canadians in southwest Ontario were overwhelmingly satisfied with the care provided by nurse practitioners. Collaborative practice with other rural health care providers, including physicians and public health nurses, is another feasible alternative requiring exploration.

Health Care Policy and Programs

While study replication is needed to verify results, the results from this study provide preliminary evidence that health prevention and promotion programs should be developed for both urban and rural primary caregivers of children with disabilities. Due to the multidimensional nature of the facilitators and barriers to health promoting behaviors experienced by these caregivers, multi-level interventions need to be developed to address both caregivers and components of their environment. Therefore, it is critical that any programs or policies developed to address the concerns identified in this dissertation take a social ecological approach (Richard & Gauvin, 2012). Change needs to be affected at the individual, family, organizational, community, and policy level in order to be effective in influencing sustainable changes in health promoting behaviors as facilitators and barriers were identified regarding each of these levels of factors. Building community capacity will need to start with community participation – program developers and researchers will need to partner with caregivers and key individuals in their communities so that their specific health and health promoting needs are considered at all levels of program planning, implementation, and evaluation (Flaman, Plotnikoff, Nykiforuk, & Raine, 2011; Habjan, Kortes-Miller, Kelley, Sullivan, & Pisco, 2012). Programs also need to be tailored to address caregivers with limited incomes.

Small rural communities have limited populations contributing to their tax base, so it is not feasible that all communities could acquire funding to build multiplexes or other infrastructure to promote physical activity. One possible lower cost alternative may be to have local school gymnasiums available during the evening or weekends to promote physical activity in the winter (Shill et al., 2012). The government currently allows Canadians to claim up to a maximum of $500 per child related to the cost of prescribed programs of physical activity (Canada Revenue Agency, 2014); tax incentives for adults may enable caregivers to engage in and to role model physical activities. A survey by the Alberta Centre for Active Living (2011) indicated that 75% of Albertans would use this partial tax relief on annual fees for physical activities; health professionals working with caregivers of children with disabilities could partner with families in lobbying government for this tax benefit. Lobbying could also include discussions with key individuals at FSCD about making respite services available to primary caregivers so that they can participate in physical activities to improve their health.

Primary caregivers in both urban and rural settings spent a lot of time commuting; this often conflicted with meal times. For many caregivers, a fast and economical alternative to sitting down for a meal was picking up food at fast food restaurants to eat while commuting. Overall, caregivers were aware of the need to choose healthy options when eating out. However, they were not always able to make healthy choices because nutritional content of food was not available in the restaurant. The Government of Ontario recently advanced Bill 149, *The Healthy Decisions Made Easy Act,* requiring chain restaurants with 20 or more locations in the province to post calorie and sodium content on their menus (Legislative Assembly of Ontario, 2014). The Minister of Health for Alberta needs to develop legislation that mandates restaurants to post in their facilities nutrition content – including calories, sodium, sugar, and fat – of the food that they serve (Center for Science in the Public Interest, 2013). While some restaurants do this voluntarily, legislation is needed to require this for all chain and other restaurants as one way of facilitating healthy meal choices.

Strategies also need to be developed to address the continued gap in availability of physicians and nurse practitioners in rural Alberta. Several of the 10 rural caregivers interviewed were unable to get regular checkups because of the lack of availability of physicians in their community. Primary caregivers who are experiencing both acute and chronic health problems related to obesity, stress, and depression need access to both programs and health professionals in their communities if they are to continue to provide care to their child with a disability over the long-term. Therefore, policies and legislation from Alberta Health Services that facilitate the inclusion of nurse practitioners in rural practice are needed; attention is needed to the barriers that impede deployment and integration of this role (Martin-Misener, Reilly, & Vollman, 2010). To ensure that these practitioners remain in rural communities, professional resources, support, and networking should be facilitated through technology such as videoconferencing to decrease professional isolation (Habjan et al., 2012).

A final caveat should be noted; no generalizations or conclusions can be drawn from this study about the respective health merits of city or country life. Not all urban communities have all levels of services and programs and some rural communities are very well-resourced (Monette, 2012). Given these differences, it would be counterintuitive to take a one-size-fits-all approach to health program and policy development. For this reason, and due to the complexity of these caregivers' lives and the diversity in the services available in their communities, there is a need for a collaborative, inter-ministerial approach to program and policy development (Wiart et al., 2010). In Alberta, inter-ministerial collaboration to address the aforementioned issues would include Health; Human Services; Agricultural and Rural Development; and Tourism, Parks, and Recreation, to name but a few.

Future Research

This study, one of the first to assess and compare the health, health promoting behaviors, and facilitators and barriers to health promoting behaviors of urban and rural primary caregivers of children with disabilities in Canada, clearly indicates that more research is needed on this and other topics. Studies are also needed to assess the effectiveness of the aforementioned recommended practice, program, and policy initiatives. For example, does posting nutrition information in large chain restaurants result in caregivers making healthier meal choices?

Issues with self-report can be avoided with studies similar to the Canadian Health Measures Survey (Statistics Canada, 2011a) that obtains blood work, weights, and waist circumference, as well as uses accelerometers or pedometers to measure physical activity (Garriguet & Colley, 2014). Future research also needs to assess the long-term impact of career loss to these caregivers and to determine barriers to maternal workforce participation, as well as investigation of services needed to support their employment.

In both the urban group and the rural group some caregivers were doing very well, while others were struggling. In both groups some were in good health and participating in a number of health promoting behaviors while others were struggling to engage in health promoting behaviors for a variety of reasons. Recommendations include doing studies to determine those factors that contribute to the resilience in those caregivers who are doing well as a way to inform the development of interventions to help caregivers whose health and health promoting behaviors are most at risk. Given the many similarities between the urban and rural samples, it would appear that studying urban families separate from rural families may not assist in identifying those families that are having the most challenges. As such, there is a need to develop and evaluate assessments that facilitate the identification of these at risk caregivers.

Future studies assessing the health and health promoting behaviors of primary caregivers should also include a question about behavioral issues of the child with a disability as previous studies have shown that child behavior issues are significantly associated with poorer caregiver health (Bourke et al., 2008; Eisenhower et al., 2009; Gallagher et al., 2009; Lach et al., 2009; Laurvick et al., 2006). Future research should include larger samples to facilitate multiple regression to test the predictive value of child behavior issues and other variables that have been shown to affect caregiver health. Findings from Phase 2 indicated that child behaviors impacted caregivers` ability to increase physical activity, to eat a healthy diet, and to get regular checkups. Studies should be done to identify and determine the effectiveness of interventions designed to minimize the effect of these behaviors on the health and health promoting behaviors of these caregivers.

Providing caregivers with the motivation and skills to change their health promoting behaviors will be ineffective if their environment makes it difficult or impossible to engage in these behaviors. Using a social ecology model as a framework for future studies will facilitate understanding of the multiple influences on the health promoting behaviors of urban and rural caregivers of children with disabilities, including the care needs of their other children without disabilities. Ecology models are also most powerful when they are specific to certain behaviors (e.g. laws preventing public smoking may not promote exercise). Multi-level interventions designed from these studies can result in sustainable health promoting behaviors that are maximized with environments and policies that support healthy behaviors.

It is also important to acknowledge the multiple daily demands faced by some of these caregivers and to be wary of imposing more demands on individuals who are already at the maximum of their capabilities. While it would be unethical to not do research on ways to promote the health and health promoting behaviors of this vulnerable population, it is just as critical to partner with these caregivers to determine what exactly is feasible for them to do. In that way, interventions can be designed that promote their health without further taxing their already limited resources.

Conceptual Framework

The Integrated Social Ecology Model (Bronfenbrenner, 1979; Flack, 2009; McLeroy et al., 1988; Sallis et al., 1998) was used as a framework for this study. Overall, the principles of the model were useful in fully exploring the contextual factors that influenced primary caregiver health promoting behaviors. These included factors related to both urban and rural living, as well as factors related to caring for a child with a disability. Furthermore, caregivers reported other intrapersonal, interpersonal, organizational, community, and policy facilitators and barriers to improving/maintaining their health.

There were pros and cons to using the model. Using the various elements of the model to guide the interviews allowed the investigator to develop a deeper and broader understanding of the multitude of facilitators and barriers to health promoting activities experienced by these primary caregivers. However, the model did not include technology as a potential facilitator or barrier and it was difficult to categorize data regarding how technology helped and hindered caregivers in their health promoting behaviors. In this study, technology was subsumed under intrapersonal factors since phone applications provided caregivers with knowledge to help them make healthy meal choices. However, the municipal government in one city included in this study is working to acquire more internet access since their population has limited access, also making this a community factor. A suggestion to update the model would be to have another category for technology factors that influence health promoting behaviors, including internet access, media, social media, phone applications, websites, and other online resources/programs (Korda & Itani, 2013). Another issue was that some concepts did not support clear deductive coding with mutually exclusive categories, thus requiring interpretation and presentation of overlapping categories. For example, monetary resource barriers could be categorized as intrapersonal (being too tired to exercise after work), interpersonal (lack of a partner to contribute to family income or being unable to work because of care needs of the child with a disability), or organizational (having a low paying job with few benefits or days off). This also illuminates the need for multi-level factors/categories.

Plans for Dissemination of Findings

The Canadian Institutes of Health Research (2013) outlines a four-point process for knowledge translation that includes synthesis, dissemination, exchange, and ethically sound application of knowledge to accelerate the benefits of knowledge in the improvement of the health of Canadians. While the quality of the studies was not assessed in-depth, knowledge synthesis of the health, health promoting behaviors, and facilitators and barriers to health promoting behaviors of primary caregivers of children with disabilities occurred during the review of the literature and while comparing results to previous findings in the discussion section of this study. Results garnered from this study will be disseminated to key audiences, including nurses and other health professionals who work with primary caregivers of children with disabilities, through presentations and peer-reviewed publications. Given that the health promoting behaviors of primary caregivers of children with disabilities has received scant attention to date, it is anticipated that further research in this field by other health professionals will help move this knowledge forward. Dissemination will also include plain language summaries that will be sent out to participants in the study and, with assistance from FSCD, to all caregivers and their families in Central Alberta. Results of the study will also be discussed with program and policy developers at FSCD, Primary Care Networks in Central Alberta, AHS, and the ministry of Human Services. Exchange of ideas and mutual learning will occur when results of the study are shared with these key stakeholders. Processes for sharing information will include both didactic and interactive sessions, small group learning activities, and blended learning such as videos and self-directed learning modules (Davis & Davis, 2009).

As a full time instructor at Red Deer College, the investigator will use this dissertation as a foundation to build a program of research on the health and health promoting behaviors of primary caregivers of children with disabilities. Program development, implementation, and evaluation developed in partnership with urban and rural caregivers, their families, government, and key individuals in their communities can promote community capacity and result in the ethically sound application of the findings from this study. Key messages and interventions for health promotion that are tailored to both their unique needs and contexts will facilitate community capacity and ultimately improve their health.

Conclusion

Overall, caring for children with disabilities in the family home is considered beneficial, both to the child and family. Findings from this study provide preliminary evidence that providing such care can have consequences – both positive and negative – on the health promoting behaviors and ultimately the health of some of these primary caregivers. The quantitative data provided details of a generalized pattern of overall good health and some participation in health promoting behaviors. The qualitative data provided more depth to these findings; they support the notion that facilitators and barriers to increasing physical activity, healthy eating, achieving a healthy weight, and getting regular checkups experienced by these caregivers are multidimensional and complex.

The knowledge gained from this study provides an initial understanding of the impact that both context and having a child with a disability has on primary caregiver health promoting behaviors and subsequently caregiver health. As such, there is a need for nurses, other health professionals, and communities to partner with primary caregivers of children with disabilities to develop, implement, and evaluate individualized health promotion programs that consider caregivers' particular needs for maintaining and improving their health. These programs need to accommodate for the uniqueness of each caregiver's circumstances as well as for differences in the health and health promoting resources that exist between some urban and rural communities.

In summary, doing a mixed methods study based on a social ecology model was both rewarding and challenging. It was rewarding in that the use of a mixed methods design enhanced understanding of the complex issues faced by these primary caregivers beyond that which would have been elucidated using a single quantitative or qualitative approach. However, it was also challenging – the scope and length of time to complete the study was significant. Still, this challenge is something that researchers working with primary caregivers of children with disabilities should welcome since it is clear that strategies to enhance health promoting behaviors need to include multi-level interventions if they are to be effective in maintaining or improving caregiver health.

References

Adachi-Mejia, A. M., Drake, K. M., Mackenzie, T. A., Titus-Ernstoff, L., Longacre M. R., Hendricks, K. M., Beach, M. L., Dalton, M. A. (2010). Perceived intrinsic barriers to physical activity among rural mothers. *Journal of Women's Health, 19*(12), 2197-2202. doi:10.1089=jwh.2009.1879

Ader, R., & Cohen, N. (1995). Psychoneuroimmunoloygy: Interactions between the nervous systems and the immune system. *The Lancet, 345,* 99-103.

Alberta Centre for Active Living. (2008). *Physical activity for all: Understanding inclusion.* Retrieved from http://www.centre4activeliving.ca/physical-activity-for-all/project/summary.pdf

Alberta Centre for Active Living. (2011). *2011 Alberta survey on physical activity: A concise report.* Retrieved from http://www.centre4activeliving.ca/publications/ab-survey-physical-activity/2011-report.pdf

Alberta Rural Physician Action Plan. (2014). *RPAP: The Alberta rural physician action plan.* Retrieved from http://www.rpap.ab.ca/

Allik, H., Larsson, J., & Smedje, H. (2006). Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. *Health and Quality of Life Outcomes, 4,* 1-8. doi:10.1186/1477-7525-4-1

Alvaro, C., Jackson, L. A., Kirk, S., McHugh, T. L., Hughes, J., Chircop, A., & Lyons, R. F. (2010). Moving governmental policies beyond a focus on individual lifestyle: Some insights from complexity and critical theories. *Health Promotion International, 25,* 1-9. doi:10.1093/heapro/daq052

Anderson, D., Dumont, S., Jacobs, P., & Azzaria, L. (2007). The personal costs of caring for a child with a disability: A review of the literature. *Public Health Reports, 122,* 3-16.

Armstrong, P. (2007). Relocating care: Home care in Ontario. In M. Morrow, O. Hankivsky, & C. Varcoe (Eds.), *Women's health in Canada: Critical perspectives on theory and policy* (pp. 528-553). Toronto, Ontario, Canada: University of Toronto Press.

Bailis, D. S., Segall, A., & Chipperfield, J. G. (2003). Two views of self-rated general health status. *Social Science and Medicine, 56,* 203-217.

Bailis, D. S., Segall, A., Mahon, M. J., Chipperfield, J. G., & Dunn, E. M. (2001). Perceived control in relation to socioeconomic and behavioral resources for health. *Social Science and Medicine, 52,* 1661-1676.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without development delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47,* 217-230.

Balmford, J., Borland, R., & Burney, S. (2010). The influence of having a quit date on prediction of smoking cessation outcome. *Health Education Research, 25,* 698-706. doi:10.1093/her/cyq013

Bandini, L. G., Anderson, S. E., Curtin, C., Cermak, S., Evans, E. W., Scampini, R., Maslin, M., & Must, A. (2010). Food selectivity in children with autism spectrum disorders and typically developing children. *The Journal of Pediatrics, 157,* 259-264. doi:10.1016/j.jpeds.2010.02.013

Barnidge, E. K., Radvanyi, C., Duggan, K., Motton, F., Wiggs, I., Baker, E. A., & Brownson, R. C. (2013). Understanding and addressing barriers to implementation of environmental and policy interventions to support physical activity and health eating in rural communities. *The Journal of Rural Health, 29,* 97-105. doi:10.1111/j.1748-0361.2012.00431.x

Baum, F. (2008). The commission on the social determinants of health: Reinventing health promotion for the twenty-first century? *Critical Public Health, 18,* 457-466. doi:10.1080/09581590802443612

Baum, F., & Fisher, M. (2014). Why behavioral health promotion endures despite its failure to reduce health inequities. *Sociology of Health & Illness, 36,* 213-225. doi:10.1111/1467-9566.12112

Bauman, A., Madill, J., Craig, C. L., & Salmon, A. (2004). ParticipACTION: This mouse roared, but did it get the cheese? *Canadian Journal of Public Health, 95,* S14-S19.

Beagan, B., Stadnyk, R., Loppie, C., MacDonald, N., Hamilton-Hinch, B., & MacDonald, J. (2005). *Snapshots of the lives of caregivers.* Retrieved from http://www.acewh.dal.ca/eng/reports/TeamP-Report-web.pdf

Bella, G. P., Garcia, M. C., & Spadari-Bratfisch, R. C. (2011). Salivary cortisol, stress, and health in primary caregivers (mothers) of children with cerebral palsy. *Psychoneuroendocrinology, 36,* 834-842. doi:10.1016/j.psyneuen.2010.11.005

Bencivenga, R. (2012). *Nursing statistics: Methods and concepts for professional nurses.* Edmonton, Alberta, Canada: Fast Track Technologies.

Benjak, T., Mavrinac, G. V., Simetin, I. P. (2009). Comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia. *Croatian Medical Journal, 50,* 403-409. doi:10.3325/cmj.2009.50.403

Benjamins, M. R., Hummer, R. A., Eberstein, I. W., & Nam, C. B. (2004). Self-reported health and adult mortality risk: An analysis of cause-specific mortality. *Social Science and Medicine, 59,* 1297-1306. doi:10.1016/j.socscimed.2003.01.001

Benson, A., & Latter, S. (1998). Implementing health promoting nursing: The integration of interpersonal skills and health promotion. *Journal of Advanced Nursing, 27,* 100-107.

Benyamini, Y., & Idler, E. L. (1999). Community studies reporting association between self-rated health and mortality: Additional studies, 1995 to 1998. *Research on Aging, 21,* 392-401. doi:10.1177/0164027599213002

Benyamini, Y., Idler, E. L., Leventhal, H., & Leventhal, E. A. (2000). Positive affect and function as influences on self-assessments of health: Expanding our view beyond illness and disability. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 55*(2), P107-P116.

Benyamini, Y., Leventhal, H., & Leventhal, E. A. (1999). Self-assessments of health. *Research on Aging, 21,* 477-500. doi:10.1177/0164027599213007

Bosak, J., & Perlman, B. (1982). A review of the definition of rural. *Journal of Rural Community Psychology, 3,* 3-34.

Bourke, J., Ricciardo, B., Bebbington, A., Aiberti, K., Jacoby, P., Dyke, P., Msall, M., Bower, C., & Leonard, H. (2008). Physical and mental health in mothers of children with down syndrome. *The Journal of Pediatrics, 153,* 320-326. doi:10.1016/j.jpeds.2008.02.047

Bourke-Taylor, H., Cotter, C., & Stephan, R. (2013a). Young children with cerebral palsy: Families self-reported equipment needs and out-of-pocket expenditure. *Child: Care, Health and Development,* 1-9. Advance online publication. doi:10.1111/cch.12098

Bourke-Taylor, H., Howie, L., & Law, M. (2011). Barriers to maternal workforce participation and relationship between paid work and health. *Journal of Intellectual Disability Research, 55,* 511-520. doi:10.1111/j.1365-2788.2011.01407.x

Bourke-Taylor, H., Pallant, J. F., Law, M., & Howie, L. (2013b). Relationships between sleep disruptions, health and care responsibilities among mothers of school-aged children with disabilities. *Journal of Pediatrics and Child Health, 49,* 775-782. doi:10.1111/jpc.12254

Boutcher, S. H., & Dunn, S. L. (2009). Factors that may impede the weight loss response to exercise-based interventions. *Obesity Reviews, 10,* 671-680. doi:10.1111/j.1467-789X.2009.00621.x

Bowie, J. R. (2006). *The perceptions of continuity of care of rural Albertans following acute myocardial infarction* (Unpublished master's thesis). University of Alberta, Edmonton, Alberta, Canada.

Brasfield, C. D. (2008). *An exploration of the stressors, coping resources, and resiliency of rural mothers of children with special needs* (Unpublished doctoral dissertation). Georgia State University, Atlanta, Georgia.

Brehaut, J. C., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., Rosenbaum, P. L., & Kohen, D. E. (2011). Changes over time in the health of caregivers of children with health problems: Growth-curve findings from a 10-year Canadian population-based study. *American Journal of Public Health, 101,* 2308 - 2316. doi:10.2105/AJPH.2011.300298

Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., & Rosenbaum, P. L. (2009). Health among caregivers of children with health problems:

Findings from a Canadian Population-Based Study. *American Journal of Public Health, 99,* 1254 - 1262. doi:10.2105/AJPH.2007,129817

Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., O'Donnell, M., Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers? *Pediatrics, 114,* e182-e191.

Breslow, L. (1996). Social ecological strategies for promoting healthy lifestyles. *American Journal of Health Promotion, 10,* 253-257.

Brobeck, E., Bergh, H., Odencrants, S., & Hildingh, C. (2014). Lifestyle advice and lifestyle change: To what degree does lifestyle advice of healthcare professionals reach the population, focusing on gender, age and education. *Scandinavian Journal of Caring Sciences,* 1-8. Advance online publication. doi:10.1111/scs.12139

Bronfenbrenner, U. (1979). *The ecology of human development.* Cambridge, MA: Harvard University Press.

Bruns, D. A. (2000). Leaving home at an early age: Parents' decisions about out-of-home placement for young children with complex medical needs. *Mental Retardation, 38,* 50-60.

Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research, 6*, 97-113. doi:10.1177/1468794106058877

Buelow, J. M., McNelis, A., Shore, C. P., & Austin, J. K. (2006). *Journal of Neuroscience Nursing, 38*, 147-154, 176.

Bullen, C., Howe, C., Laugesen, M., McRobbie, H., Parag, V., Williman, J., & Walker, N. (2013). Electronic cigarettes for smoking cessation: A randomized control trial. *Lancet, 382,* 1629-1637. doi:10.1016/S0140-6736(13)61842-5

Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities, 117,* 33-47. doi:10.1352/1944-7558-117.1.33

Burke, V., Giangiulio, N., Gillam, H. F., Beilin, L. J., Houghton, S., & Milligan, R. A. K. (1999). Health promotionin couples adapting to a shared lifestyle. *Health Education Research, 14,* 269-288.

Burkhard, A. (2013). A different life: Caring for an adolescent or young adult with severe cerebral palsy. *Journal of Pediatric Nursing, 28,* 357-363. doi:10.1016/j.pedn.2013.01.001

Burnard, P. (1991). A method of analyzing interview transcripts in qualitative research. *Nurse Education Today, 22,* 461-466.

Burns, A., Bruce, D., & Marlin, A. (2007). *Rural poverty discussion paper.* Retrieved from http://www4.agr.gc.ca/resources/prod/rural/doc/poverty_pauvrete_e.pdf

Burton, P., Lethbridge, L., & Phipps, S. (2007). *Child health and parental paid work.* Retrieved from http://www.cerforum.org/conferences/200705/papers/BurtonLethbridgePhipps.pdf

Burton, P., Lethbridge, L., & Phipps, S. (2008a). Children with disabilities and chronic conditions and longer-term parental health. *The Journal of Socio-economics, 37,* 1168-1186. doi:10.1016/j.socec.2007.01.032

Burton, P., Lethbridge, L., & Phipps, S. (2008b). Mothering children with disabilities and chronic conditions: Long-term implications for self-reported health. *Canadian Public Policy, 34,* 359-378.

Burton, P., & Phipps, S. (2009). Economic costs of caring for children with disabilities in Canada. *Canadian Public Policy, 35,* 269-290.

Butcher, P. R., Wind, T., & Bouma, A. (2008). Parenting stress in mothers and fathers of a child with hemiparesis: Sources of stress, intervening factors and long-term expressions of stress. *Child: Care, Health and Development, 34*, 530-541. doi:10.1111/j.1365-2214.2008.00842.x

Butler-Jones, D. (2008). *The Chief Public Health Officer's report on the state of public health in Canada.* Retrieved from http://www.sportmatters.ca/Groups/SMG%20Resources/Health/2008-cpho-report-eng.pdf

Byrne, M. (2001). Interviewing as a data collection method. *AORN Journal, 74,* 233-235.

Byrne, M. B., Hurley, D. A., Daly, L., & Cunningham, C. G. (2010). Health status of caregivers of children with cerebral palsy. *Child: Care, Health and Development, 36,* 696-702. doi:10.1111/j.1365-2214.2009.01047.x

Caelli, K., Downie, J., & Caelli, T. (2003). Towards a decision support system for health promotion in nursing. *Journal of Advanced Nursing, 43,* 170-180.

Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods, 2*(2), 1-24.

Cairns, D., Tolson, D., Brown, J., & Darbyshire, C. (2013). The need for future alternatives: An investigation of the experiences and future of older parents caring for offspring with learning disabilities over a prolonged period of time. *British Journal of Learning Disabilities, 41,* 73-82. doi:10.1111/j.1468-3156.2012.00729.x

Cairns, I. (1992). The health of mothers and fathers with a child with a disability. *Health Visitor, 65,* 238-239.

Canada Revenue Agency. (2014). *Line 365- children's fitness amount.* Retrieved from http://www.cra-arc.gc.ca/fitness/

Canadian Fitness and Lifestyle Research Institute. (2007). 2007 Physical activity monitor. Retrieved from http://www.cflri.ca/eng/statistics/surveys/pam2007.php

Canadian Healthcare Association. (2012). *Respite care in Canada.* Retrieved from http://www.cha.ca/wp-content/uploads/2012/11/Respite_Care_in_Canada_EN_web.pdf

Canadian Institute for Health Information. (2000). *Supply and distribution of registered nurses in rural and small town Canada.* Retrieved from http://secure.cihi.ca/cihiweb/products/NursingRuralSmallTownCanada2000.pdf

Canadian Institute for Health Information. (2005). *Geographic distribution of physicians in Canada: Beyond how many and where.* Retrieved from http://secure.cihi.ca/cihiweb/products/Geographic_Distribution_of_Physicians_FINAL_e.pdf

Canadian Institute for Health Information. (2006a). *How healthy are rural Canadians? An assessment of their health and health determinants.* Retrieved from http://www.phac-aspc.gc.ca/publicat/rural06/pdf/rural_canadians_2006_report_e.pdf

Canadian Institute for Health Information. (2006b). *Improving the health of Canadians: Promoting healthy weights.* Retrieved from http://secure.cihi.ca/cihiweb/products/healthyweights06_e.pdf

Canadian Institute for Health Information. (2008). *Supply, distribution, and migration of Canadian physicians.* Retrieved from http://secure.cihi.ca/cihiweb/products/SMDB_2008_e.pdf

Canadian Institute for Health Information. (2012). *Health care in Canada, 2012: A focus on wait times.* Retrieved from https://secure.cihi.ca/free_products/HCIC2012-FullReport-ENweb.pdf

Canadian Institute for Health Information. (2013). *Our health system.ca.* Retrieved from http://ourhealthsystem.ca/

Canadian Institutes of Health Research. (2013). *More about knowledge translation at CIHR.* Retrieved from http://www.cihr-irsc.gc.ca/e/39033.html

Canadian Lung Association. (2008). *Making quit happen: Canada's challenges to smoking cessation.* Retrieved from http://www.lung.ca/_resources/Making_quit_happen_report.pdf

Canadian Nurses Association. (2005a). *Chronic disease and nursing: A summary of the issues.* Retrieved from http://www.cna-nurses.ca/CNA/documents/pdf/publications/BG3_Chronic_Disease_and_Nursing_e.pdf

Canadian Nurses Association. (2005b). *Social determinants of health and nursing: A summary of the issues.* Retrieved from http://www.cna-nurses.ca/CNA/documents/pdf/publications/BG8_Social_Determinants_e.pdf

Canadian Nurses Association. (2009). *Position statement: Determinants of health.* Retrieved from http://www.cna-aiic.ca/CNA/documents/pdf/publications/PS_Determinants_of_Health_e.pdf

Canadian Nurses Association. (2011). *Promoting physical activity.* Retrieved from http://www.cna-aiic.ca/~/media/cna/page%20content/pdf%20en/2013/07/26/10/37/brief_on_physical_activity_e.pdf

Canadian Radio-television and Telecommunications Commission. (2012). *Communications monitoring report.* Retrieved from http://www.crtc.gc.ca/eng/publications/reports/policymonitoring/2012/cmr2012.pdf

Canadian Society for Exercise Physiology. (2013). *Canadian physical activity guidelines for adults 18-64 years.* Retrieved from http://www.csep.ca/CMFiles/Guidelines/CSEP_PAGuidelines_adults_en.pdf

Caracelli, V. J., & Greene, J. C. (1993). Data analysis strategies for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis, 15,* 195-207. doi:10.3102/01623737015002195

Carper, B. A. (1975). *Fundamental patterns of knowing in nursing* (Unpublished doctoral dissertation). Columbia University Teachers College, New York, New York.

Casazza, K., Cardel, M., Dulin-Keita, A., Hanks, L. J., Gower, B. A., Newton, A. L., & Wallace, S. (2012). Reduced carbohydrate diet to improve metabolic outcomes and decrease adiposity in obese peripubertal African American girls. *Journal of Pediatric Gastroenterology and Nutrition, 54,* 336-342. doi:10.1097/MPG.0b013e31823df207

Catholic Family Counseling Centre. (2005). *The rural think tank: Understanding issues families face living in rural and remote communities.* Retrieved from http://www.phac-aspc.gc.ca/hp-ps/dca-dea/publications/rtt-grr-2005/pdf/rtt-grr-2005_e.pdf

Center for Science in the Public Interest. (2013). *Experts, health and citizens' groups call on governments to mandate nutrition information on menus at outlets of large chain restaurants.* Retrieved from http://cspinet.org/canada/pdf/expert_ngo.joint-statement.menu-labelling.pdf

Central Alberta Child and Family Services. (2010). *CFSA regional map.* Retrieved from http://www.centralalbertacfsa.gov.ab.ca/home/documents/AboutUs/Regional_Map.pdf

Centre for Addiction and Mental Health. (2010). *Low-risk drinking guidelines.* Retrieved from http://www.camh.net/About_Addiction_Mental_Health/Drug_and_Addiction_Information/low_risk_drinking_guidelines.html

Centre for Rural and Northern Health Research. (2001). *A situational analysis of physician recruitment and retention in rural and northern Canada: Models, programs, and evaluations.* Retrieved from http://www.cranhr.ca/pdf/CRaNHR_Physician_Recruitment_and_Retention_2001.pdf

Chan, C. B., Ryan, D. A. J., & Tudor-Locke, C. (2006). Relationship between objective measures of physical activity and weather: A longitudinal study. *International Journal of Behavioral Nutrition and Physical Activity, 3,* 21-29. doi:10.1186/1479-5868-3-21

Chen, Y., Rennie, D. C., & Dosman, J. A. (2009). Changing prevalence of obesity in a rural community between 1977 and 2003: A multiple cross-sectional study. *Public Health, 123,* 15-19. doi:10.1016/j.puhe.2008.06.006

Chrisman, M. S. (2013). *Perceived environmental, social, and policy influences on physical activity in rural Midwestern adults* (Unpublished doctoral dissertation). University of Iowa, Iowa City, Iowa.

Chronic Disease Prevention Alliance of Canada. (2007). *Improving the health of Canadians: Health promotion priorities for Canada.* Retrieved from http://cdpac.4poyntzdezign.com/media.php?mid=349

Cockerham, W. C., Kunz, G., & Lueschen, G. (1988). Psychological distress, perceived health status, and physician utilization in America and West Germany. *Social Science and Medicine, 26,* 829-838.

Cohen, B. (2005). Health promotion. In L. L. Stamler & L. Yiu (Eds.), *Community health nursing: A Canadian perspective* (2nd ed., pp. 117-136). Toronto, Ontario, Canada: Pearson Prentice Hall.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). New York, NY: Psychology Press.

Cohen, S., & Herbert, T. B. (1996). Health psychology: Psychological factors and physical disease from the perspective of human psychoneuroimmunology. *Annual Review of Psychology, 47*, 113-142.

Colley, R. C., Garriguet, D., Janssen, I., Craig, C. L., Clarke, J., & Tremblay, M. S. (2011). Physical activity of Canadian adults: Accelerometer results from the 2007 to 2009 Canadian Health Measures Survey. *Health Reports, 22*(1), 1-9.

Cometto, A. C. (2011). *Barriers to weight management and the methods used to overcome them by overweight and obese adults* (Unpublished master's thesis). D'Youville College, Buffalo, New York.

Cooksey, J. L. (2006). *Women's perceptions of barriers to alcoholism treatment* (Unpublished doctoral dissertation). California State University, Long Beach, California.

Corbalan, M. D., Morales, E. M., Canteras, M., Espallardo, A., Hernandez, T., & Garaulet, M. (2009). Effectiveness of cognitive-behavioral therapy based on the Mediterranean diet for the treatment of obesity. *Nutrition, 25,* 861-869. doi:10.1016/j.nut.2009.02.013

Corman, M. K. (2007). *Primary caregivers of children with autism spectrum disorders: An exploration of the stressors, joys, and parental coping before and after out-of-home placement* (Unpublished master's thesis). University of Victoria, Victoria, British Columbia, Canada.

Corman, M. K. (2013). How mothers talked about placement of their child with autism outside the home. *Qualitative Health Research, 23,* 1320-1332. doi:10.1177/1049732313505225

Corty, E. W. (2007). *Using and interpreting statistics: A practical text for the health, behavioral, and social sciences.* St. Louis, MO: Mosby Elsevier.

Cott, C. A., Gignac, M. A. M., & Bradley, E. M. (1999). Determinants of self rated health for Canadians with chronic disease and disability. *Journal of Epidemiology and Community Health, 53,* 731-736.

Couper, I. D. (2003). Rural hospital focus: Defining rural. *Rural and Remote Health, 3*(2), 1-3.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches.* Thousand Oaks, CA: Sage Publications.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2008). Advanced mixed methods research designs. In V. W. Plano Clark & J. W. Creswell (Eds.), *The mixed methods reader* (pp. 161-198). Thousand Oaks, CA: Sage.

Cummins, R. A. (2001). The subjective well-being of people caring for a family member with a severe disability at home: A review. *Journal of Intellectual and Developmental Disability, 26,* 83-100. doi:10.1080/1366825002003278 7

Damiani, G., Rosenbaum, P., Swinton, M., & Russell, D. (2004). Frequency and determinants of formal respite service use among caregivers of children with cerebral palsy in Ontario. *Child: Care, Health and Development, 30,* 77-86.

Dart, M. A. (2011). *Motivational interviewing in nursing practice.* Sudbury, MA: Jones and Bartlett.

Daruna, J. H. (2004). *Introduction to psychoneuroimmunology.* San Francisco, CA: Elsevier.

Davis, D., & Davis N. (2009). Educational interventions. In S. Strauss, J. Tetroe, & I. D. Graham (Eds.), *Knowledge translation in health care: Moving from evidence to practice* (pp. 113-123). Hoboken, NJ: Wiley-Blackwell.

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *36,* 63-73.

De Andres-Garcia, S., Moya-Albiol, L., & Gonzalez-Bono, E. (2012). Salivary cortisol and immunoglobulin A: Responses to stress as predictors of health complains reported by caregivers of offspring with autistic spectrum disorder. *Hormones and Behavior, 62,* 464-474. doi:10.1016/j.yhbeh.2012.08.00

Denham, S. A., & Looman, W. (2010). Families with chronic illness. In J. R. Kaakinen, V. Gedaly-Duff, D. P. Coehlo, & S. M. H. Hanson (Eds.), *Family health care nursing* (4th ed., pp. 235-272). Philadelphia, PA: F. A. Davis.

Denton, M., & Walters, V. (1999). Gender differences in structural and behavioral determinants of health: An analysis of the social production of health. *Social Science and Medicine, 48,* 1221-1235.

Dickinson, W. B. (2010). Visual displays for mixed methods findings. In A. Tashakkori & C. Teddlie (Eds.), *Sage handbook of mixed methods in social and behavioral research* (2nd ed., pp. 469-504). Thousand Oaks, CA: Sage.

DiFazio, R. L., & Vessey, J. A. (2013). Non-medical out-of-pocket expenses incurred by families during their child's hospitalization. *Journal of Child Health Care, 17,* 230-241. doi:10.1177/1367493512461459

Dillman, D. A., Smyth, J. D., & Christian, L. M. (2009). *Internet, mail, and mixed-mode surveys: The tailored design method* (3rd ed.). Hoboken, NJ: Wiley.

Dishman, R. K., Sallis, J. F., & Orenstein, D. R. (1985). The determinants of physical activity and exercise. *Public Health Reports, 100,* 158-171.

Doig, J. L., McLennan, J. D., & Urichuk, L. (2009). 'Jumping through hoops': Parents' experiences with seeking respite care for children with special needs. *Child: Care, Health and Development, 35,* 234-242.

Donaldson, S. K., & Crowley, D. M. (1978). The discipline of nursing. *Nursing Outlook, 26*, 113-120.

Duffy, M. E. (1986). Primary prevention behaviors: The female-headed, one-parent family. *Research in Nursing & Health, 9,* 115-122.

du Plessis, V., Beshiri, R., Bollman, R. D., & Clemenson, H. (2002). *Definitions of "rural".* Retrieved from http://www.statcan.gc.ca/pub/21-601-m/2002061/4224867-eng.pdf

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2009). Children's delayed development and behavior problems: Impact on mothers' perceived physical health across early childhood. *Social Science and Medicine, 68,* 89-99.

Eker, L., & Tuzun, E. H. (2004). An evaluation of quality of life of mothers of children with cerebral palsy. *Disability and Rehabilitation, 26,* 1354-1359. doi:10.1080/09638280400000187

Elder, C. R., Gullion, C. M., Funk, K. L., DeBar, L. L., Lindberg, N. M., & Stevens, V. J. (2012). Impact of sleep, screen time, depression and stress on weight change in the intensive weight loss phase of the LIFE study. *International Journal of Obesity, 36,* 86-92. doi:10.1038/ijo.2011.60

Emond, A., Emmett, P., Steer, C., & Golding, J. (2010). Feeding symptoms, dietary patterns, and growth in young children with autism spectrum disorders. *Pediatrics, 126,* e337-e343. doi:10.1542/peds.2009-2391

Epel, E. S. (2009). Psychological and metabolic stress: A recipe for accelerated cellular aging? *Hormones, 8,* 7-22.

Epel, E. S., Blackburn, E. H., Lin, J., Dhabhar, F. S., Adler, N. E., Morrow, J. D., Cawthon, R. M. (2004). Accelerated telomere shortening in response to life stress. *Proceedings of the National Academy of Sciences of the United States of America, 101,* 17312-17315. doi:10.1073/pnas.0407162101

Epel, E. S., Lin, J., Wilhelm, F. H., Wolkowitz, O. M., Cawthon, R. Adler, N. E., Dolbier, C., Mendes, W. B., & Blackburn, E. H. (2006). Cell aging in relation to stress arousal and cardiovascular disease risk factors. *Psychoneuroendocrinology, 31,* 277-287. doi:10.1016/j.psyneuen.2005.08.011

Epp, J. (1986). *Achieving health for all: A framework for health promotion.* Ottawa, Ontario, Canada: Health and Welfare Canada.

Environmental Protection Agency. (2010). *Sustainable rural development: Managing housing in the countryside.* Retrieved from http://www.epa.ie/downloads/pubs/research/econ/STRIVE_44_Scott_SustainableDevelopment_syn.web.pdf

Esdaile, S. A., & Greenwood, K. M. (2003). A comparison of mothers' and fathers' experience of parenting stress and attributions for parent-child interaction outcomes. *Occupational Therapy International, 10,* 115 - 126.

Everett, T., Bryant, A., Griffin, M. F., Martin-Hirsch, P. P. L., Forbes, C. A., & Jepson, R. G. (2011). Interventions targeted at women to encourage the uptake of cervical screening (review). *Cochrane Database of Systematic Reviews, 5,* 1-96. doi:10.1002/14651858.CD002834.pub2.

Faltz, B. G., & Wing, R. V. (2005). Substance use and disorders. In M. A. Boyd (Ed.), *Psychiatric nursing: Contemporary practice* (3rd ed., pp. 524-564). Philadelphia, PA: Lippincott, Williams, & Wilkins.

Fast, J., Dosman, D., Lero, D., & Lucas, S. (2013). *The intersection of caregiving and employment across the life course.* Retrieved from http://www.worklifecanada.ca/cms/resources/files/679/Caregiving_and_employment.pdf

Fast, J., Keating, N., & Yacyshyn, A. (2008). *I wish that I could just have a break: Consequences of supporting adults with disabilities.* Retrieved from http://www.uofaweb.ualberta.ca/hcic/pdf/I_wish_that_I_could_just_have_a_break_2008Aug.pdf

Faul, F., Endfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39,* 175-191.

Fawcett, J. (1995). *Analysis and evaluation of conceptual models of nursing* (3rd ed.). Philadelphia, PA: F. A. Davis.

Federal, Provincial, and Territorial Advisory Committee on Population Health. (1994). *Strategies for population health: Investing in the health of Canadians.* Retrieved from http://www.phac-aspc.gc.ca/ph-sp/pdf/strateg-eng.pdf

Ferraro, K. F., & Yu, Y. (1995). Body weight and self-ratings of health. *Journal of Health and Social Behavior, 36,* 274-284.

Field, P. A., & Morse, J. M. (1985). *Nursing research: The application of qualitative approaches.* Rockville, MD: Aspen.

Finnegan, L., Marion, L., & Cox, C. (2005). Profiles of self-rated health in midlife adults with chronic illnesses. *Nursing Research, 54,* 167-177.

Flack, A. (2009). *The influence of personal, social, and environmental factors on youths' engagement in physical activity* (Unpublished master's thesis). University of Waterloo, Waterloo, Ontario, Canada.

Flaman, L. M., Plotnikoff, R. C., Nykiforuk, C. I. J., & Raine, K. (2011). Mechanisms for understanding the facilitators and barriers to capacity building for chronic disease prevention activities: An illustration. *Health Promotion Practice, 12,* 858-866. doi:10.1177/1524839910366424

Flom-Meland, C. (2004). *The quality of life of caregivers of children with special needs* (Unpublished doctoral dissertation). University of North Dakota, Grand Forks, North Dakota.

Ford, E. S., Ajani, U. A., Croft, J. B., Critchley, J. A., Labarthe, D. R., Kottke, T. E., Giles, W. H., & Capewell, S. (2007). Explaining the decrease in U. S. deaths from coronary disease, 1980 - 2000. *The New England Journal of Medicine, 356,* 2388-2398.

Fox, K. R. (1999). The influence of physical activity on mental well-being. *Public Health Nutrition, 2,* 411-418.

Frank, L. D., Andresen, M. A., & Schmid, T. L. (2004). Obesity relationships with community design, physical activity, and time spent in cars. *American Journal of Preventive Medicine, 27*(2), 87-96. doi:10.1016/j.amepre.2004.04.011

Frech, A., & Damaske, S. (2012). The relationships between mothers' work pathways and physical and mental health. *Journal of Health and Social Behavior, 53*(4), 396-412. doi:10.1177/0022146512453929

Frohlich, K. L., & Potvin, K. (1999). Collective lifestyles as the target for health promotion. *Canadian Journal of Public Health, 90,* S11-S14.

Gallagher, S., Phillips, A. C., Drayson, M. T., & Carroll, D. (2009). Parental caregivers of children with developmental disabilities mount a poor antibody response to pneumococcal vaccination. *Brain, Behavior, and Immunity, 23*, 338-346. doi:10.1016/j.bbi.2008.05.006

Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology, 33,* 1129-1136. doi:10.1093/jpepsy/jsn040

Garcia, A. C., Sykes, L., Matthews, J., Martin, N., & Leipert, B. (2010). Perceived facilitators of and barriers to healthful eating among university students. *Canadian Journal of Dietetic Practice and Research, 71,* e28-e33. doi: 10.3148/71.2.2010.XX

Garriguet, D., & Colley, R. C. (2012). Daily patterns of physical activity among Canadians. *Health Reports, 23*(2), 1-6. Retrieved from http://www.statcan.gc.ca/pub/82-003-x/2012002/article/11649-eng.pdf

Garriguet, D., & Colley, R. C. (2014). A comparison of self-reported leisure-time physical activity and measured moderate-to-vigorous physical activity in adolescents and adults. *Health Reports, 25* (7), 3-11. Retrieved from http://www.statcan.gc.ca/pub/82-003-x/2014007/article/14038-eng.pdf

Gerard, N., Kulig, J., & Nowatzki, N. (2004). What doesn't kill you makes you stronger: Determinants of stress resiliency in rural people of Saskatchewan, Canada. *The Journal of Rural Health, 20*(1)*,* 59-66.

Gillis, A. J. (1993). Determinants of a health-promoting lifestyle: An integrative review. *Journal of Advanced Nursing, 18,* 345-353.

Glenn, S., Cunningham, C., Poole, H., Reeves, D., & Weindling, M. (2009). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child: Care, Health and Development, 35,* 71-78. doi:10.1111/j.1365-2214.2008.00891.x

Goldman, N., Glei, D. A., & Chang, M. (2004). The role of clinical risk factors in understanding self-rated health. *Annals of Epidemiology, 14,* 49-57.

Gorin, S. S., & Schnoll, R. A. (2006). Smoking cessation. In S. S. Gorin & J. Arnold (Eds.), *Health promotion in practice* (pp. 287-328). San Fransisco: John Wiley and Sons.

Government of Alberta. (2003). *Family support for children with disabilities act.* Edmonton, Alberta, Canada: Alberta Queen's Printer.

Government of Alberta. (2007). *Family support for children with disabilities (FSCD) program.* Retrieved August 1, 2010, from http://www.child.alberta.ca/home/591.cfm

Government of Alberta. (2013). *2013 Municipal Affairs population list.* Retrieved from http://municipalaffairs.gov.ab.ca/documents/msb/2013_Municipal_Affairs_Population_List.pdf

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24,* 105-112.

Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: Towards a refined model of caring and coping. *Journal of Intellectual Disability Research, 42,* 58-71.

Green, K. E. (1996). Sociodemographic factors and mail survey response. *Psychology & Marketing, 13*(2), 171-184.

Green, L. W., & Kreuter, M. W. (2005). *Health program planning: An educational and ecological approach* (4th ed.). New York, NY: McGraw-Hill.

Green, L. W., Richard, L., & Potvin, L. (1996). Ecological foundations of health promotion. *American Journal of Health Promotion, 10,* 270-282.

Greenberg, L., & Normandin, C. (2011). *Disparities in life expectancy at birth.* Retrieved from http://www.statcan.gc.ca/pub/82-624-x/2011001/article/11427-eng.pdf

Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis, 11*, 255-274.

Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: A systematic review. *BMC Psychiatry, 10*(9), 1-9. doi:10.1186/1471-244X-10-113

Habjan, S., Kortes-Miller, K., Kelley, M. L., Sullivan, H., & Pisco, L. (2012). Building capacity in rural health services: The effect of continuing education. In J. Kulig & A. M. Williams

(Eds.), *Health in rural Canada* (pp. 118-136). Vancouver, British Columbia, Canada: UBC Press.

Haddock, C., K., Poston, W. S. C., Pyle, S. A., Klesges, R. C., Vander Weg, M. W., Peterson, A., & Debon, M. (2006). The validity of self-rated health as a measure of health status among young military personnel: Evidence from a cross-sectional survey. *Health and Quality of Life Outcomes, 4,* 57-65. doi:10.1186/1477-7525-4-57

Halls, T. T. (2008). *The experience of parents raising a child with special health care needs while living in a rural area* (Unpublished master's thesis). University of Wyoming, Laramie, Wyoming.

Hamilton, N., & Bhatti, T. (1996). *Population health promotion: An integrated model of population health and health promotion.* Retrieved from http://www.phac-aspc.gc.ca/ph-sp/php-psp/php2-eng.php#Doing

Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. *Autism, 11*, 489-501. doi:10.1177/1362361307083258

Hammond, D., McDonald, P. W., Fong, G. T., & Borland, R. (2004). Do smokers know how to quit? Knowledge and perceived effectiveness of cessation assistance as predictors of cessation behavior. *Addiction, 99,* 1042-1048. doi:0,1111/j,1360-0443,2004,00754.x

Hanvey, L. (2001). *Children and youth with special needs: Summary report of findings.* Retrieved from http://www.ccsd.ca/pubs/2001/specialneeds/specialneeds.pdf

Hanvey, L. (2002). *Children with disabilities and their families in Canada: A discussion paper.* Retrieved from http://www.nationalchildrensalliance.com/nca/pubs/2002/hanvey02.pdf

Hanvey, L. (2005). *Rural nursing practice in Canada: A discussion paper.* Retrieved from http://www.carrn.com/files/Rural-Nursing-discussion-paper_Draft3-Sept%2005-1.pdf

Hardcastle, S. J., Taylor, A. H., Bailey, M. P., Harley, R. A., & Hagger, M. S. (2013). Effectiveness of a motivational interviewing intervention on weight loss, physical activity and cardiovascular disease risk factors: A randomized controlled trial with a 12-month post-intervention follow-up. *International Journal of Behavioral Nutrition and Physical Activity, 10,* 1-16. doi:10.1186/1479-5868-10-40

Harrison, M. J., & Neufeld, A. (1997). Women's experiences of barriers to support while caregiving. *Health Care for Women International, 18,* 591-602.

Harrison, M. J., Neufeld, A., & Kushner, K. (1995). Women in transition: Access and barriers to social support. *Journal of Advanced Nursing, 21,* 858-864.

Harvey, L. (1987). Factors affecting response rates to mailed questionnaires: A comprehensive literature review. *Journal of the Market Research Society, 29*, 341-353.

Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions. *Journal of Intellectual Disabilities, 9,* 155-165. doi:10.1177/1744629505053930

Haufe, S., Utz, W., Engeli, S., Kast, P., Bohnke, J., Pofahl, M., Traber, J., Haas, V., Hermsdorf, M., Mahler, A., Busjahn, A., Wiesner, S., Otto, C., Mehling, H., Luft, F. C., Boschmann, M., Schulz-Menger, J., & Jordan, J. (2012). Left ventricular mass and function with reduced-fat or reduced-carbohydrate hypocaloric diets in overweight and obese subjects. *Hypertension, 59,* 70-75. doi:10.1161/HYPERTENSIONAHA.111.178616

Hauge, L. J., Kornstad, T., Nes, R. B., Kristensen, P., Irgens, L. M., Eskedal, L. T., Landolt, M. A., & Vollrath, M. E. (2013). The impact of a child’s special health care needs on maternal work participation during early motherhood. *Paediatric and Perinatal Epidemiology, 27,* 353-360. doi:10.1111/ppe.12063

Health Canada. (2007). *Eating well with Canada's food guide.* Retrieved from http://www.hc-sc.gc.ca/fn-an/alt_formats/hpfb-dgpsa/pdf/food-guide-aliment/print_eatwell_bienmang-eng.pdf

Health Canada. (2012). *Body mass index (BMI) nomogram.* Retrieved from http://www.hc-sc.gc.ca/fn-an/nutrition/weights-poids/guide-ld-adult/bmi_chart_java-graph_imc_java-eng.php

Health Canada. (2014). *Food labelling.* Retrieved from http://www.hc-sc.gc.ca/fn-an/label-etiquet/index-eng.php

Health Council of Canada. (2007). *Population patterns of chronic health conditions in Canada.* Retrieved from http://www.healthcouncilcanada.ca/docs/rpts/2007/outcomes2/Outcomes2PopulationPatternsFINAL.pdf

Heather, B., Skillen, D. L., Cross, J., & Vladicka, T. (2012). Being a good woman: The gendered impacts of restructuring in rural Alberta. In B. D. Leipert, B. Leach, & W. E. Thurston (Eds.), *Rural women's health* (pp. 253-268). Toronto, Ontario, Canada: University of Toronto.

Heavner, K. K., Rosenberg, Z., & Phillips. C. V. (2009). Survey of smokers' reasons for not switching to safer sources of nicotine and their willingness to do so in the future. *Harm Reduction Journal, 6,* 14-21. doi:10.1186/1477-7517-6-14

Hedov, G., Anneren, G., & Wikblad, K. (2000). Self-perceived health in Swedish parents of children with Down's syndrome. *Quality of Life Research, 9,* 415-422.

Heim, C., Ehlert, U., & Hellhammer, D. H. (2000). The potential role of hypocortisolism in the pathophysiology of stress-related bodily disorders. *Psychoneuroendocrinology, 25,* 1-35.

Hemmingsson, H., Stenhammar, A. M., & Paulsson, K. (2008). Sleep problems and the need for parental night-time attention in children with physical disabilities. *Child: Care, Health and Development, 35.* 89-95. doi:10.1111/j.1365-2214.2008.00907.x

Hoehner, C. M., Barlow, C. E., Allen, P., & Schootman, M. (2012). *American Journal of Preventive Medicine, 42*(6), 571-578. doi:10.1016/j.amepre.2012.02.020

Holm, K. E. (2004). *The impact of childhood chronic health conditions on mothers' and fathers' health* (Unpublished doctoral dissertation). University of Minnesota, Minneapolis, Minnesota.

Hood, C., Martinez-Donate, A., & Meinen, A. (2012). Promoting healthy food consumption: A review of state-level policies to improve access to fruits and vegetables. *Wisconsin Medical Journal, 111,* 283-288.

Hoogsteen, L., & Woodgate, R. L. (2013). Embracing autism in Canadian rural communities. *The Australian Journal of Rural Health, 21,* 178-182. doi:10.1111/ajr.12030

Howe, K. R. (1988). Against the quantitative-qualitative incompatibility thesis or dogmas die hard. *Educationa Researcher, 17*(8), 10-16. doi:10.3102/0013189X017008010

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15,* 1277-1288. doi:10.1177/1049732305276687

Hunt, A. N. (2012). *Caregiving for children with disabilities: Effects on parental employment and mental health* (Unpublished doctoral dissertation). North Carolina State University, Raleigh, North Carolina.

Hyppa, M. T., & Maki, J. (2001). Individual-level relationships between social capital and self-rated health in a bilingual community. *Preventive Medicine, 32,* 148-155. doi:10.1006/pmed.2000.0782

Idler, E. L., & Benyamini, Y. (1997). Self-rated health and mortality: A review of twenty-seven community studies. *Journal of Health and Social Behavior, 38,* 21-37.

Idler, E. L., Hudson, S. V., & Leventhal, H. (1999). The meanings of self-ratings of health. *Research on Aging, 21,* 458-476. doi:10.1177/0164027599213006

Ivankova, N. V., & Stick, S. I. (2007). Students' persistence in a distributed doctoral program in education leadership in higher education. *Research in Higher Education, 48*, 93-135. doi:10.1007/s11162-006-9025-4

Janz, T. (2012). *Current smoking trends.* Retrieved from http://www.statcan.gc.ca/pub/82-624-x/2012001/article/11676-eng.pdf

Jensen, L., & Allen, M. (1993). Wellness: The dialectic of illness. *IMAGE: Journal of Nursing Scholarship, 25, 220-224.*

Johnson, J. L., Ratner, P. A., & Bottorff, J. L. (1995). Urban-rural differences in the health-promoting behaviors of Albertans. *Canadian Journal of Public Health, 86,* 103-108.

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher, 33*(7), 14-26. doi:10.3102/0013189X033007014

Jones, L. L., Atkinson, O., Longman, J., Coleman, T., McNeill, A., & Lewis. S. A. (2011). The motivators and barriers to a smoke-free home among disadvantaged caregivers:

Identifying the positive levels for change. *Nicotine and Tobacco Research, 13,* 479-486. doi:10.1093/ntr/ntr030

Kaplan, G., & Baron-Epel, O. (2003). What lies behind the subjective evaluation of health status? *Social Science and Medicine, 56,* 1669-1676.

Kaya, K., Unsal-Delialioglu, S., Ordu-Gokkaya, N. K., Ozisler, Z., Ergun, N., Ozel, S., & Ucan, H. (2010). Musculo-skeletal pain, quality of life and depression in mothers of children with cerebral palsy. *Disability and Rehabilitation, 32,* 1666-1672. doi:10.3109/09638281003649912

Keating, N., Lero, D. S., Fast, J., Lucas, S., & Eales, J. (2013). *A framework and literature review on the economic costs of care: Final report.* Retrieved from http://www.rapp.ualberta.ca/~/media/rapp/Publications/Documents/EconomicCostsofCareFrameworkLitReview2013.pdf

Keefe, J., Hawkins, G., & Fancey, P. (2006). *A portrait of unpaid care in Nova Scotia.* Retrieved from http://www.cewh-cesf.ca/PDF/acewh/PortraitUnpaidCare.pdf

Keith, S. W., Redden, D. T., Katzmarzyk, P. T., Hanlon, E. C., Benca, R. M., Ruden, D., Pietrobelli, A., Barger, J. L., Fontaine, K. R., Wang, C., Aronne, L. J., Wright, S. M., Baskin, M., Dhurandhar, N. V., Lijoi, M. C., Grilo, C. M., DeLuca, M., Westfall, A. O., & Allison, D. B. (2006). Putative contributors to the secular increase in obesity: Exploring the roads less traveled. *International Journal of Obesity, 30,* 1585-1594. doi:10.1038/sj.ijo.0803326

Kelso, T., French, D., & Fernandez, M. (2005). Stress and coping in primary caregivers of children with a disability: A qualitative study using the Lazarus and Folkman Process Model of Coping. *Journal of Research in Special Educational Needs, 5*, 3-10. doi:10.1111/J.1471-3802.2005.00033.x

Ketelaar, M., Volman, M. J. M., Gorter, J. W., & Vermeer, A. (2008). Stress in parents of children with cerebral palsy: What sources of stress are we talking about? *Child: Care, Health and Development, 34*, 825-829. doi:10.1111/j.1365-2214.2008.00876.x

Kiecolt-Glaser, J. K. (1999). Stress, personal relationships, and immune function: Health implications. *Brain, Behavior, and Immunity, 13*, 61-72.

Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, O. J., & Glaser, R. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosomatic Medicine, 53*, 345-362.

Kirk, S. F. L., Penney, T. L., McHugh, T. L. F., & Sharma, A. M. (2012). Effective weight management practice: A review of the lifestyle intervention evidence. *International Journal of Obesity, 36,* 178-185. doi:10.1038/ijo.2011.80

Kirby, M. J. L., & LeBreton, M. (2002). *The health of Canadians - the federal role: Volume two: Current trends and future challenges.* Retrieved from http://www.parl.gc.ca/37/1/parlbus/commbus/senate/com-e/soci-e/rep-e/repjan01vol2-e.pdf

Klockars, A. J., & Sax, G. (1986). *Multiple comparisons.* Newbury Park, CA: Sage.

Korda, H., & Itani, Z. (2013). Harnessing social media for health promotion and behavior change. *Health Promotion Practice,14*(1), 15-23. doi:10.1177/0022146512453929

Kowal, J., & Fortier, M. S. (2007). Physical activity behavior change in middle-aged and older women: The role of barriers and of environmental characteristics. *Journal of Behavioral Medicine, 30,* 233-242. doi:10.1007/s10865-007-9102-y

Kral, T. V. E., Eriksen, W. T., Souders, M. C., & Pinto-Martin, J. A. (2013). Eating behaviors, diet quality, and gastrointestinal symptoms in children with autism spectrum disorders: A brief review. *Journal of Pediatric Nursing, 28,* 548-556. doi:10.1016/j.pedn.2013.01.008

Kral, T. V. E., Souders, M. C., Tompkins, V. H., Remiker, A. M., Eriksen, W. T., & Pinto-Martin, J. A. (2014). Child eating behaviors and caregiver feeding practices in children with autism spectrum disorders. *Public Health Nursing,* 1-10. Advance online publication. doi:10.1111/phn.12146

Krause, N. M., & Jay, G. M. (1994). What do global self-rated health items measure? *Medical Care, 32,* 930-942.

Kroll, T., & Neri, M. (2009). Designs for mixed methods research. In S. Andrew & E. J. Halcomb (Eds)., *Mixed methods research for nursing and the health sciences* (pp. 31-49). West Sussex, England: Wiley-Blackwell.

Kruger, J. (2009). Habits associated with successful weight loss and maintenance. *Review of Endocrinology, (Sep/Oct),* 17-22. Retrieved from http://www.reviewofendo.com/articles/0909/0909_03.pdf

Kruijsen-Terpstra, A. J. A., Ketelaar, M., Boeije, H., Jongmans, M. J., Gorter, J. W., Verheijden, J., Lindeman, E., & Verschuren, O. (2013). Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: A mixed studies review. *Child: Care, Health and Development,* 1-10. Advance online publication. doi:10.1111/cch.12097

Krulik, T., Turner-Henson, A., Kanematsu, Y., Al-Ma'aitah, R., Swan, J., & Holaday, B. (1999). Parenting stress and mothers of young children with chronic illness: A cross-cultural study. *Journal of Pediatric Nursing, 14*, 130-140.

Kuhlthau, K., Kahn, R., Hill, K. S., Gnanasekaran, S., & Ettner, S. L. (2010). The well-being of parental caregivers of children with activity limitations. *Maternal and Child Health Journal, 14,* 155-163. doi:10.1007/s10995-008-0434-1

Kulig, J., Edge, D., & Joyce, B. (2008). Community resiliency as a measure of collective health status: Perspectives from rural communities. *Canadian Journal of Nursing Research, 40*(4), 92-110.

Kulig, J., MacLeod, M., Stewart, N., & Pitblado, R. (2008). Clients in rural areas. In L. L. Stamler & L. Yiu (Eds.), *Community health nursing: A Canadian perspective* (2nd ed., pp. 301-310). Toronto, Ontario, Canada: Pearson Prentice Hall.

Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. H. (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Archives of Pediatric and Adolescent Medicine, 165,* 1020-1026.

Kuster, P. A. (2002). *Health outcomes of mothers caring for ventilator-assisted children at home: The influence of social support, coping, and community resources* (Unpublished doctoral dissertation). University of California, Los Angeles, California.

Kuster, P. A., Badr, L. K., Chang, B. L., Wuerker, A. K., & Benjamin, A. E. (2004). Factors influencing health promoting activities of mothers caring for ventilator-assisted children. *Journal of Pediatric Nursing, 19,* 276-287. doi:10.1016/j.pedn.2004.05.009

Kuster, P. A., & Merkle, C. J. (2004). Caregiving stress, immune function, and health: Implications for research with parents of medically fragile children. *Issues in Comprehensive Pediatric Nursing, 27*, 257-276. doi:10.1080/01460860490884165

Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing* (2nd ed.). Thousand Oaks, CA: Sage.

Lach, L. M., Kohen, D. E., Garner, R. E., Brehaut, J. C., Miller, A. R., Klassen, A. F., & Rosenbaum, P. L. (2009). The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disability and Rehabilitation, 31*, 741-752. doi:10.1080/08916930802354948

Lalonde, M. A. (1974). *A new perspective on the health of Canadians.* Ottawa, Ontario, Canada: Health and Welfare Canada.

Laurvick, C. L., Msall, M. E., Silburn, S., Bower, C., de Klerk, N., & Leonard, H. (2006). Physical and mental health of mothers caring for a child with Rett Syndrome. *Pediatrics, 118,* e1152-e1164. doi:10.1542/peds.2006-0439

Lauver, L. S. (2010). The lived experience of foster parents of children with special needs living in rural areas. *Journal of Pediatric Nursing, 25,* 289-298. doi:10.1016/j.pedn.2009.04.004

Lavergne, M. R., & Kephart, G. (2012). Examining variations in health within rural Canada. *Rural and Remote Health, 12*, 1-13.

Legislative Assembly of Ontario. (2014). *Bill 149, Health Statute Law Amendment Act (Healthy Decisions Made Easy), 2014.* Retrieved from http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=2919

Leinonen, R., Heikkinen, E., & Jylha, M. (2001). Predictors of decline in self-assessments of health among older people - a 5-year longitudinal study. *Social Science and Medicine, 52,* 1329-1341.

Leipert, B. D. (2005). Women's health in northern British Columbia: The role of geography and gender. *Canadian Journal of Rural Medicine, 10*, 241-253.

Leipert, B. D. (2006). Women and pharmacologic therapy in rural and remote Canada. *Canadian Journal of Rural Medicine, 11*, 296-300.

Leipert, B. D. (2008a). Determinants of rural women's health: A qualitative study in southwest Ontario. *The Journal of Rural Health, 24*(2)*,* 210-218. doi:10.1111/j.1748-0361.2008.00160

Leipert, B. D. (2008b). Rural women and pharmacologic therapy: Needs and issues in rural Canada. *Canadian Journal of Rural Medicine, 13,* 171-179.

Leipert, B. D., Delaney, J. W., Forbes, D., & Forchuk, C. (2011). Canadian rural women's experiences with rural primary health care nurse practitioners. *Online Journal of Rural Nursing and Health Care, 11*(1), 37-53.

Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004). The consequences of caring: Effects of mothering a child with special health needs. *Journal of Family Issues, 25*, 379-403. doi:10.1177/0192513X03257415

Lemstra, M., Neudorf, C., & Opondo, J. (2008). Implications of a public smoking ban. *Canadian Journal of Public Health, 99,* 62-65.

Leninger, M. (1978). *Transcultural nursing: Concept, theories and practices.* New York, NY: Wiley.

Leonard, B. J., Johnson, A. L., & Brust, J. D. (1993). Caregivers of children with disabilities: A comparison of those managing OK and those needing more help. *Children's Health Care, 22,* 93-105.

Letourneau, N. L., Tramonte, L., & Willms, J. D. (2013). Maternal depression, family functioning, and children's longitudinal development. *Journal of Pediatric Nursing, 28,* 223-234. doi:10.1016/j.pedn.2012.07.014

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Lincoln, Y. S., & Guba, E. G. (1990). Judging the quality of case study reports. *International Journal of Qualitative Studies in Education, 3,* 53-59. doi:10.1080/0951839900030105

Lombardo, A. P., Angus, J. E., Lowndes, R., Cechetto, N., Khattak, S., Ahmad, F., & Bierman, A. S. (2014). Women`s strategies to achieve access to healthcare in Ontario, Canada: A meta-synthesis. *Health and Social Care in the Community,* 1-13. Advance online publication. doi:10.1111/hsc.12093

Luo, W., Morrison, H., de Groh, M., Waters, C., DesMeules, M., Jones-McLean, E., Ugnat, A., Desjardins, S., Lim, M., & Mao, Y. (2007). The burden of adult obesity in Canada. *Chronic Diseases in Canada, 27*(4), 135-144.

Maben, J., & Clark, J. (1995). Health promotion: A concept analysis. *Journal of Advanced Nursing, 22,* 1158-1165.

Mackey, S., & Goddard, L. D. (2006). The experience of health and wellness in mothers of young children with intellectual disabilities. *Journal of Intellectual Disabilities, 10,* 305-315. doi:10.1177/1744629506070055

Maclagan, L. C., Park, J., Sanmartin, C., Mathur, K. R., Roth, D., Manuel, D. G., Gershon, A., Booth, G. L., Bhatia, S., Atzema, C. L., & Tu, J. V. (2014). The CAHHEART health index: A tool for monitoring the cardiovascular health of the Canadian population. *Canadian Medical Association Journal, 186,* 180-187. doi:10.1503/cmaj.131358

MacLeod, M., Kulig, J., Stewart, N., & Pitblado, R. (2004). *Nursing practice in rural and remote Canada.* Retrieved from http://www.ruralnursing.unbc.ca/reports/study/RRNFinalReport.pdf

Magana, S., & Smith, M. J. (2008). Health behaviors, service utilization, and access to care among older mothers of color who have children with developmental disabilities. *Intellectual and Developmental Disabilities, 46,* 267-280. doi:10.1352/2008.46:267–280

Maltais, V. (2007). *Risk factors associated with farm injuries in Canada.* Retrieved from http://www.statcan.gc.ca/pub/21-601-m/21-601-m2007084-eng.pdf

Mantyselka, P. T., Turunen, J. H. O., Ahonen, R, S., & Kumpusalo, E. A. (2003). Chronic pain and poor self-rated health. *JAMA: Journal of the American Medical Association, 290,* 2435-2442. doi:10.1001/jama.290.18.2435

Martin-Misener, R., Reilly, S. M., & Vollman, A. R. (2010). Defining the role of primary health care nurse practitioners in rural Nova Scotia. *Canadian Journal of Nursing Research, 42*(2), 30-47.

Masley, M. L., Semchuk, K. M., Senthilselvan, A., McDuffie, H. H., Hanke, P., Dosman, J. A., Cessna, A. J., Crossley, M. F. O., Irvine, D. G., Rosenberg, A. M., & Hagel, L. M. (2000). Health and environment of rural families: Results of a community canvass survey in the Prairie Ecosystem Study (PECOS). *Journal of Agricultural Safety and Health, 6,* 103-115.

Masters, R. K., Reither, E. N., Powers, D. A., Yang, C., Burger, A. E., & Link, B. G. (2013). The impact of obesity on US mortality levels: The importance of age and cohort factors in population estimates. *American Journal of Public Health, 103,* 1895-1901. doi:10.2105/AJPH.2013.301379

Mauro, M., Taylor, V., Wharton, S., & Sharma, A. M. (2008). Barriers to obesity treatment. *European Journal of Internal Medicine, 19,* 173-180. doi:10.1016/j.ejim.2007.09.011

McConnell, D., & Llewellyn, G. (2006). Health of mothers of school-age children with disabilities. *Australian and New Zealand Journal of Public Health, 30,* 572-574.

McDowell, I. (2006). *Measuring health: A guide to rating scales and questionnaires* (3rd ed.). New York, NY: Oxford University Press.

McIvor, A. (2009). Tobacco control and nicotine addiction in Canada: Current trends, management and challenges. *Canadian Respiratory Journal, 16,* 21-26.

McKeown, L., Noce, A., & Czerny, P. (2007). Factors associated with internet use: Does rurality matter? *Rural and Small Town Canada Analysis Bulleting, 7*(3), 1-15.

McLaren, L., & Hawe, P. (2005). Ecological perspectives in health research. *Journal of Epidemiology and Community Health, 59,* 6-14. doi:10.1136/jech.2003.018044

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly, 15,* 351-377.

Mellner, C., Krantz, C., & Lundberg, U. (2006). Symptom reporting and self-rated health among women in mid-life: The role of work characteristics and family responsibilities. *International Journal of Behavioral Medicine, 13,* 1-7.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.

Minister of Health. (2005). *The integrated pan-Canadian healthy living strategy.* Retrieved from http://www.phac-aspc.gc.ca/hl-vs-strat/pdf/hls_e.pdf

Ministerial Advisory Council on Rural Health. (2002). *Rural health in rural hands: Strategic directions for rural, remote, northern, and aboriginal communities.* Retrieved from http://www.srpc.ca/PDF/rural_hands.pdf

Minke, S. W., Raine, K. D., Plotnikoff, R. C., Anderson, D., Khalema, E., & Smith, C. (2007). Resources for health promotion: Rhetoric, research, and reality. *Canadian Journal of Public Health, 98,* 489-494.

Minore, B., Hill, M. E., Pugliese, I., & Gauld, T. (2008). *Rurality literature review.* Retrieved from http://www.ontla.on.ca/library/repository/mon/24003/299628.pdf

Mitura, V., & Bollman, R. D. (2003). The health of rural Canadians: A rural-urban comparison of health indicators. *Rural and Small Town Canada Analysis Bulletin, 4*(6), 1-23.

Monette, M. (2012). Rural life hardly healthier. *Canadian Medical Association Journal, 184,* E889-E890. doi:10.1503/cmaj.109-4289

Morelius, E., & Hemmingsson, H. (2013). Parents of children with physical disabilities – perceived health in parents related to the child’s sleep problems and need for attention at night. *Child: Care, Health and Development, 40,* 412-418. doi:10.1111/cch.12079

Morgan, D. L. (2007). Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research, 1,* 48-76. doi:10.1177/2345678906292462

Morris, L. A. (2014). The impact of work on the mental health of parents of children with disabilities. *Family Relations, 63,* 101-121. doi:10.1111/fare.12050

Morse, J. M. (1991). Strategies for sampling. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (Rev. ed., pp. 127-145). Newbury Park, CA: Sage.

Morse, J. M., & Niehaus, L. (2009). *Mixed method design: Principles and procedures.* Walnut Creek, CA: Left Coast Press.

Mossey, J. M., & Shapiro, E. (1982). Self-rated health: A predictor of mortality among the elderly. *American Journal of Public Health, 72*(8), 800-808.

Munro, B. H. (2005). *Statistical methods for health care research* (5th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2006). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development, 33,* 180-187. doi:10.1111/j.1365-2214.2006.00644.x

Navaneelan, T., & Janz, T. (2014). *Adjusting the scales: Obesity in the Canadian population after correcting for response bias.* Retrieved from http://www.statcan.gc.ca/pub/82-624-x/2014001/article/11922-eng.pdf

Nelson, C. H., & Park, J. (2006). The nature and correlates of unmet health care needs in Ontario, Canada. *Social Science & Medicine, 62,* 2291-2300. doi:10.1016/j.socscimed.2005.10.014

Neufeld, A., & Harrison, M. (2010). *Nursing and family caregiving: Social support and nonsupport.* New York, NY: Springer Publishing.

Neufeld, S. M. (1997). *Primary caregivers of children with chronic illness and disabilities: A descriptive study of caregiving and respite* (Unpublished master's thesis). University of Alberta, Edmonton, Alberta, Canada.

Neufeld, S. M., Query, B., & Drummond, J. E. (2001). Respite care users who have children with chronic conditions: Are they getting a break? *Journal of Pediatric Nursing, 16,* 234-244. doi:10.1053/jpdn.2001.24183

Newman, M. A. (2003). A world of no boundaries. *Advances in Nursing Science, 26*(4), 240-245.

Nielsen, L. S., Danielsen, K. V., & Sorensen, T. I. A. (2011). Short sleep duration as a possible cause of obesity: Critical analysis of the epidemiological evidence. *Obesity Reviews, 12,* 78-92. doi:10.1111/j.1467-789X.2010.00724.x

Nightingale, F. (1859). *Notes on nursing: What it is and what it is not.* London, England: Harrison and Sons.

Norton, L. (1998). Health promotion and health education: What role should the nurse adopt in practice? *Journal of Advanced Nursing, 28,* 1269-1275.

Novilla, M. L. B., Barnes, M. D., De La Cruz, N. G., Williams, P. N., & Rogers, J. (2006). An ecological approach to promoting health in the family and community. *Family and Community Health, 29,* 28-42.

Núñez-Córdoba, J. M., Bes-Rastrollo, M., Pollack, K. M., Seguí-Gómez, M., Beunza, J. J., Sayón-Orea, C., & Martínez-González, M. A. (2013). Annual motor vehicle travel distance and incident obesity. *American Journal of Public Health, 44*(3), 254-259. doi:10.1016/j.amepre.2012.10.019

Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* (3rd ed.). New York, NY: McGraw-Hill.

Obesity Canada. (2006). *Canadian clinical practice guidelines on the management and prevention of obesity in adults and children.* Retrieved from http://www.cmaj.ca/cgi/data/176/8/S1/DC1/1

O'Cathain, A. (2010). Assessing the quality of mixed methods research. In A. Tashakkori & C. Teddlie (Eds.), *Sage handbook of mixed methods in social and behavioral research* (2nd ed., pp. 531-555). Thousand Oaks, CA: Sage.

Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability, 31,* 1-12. doi:10.1080/13668250500349367

Offer, S. (2010, May). *Barriers to social support among low-income women.* Paper presented at the meeting of the International Sociological Association, Haifa, Israel. Retrieved from http://soc.haifa.ac.il/~haifa2010/wp-content/uploads/ShiraOffer.pdf

Olsen, J. (2013). An integrative review of literature on the determinants of physical activity among rural women. *Public Health Nursing,30*(4), 288-311. doi:10.1111/phn.12023

Olson, C. M., & Bove, C. F. (2006). Obesity in rural women: Emerging risk factors and hypotheses. In R. T. Coward, L. A. Davis, C. H. Gold, H. Smiciklas-Wright, L. E. Thorndyke, & F. W. Vondracek (Eds.), *Rural women's health: Mental, behavioral, and physical issues* (pp. 63-81). New York, NY: Springer.

Olsson, M. B., & Hwang, C. P. (2006). Well-being, involvement in paid work, and division of child-care in parents of children with intellectual disabilities in Sweden. *Journal of Intellectual Disability Research, 50,* 963-969. doi:10.1111/j.1365-2788.2006.00930.x

Ones, K., Yilmaz, E., Cetinkaya, B., & Caglar, N. (2005). Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabilitation and Neural Repair, 19,* 232-237. doi:10.1177/1545968305278857

Onwuegbuzie, A. J., & Johnson, R. B. (2006). The validity issue in mixed methods research. *Research in the Schools, 13,* 48-63.

Orpana, H. M., Lemyre, L., & Kelly, S. (2007). Do stressors explain the association between income and declines in self-rated health? A longitudinal analysis of the National Population Health Survey. *International Journal of Behavioral Medicine, 14,* 40-47.

Orpana, H. M., Tremblay, M. S., & Fines, P. (2007). Trends in weight change among Canadian adults. *Health Reports, 18,* 9-16.

Ottenbacher, H. (2001). *Perceived barriers to weight control for stay-at-home mothers with pre-school aged children* (Unpublished doctoral dissertation). Texas Women's University, Denton, Texas.

Paluck, E. C., Allerdings, M., Kealy, K., & Dorgan, H. (2006). Health promotion needs of women living in rural areas: An exploratory study. *Canadian Journal of Rural Medicine, 11,* 111-116.

Pariante, C. M., Carpiniello, B., Orru, M. G., Sitzia, R., Piras, A., Farci, A. M. G., Del Giacco, G. S., Piludu, G., & Miller, A. H. (1997). Chronic caregiving stress alters peripheral blood immune parameters: The role of age and severity of stress. *Psychotherapy and Psychosomatics, 66,* 199-207.

Parkes, J., McCullough, N., Madden, A., & McCahey, E. (2009). The health of children with cerebral palsy and stress in their parents. *Journal of Advanced Nursing, 65,* 2311-2323. doi:10.1111/j.1365-2648.2009.05089.x

ParticiPACTION. (2013). *ParticipACTION: About.* Retrieved from http://www.participaction.com/about/

Pearson, C., Janz, T., & Ali, J. (2013). *Mental and substance use disorders in Canada.* Retrieved from http://www.statcan.gc.ca/pub/82-624-x/2013001/article/11855-eng.pdf

Pender, N., Murdaugh, C., and Parsons, M. A. (2011). *Health promotion in nursing practice* (6th ed.). Upper Saddle River, NJ: Pearson.

Pender, N. J., Walker, S. N., Sechrist, K. R., & Frank-Stromborg, M. (1990). Predicting health-promoting lifestyles in the workplace. *Nursing Research, 39,* 326-332.

Pennesi, C. M., & Klein, L. C. (2012). Effectiveness of the gluten-free, casein-free diet for children diagnosed with autism spectrum disorder: Based on parental report. *Nutritional Neuroscience, 15,* 85-91. doi:10.1179/1476830512Y.0000000003

Perruccio, A. V. (2009). *The contribution of physical, mental, and social dimensions of health to predicting self-rated health over the course of recovery following total joint replacement surgery* (Unpublished doctoral dissertation). University of Toronto, Toronto, Ontario, Canada.

Perruccio, A. V., Power, J. D., & Badley, E. M. (2007). The relative impact of 13 chronic conditions across three different outcomes. *Journal of Epidemiology and Community Health, 61,* 1056-1061. doi:10.1136/jech.2006.047308

Phetrasuwan, S., & Miles, M. S. (2009). Parenting stress in mothers of children with autism spectrum disorder. *Journal for Specialists in Pediatric Nursing, 14,* 157-165.

Phipps, S. (2003). *The impact of poverty on health: A scan of research literature.* Retrieved from http://secure.cihi.ca/cihiweb/products/CPHIImpactonPoverty_e.pdf

Pickett, W., Day, A. G., Hagel, L., Sun, X., Day, L., Marlenga, B., Brison, R. J., Pahwa, P., Crowe, T., Voaklander, D. C., & Dosman, J. (2011). Socioeconomic status and injury in a cohort of Saskatchewan farmers. *The Journal of Rural Health, 27,* 245-254. doi:10.1111/j.1748-0361.2010.00344.x

Poland, B. D. (2003). Transcription quality. In J. A. Holstein & J. F. Gubrium (Eds.), *Inside interviewing: New lenses, new concerns* (3rd ed., pp. 267-287). Thousand Oaks, CA: Sage.

Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (9th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Pong, R. W., DesMeules, M., Heng, D., Lagace, C., Guernsey, J. R., Kazanjian, A., Manuel, D., Pitblado, J. R., Bollman, R., Koren, I., Dressler, M. P., Wang, F., & Luo, W. (2011). Patterns of health services utilization in rural Canada. *Chronic Diseases and Injuries in Canada, 31*(1), 1-36.

Pong, R. W., DesMeules, M., & Lagace, C. (2009). Rural-urban disparities in health: How does Canada fare and how does Canada compare with Australia? *Australian Journal of Rural Health, 17,* 58-64. doi:10.1111/j.1440-1584.2008.01039.x

Population Health. (2007). *Health report 2007.* Red Deer, Alberta, Canada: David Thompson Health Region.

Powell, S. E., & Bauer, J. W. (2010). Resource use of rural low-income families caring for children with disabilities. *Journal of Children and Poverty, 16,* 67-83. doi:10.1080/10796120903575101

Premier's Advisory Council on Health for Alberta. (2001). *A framework for health reform: Report of the Premier's Advisory Council on health.* Retrieved from http://www.assembly.ab.ca/lao/library/egovdocs/alpm/2001/132279.pdf

Prince, M. M. (2006). *Governing in an integrated fashion: Lessons from the disability domain.* Retrieved from http://www.disabilitytax.ca/governing.pdf

Prosper, M. H., Moczulski, V. L., & Qureshi, A. (2009). Obesity as a predictor of self-rated health. *American Journal of Health Behavior, 33,* 319-329.

Puhl, R. M., & Heuer, C. A. (2009). The stigma of obesity: A review and update. *Obesity, 17,* 941-964. doi:10.1038/oby.2008.636

Racher, F. E., Vollman, A. R., & Annis, R. C. (2004). Conceptualizations of "rural": Challenges and implications for nursing research. *Online Journal of Rural Nursing and Health Care, 4*(2), 61-77.

Raeburn, J., & Rootman, I. (2007). A new appraisal of the concept of health. In M. O'Neill, A. Pederson, S. Dupere, & I. Rootman (Eds.), *Health promotion in Canada: Critical perspectives* (2nd ed., pp. 19-31). Toronto, Ontario, Canada: Canadian Scholars Press.

Raina., P., O'Donnell, M., Rosenbaum, P., Berhaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115,* e626-e636. doi:10.1542/peds.2004-1689

Ramage-Morin, P. L., Shields, M., & Martel, L. (2010). *Health-promoting factors and good health among Canadians in mid- to late life.* Retrieved from http://www.statcan.gc.ca/pub/82-003-x/2010003/article/11289-eng.pdf

Raphael, D. (2001). *Why inequality is bad for our hearts: Why low income and social exclusion are major causes of heart disease in Canada.* Retrieved from http://www.precaution.org/lib/inequality_bad_for_our_hearts.2001.pdf

Raphael, D. (2008). Grasping at straws: A recent history of health promotion in Canada. *Critical Public Health, 18,* 483-495. doi:10.1080/09581590802443604

Ray, G. T., Croen, L. A., & Habel, L. A. (2009). Mothers of children diagnosed with attention-deficit/hyperactivity disorder: Health conditions and medical care utilization in periods before and after birth of the child. *Medical Care, 47,* 105-114.

Ray, L. D. (2002). Parenting and childhood chronicity: Making visible the invisible work. *Journal of Pediatric Nursing, 17,* 424-438. doi:10.1053/jpdn.2002.127172

Reeder, B. A., Chen, Y., Macdonald, S. M., Angel, A., & Sweet, L. (1997). Regional and rural-urban differences in obesity in Canada. *Canadian Medical Association Journal, 157,* S10-S16.

Research Ethics Office. (2009). *Compensation of human research participants.* Retrieved from http://www.reo.ualberta.ca/en/~/media/University%20of%20Alberta/Administration/Research/Health%20Research%20Ethics%20Board/Documents/Test_Compensation_Guidelines_March__2009.pdf

Reutter, L. I. (2000). Socioeconomic determinants of health. In M. J. Stewart (Ed.), *Community nursing: Promoting Canadians' health* (2nd ed., pp. 174-193). Toronto, Ontario, Canada: W. B. Saunders.

Reutter, L. I., & Kushner, K. (2009). Health and wellness. In P. A. Potter, A. G. Perry, J. C. Ross-Kerr, & M. J. Wood (Eds.), *Canadian fundamentals of nursing* (4th ed., pp. 1-13). Toronto, Ontario, Canada: Elsevier.

Reyes-Gibby, C. C., Aday, L., & Cleeland, C. (2002). Impact of pain on self-rated health in the community-dwelling older adults. *Pain, 95,* 75-82.

Reynolds, C. L. (1988). The measurement of health in nursing research. *Advances in Nursing Science, 10*(4), 23-31.

Richard, L., & Gauvin, L. (2012). Building and implementing ecological health promotion interventions. In I Rootman, S. Dupere, A. Pederson, & M. O'Neill (Eds.), *Health promotion in Canada: Critical perspectives on practice* (3rd ed., pp. 67-80). Toronto, Ontario, Canada: Canadian Scholars Press.

Roach, M. A., Orsmond, G. I., & Barratt, M. S. (1999). Mothers and fathers of children with Down syndrome: Parental stress and involvement in childcare. *American Journal on Mental Retardation, 104,* 422-436.

Roberta, J., & Falk, M. (2000). *Women and health: Experiences in a rural regional health authority.* Retrieved from http://www.cewh-cesf.ca/PDF/pwhce/rha.pdf

Robertson, A. (1998). Shifting discourses on health in Canada: From health promotion to population health. *Health Promotion International, 13,* 155-166.

Robinson, A. M., & Richdale, A. L. (2004). Sleep problems in children with an intellectual disability: Parental perceptions of sleep problems, and views of treatment effectiveness. *Child: Care, Health and Development, 30,* 139-150.

Rogers, L. G., Magill-Evans, J., & Rempel, G. R. (2012). Mothers' challenges in feeding their children with autism spectrum disorder – managing more than just picky eating. *Journal of Developmental and Physical Disabilities, 24,* 19-33. doi:10.1007/s10882-011-9252-2

Romanow, R. J. (2002). *Building on values: The future of health care in Canada.* Retrieved from http://dsp-psd.pwgsc.gc.ca/Collection/CP32-85-2002E.pdf

Ryan, G. W., & Bernard, H. R. (2000). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 769-802). Thousand Oaks, CA: Sage.

Sallis, J. F., Bauman, A., & Pratt, M. (1998). Environmental and policy interventions to promote physical activity. *American Journal of Preventive Medicine, 15,* 379-397.

Sallis, J. F., Owen, N., & Fisher, E. B. (2008). Ecological models of health behavior. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice* (4th ed., pp. 465-485). San Fransisco, CA: Jossey-Bass.

Salmon, J., Owen, N., Crawford, D., Bauman, A., & Sallis, J. F. (2003). Physical activity and sedentary behavior: A population-based study of barriers, enjoyment, and preference. *Health Psychology, 22,* 178-188. doi:10.1037/0278-6133.22.2.178

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Sandelowski, M. (2014). Unmixing mixed methods. *Research in Nursing and Health, 37,* 3-8. doi:10.1002/nur.21570

Saylor, C. (2004). The circle of health: A health definition model. *Journal of Holistic Nursing, 22*, 97-115. doi:10.1177/0898010104264775

Schmied, E. A., Parada, H., Horton, L. A., Madanat, H., & Ayala, G. X. (2014). Family support is associated with behavioral strategies for health eating among Latinas. *Health Education and Behavior, 41,* 34-41. doi:10.1177/1090198113485754

Schmitt, L., Heiss, C. J., & Campbell, E. E. (2008). A comparison of nutrient intake and eating behaviors of boys with and without autism. *Topics in Clinical Nutrition, 23,* 23-31.

Schnittker, J. (2005). When mental health becomes health: Age and the shifting meaning of self-evaluations of general health. *The Milbank Quarterly, 83,* 397-423.

Scott, G. W. S. (1999). Physician practice in a rural setting. In W. Ramp, J. Kulig, I. Townshend, & V. McGowan (Eds.), *Health in rural settings: Contexts for action* (pp. 179-188). Lethbridge, Alberta, Canada: University of Lethbridge.

Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (3rd ed.). New York, NY: Teacher's College Press.

Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation, 106,* 265-286.

Selye, H. (1950). *The physiology and pathology of exposure to stress*. Montreal, Quebec, Canada: ACTA.

Selye, H. (1976). Forty years of stress research: Principal remaining problems and misconceptions. *Canadian Medical Association Journal, 115,* 53-56.

Shearn, J., & Todd, S. (2000). Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 13,* 109-131.

Shepard, M. P., Orsi, A. J., Jahon, M. M., & Carroll, R. M. (2002). Mixed-methods research with vulnerable families. *Journal of Family Nursing, 8,* 334-352. doi:10.1177/107484002237511

Shields, M. (2008). *Community belonging and self-perceived health.* Retrieved from http://www.statcan.gc.ca/pub/82-003-x/2008002/article/10552-eng.pdf

Shields, M., & Shooshtari, S. (2001). Determinants of self-perceived health. *Health Reports, 13*(1), 35-52.

Shields, M., & Tjepkema, M. (2006a). *Regional differences in obesity.* Retrieved from http://www.statcan.gc.ca/studies-etudes/82-003/archive/2006/9280-eng.pdf

Shields, M., & Tjepkema, M. (2006b). Trends in adult obesity. *Health Reports, 17,* 53-59.

Shields, M., & Tremblay, S. (2002). *The health of Canada's communities.* Retrieved from http://dsp-psd.pwgsc.gc.ca/Collection-R/Statcan/82-003-XIE/82-003-SIE2002001.pdf

Shields, M., & Tremblay, S. (2008a). *Screen time among Canadian adults: A profile.* Retrieved from http://www.statcan.gc.ca/pub/82-003-x/2008002/article/10600-eng.pdf

Shields, M., & Tremblay, S. (2008b). Sedentary behavior and obesity. *Health Reports, 19,* 19-30.

Shill, J., Mavoa, H., Allender, S., Lawrence, M., Sacks, G., Peeters, A., Crammond, B., & Swinburn, B. (2011). Government regulation to promote healthy food environments – a view from inside state governments. *Obesity Reviews, 13,* 162-173. doi:10.1111/j.1467-789X.2011.00937.x

Shill, J., Mavoa, H., Crammond, B., Loff, B., Peeters, A., Lawrence, M., Allender, S., Sacks, G., & Swinburn, B. A. (2012). Regulation to create environments conducive to physical activity: Understanding the barriers and facilitators at the Australian state government level. *PLOS ONE, 7*(9)*,* 1-11. doi:10.1371/journal.pone.0042831

Shuler, R. (2000). The cost of kindness: Self-sacrifice can cripple caregivers. *University of Alabama at Birmingham Magazine, 20*(2), 1-3.

Shuy, R. W. (2003). In person versus telephone interviewing. In J. A. Holstein & J. F. Gubrium (Eds.), *Inside interviewing: New lenses, new concerns* (3rd ed., pp. 175-193). Thousand Oaks, CA: Sage.

Siahpush, M., Borland, R., & Scollo, M. (2003). Smoking and financial stress. *Tobacco Control, 12,* 60-66. doi:10.1136/tc.12.1.60

Sibley, L. M., & Weiner, J. P. (2011). An evaluation of access to health care services along the rural-urban continuum in Canada. *BMC Health Services Research, 11,* 1-11. doi:10.1186/1472-6963-11-20

Simpson, F. (2009). *Access to respite care for parents who have children with disabilities in B. C.* (Unpublished master's thesis). Simon Fraser University, Burnaby, British Columbia, Canada.

Singh, V. (2004). The rural-urban income gap within provinces: An update to 2000. *Rural and Small Town Canada Analysis Bulletin, 5*(7), 1-20.

Singh-Manoux, A., Martikanen, P., Ferrie, J., Zins, M., Marmot, M., & Goldberg, M. (2006). What does self-rated health measure? Results from the British Whitehall II and French Gazel cohort studies. *Journal of Epidemiology and Community Health, 60,* 364-372. doi:10.1136/jech.2005.039883

Sinha, M. (2013). *Portrait of caregivers, 2012.* Retrieved from http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf

Smith, J. A. (1981). The idea of health: A philosophical inquiry. *Advances in Nursing Science, 3*(3), 43-50.

Smith, M. C. (1990). Nursing's unique focus on health promotion. *Nursing Science Quarterly, 3,* 105-106. doi:10.1177/089431849000300304

Smoyer-Tomic, K. E., Spence, J. C., Raine, K. D., Amrhein, C., Cameron, N., Yasenovskiy, V., Cutumisu, N., Hemphill, E., & Healy, J. (2008). The association between neighborhood socioeconomic status and exposure to supermarkets and fast food outlets. *Health & Place, 14,* 740-754. doi:10.1016/j.healthplace.2007.12.001

Sosu, E. M., McWilliam, A., & Gray, D. S. (2008). The complexities of teachers' commitment to environmental education: A mixed methods approach. *Journal of Mixed Methods Research, 2,* 169-189. doi:10.1177/1558689807313163

Spence, J. C., & Lee, R. E. (2003). Toward a comprehensive model of physical activity. *Psychology of Sport and Exercise, 4,* 7-24. doi:10.1016/S1469-0292(02)00014-6

Statistics Canada. (2006a). *Participation and activity limitation survey 2006.* Retrieved from http://www.statcan.gc.ca/imdb-bmdi/instrument/3251_Q1_V2-eng.pdf

Statistics Canada. (2006b). *Participation and activity limitation survey 2006: Tables.* Retrieved from http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007003-eng.pdf

Statistics Canada (2007a). *Participation and activity limitation survey 2006: Analytical report.* Retrieved from http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.pdf

Statistics Canada (2007b). *Participation and activity limitation survey 2006: Technical and methodological report.* Retrieved from http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007001-eng.pdf

Statistics Canada. (2008). *Participation and activity limitation survey 2006: Families of children with disabilities in Canada.* Retrieved from http://www.statcan.gc.ca/pub/89-628-x/89-628-x2008009-eng.pdf

Statistics Canada. (2010a). *Canadian community health survey: Annual component - 2010 questionnaire.* Retrieved from http://www.statcan.gc.ca/imdb-bmdi/instrument/3226_Q1_V7-eng.pdf

Statistics Canada. (2010b). *Health fact sheets 2008.* Retrieved from http://www.statcan.gc.ca/pub/82-625-x/82-625-x2010001-eng.htm

Statistics Canada. (2011a, January 19). Canadian health measures survey: Physical activity of youth and adults 2007 to 2009. *The Daily.* Retrieved from http://www.statcan.gc.ca/daily-quotidien/110119/dq110119-eng.pdf

Statistics Canada. (2011b). *Health fact sheets 2010.* Retrieved from http://www.statcan.gc.ca/pub/82-625-x/82-625-x2011001-eng.htm

Statistics Canada. (2011c). *Population urban and rural, by province and territory.* Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo62a-eng.htm

Statistics Canada. (2012). *Life expectancy.* Retrieved from http://www5.statcan.gc.ca/cansim/a05?lang=eng&id=01024307

Statistics Canada. (2013a). *Directly measured physical activity of Canadian adults, 2007 to 2011.* Retrieved from http://www.statcan.gc.ca/pub/82-625-x/2013001/article/11807-eng.pdf

Statistics Canada. (2013b). *Health fact sheets 2012.* Retrieved from http://www.statcan.gc.ca/pub/82-625-x/2013001/article/11844-eng.htm

Statistics Canada. (2013c). *Health profile.* Retrieved from http://www12.statcan.gc.ca/health-sante/82-228/index.cfm?Lang=E

Statistics Canada. (2013d). *Low income lines, 2011-2012.* Retrieved from http://www.statcan.gc.ca/pub/75f0002m/75f0002m2013002-eng.pdf

Statistics Canada. (2013e). *Median total income, by family type, by province and territory.* Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/famil108a-eng.htm

Statistics Canada. (2014). Work – employment rate. Retrieved from http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=13#M_7

Stein, R. E. K., & Jessop, D. J. (1982). A noncategorical approach to chronic childhood illness. *Public Health Reports, 97,* 354-362.

Stein, R. E. K., & Jessop, D. J. (1989). What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. *Social Science and Medicine, 29,* 769-778.

Stenberg, G., Fjellman-Wiklund, A., & Ahlgren, C. (2014). 'I am afraid to make the damage worse' – fear of engaging in physical activity among patients with neck or back pain – a gender perspective. *Scandinavian Journal of Caring Sciences, 28,* 146-154. doi:10.1111/scs.12043

Stewart, M. J., & Langille, L. (2000). A framework for social support assessment and intervention int he context of chronic conditions and caregiving. In M. J. Stewart (Ed.), *Chronic conditions and caregiving in Canada: Social support strategies* (pp. 3-28). Toronto, Ontario, Canada: University of Toronto Press.

Stokols, D. (1992). Establishing and maintaining health environments: Toward a social ecology of health promotion. *American Psychologist, 47,* 6-22.

Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion, 10,* 282-298.

Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed.). Philadelphia, PA: Lippincott, Williams & Wilkins.

Sullivan, A. D. (2003). Determining how low-income food shoppers perceive, understand, and use food labels. *Canadian Journal of Dietetic Practice and Research, 64,* 25-27.

Sutherns, R., McPhedran, M., & Haworth-Brockman, M. (2004). *Rural, remote, and northern women's health: Policy and research directions.* Retrieved from http://www.cewh-cesf.ca/PDF/cross_cex/RRN_Summary_CompleteE.pdf

Svedberg, L. E., Englund, E., Malker, H., & Stener-Victorin, E. (2010). Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with cerebral palsy and provided community services report. *European Journal of Paediatric Neurology, 14,* 239-246. doi:10.1016/j.ejpn.2009.07.001

Talbott, S. (2007). *The cortisol connection*. Alameda, CA: Hunter House.

Tarasuk, V. (2010). Policy directions to promote healthy dietary patterns in Canada. *Applied Physiology, Nutrition, and Metabolism, 35,* 229-233. doi:10.1139/H10-009

Tashakkori, A., & Creswell, J. W. (2007). The new era of mixed methods [Editorial]. *Journal of Mixed Methods Research, 1*, 3-7. doi:10.1177/2345678906293042

Tavares, L. S., & Plotnikoff, R. C. (2008). Not enough time? Individual and environmental implications for workplace physical activity programming among women with and without young children. *Health Care for Women International, 29,* 244-281. doi:10.1080/07399330701880911

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences.* Thousand Oaks, CA: Sage.

Thomas, R. M. (2003). *Blending qualitative and quantitative research methods in theses and dissertations.* Thousand Oaks, CA: Corwin Press.

Thompson, D. R., Chair, S. Y., Chan, S. W., Astin, F., Davidson, P. M., & Ski, C. F. (2011). Motivational interviewing: A useful approach to improving cardiovascular health. *Journal of Clinical Nursing, 20,* 1236-1244. doi:10.1111/j.1365-2702.2010.03558.x

Thurston, W. E., & Blundell-Gosselin, H. J. (2005). The farm as a setting for health promotion: Results of a needs assessment in South Central Alberta. *Health & Place, 11,* 31-43. doi:10.1016/j.healthplace.2004.01.001

Thurston, W. E., Blundell-Gosselin, H. J., & Vollman, A. R. (2003). Health concerns of male and female farmers: Implications for health promotion planning. *Canadian Journal of Rural Medicine, 8,* 239-246.

Thyen, U., Terres, N. M., Yazdgerdi, S. R., & Perrin, J. M. (1998). Impact of long-term care of children assisted by technology on maternal health. *Developmental and Behavioral Pediatrics, 19,* 273-282.

Timmerman, G. M. (1999). Using self-care strategies to make lifestyle changes. *Journal of Holistic Nursing, 17,* 169-183. doi:10.1177/089801019901700205

Tjepkema, M., Wilkins, R., & Long, A. (2012). Cause-specific mortality by education in Canada: A 16-year follow-up study. *Health Reports, 23*(3), 1-11.

Tong, H. C., Haig, A. J., Nelson, V. S., Yamakawa, K. S. J., & Kandala, G. (2003). Low back pain in adult female caregivers of children with physical disabilities. *Archives of Pediatric Adolescent Medicine, 157,* 1128-1133.

Tong, H. C., Kandala, G., Haig, A. J., Nelson, V. S., Yamadawa, K. S. J., & Shin, K. Y. (2002). Physical functioning in female caregivers of children with physical disabilities compared with female caregivers of children with a chronic medical condition. *Archives of Pediatric Adolescent Medicine, 156,* 1138-1142.

Tripp-Reimer, T. (1984). Reconceptualizing the construct of health: Integrating emic and etic perspectives. *Research in Nursing and Health, 7,* 101-109. doi:0160-6891/84/020101-0

Troughton, M. J. (1999). Redefining 'rural' for the twenty-first century. In W. Ramp, J. Kulig, I. Townshend, & V. McGowan (Eds.), *Health in rural settings: Contexts for action* (pp. 21-38). Lethbridge, Alberta, Canada: University of Lethbridge.

Trute, B., Benzies, K. M., Worthington, C., Reddon, J. R., & Moore, M. (2010). Accentuate the positive to mitigate the negative: Mother psychological coping resources and family adjustment in childhood disability. *Journal of Intellectual and Developmental Disability, 35,* 36-43. doi:10.3109/13668250903496328

Tsigos, C., Kyrou, I., & Chrousos, G. P. (2005). Stress, endocrine manifestations, and diseases. In G. L. Cooper (Ed.), *Handbook of stress medicine and health* (2nd ed., pp. 101-130). Boca Raton, FL: CRC Press.

Tucker, C. M., Butler, A. M., Loyuk, I. S., Desmond, F. F., & Surrency, S. L. (2009). Predictors of a health-promoting lifestyle and behaviors among low-income African American and white mothers of chronically ill children. *Journal of the National Medical Association, 101,* 103-110.

Tudoran, A. A., Scholderer, J., & Brunso, K. (2012). Regulatory focus, self-efficacy and outcome expectations as drivers of motivation to consume healthy food products. *Appetite, 59,* 243-251. doi:10.1016/j.appet.2012.05.002

Tuna, H., Unalan, H., Tuna, F., & Kokino, S. (2004). Quality of life of primary caregivers of children with cerebral palsy: A controlled study with Short Form-36 questionnaire. *Developmental Medicine & Child Neurology, 46,* 647-648.

Turcotte, M. (2013). *Family caregiving: What are the consequences?* Retrieved from http://www.statcan.gc.ca/pub/75-006-x/2013001/article/11858-eng.pdf

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences, 15,* 398-405. doi:10.1111/nhs.12048

Valentine, F. (2001). *Enabling citizenship: Full inclusion of children with disabilities and their parents.* Retrieved from http://cprn.org/documents/3594_en.pdf

van Zandvoort, M., Irwin, J. D., & Morrow, D. (2009). The impact of co-active life coaching on female university students with obesity. *International Journal of Evidence Based Coaching and Mentoring, 7*(1), 104-118.

Verweij, L. M., Porper, K. I., Leffelaar, E. R., Weel, A. N. H., Nauta, A. P., Hulshof, C. T. J., & van Mechelen, W. (2012). Barriers and facilitators to implementation of an occupational health guideline aimed at preventing weight gain among employees in the Netherlands. *Journal of Occupational and Environmental Medicine, 54,* 954-960. doi:10.1097/JOM.0b013e3182511c9f

Wallander, J. L., Varni, J. W., Babani, L., Banis, T., DeHaan, C. B., & Wilcox, K. T. (1989). Disability parameters, chronic strain, and adaptation of physically handicapped children and their mothers. *Journal of Pediatric Psychology, 14,* 23-42.

Walker, S. N. (2011a). *HPLP II: Background and permission for use.* Retrieved from http://www.unmc.edu/nursing/docs/HPLPII_Background_and_Permission_for_Use.pdf

Walker, S. N. (2011b). *HPLP II: Scoring.* Retrieved from http://www.unmc.edu/nursing/docs/HPLPII_Scoring.pdf

Walker, S. N. (2011c). *HPLP and HPLP II bibliography.* Retrieved from http://www.unmc.edu/nursing/docs/HPLP_HPLPII_Bibliography.pdf

Walker, S. N., & Hill-Polerecky, D. M. (1996). *Psychometric evaluation of the health-promoting lifestyle profile II.* Unpublished manuscript, University of Nebraska Medical Center.

Walker, S. N., Sechrist, K. R., & Pender, N. J. (1987). The health promoting lifestyle profile: Development and psychometric characteristics. *Nursing Research, 36,* 76-81.

Walker, S. N., Sechrist, K. R., & Pender, N. J. (1995). *Health-promoting lifestyle profile II.* Retrieved from http://www.unmc.edu/nursing/docs/English_HPLPII.pdf

Warburton, D. E. R., Nicol, C. W., & Bredin, S. S. D. (2006). Health benefits of physical activity: The evidence. *Canadian Medical Association Journal, 174,* 801-809. doi:10.1503/cmaj.051351

Ware, J. E. (2000). SF-36 health survey update. *Spine, 25,* 3130-3139.

Wathen, C. N., & Harris, R. M. (2007). "I take care of it myself." How rural women search for health information. *Qualitative Health Research, 17,* 639-651. doi:10.1177/1049732307301236

Webber, K. J., & Loescher, L. J. (2013). A systematic review of parent role modeling of health eating and physical activity for their young African American children. *Journal of Specialists in Pediatric Nursing, 18,* 173-188. doi:10.1111/jspn.12033

Weber, R. P. (1990). *Basis content analysis* (2nd ed.). Newbury Park, CA: Sage.

Whitehead, D. (2004). Health promotion and health education: Advancing the concepts. *Journal of Advanced Nursing, 3,* 311-320.

Whitehead, D. (2009). Reconciling the differences between health promotion in nursing and 'general' health promotion. *International Journal of Nursing Studies, 46,* 865-874. doi:10.1016/j.ijnurstu.2008.12.014

Whiton, D. N. (1997). *The perceived barriers to smoking cessation that exist for women* (Unpublished doctoral dissertation). Madonna University, Livonia, Michigan.

Wiart, L., Church, J., Darrah, J., Ray, L., Magill-Evans, J., & Anderson, J. (2010). Cross-ministerial collaboration related to paediatric rehabilitation for children with disabilities and their families in one Canadian province. *Health and Social Care in the Community, 18,* 379-388. doi:10.1111/j.1365-2524.2009.00909.x

Wilkins, K., & Woodgate, R. (2008). Designing a mixed methods study in pediatric oncology nursing research. *Journal of Pediatric Oncology Nursing, 25,* 24-33. doi:10.1177/1043454207311914

Winstead-Fry, P. (1980). The scientific method and its impact on holistic health. *Advances in Nursing Science, 2*(4), 1-8.

Woodman, A. C. (2014). Trajectories of stress among parents of children with disabilities: A dyadic analysis. *Family Relations, 63,* 39-54. doi:10.1111/fare.12049

World Health Organization. (1948). *WHO definition of health.* Retrieved from http://www.who.int/about/definition/en/print.html

World Health Organization. (1986). *Ottawa charter for health promotion.* Retrieved from http://whqlibdoc.who.int/hq/1995/WHO_HPR_HEP_95.1.pdf

World Health Organization. (1998). *Health promotion glossary.* Retrieved from http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf

World Health Organization. (2001). *International classification of functioning, disability and health.* Geneva, Switzerland: Author.

World Health Organization. (2005). *Facing the facts: The impact of chronic disease in Canada.* Retrieved from http://www.who.int/chp/chronic_disease_report/media/CANADA.pdf

World Health Organization. (2007). *Smoke-free inside.* Retrieved from http://www.who.int/tobacco/resources/publications/wntd/2007/Smoke-free%20inside%2012pages_FINAL.pdf

World Health Organization. (2013). *Global database on body mass index.* Retrieved from http://apps.who.int/bmi/index.jsp?introPage=intro_3.html

Wuest, J., Merritt-Gray, M., Berman, H., & Ford-Gilboe, M. (2002). Illuminating social determinants of women's health using grounded theory. *Health Care for Women International, 23,* 794-808. doi:10.1080/0739933029011232 6

Wyatt, J. S. (1991). *Family coping and level of health of parents with technology assisted home-bound children with respiratory disabilities* (Unpublished doctoral dissertation). University of Maryland, College Park, Maryland.

Yantzi, N. M. (1998). *The critical role of distance on the subjective and objective impacts of families caring for a child with a chronic condition* (Unpublished master's thesis). Queen's University, Kingston, Ontario, Canada.

Yantzi, N. M. (2005). *Balancing and negotiating the home as a place of caring: The experiences of families caring for children with long-term care needs* (Unpublished doctoral dissertation). Queen's University, Kingston, Ontario, Canada.

Yantzi, N. M., Rosenberg, M. W., Burke, S. O., & Harrison, M. (2001). The impacts of distance to hospital on families with a child with a chronic condition. *Social Science and Medicine, 52,* 1777-1791.

Yantzi, N. M., Rosenberg, M. W., & McKeever, P. (2006). Getting out of the house: The challenges mothers face when their children have long-term care needs. *Health and Social Care in the Community, 15,* 45-55. doi:10.1111/j.1365-2524.2006.00663.x

Yeh, M., Ickes, S. B., Lowenstein, L. M., Shuval, K., Ammerman, A. S., Farris, R., & Katz, D. L. (2008). Understanding barriers and facilitators of fruit and vegetable consumption among a diverse multi-ethnic population in the USA. *Health Promotion International, 23,* 42-51. doi:10.1093/heapro/dam044

Young, J. J. (1997). *Farm women of Alberta: Their perceptions of their health and work* (Unpublished master's thesis). University of Alberta, Edmonton, Alberta, Canada.

Young, L. E., & Higgins, J. W. (2005). Concepts of health. In L. L. Stamler & L. Yiu (Eds.), *Community health nursing: A Canadian perspective* (2nd ed., pp. 73-86). Toronto, Ontario, Canada: Pearson.

Yu, V. L., & Raphael, D. (2004). Identifying and addressing the social determinants of the incidence and successful management of Type 2 diabetes mellitus in Canada. *Canadian Journal of Public Health, 95*, 366-368.

Zhu, B., Walter, S. D., Rosenbaum, P. L., Russell, D. J., & Raina, P. (2006). Structural equation and log-linear modeling: A comparison of methods in the analysis of a study on caregivers' health. *BMC Medical Research Methodology, 6,* 49-62. doi:10.1186/1471-2288-6-49

Zunzunegui, M. V., Kone, A., Johri, M., Beland, F., Wolfson, C., & Bergman, H. (2004). Social networks and self-rated health in two French-speaking Canadian community dwelling populations over 65. *Social Science and Medicine, 58,* 2069-2081. doi:10.1016/j.socscimed.2003.08.005

Appendices

Appendix A

Table 1

Studies That Assessed Multiple Domains of Health of Caregivers (CGs) of Children with Disabilities

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Allik, Larsson, & Smedje, 2006 -no framework specified. Discuss parent stress and health outcomes	-31 mothers & 30 fathers (age 28-64) of children with AS/HFA compared with 30 mothers and 29 fathers (age 31-53) of children with typical development Sweden	32 school-age (8 - 13) years old) children with Asperger syndrome (AS) or high functioning autism (HFA) and 32 age and gender matched children with typical development	No	Physical Mental	Medical Outcomes Study Short Form Health Survey (MOS SF-12)	Quantitative -compared mothers and fathers of children with AS/HFA to mothers and fathers of children with typical development	Only the mothers of children with AS/HFA had lower SF-12 scores than the controls in physical health. Their mental health status scores did not differ. Mothers in the AS/HFA group had lower physical SF-12 scores than the fathers of children with AS/HFA. Mother's SF-12 scores in the AS/HFA group were related to the extent of symptoms of hyperactivity and conduct problems in the child. Mothers of school-age children with AS/HFA had an increased risk of impaired physical well-being compared to fathers.
Bella, Garcia, & Spadari-Bratfisch, 2011 -stress and immunity	-37 mothers (mean age 34.7 years) of children with cerebral palsy (CP) compared with 38 mothers (mean age 33.3 years) of children with typical development (children aged 4-11 years) Brazil	Children with cerebral palsy (mean age 7.8 years) and children without developmental problems (mean age 7.2 years). Children in both groups aged 4-11 years.	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	-Medical Outcomes Study 36 Item Short Form Health Survey (MOS SF-36) Portuguese Version -Burden Interview -Perceived Stress Questionnaire -salivary cortisol levels	Quantitative -compared mothers of children with CP to mothers of children without developmental problems	There was no difference in the scores between the two groups in perceived stress. Mothers of children with CP had significantly lower scores in the SF-36 in the physical functioning, role-physical, bodily pain, and general health. While the scores of mothers of children with CP were higher for vitality, social functioning, role-emotional, and mental health, there was no significant difference. Mothers of children with CP had hypo-cortisol responses associated with chronic stress.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Benjak, Mavrinac, & Simetin, 2009 -no framework specified	105 mothers and 75 fathers (mean age 43) of children with ASD compared to 101 mothers and 71 fathers (mean age 42) of children without disabilities Croatia	-children with autism spectrum disorder (ASD) and a control group of non-disabled children matched by age, education, and place of living (age not specified)	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	Medical Outcomes Study 36 Item Short Form Health Survey (MOS SF-36) Croatian version -additional questions included chronic medical conditions and needs	Quantitative -compared mothers and fathers of children with ASD to control group of mothers and fathers	Parents of children with ASD had significantly poorer self-perceived health in all components, except physical functioning, than the control group. They also reported significantly more deteriorated health in the last year than the control group and reported more psychological disorders.
Bourke et al., 2008 -Stress	250 Mothers of children/young adults with Down Syndrome (mean age 44.4 years) Australia	Child/Young adult (aged 0 - 25) with Down syndrome	No	Physical Mental	MOS SF - 12	Quantitative -regression used to determine affect between child characteristics and mother's health	Predictors of maternal health included child behavior difficulties, the child's level of functioning, and the child's current health status. Lower physical health scores were related to the presence of heart problems in the child, a higher body mass index, and children with more disruptive behaviors. Mental health scores were lower than norms. Worse mental health scores were noted in mothers of children with ear problems, muscle/bone problems, > 3 health problems, >4 illness episodes in the past year, and children with more disruptive behaviors.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Brehaut et al., 2004 - Caregiving Stress Process Model	-468 primary CGs (mean age 40.3 years) of children with Cerebral Palsy (CP) living in Ontario -compared to CGs of children from NLSCY (n=2414 - mean age 40.2 years) and NPHS (n=5549 - mean age 39.9 years) Canada	-compared children with CP aged 7 - 15 years from rehab centers in Ontario with children reported in NLSCY and NPHS	No	Physical Mental Financial	-McMaster Health Utility Index -Social Provisions Scale -Social Network and Frequency of Contact Index -Family Assessment Device -#chronic conditions -Composite International Diagnostic Interview -Income, work for pay, hours per week worked, main activity	Quantitative -compared primary CGs of children with cerebral palsy to CGs from the NLSCY and NPHS	CGs of children with CP had lower incomes than the general population (no difference in levels of education), were less likely to work full time, and were more likely to list caring for family as their main activity. No difference in social support; did have greater support contacts. CGs of children with CP reported greater distress, more chronic stress, emotional problems and cognitive problems. CGs of children with CP were also more likely to have back problems, migraine headaches, stomach/intestinal ulcers, asthma, pain, arthritis/rheumatism, as well as a greater number of chronic physical conditions.
Brehaut et al., 2009 - Caregiving Stress Process Model	9401 (total) Canadian primary CGs (90% women, 88.8% mothers) of children from NLSCY - compared subgroup of CGs of children with health problems (n=2495) to CGs of healthy children (n=3633) -mean age of CGs 35.8 years Canada	Children aged 4-11 years in 1994-1995 9401 child-caregiver pairs Subgroups: -Child with Health Problems (variety of issues) n=2495 -Healthy Children n=3633	No	Physical Mental Financial	-# chronic conditions, -any activity limitations -General SRH - Center for Epidemiological Studies Depression Scale -McMaster Family Assessment Device -Social Provisions Scale -asked about marital satisfaction, smoking, education, household income	Quantitative -compared CGs of healthy children to children with health problems	Health of CGs of children with health problems was significantly poorer than the health of caregivers of healthy children. They were less likely to report their health as excellent or very good. They had more chronic conditions, activity limitations, and depressive symptoms. They did not differ in measures of family functioning, social support, and family functioning. Logistic regression showed that CGs of children with health problems were more than twice as likely to report chronic conditions, activity limitations, and elevated depressive symptoms. They were also more likely to report poorer general health than CGs of healthy children. This sample had higher rates of caregiver income, education, and two parent households than national population norms.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Burton, Lethbridge, & Phipps, 2008a -Akerlof and Kranton (2000) economics and identity and Grossman 1972 health produced by how allocate time and money	-primary CGs (98% mothers - mean age 39.8) and their spouses (mean age 42.2 years) from NLSCY n=5880 (14.4% CGS of children with disabilities) compared to parents of a child without a disability Canada	-children aged 6-15 years in 2000 in NLSCY 1994-2000 -n=5880 (14.4% of sample had disability or sibling with disability, 85.6% no disability) -variety of disabilities	No	General SRH	-General self-rated health status	Quantitative -compared mothers and fathers of children with a disability to mothers and fathers of a children without a disability	Having a child with a disability is associated with poorer health status in mothers. Having a child with a longer-standing disability and with a health problem that has just appeared were both associated with poorer health status of the mother. Controlling for initial parental health status and other health determinants, mothers of children with longer-term disabilities experienced poorer health. Health of fathers was unaffected by the child's disability status. The probability of the mother's health deteriorating relative to the father's health was significantly higher when a child with a disability was in the household.
Burton, Lethbridge, & Phipps, 2008b -Akerlof and Kranton (2000) economics and identity and Grossman 1972 health produced by how allocate time and money	-married mothers and lone mothers of children from NLSCY -Married n=5217 (mean age 39.8 years) -Lone n=1191 (mean age 38.4 years) Canada	-children aged 6-15 years in 1994-2000 Married n=5217 (14.5% disabled) Lone n=1191(17.3% disabled) -variety of disabilities	No	General SRH	-General self-rated health status	Quantitative -multivariate regression was used to determine if health status of married and lone mothers was affected by child with a disability	Mothering a child with a disability or chronic condition resulted in poorer self-rated health for both married and lone mothers. Health status of lone mothers was poorer than the health of the married mothers. However, this difference was not evident after controlling for various health determinants.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Byrne, Hurley, Daly, and Cunningham, 2010 -holistic and family centered approach.	-93 mothers, 60 fathers, and 8 others CGS (mean age 40.6 years) compared to Irish general population (30 men and 43 women aged 35-44 years) Ireland	156 children with cerebral palsy aged 18 years and younger	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	MOS SF-36 v. 2 -# hours per day spent with child	Quantitative -compared health of male and female CGs of children with CP to each other and to norms of general Irish population	CGs of children with CP were found to have poorer health than Irish population norms. Female CGs had poorer health than male CGs in both the physical and mental health domains. CGs spending more time caring had significantly poorer mental health than those spending less time caring. No difference in the health was found between CGs of more dependent vs. more independent children, although CGs of more dependent children reported having more pain.
Cairns, 1992 -no framework specified; does refer to stress resulting in psychiatric illness	19 mothers and 19 fathers -age of parents not specified Scotland	-19 preschool children (age not specified) with neurological disabilities e.g. epilepsy, mental and/or physical handicap, epilepsy	No	Physical Mental Social Financial	Malaise Inventory -additional questionnaire that assessed SES, caring roles, religious beliefs, support networks	Quantitative -described health effects of child's disability on mothers and fathers and compared them to population norms	Parents had higher malaise scores than normal population. 50% mothers and fathers had backaches, felt tired, worried, and were easily annoyed. Fathers had more difficulty falling asleep and suffered from indigestion more than mothers. 16 fathers worked full time; only 2 mothers were employed and only part-time. The majority of parents reported that their social life was severely restricted. Mothers and fathers were prone to stress and depression. 95% mothers and 84% fathers perceived their health as being adversely affected as a result of the child's disability.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Davis et al., 2010 -none (qualitative)	24 mothers and 13 fathers -age of CG not specified Australia	37 children with cerebral palsy aged 3 - 18 years	No	Physical Social Financial Leisure	-no instruments used as was qualitative. Asked 'How does having a child with CP impact on your life?'	Qualitative -exploratory descriptive using grounded theory approach	Caring for a child with CP negatively impacted parents in terms of physical health (got worse as child got older), disrupted sleep, social relationships, marital relationship, family holidays, limited freedom, limited time, maternal employment, and financial burden. Caring for a child with CP positively affected social support networks and parents drew inspiration from their children.
De Andres-Garcia, Moya-Albiol, & Gonzalez-Bono, 2012 -stress and immunity	41 CGs (mean age 45.7) of children with autism spectrum disorder (ASD) compared to 37 parents (mean age 43.9) of typically developing children Spain	Children with ASD (mean age 11.63) and typically developing children (ages not provided)	No	General SRH Physical Mental	-General Health Questionnaire -Profile of Mood States -State-Trait Anxiety Inventory -Somatic Symptoms Scale -BMI -saliva samples to assess cortisol levels and immunoglobulin A (IGA)	Quantitative - compared CGs of children with ASD to typically developing children	CGs of children with ASD reported a great number of immunological, gastrointestinal, neuro-sensorial, muscular, genito-urinal, and total complaints than controls. These caregivers also reported more anxiety, insomnia, social dysfunction, and depression than controls. Perceived general health was also worse. When feelings of frustration were controlled, CGs of children with ASD had a reduced IGA and suppressed cortisol response.
Eisenhower, Baker & Blacher, 2009 -negative impact of chronic stress on physical well-being	91 mothers (mean age 32.5) of children with developmental delays compared to 127 mothers (mean age 34.1) of typically developing children United States	91 children with developmental delays and 127 typically developing children aged 3 years (followed until age of 5)	No	General SRH Mental	-General Health Status -Center for Epidemiologic Studies Depression Scale -Family Impact Questionnaire	Quantitative - compared mothers of children with developmental delays to typically developing children and to child characteristics	Mothers of children with developmental delays reported poorer physical health than mothers of typically developing children. Mothers who had had a child with behavior problems and who reported clinical levels of depression had the poorest physical health. Child behavior problems and the interaction of developmental status and behavior problems predicted 13.7% of the variance in maternal health.

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Eker & Tuzun, 2004 -no framework specified	40 Mothers (mean age 26.4 years) of children with CP compared to 44 mothers (mean age of 28.2 years) of children with minor health problems Turkey	40 children with cerebral palsy compared to 44 children with minor health problems (mean age 4.7 years in both groups)	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	Turkish version of the Medical Outcomes SF-36	Quantitative -compared CGs of children with CP to CGs of children with minor health problems	Mothers of children with cerebral palsy reported lower scores on all of the subscales of the SF-36 when compared to children with minor health problems, with the exception of the physical functioning subscale. Mothers of children with lower levels of functioning reported worse scores on all of the SF-36 subscales.
Epel et al., 2004 -stress and immunity	39 mothers of a chronically ill child and 19 mothers of a healthy child -mothers aged 20 - 50 years old, mean 38 years. United States	39 children with a chronic illness and 19 healthy children (child's age and illness not specified)	No	Mental -Physical: measured length of telomeres, oxidative stress, and telomerase activity (marks of cellular aging) and BMI	-10 item standardized questionnaire assessing level of perceived stress over the past month (name not provided -blood test to measure length of telomeres, oxidative stress, and telomerase activity	Quantitative -compared mothers of chronically ill children to mothers of a healthy child	Mean perceived stress level was significantly higher in CGs of children with chronic illness than in controls. The CGs did not differ from controls in telomere length, telomerase activity, or oxidative stress index. However, within the caregivers of children with chronic illness group (and controlling for the mother's age), the longer the years of caregiving, the shorter the mother's telomere length, the lower the telomerase activity, and the greater the oxidative stress. Higher perceived stress in both groups was significantly correlated with a higher BMI, shorter telomeres, lower telomerase activity, and higher oxidative stress. Mothers with the highest stress levels had telomeres shorter on average by the equivalent of at least one decade of additional aging compared to mothers who reported lower levels of perceived stress. Shorter telomeres have been associated with vulnerability to infections, higher mortality rates in the elderly, and patients with early myocardial infarction. Therefore, it appears that stress can promote an earlier onset of age-related diseases at the cellular level.

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Flom-Meland, 2004 -Lazarus Stress and Coping	59 CGs of children with special needs (CCWSN) (55 females and 4 males) aged 30 to 61 years (mean age 42 years) and 44 caregivers of children without special needs (CCWOSN) (42 females and 2 males) aged 22 to 47 years (mean age 35 years United States	Children with special needs and children without special needs -no information is provided about the exact number, ages, or type of disability of the children with special needs of the children or how many children were in the mild, moderate, and severe levels of disability	Yes	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	MOS SF-36 v. 2 -Holmes Stress Quotient Inventory	Quantitative -compared caregivers of children with special needs with caregivers of children without special needs and to established norms. Also compared the health of urban and rural caregivers of children with special needs.	The majority of the CCWSN were married (40 out of the 44 who reported marital status). Of these, the majority worked outside of the home (42 of 58 reporting occupation). The only statistically significant difference in the demographics between the two groups was that the CGs of children with special needs were older; there was no difference between the two groups in occupation. There was no significant difference between urban and rural caregivers in any of the components of the SF-36 or in the PCS or MCS. CCWSN scored worse than established norms on the SF-36 in the areas of vitality, social functioning, role-emotional, mental health, and the Mental health component summary score (MCS). They scored at or better than established norms in physical functioning, role-physical, bodily pain, general health, and the physical component summary score (PCS). CCWOSN scored either at or above established norms in all eight components of the SF-36 and in the MCS and PCS. The differences between the two groups was significant for the physical functioning, mental health, role-physical, general health, vitality, social functioning, and MCS scores. There was no significant difference in the bodily pain or physical component summary scores. There was no relationship between the level of severity of the child's disability and the PCS or MCS. Although the scores in the Holmes Stress Quotient Inventory for CCWSN were worse than the scores of CCWOSN, the difference was not significant. CGs in both groups scored in the moderate range of stress. There was no significant relationship between the stress score and the PCS. As stress scores increased, worse scores were evident in the MCS.

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Gallagher, Phillips, Drayson, & Carroll, 2009 -effect of chronic stress on immunity	-30 parents (mean age 42.8 years) of children with developmental disabilities compared to 29 parents (mean age 39.9 years) of typically developing children England	-children aged 3 to 19 years with developmental disabilities and children the same age with typical development	No	Mental Social Physical: aggregate antibody titre	-Hospital Anxiety & Depression Scale -Perceived Stress Scale -Support Functions Scale -Caregiver Burden Index -Strengths and Difficulties Questionnaire -antibody titre	Quantitative -prospective design that compared experimental and control group at 1 and 6 months	Both samples were vaccinated with pneumococcal polysaccharide vaccine and then blood was taken at 1 and 6 months. CGs of children with disabilities mounted a poorer antibody response to vaccination than control parents at both 1 and 6 months. Child problem behaviors were a significant predictor of 1 month antibody response. CGs of children with more disruptive behaviors had a poorer response to the vaccination than CGs of children with less disruptive behaviors. -CGs of children with disabilities spent significantly more hours on caregiving, were less likely to be employed outside the home, had a poorer quality of sleep, and had higher mean depression, perceived stress, and caregiver burden scores.
Hedov, Anneren, & Wikblad, 2000 -no framework specified	86 mothers (mean age 37.8) and 79 fathers (mean age 39.6) compared to 100 mothers (mean age 36.2) and 100 fathers (mean age 36) Sweden	-86 children aged 3.5 to 7 years with Down Syndrome (DS)	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	Swedish version of the SF-36 -asked question about how many hours per day spent in caring for the child with DS	Quantitative -compared parents of children with DS to control group from population of Sweden	DS mothers had worse scores than DS fathers in the Vitality domain of the SF-36. Compared to the control group, DS mothers had significantly poorer scores in the Vitality, Mental Health, General Health, Social Functioning, and Role-Emotional domains. DS fathers had lower scores in the Vitality and Mental Health Domains than controls. There was no significant difference in the employments levels of the DS mothers or fathers, but mothers spent significantly more time than fathers caring for their child with DS. DS mothers had poorer health than the DS fathers and the control mothers; there was no difference in the health status of control mothers and fathers.

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Holm, 2004 -Family Adaptation and Response Model And Uncertainty in Illness	220 mothers (mean age ranged from 31.6 to 38.7 years) and 188 fathers (mean age ranged from 34.7 to 40.4 years) -included adoptive parents and stepparents - lived in Minneapolis-St. Paul, MN and Seattle, WA United States	228 children aged 5 months to 11 years with various disabilities and chronic health issues	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	Functional status Questionnaire (FS I and II) -Beck Depression Inventory -MOS SF-36	Quantitative -measured uncertainty at time 1, mental symptoms at time 1 and 2, and physical symptoms at times 1 and 3 -structural equation modeling used to test model and to determine associations	Waves of data were collected every 12 - 18 months. Overall, participants reported low amounts of uncertainly and low levels of psychological and physical symptoms. Both mothers and fathers reported a lack of energy. Of the physical symptoms, both mothers and fathers reported general health problems. Higher parental uncertainty was associated with more psychological symptoms in mothers. Mothers and fathers who reported higher psychological symptoms at time 2 reported greater increases in physical symptoms at time 3 compared to other mothers and fathers in the study. Mothers reported more psychological symptoms than fathers. Mothers only differed from fathers at time 3, when they reported more role problems.
Kaya et al, 2010 -no framework specified	81 mothers (mean age 31.07 years) of children with Cerebral Palsy (CP) and 60 mothers (mean age 31.08 years) of healthy children Turkey	81 children (mean age 6.06 years) with cerebral palsy and 60 healthy children (mean age 6.2 years)	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	-MOS SF-36 (Turkish Version) -Visual Analog Scale of Pain -Standardized Nordic Questionnaire -Beck Depression Inventory.	Quantitative -compared the health of mothers of children with CP to the health of mothers of healthy children	Mothers of children with CP were found to have significantly more musculoskeletal pain and lower back pain. Their duration of pain was longer, and their pain during the day was significantly higher than controls. Mothers of children with CP had worse depression scores. The scores of mothers of children with CP were worse than mothers of healthy children in the domains of general health, physical functioning, physical role, emotional role, and mental health. There was no difference between the two groups in vitality and social functioning. Having a child with CP was associated with worse depression and mental health scores. Mothers with low back pain had children who were older, taller, and weighed more.

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Kuhlthau, Kahn, Hill, Gnanasekaran, & Ettner, 2010 -Caregiving Stress Process Model	Parents (56% female) aged 25-54 years from Medical Expenditure Panel Survey Date 1996-2001 -Parents With n=2412 -Parents Without n= 13560 United States	Children with and without activity limitations (age of children not specified) -total number of children not stated	No	Physical Mental Financial Social Leisure	SF-12: physical and mental components -activity limitations -EuroQol -Self-reported health -limit in social and recreational activity -#preventive and sick visits per year -employment -financial status	Quantitative -retrospective comparison of parents with a child with an activity limitation to parents with a child and without an activity limitation	Parents of children with activity limitations had significantly worse physical, mental and general health scores , quality of life, social and recreational limitations, used more sick visits, more preventive visits, more work loss days, more out of pocket expenses, were less likely to work full time, and were more likely to work part time or be unemployed than parents of children without activity limitations. Mothers of children with activity limitations were more likely to be unemployed and have more work loss days than fathers.
Kuster, 2002 -sources, mediators, and manifestations of stress	38 female primary caregivers (34 mothers, 2 adoptive mothers, 1 grandmother, 1 foster mother) aged 22 to 62 years (mean age 37.5 years) United States	38 children aged 4 months to 18 years (mean age 6.8 years) who were ventilator-assisted with varying reasons for ventilator support	No	General SRH Physical Social Mental	Functional Status II -Impact on Family -Coping Health Inventory for Parents -Social Support Index -Global Health Item -Centers for Epidemiological Studies Depression Scale -Personal Lifestyle Questionnaire	Quantitative -descriptive study. Compared results to norms	50% of mothers ranked their health as good to excellent, 21.1% fair, and 7.9% poor. Many participated in few wellness behaviors. Almost half (45%) of the mothers experienced depressive mood symptoms. 57.9% were full time CGs, 10.5% were unemployed, 18.4% worked full time, and 10.5% worked part time. Many mothers reported backaches, fatigue, tension, muscle or joint aches, stomach discomfort, dizziness, anxiety, depression, elevated blood pressure, and frequent colds. Functional status of the child and coping were positively correlated with perceived general health and wellness behaviors in the mothers. Higher burden of care had a negative effect on the mother's health and the child's illness restricted social activities for mothers. As a result, mothers experienced isolation and diminished social support. Social support was positively related to perceived general health and inversely related to wellness behaviors. Mothers had less depressive symptoms when they reported higher levels of social support. Regression analysis revealed that functional status of the child and coping were significant predictors of perceived general health and wellness behaviors.

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Lach et al., 2009 -no framework specified	Four groups of caregivers of 4 to 11 year old children: 'Both' (mean age 34.98, 92.81% female), 'Neuro only' (mean age 35.32, 92.93% female), 'Ext only' (mean age 35.12, 89.8% female), and 'Neither' (mean age 36, 89.53% female) NLSCY 1994 Canada	4 to 11 year old children 'Neuro' disorder and externalizing behaviour problems (Both; n=414), with a 'Neuro' disorder only (Neuro Only; n=750), with an externalizing behaviour problem only (Ext Only; n=1067), and with neither health condition (Neither; n=7236)	No	General SRH Physical Mental Social	-list of chronic conditions -areas of activity limitations -General health -Center for Epidemiological Studies' Depression scale -Family Assessment Device -rating of marital satisfaction -Social Provisions Scale -support for personal problems not family or friends	Quantitative -retrospective design compared the four groups of caregivers	CGs of children with both behavior problems and neurodevelopmental disorders had more health and psychosocial problems than CGs of children with neither health issue. CGs in the 'Both' group more frequently reported chronic conditions including asthma, arthritis, back problems, migraine headaches, and limitations in activities than CGs in the 'Neither' group. CGs in the 'Both' group also reported higher depression scores, decreased family functioning, and had lower social support scores than the 'Neither' group. Scores for caregivers in the neurodevelopmental disorder only and behavior problem only were found to lie between the scores of the 'Both' and 'Neither' group and often did not differ from one another. Caregivers of children with both behavior problems and neurodevelopmental disorders were least likely to report their health as being excellent or very good while caregivers of children with neither health problem were most likely to report their health as excellent or very good.
Laurvick et al., 2006 -Lazarus and Folkman stress and coping	135 mothers (aged 21-60 years) of children with Rett Syndrome Australia	135 Children aged 3 to 27 with Rett Syndrome	No	Physical Mental	SF-12 version 1 -Family Resource Scale (FRS) - time -Support Functions Scale (short form) -Family Assessment Device -Abbreviated Dyadic Adjustment Scale -Depression, Anxiety and Stress Scale -Family Support scale	Quantitative -regression used to determine effect on physical and mental health scores of maternal, family, and child characteristics	Better maternal physical health was positively associated with mother working full or part time outside of the home, having some high school education, having private health insurance, the child not having breathing problems or home based structured therapy, and a high score on the FRS. Better mental health was positively associated with mother working full or part time outside the home, being in a well adjusted marriage, having low stress scores, the child not having a fracture in the last 2 years, and the child having fewer facial stereotypes and involuntary facial movements.

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Leonard, Johnson, & Brust 1993 -no framework specified	132 caregiving mothers and 1 stepmother and 1 grandmother (age not specified) of children with disabilities. OK n= 95 Not Ok n= 37 United States	Children with disabilities 18 years of age or younger	Yes - OK vs. Not OK, but not specific r/t health	General SRH rating for both Physical and Mental	-General rating of both physical and mental health -list of 6 groups of health problems -time required to perform CG tasks -monthly out of pocket costs for CG expenses	Quantitative -CGs managing 'OK' were compared to CGs managing 'Not OK' (needed more help or could not manage much longer)	More rural CGs and those younger than 30 years of age were managing OK. Significantly more CGs in the Not OK group rated their physical and mental health as poor or fair and more in the OK group rated their physical and mental health as excellent. The most frequently reported health problem was a musculoskeletal condition. Children in the Not OK group were more likely to have cerebral palsy, need more time for CG tasks, and had more serious health problems.
McConnell & Llewellyn, 2006 -no framework specified	74 Mothers in initial survey, 2 mothers in second administration 11 to 15 months later -age range from 28-74 years of age, with a mean of 42 years -compared to health of normal Australia	74 school age (6-13) children with disabilities and high support needs including ADD, ADHD, autism, and physical, hearing, visual, and/or developmental disability	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	MOS 36 Item Short Form Health Survey (SF-36) v. 2	Quantitative -paired sample *t* test -survey administered then again 11 to 15 months later -compared to population norms in Australia	Compared with Australian population norms for women in New South Wales, mothers reported significantly poorer health in 5 of the 8 subscales of the SF-36 (role limit physical, vitality, social functioning, role limit emotional, mental health) and in the physical health and mental health summary scales at time one. Compared to Australian mothers with partners, mothers of children with disabilities reported significantly poorer health in 4 of 8 domains (vitality, social functioning, mental health, and mental health summary scale) at time 2. There was no statistically significant difference found between time 1 and time 2 in the SF-36 scores. At both time 1 and 2 mothers of children with disabilities reported significantly poorer mental health.

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Morelius & Hemmingsson, 2013 -General Adaptation Syndrome Theory	377 mothers and fathers of children with moderate to severe physical disabilities Sweden	377 children aged 1 – 16 years with moderate to severe motor disabilities	No	General SRH Physical Mental	-Perceived health compared to other parents -additional questions about variables affecting their own health (yes/no): headache, pain to due to heavy lifting, psychological exhaustion, disrupted sleep	Quantitative -used logistic regression to compare the health of mothers and fathers	When their child had sleep problems or needed attention during the night, both parents reported poor health, psychological exhaustion, and disrupted sleep. Overall, mothers had significantly poorer health, pain due to heavy lifting, disrupted sleep, headaches and psychological exhaustion than fathers.
Murphy, Christian, Caplin, & Young, 2006 -Conceptual Model of Caregiving Process and Caregiving Burden	40 parents (33 mothers, 6 fathers) or caregivers (one aunt) aged 26 to 72 years living in urban, suburban, and rural Utah United States	58 children with developmental disabilities -age ranged from 4 to 35, mean age 13.4 years	Yes, but not r/t health	Physical Mental Overall health	-no instruments used as was qualitative. Focus group discussion guide included questions on physical health, mental health, burnout, impact on family functioning and overall health	Qualitative -focus groups to understand the demands of caregiving and the effects on their health	Rural CGs reported less peer support than their urban and suburban counterparts. Nearly all reported negative physical and mental health effects related to caregiving and pervasive anxiety from concerns about their child's health and future. CGs often overlooked their own chronic conditions and placed low priority on their own health. 67% were unable to maintain employment after their child's birth. Barriers to promoting their own health included lack of time and respite. Many were worried that their worsening health would affect their ability to continue to meet the long-term needs of their child.

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Neufeld, 1997 -conceptual framework of respite	55 Primary CGs (all women) aged 28 to 60 (mean age 41 years) Western Canada	Children aged 2 to 18 (mean age 10) with a chronic illness or disability (wide range of diagnoses)	No	General SRH Physical Financial	-General SRH -list of 6 health issues and other category -income and costs	Quantitative -descriptive study of respite. Also measured parent health.	-19 CGs were not employed, 16 worked full time, 4 part time, 2 retired, and 13 were students. Only 7% of CGs did not identify health concerns in the last 12 months. 66% reported 3 or more health concerns. Fatigue was the most common, followed by back pain and trouble sleeping. Other included migraines and physical injury. 41 women rated their health as good to excellent; 13 reported their health as being fair and 1 rated her health as poor. 36 respondents indicated that extra costs related to their child's needs resulted in financial difficulty for the family. 10 families identified a family income well below the poverty line.
Ones, Yilmaz, Cetinkaya, & Caglar, 2005 -no framework specified	46 mothers (mean age 34.96 years) of children with CP and 46 mothers (mean age 34.24 years) of healthy children Turkey	46 children with cerebral palsy aged 1.5 to 12 years compared to 46 healthy children (age not provided)	No	Physical Mental	Nottingham Health Profile-1 (NHP) -Beck Depression Inventory (BDI) -Beck Anxiety Inventory (BAI)	Quantitative -compared mothers of children with CP to mothers of healthy children	Mothers of children with CP had significantly worse scores in the pain, physical activity, energy, sleep, social isolation, and emotional subscales of the NHP. Mothers of children with CP had significantly worse depression scores than the mothers of the healthy children. 78.4% of mothers of children with CP were clinically depressed, vs. 21.7% in the control group. There was no difference in scores on the BAI.

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Pariante et al., 1997 -stress and immunity	18 female CGs of handicapped people (mean age 44.3) and 18 age- and sex- matched control CGs (mean age 44.5) of children attending junior or high school in the same district Italy	Children diagnosed with mental retardation, autism, or quadriplegia aged 5-26 years (mean age was 15.1 years)	No	Physical Mental	-Assessment of Disability and Family Burden (ADC) -State-Trait Anxiety Inventory (form X1 and X2) -Beck Depression Inventory -Self-Reporting Questionnaire (SRQ) -blood test to measure immunologic parameters including T cell number (T cells, T helper cells, and T suppressor/cytotoxic cells). T cells are lymphocytes that mediate cellular immunity. -blood test to measure antibody titers for latent herpes viruses, roseola, and immunoglobulins -blood test to measure C3 and C4 complement factors and c-reactive protein (markers for an inflammatory response)	Quantitative -compared female CGs of children with handicaps to age and sex matched control group of female CGs -CGs were also divided into two comparison groups according to the median age of 45 years	CGs of handicapped children had worse scores on the SRQ (psychopathology) and STAIX2 (increased trait anxiety) than controls. There was no difference between the two groups in the level of state anxiety or depressive symptoms. 6 of the 18 CGs of handicapped children were clinically significantly depressed. No psychiatric diagnoses were detectable among control subjects. CGs of handicapped children reported lack of social contacts, restriction in leisure activities, a decrease in ability to work, and financial difficulties. Family burden and level of functioning of the child were not significantly correlated. -CGs of handicapped children had a significantly lower percentage of T cells, a significantly higher percentage of T suppressor/cytotoxic cells, and lower T helper: suppressor ratio than controls,. They also had a lower percentage of T helper cells and significantly higher antibody titres for cytomegalovirus (CMV) than controls. -older CGs of handicapped children had a significantly lower percentage of T cells, a significantly higher percentage of T suppressor/cytotoxic cells and a significantly lower T helper:suppressor ratio than controls. There was no difference in immune parameters between younger CGs of handicapped children and controls. -CGs with worse burden scores had a higher percentage of T suppressor/cytotoxic cells, lower T helper cells, and lower T helper: suppressor ratios. -there were no correlations between immune parameters of CGs and presence of depression, or level of function of duration of illness of the child. -there was no difference between CGs and controls in the inflammation markers (C3, C4, c-reactive protein)

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Raina et al., 2005 -Caregiving Stress Process Model	468 primary caregivers (420 mothers, 25 fathers, 15 foster parents, and 8 other) (94.4% female, mean age 40.06 years, and 5.6% males - mean age 44.42 years) of children with CP Canada	Children with CP (exact number not specified) -mean age 10.6 years	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality Financial	MOS SF-36 -Measures of Processes of Care -Coping Health Inventory for Parents -NLSCY: questions about occupational status, income, chronic conditions lasting more than 6 months and diagnosed by health professional, -NPHS: questions about distress, chronicity of distress, depressive episodes, self control, self concept, self esteem -McMaster Health Utility Index -Pediatric Evaluation of Disability (Parts II and III) -Pearlin's Scale -Social Network and Frequency of Contact Index -Social Provision Scale -Family Assessment Device	Quantitative -used structural equation modeling to examine direct and indirect determinants of physical and psychological health of CGs of children with CP	Important predictors of CGs' well-being were child behavior, caregiving demands, and family function. A higher level of behavior problems were correlated with decreased physical and psychological health in CGs. Fewer child behavior problems were associated with an increased ability to manage stress and higher self-perception in CGs. CGs with fewer demands and higher reported family functioning had better physical and psychological health. CG self-perception and stress management predicted CG psychological health but not physical health. Better psychological health was predicted by CGs' higher self-esteem, sense of mastery, and use of more stress management strategies. Gross income and social support indirectly affected psychological health. Self-perception, stress management, gross income, and social support indirectly affected physical health.

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Ray, 2002 -Parenting and Childhood Chronicity	30 mothers and 13 fathers of children with chronic health problems - age not provided Canada	34 children with chronic health problems aged 15 months to 16 years -those with a developmental or behavioral disorder alone were excluded	No	General comment r/t health Physical Mental	--no instruments used as was qualitative. Purpose of the study was to validate a model describing the work required to raise a child with a chronic health condition; discussion included aspects of physical and mental health	Qualitative -philosophic hermeneutics	All parents spoke of fatigue with the degree of fatigue ranging from manageable to incapacitating. Most of the parents were ignoring the long-term consequences that this degree of fatigue might have for their own health. Three of the parents were on long-term stress leave from paid employment. There seemed to be a disproportionate number of parents injured from motor vehicle accidents, work injuries, back pain, and hernias from lifting. Many parents spoke of reaching or approaching 'burn out'. Most of the parents acknowledged that they were not caring for their own physical health; however, a few parents were able to exercise.
Ray, Croen, & Habel, 2009 -no framework specified	1379 mothers aged 15 to 45 of children with ADHD but not asthma, 457 mothers of children with ADHD and asthma, 4973 mothers of children with asthma and not ADHD United States	-1379 children with ADHD, 457 children with asthma and ADHD, and 4973 children with asthma. ADHD was diagnosed between the ages of 2 and 11. Age of children at time of study not provided. Child with health issue considered index child.	No	Physical Mental Health Costs	-diagnoses received by the mother the year before and 2 years after the birth of the index child -Health Cost data collected on hospitalization length of stay, emergency room visits, outpatient office visits, pharmacy costs	Quantitative - Mothers of children with ADHD compared to mothers of children without ADHD and mothers of children with asthma	Mothers of children with ADHD (attention deficit/hyperactivity disorder) were more likely than mothers of children without ADHD to have a number of physical and mental health problems in both the year before the child's delivery and 2 years after the birth of their child. As a result, they also had higher total health care costs. These health problems included depression, anxiety neuroses, obesity, and musculoskeletal symptoms. Mothers of children with ADHD also had higher health care costs and were diagnosed with more health conditions than mothers of children with asthma.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001 -Life Course Theory	73 fathers and 43 mothers of children with developmental disabilities -19 fathers and 34 mothers of children with severe mental health issues at age 18, 36, and 53 or 54 compared to normative sample of men and women aged 18 (1957; n=10,317), 36 (1975; n=9138), and 53 or 54 (1992; n=8493) -siblings also contacted United States	165 children with disabilities and 53 children severe mental health problems (mean age was 9.96 years in 1975 and 26 years in 1992) compared to 218 children in a normal comparative group	No	General SRH Physical Mental Social (physical and mental only available for data collected in 1992)	-General SRH -number of physical symptoms reported from a list of 22 symptoms -Center for Epidemiological Studies Depression Scale -alcohol symptoms	Quantitative -longitudinal design with data collected when parents were age 18 (in 1957), 36 (in 1975), and early 50s (in 1992) -parents of children with disabilities compared to parents of children with severe mental health issues and also to a normative group	Parents of a child with a developmental disability had lower rates of employment and social participation compared to the normative group in their 30s and 50s. At age 50, there was no difference between parents of children with disabilities and the normative group in self-rated physical health or psychological well-being. At age 50, parents whose child had a serious mental health problem had elevated levels of physical symptoms, depression, and alcohol symptoms compared to the normative group. At age 50, children with mental health concerns and disabilities were significantly more likely to reside with their parents.
Svedberg, Englund, Malker, & Stener-Victorin, 2010 -no framework specified	78 Primary CGs (67 mothers and 11 fathers - age not specified) of children with CP Sweden	106 Walking (n=63) and non-walking children (n= 43) with cerebral palsy aged 5-16	No	General SRH Mental Social	-General SRH -General question related to anxiousness -general question related to time for themselves	Quantitative -compared impact on mood, health, and daily living of primary CGs of walking and non-walking children with CP	Parents of children who were non-walkers were more likely than parents of walkers to experience restricted time for themselves, anxiety regarding their child's health, restricted time for themselves, frequent daily living interferences, and stated that they health was affected due to their child's health. Mothers and fathers of non-walkers were more likely to work part-time or not at all due to their child's health. General SRH of CGs not discussed.

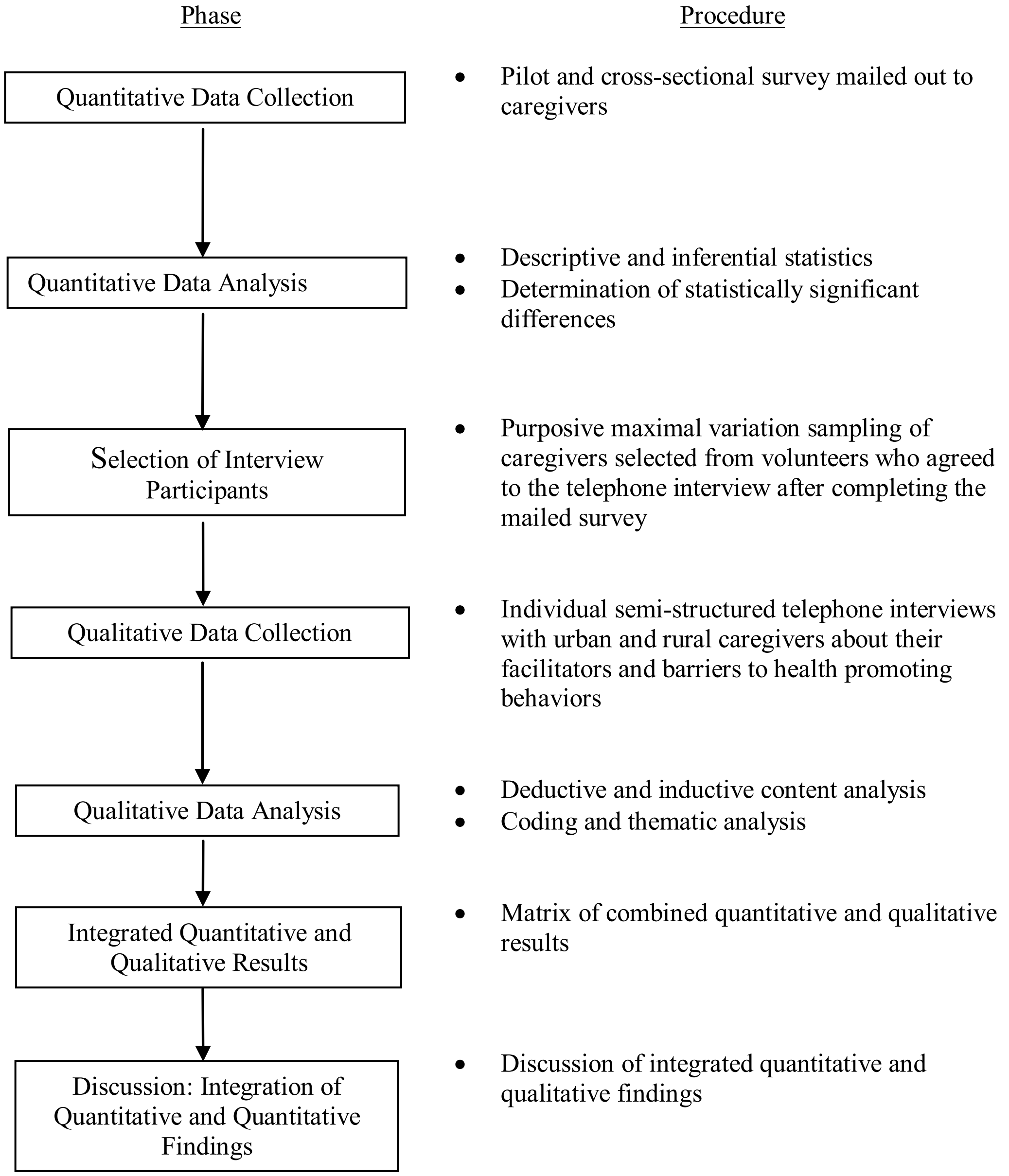
AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Thyen, Terres, Yazdgerdi, & Oerrun, 1998 -no framework specified	65 mothers (mean age 32.3 years) of children assisted by technology compared to 54 mothers (mean age 34.2 years) of children hospitalized with acute illnesses United States	99 Children (mean age 3.9 years) with a chronic illness of at least 6 months and the need for technology assistance and 131 children (mean age 3.7 years) hospitalized for acute illness	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality Financial	MOS SF-36 -CES-D -Family Environment Scale -Family Relationship Index -Social Support Appraisal Scale -Inventory of Socially Supportive Behavior	Quantitative -compared mothers of children assisted with technology with mothers of children hospitalized for acute illness	Mothers of technology assisted children were more likely than mothers in the control group to report impaired health. They had worse pain, vitality, social functioning, mental health, SRH, and depression scores than mothers in the control group. Almost half of the mothers of the technology assisted children had scored suggesting clinical depression. There was no difference between the groups in the Physical Health Component Score. Families with children assisted with technology also had lower family support scores and were less likely to engage in social activities. Mothers of children assisted with technology were less likely to be employed, had a lower family income, and higher out of pocket expenses. Half of these mothers stated they had quit their job to care for their child.
Tong et al., 2002 -no framework specified	90 female CGS (age 20 to 65 years) presenting to a physical medicine rehabilitation clinic (PM&R) and 23 female CGs (age 26-51 years) presenting to an endocrine clinic United States	90 children with physical disabilities (aged 25-237 months) and 23 children with a chronic endocrine medical condition (aged 39-215 months)	No	Physical Mental Role	SF-36 Physical Functioning Subscale (PFS) -length of time of low back pain -visual analog scale of pain -Center for Epidemiological Studies Depression Scale (CES-D)	Quantitative -CGs of children with physical disabilities compared to CGs of children with a chronic medical condition	The physical functioning subscale scores of the CGs of children with physical disabilities were significantly worse than the CGs in the endocrine clinic group. The physical functioning subscale scores were also significantly worse for CGs of children needing physical assistance with transfers vs. those not needing assistance and CGs of children in the endocrine clinic. Regression analysis indicated that physical functioning of the caregiver was significantly related to both pain severity and caregiver mood.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Tong et al., 2003 -no framework specified	90 female CGS (age 20 to 65 years) presenting to a physical medicine rehabilitation clinic (PM&R) and 23 female CGs (age 26-51 years) presenting to an endocrine clinic United States	90 children with physical disabilities (aged 25-237 months) and 23 children with a chronic endocrine medical condition (aged 39-215 months)	No	Physical: low back pain Mental	-Standardized Nordic Questionnaires (NSQ) measures low back pain -Center for Epidemiological Studies Depression Scale (CES-D)	Quantitative -CGs of children with physical disabilities compared to CGs of children with a chronic medical condition	The prevalence of CGs having low back pain (LBP) was significantly higher for those caring for children with physical disabilities than for CGs caring for children attending the endocrine clinic. CGs of children requiring physical assistance with transfers were more likely to experience low back pain compared to children not requiring physical assistance with transfers. Regression analysis indicated that factors associated with CG low bak pain were transferability of the child, depression in the CG, and a history of LBP in the CG.
Tuna, Unalan, Tuna, & Kokino, 2004 -no framework specified	40 primary CGs (mean age 35) (36 mothers, 2 fathers, 2 grandmothers) of children with CP and 40 age matched CGs of children without CP Turkey	40 children with CP compared to 40 children without cerebral palsy (age not specified)	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality	Turkish version of the SF-36	Quantitative -CGs of children with CP compared to CGs of children without CP	The SF-36 physical functioning, vitality, general health, and emotional role subscale scores were significantly worse in CGs of children with CP when contrasted with the comparison group of CGs of children without CP. There was no difference in the subscales of physical role, bodily pain, mental health, and social functioning.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Wallander et al., 1989 -Stress, coping, and adaptation	50 Mothers -mean age was 35.1 years United States	50 congenitally physically handicapped children (either spina bifida or CP) aged 6 to 11 years	No	Physical Mental Social	Malaise Inventory -Social and Activities Questionnaire	Quantitative -relationship between characteristics of child and mother -compared mothers of physically handicapped children to mothers in the Isle of Wright epidemiologic study and mothers of psychiatrically disturbed children	The mental and physical health scores were combined to allow comparisons of overall health with mothers in the Isle of Wright epidemiological study. Mothers of physically handicapped children reported significantly more health complaints than the mothers in the normative sample. There was no difference in the number of health complaints reported by mothers of children with a physical handicap vs. mothers of psychiatrically disturbed children. Maternal age was significantly negatively correlated to the number of social contacts in which they engaged.
Wyatt, 1991 -Family stress theory	40 mothers and 40 fathers (aged 20 - 46 years, mean age 33.9 years) in New York, Maryland, District of Columbia, and Virginia -all parents were married United States	-40 technology assisted home bound children aged 6 months to 6.5 years (mean age 3.98 years) with respiratory disabilities -the children had various neurologic diseases and defects of the autonomic and central nervous system and brain stem.	No	Physical Mental Social	Family Strain Index -Coping Health Inventory for Parents -Brief Symptom Inventory -Health-Promoting Lifestyle Profile	Quantitative -compared scores of mothers and fathers to population norms	Mean scores for both parents on the family strain and health symptom instruments were significantly higher than norms, while health promoting scores were significantly lower than scores for healthy adults. Parent social support coping was significantly higher than norms. There was no difference between mothers and fathers on any of the scores. Mothers' strain predicted 27% of the variability in both their health symptom and health promotion behaviors.

AUTHOR & CONCEPTUAL APPROACH	SAMPLE	CHILDREN	RURAL VS. URBAN	TYPE OF HEALTH	INSTRUMENTS TO ASSESS CAREGIVER (CG) HEALTH	DESIGN	RESULTS
Zhu, Walter, Rosenbaum, Russell, & Raina, 2006 - Caregiving Stress Process Model	450 primary caregivers of children with CP -no other details provided but sample taken from study by Raina et al., 2005 (summarized in this table) Canada	Children with CP -no other details provided but sample taken from study by Raina et al., 2005	No	General SRH Physical role Physical function Mental Role Emotional Social Pain Vitality Financial	MOS SF-36 -Measures of Processes of Care -Coping Health Inventory for Parents -NLSCY: questions about occupational status, income, chronic conditions lasting more than 6 months and diagnosed by health professional, -NPHS: questions about distress, chronicity of distress, depressive episodes, self control, self concept, self esteem -McMaster Health Utility Index -Pediatric Evaluation of Disability (Parts II and III) -Pearlin's Scale -Social Network and Frequency of Contact Index -Social Provision Scale -Family Assessment Device	Quantitative -structural equation modeling (SEM) and log linear modeling (LLM) were used to evaluate the relationships between child behavior, caregiving demands, coping factors, and the well-being of primary caregivers of children with CP	No substantial differences were found in the conclusions of the two modeling approaches. Child Behavior was the most important predictors of CG psychological wellbeing in both approaches. Self-Perception and Stress Management mediated the negative effect of stressors on the Psychological Health of CGs in both models. The SEM results also indicated that Caregiving Demands and Family Function influenced Psychological Health of CGs, but there was no evidence of this in the LLM. However, Caregiving Demands and Family Functioning were important predictors of CG physical health in both models. Child Behavior only influenced Physical Health of CGs in the SEM model. Family Functioning, Self-Perception, and Stress Management were mediating factors in the caregiving process in both models. Child Behavior was associated with Self-Perception and Stress Management in both models. The significant association between Self-perception and Stress Management was only evident in the SEM. Psychological Health and Physical Health were highly correlated in both models.

Appendix B

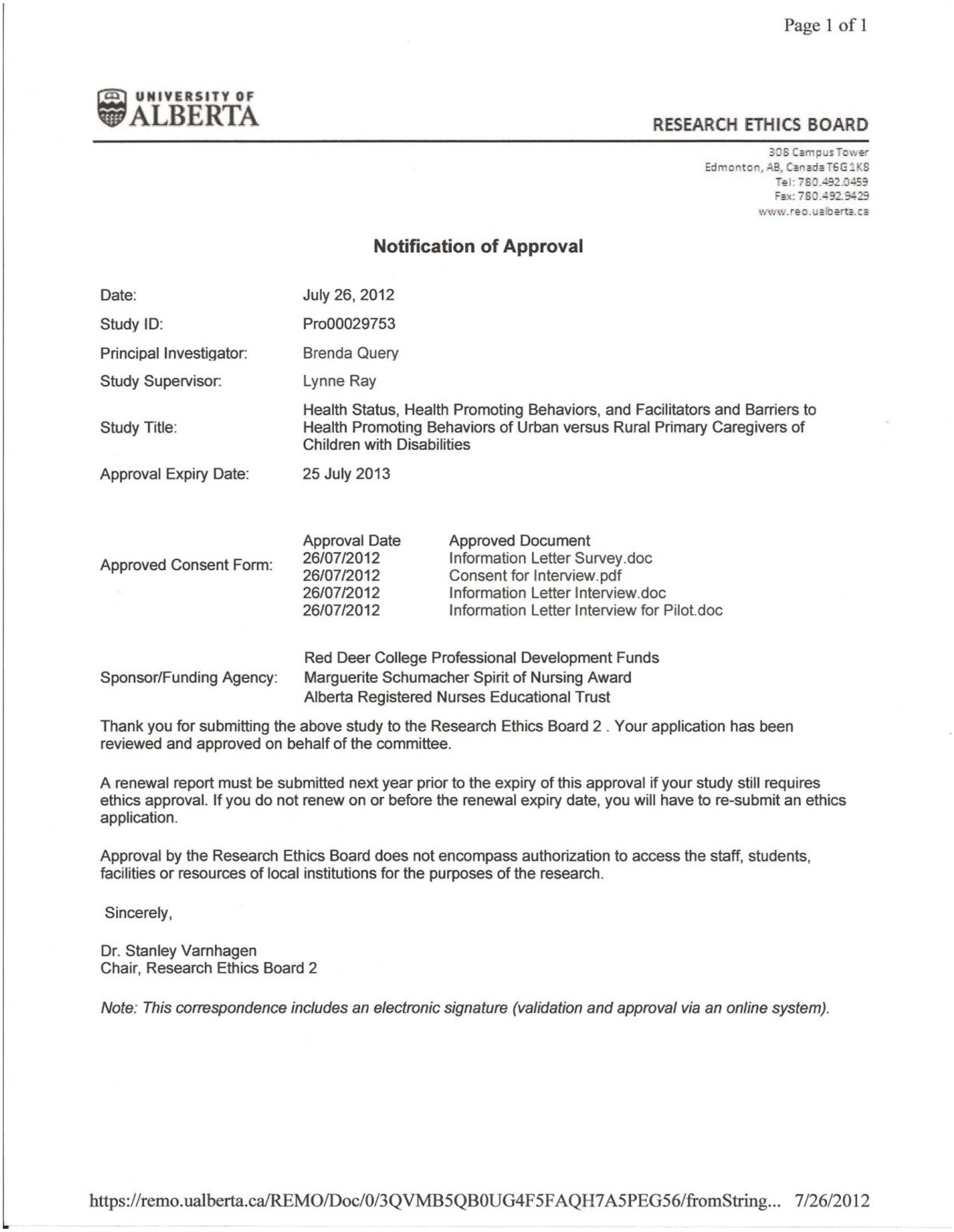


Phase	Procedure
Quantitative Data Collection	• Pilot and cross-sectional survey mailed out to caregivers
Quantitative Data Analysis	• Descriptive and inferential statistics • Determination of statistically significant differences
Selection of Interview Participants	• Purposive maximal variation sampling of caregivers selected from volunteers who agreed to the telephone interview after completing the mailed survey
Qualitative Data Collection	• Individual semi-structured telephone interviews with urban and rural caregivers about their facilitators and barriers to health promoting behaviors
Qualitative Data Analysis	• Deductive and inductive content analysis • Coding and thematic analysis
Integrated Quantitative and Qualitative Results	• Matrix of combined quantitative and qualitative results
Discussion: Integration of Quantitative and Quantitative Findings	• Discussion of integrated quantitative and qualitative findings

Figure 2. Visual Diagram of the Sequential Explanatory Study

Appendix C

Approval University of Alberta Research Ethics Board



Page 1 of 1

UNIVERSITY OF ALBERTA

RESEARCH ETHICS BOARD

308 Campus Tower
Edmonton, AB, Canada T6G 1K8
Tel: 780.492.0459
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Notification of Approval

Date:	July 26, 2012
Study ID:	Pro00029753
Principal Investigator:	Brenda Query
Study Supervisor:	Lynne Ray
Study Title:	Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Primary Caregivers of Children with Disabilities
Approval Expiry Date:	25 July 2013

Approved Consent Form:

Approval Date	Approved Document
26/07/2012	Information Letter Survey.doc
26/07/2012	Consent for Interview.pdf
26/07/2012	Information Letter Interview.doc
26/07/2012	Information Letter Interview for Pilot.doc

Sponsor/Funding Agency:

- Red Deer College Professional Development Funds
- Marguerite Schumacher Spirit of Nursing Award
- Alberta Registered Nurses Educational Trust

Thank you for submitting the above study to the Research Ethics Board 2 . Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Dr. Stanley Varnhagen
Chair, Research Ethics Board 2

Note: This correspondence includes an electronic signature (validation and approval via an online system).

https://remo.ualberta.ca/REMO/Doc/0/3QVMB5QB0UG4F5FAQH7A5PEG56/fromString... 7/26/2012

Appendix D

Map of the Central Alberta Child and Family Services Authority

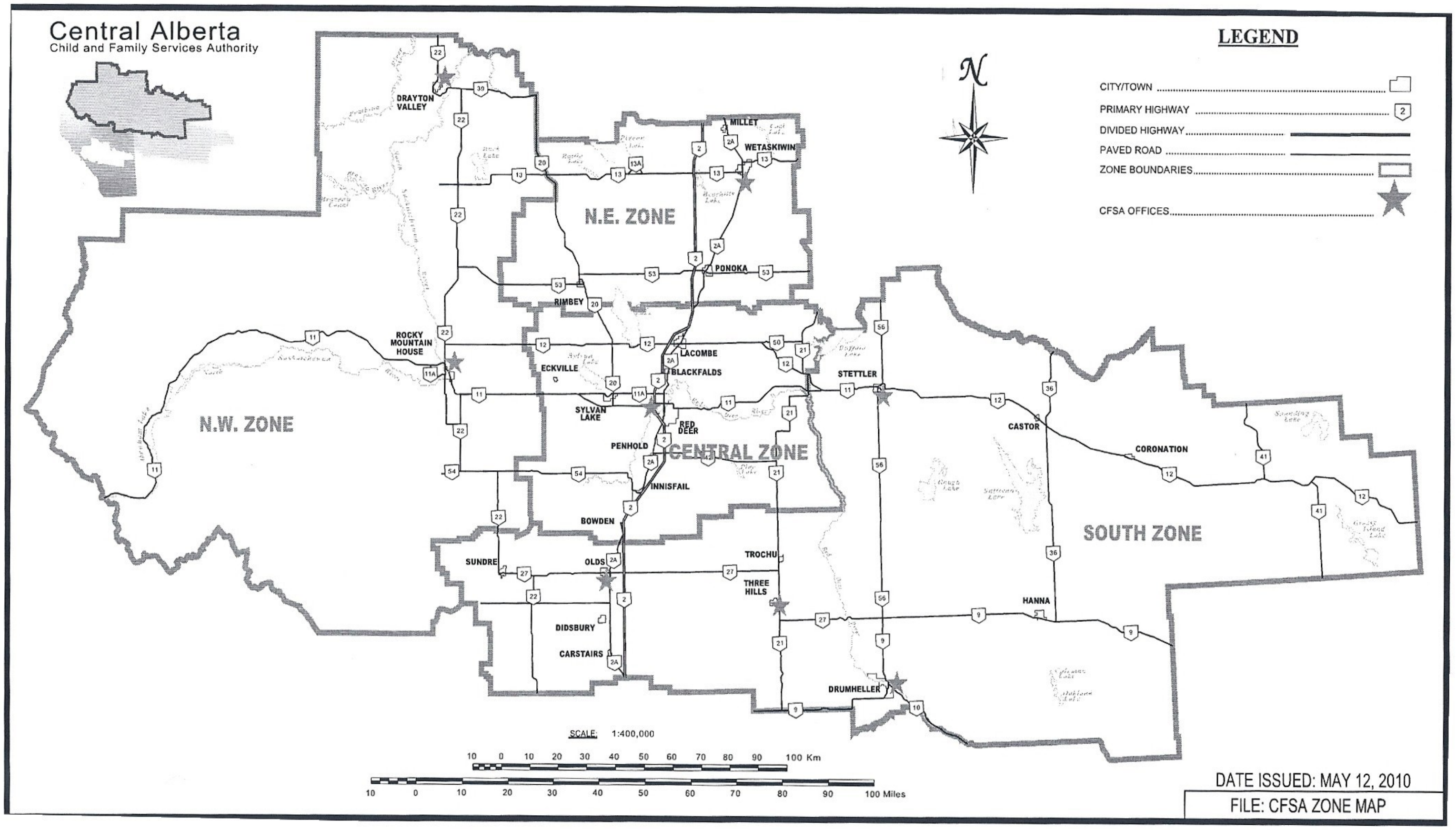
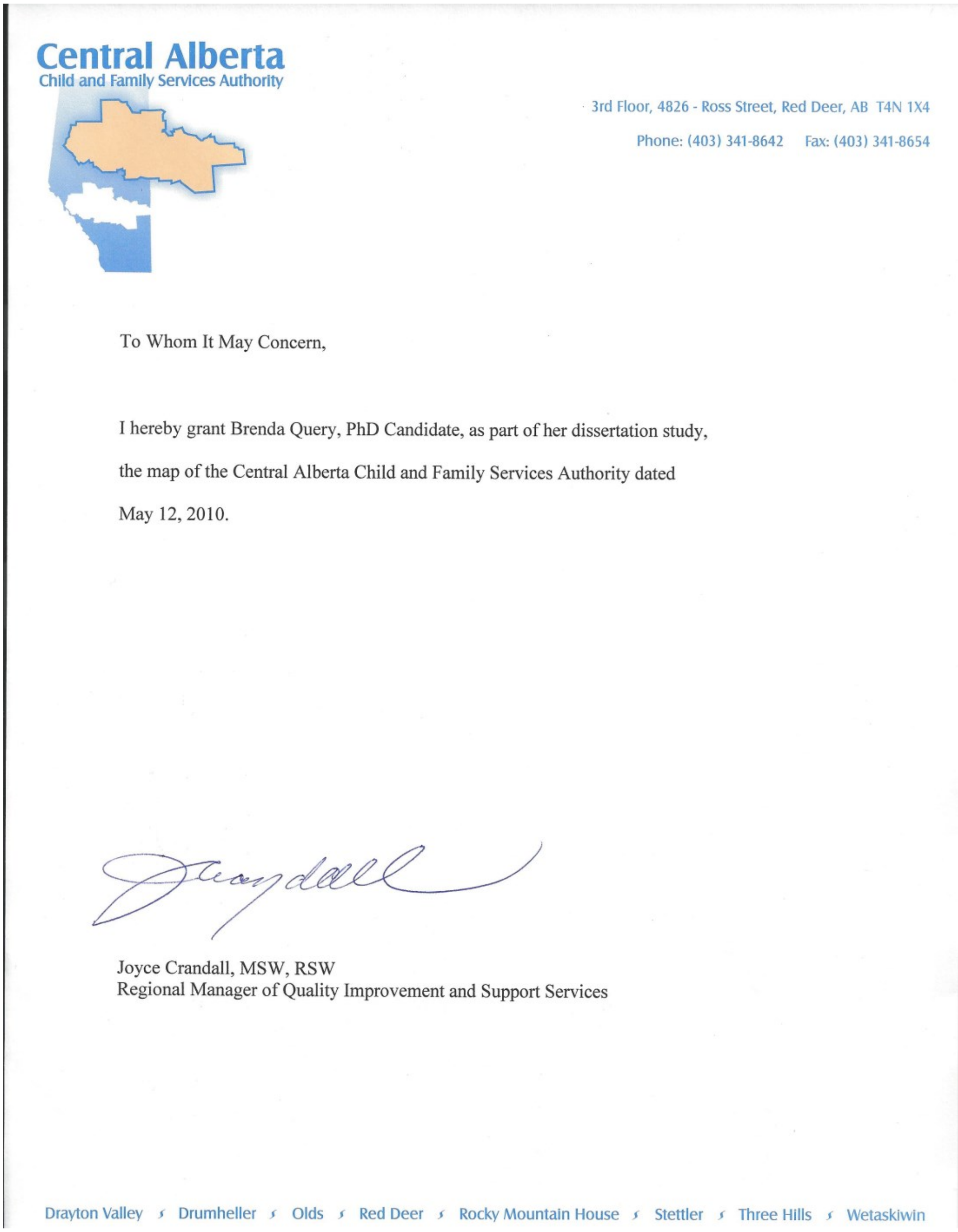


Figure 3. Map of the Central Alberta Child and Family Services Authority

Appendix E

Permission Letter to Use Map



Central Alberta
Child and Family Services Authority

3rd Floor, 4826 - Ross Street, Red Deer, AB T4N 1X4
Phone: (403) 341-8642 Fax: (403) 341-8654

To Whom It May Concern,

I hereby grant Brenda Query, PhD Candidate, as part of her dissertation study, the map of the Central Alberta Child and Family Services Authority dated May 12, 2010.

Joyce Crandall, MSW, RSW
Regional Manager of Quality Improvement and Support Services

Drayton Valley · Drumheller · Olds · Red Deer · Rocky Mountain House · Stettler · Three Hills · Wetaskiwin

Appendix F

Your Family and Your Health

This survey is to be completed by the parent or person who takes care of the child with a disability the majority of the time. **All information will be kept strictly confidential.**

Note: In case you have more than one child with a disability, another copy of this page is provided for the second child.

Your Child with a Disability

1. How old is your child with a disability? ___________________

2. Is your child a boy or a girl?

   1☐ boy
   2☐ girl

3. What is your child's diagnosis(es)? If your child does not have a diagnosis please describe the condition.

   ____

   ____

   ____

4. Overall, how would you rate the severity of your child's disability?

   1☐ Mild
   2☐ Moderate
   3☐ Severe
   4☐ Very severe

You and Your Family

1. What is your relationship to the child with a disability?

1☐ Mother
2☐ Stepmother
3☐ Foster Mother
4☐ Father
5☐ Stepfather
6☐ Foster father
7☐ Other (please specify): ______________________

2. Are you: 1☐ Female
2☐ Male

3. People in Canada come from many different cultural and racial backgrounds. Are you:

1☐ White
2☐ Arab
3☐ Black
4☐ Chinese
5☐ Filipino
6☐ Inuit
7☐ Japanese
8☐ Korean
9☐ Latin American
10☐ Métis
11☐ North American Indian
12☐ South Asian (e.g. East Indian, Pakistani, Sri Lankan)
13☐ Southeast Asian (e.g. Laotian, Cambodian, Vietnamese)
14☐ West Asian (e.g. Afghan, Iranian)
15☐ Other - Please specify: ___________________

4. How old are you? ___________________

5. What is the <u>total</u> number of children living with you? ___________________

6. What is the <u>total</u> number of children with disabilities living with you? ___________________

7. What is your marital status?

1☐ Married
2☐ Common law/living with a partner
3☐ Divorced
4☐ Separated
5☐ Single
6☐ Widowed

8. What is the highest level of education that you have achieved?

1☐ Some high school
2☐ High school graduate
3☐ University/College certificate or diploma
4☐ Technical school certificate or diploma
5☐ Undergraduate degree
6☐ Masters degree
7☐ Doctoral degree
8☐ Other - Please specify______________

9. What is your employment status?

1☐ Employed full time
2☐ Employed part time
3☐ Self-employed
4☐ Unemployed and looking for work
5☐ Full time caregiver
6☐ Full time student
7☐ Part time student
8☐ Retired
9☐ Other - please specify

____

10. Has either parent/partner given up paid employment (a job) because of your child's care needs?

1☐ No
2☐ Mother/female partner
3☐ Father/male partner
4☐ Both parents/partners

11. What is the approximate **yearly family** income (before taxes) that you have to work with?

1☐ less than $10,000
2☐ $10,000 - $19,999
3☐ $20,000 - $29,999
4☐ $30,000 - $39,999
5☐ $40,000 -$49,999
6☐ $50,000 -$59,999
7☐ $60,000 - $69,999
8☐ $70,000 - $79,999
9☐ $80,000 - $89,999
10☐ $90,000 -$99,999
11☐ $100,000 or more

12. Besides Alberta Health Care, does your family have any additional health insurance coverage?

1☐ Yes
2☐ No

Where You Live.

1. In which city, town, village, hamlet, or municipality in Alberta do you live or is nearest to you?
____

2. Do you live in an urban or rural community?
1☐ urban
2☐ rural

3. Do you live on a farm or ranch?
1☐ yes
2☐ no

4. Do you have access to the internet?
1☐ yes
2☐ no

5. If you have access to the internet, what type of access do you have?
1☐ broadband
2☐ dial-up
3☐ other: ________________________
4☐ not applicable

6. Approximately how many kilometers do you travel **one way** to see your own doctor?
____

7. Approximately how many kilometers do you travel **one way** to see a doctor or pediatrician or other specialists for your child with a disability?
____

Your Health

1. Compared to other people your age, how would you describe your usual state of health?

   1☐ Excellent
   2☐ Very Good
   3☐ Good
   4☐ Fair
   5☐ Poor

2. In one day (24 hours), what is the average amount of time that you spend **awake** and caring for your child (typical parenting **plus** care related to the disability)?

   Weekday ______ hours per day

   Weekend ______ hours per day

3. In an average **week**, on how many nights do you get an adequate amount of sleep?

   __________ nights

4. On average, how many hours of sleep do you get **each** night?

   ___________ hours

5. Thinking about the amount of stress in your life, would you say that most days are:

   1☐ Not at all stressful
   2☐ Not very stressful
   3☐ A bit stressful
   4☐ Quite a bit stressful
   5☐ Extremely stressful

6. How well do you think you are able to manage your stress?

   1☐ Manage it well most days
   2☐ Manage it well some days
   3☐ Have difficulty managing it some days
   4☐ Have difficulty managing it most days

7. Who do you know that is willing and able to help you with your child with a disability when you need it? (check all that apply)

   1☐ Spouse/Partner
   2☐ Other family members
   3☐ Friends
   4☐ Neighbors
   5☐ Community resources or organizations
   6☐ Other (please specify): ______________________
   7☐ No one is available to help

8. What is your height and weight? (please circle unit of measure)

Height ____________ ft-in / cm

Weight _________ lbs / kg

9. Do you smoke cigarettes?

1☐ Not at all
2☐ Occasionally
3☐ Daily

10. Do you drink alcohol?

1☐ Not at all
2☐ Occasionally
3☐ Daily

11. In the past 12 months, how often have you had 5 or more drinks of alcohol on one occasion?

1☐ Never
2☐ Less than once a month
3☐ Once a month
4☐ 2 or 3 times a month
5☐ Once a week
6☐ More than once a week

12. Do you have any of the following medical problems that have lasted or are expected to last 6 months or more? Please check all that apply.

1 ☐ Back pain
2 ☐ Pain (not back pain)
3 ☐ Migraine headaches
4 ☐ Headaches (not migraines)
5 ☐ Osteoporosis
6 ☐ High blood pressure
7 ☐ Trouble sleeping
8 ☐ Overly tired/lack of energy
9 ☐ Thyroid condition
10 ☐ Allergies
11 ☐ Arthritis or rheumatism
12 ☐ Depression
13 ☐ Anxiety
14 ☐ Other mental health issues (please describe):
____

15 ☐ Ulcerative colitis
16 ☐ Crohn's disease
17 ☐ Ulcers
18 ☐ Stomach problems (not IBD or ulcers)
19 ☐ Cancer
20 ☐ Frequent colds/flu
21 ☐ Bronchitis
22 ☐ Diabetes
23 ☐ Epilepsy
24 ☐ Heart disease
25 ☐ High cholesterol
26 ☐ Sinusitis
27 ☐ Other (please describe):
____
____
____

Improving Your Health.

1. Do you think that there is anything that you can do to improve or maintain your health?

   1☐ yes
   2☐ no

2. In the **next** 12 months, is there anything that you **intend to do** to try and improve or maintain your health? (check all that apply)

   1☐ Get regular checkups (medical, dental, etc.)
   2☐ Increase my physical activity
   3☐ Improve my eating habits
   4☐ Strive for a positive attitude
   5☐ Increase support from my family, friends, and neighbors
   6☐ Reduce my stress levels
   7☐ Engage in activities that enhance my personal growth
   8☐ Get more sleep
   9☐ Lose weight
   10☐ Quit smoking/reduce the amount that I smoke
   11☐ Drink less alcohol
   12☐ Other (please specify):
   ____
   ____

3. Of those things that you intend to do in the next 12 months to try and improve or maintain your health, what are the **top three most important things?** Put a "1" beside your first choice, a "2" beside your second choice, and a "3" beside your third choice:

   1☐ Get regular checkups (medical, dental, etc.)
   2☐ Increase my physical activity
   3☐ Improve my eating habits
   4☐ Strive for a positive attitude
   5☐ Increase support from family, friends, and neighbors
   6☐ Reduce my stress levels
   7☐ Engage in activities that enhance my personal growth
   8☐ Get more sleep
   9☐ Lose weight
   10☐ Quit smoking/reduce the amount I smoke
   11☐ Drink less alcohol
   12☐ Other (please specify): _______________
   ____

4. How has what you do to improve or maintain your health changed since your child was diagnosed with a disability?

   1☐ Now I do a lot more to improve or maintain my health
   2☐ Now I do a bit more to improve or maintain my health
   3☐ I did not change what I do to improve or maintain my health
   4☐ Now I do a bit less to improve or maintain my health
   5☐ Now I do at lot less to improve or maintain my health

Now I would like to ask you some questions about what you do to improve your health.

LIFESTYLE PROFILE II

DIRECTIONS: This questionnaire contains statements about your *present* way of life or personal habits. Please respond to each item as accurately as possible, and try not to skip any item. Indicate the frequency with which you engage in each behavior by **circling**:

N for never, **S** for sometimes, **O** for often, or **R** for routinely

		NEVER	**SOMETIMES**	**OFTEN**	**ROUTINELY**
1.	Discuss my problems and concerns with people close to me.	N	S	O	R
2.	Choose a diet low in fat, saturated fat, and cholesterol.	N	S	O	R
3.	Report any unusual signs or symptoms to a physician or other health professional.	N	S	O	R
4.	Follow a planned exercise program.	N	S	O	R
5.	Get enough sleep.	N	S	O	R
6.	Feel I am growing and changing in positive ways.	N	S	O	R
7.	Praise other people easily for their achievements.	N	S	O	R
8.	Limit use of sugars and food containing sugar (sweets).	N	S	O	R
9.	Read or watch TV programs about improving health.	N	S	O	R
10.	Exercise vigorously for 20 or more minutes at least three times a week (such as brisk walking, bicycling, aerobic dancing, using a stair climber).	N	S	O	R
11.	Take some time for relaxation each day.	N	S	O	R
12.	Believe that my life has purpose.	N	S	O	R
13.	Maintain meaningful and fulfilling relationships with others.	N	S	O	R
14.	Eat 6-11 servings of bread, cereal, rice and pasta each day.	N	S	O	R
15.	Question health professionals in order to understand their instructions.	N	S	O	R
16.	Take part in light to moderate physical activity (such as sustained walking 30-40 minutes 5 or more times a week).	N	S	O	R
17.	Accept those things in my life which I can not change.	N	S	O	R
18.	Look forward to the future.	N	S	O	R
19.	Spend time with close friends.	N	S	O	R

		NEVER	SOMETIMES	OFTEN	ROUTINELY
20.	Eat 2-4 servings of fruit each day.	N	S	O	R
21.	Get a second opinion when I question my health care provider's advice.	N	S	O	R
22.	Take part in leisure-time (recreational) physical activities (such as swimming, dancing, bicycling).	N	S	O	R
23.	Concentrate on pleasant thoughts at bedtime.	N	S	O	R
24.	Feel content and at peace with myself.	N	S	O	R
25.	Find it easy to show concern, love and warmth to others.	N	S	O	R
26.	Eat 3-5 servings of vegetables each day.	N	S	O	R
27.	Discuss my health concerns with health professionals.	N	S	O	R
28.	Do stretching exercises at least 3 times per week.	N	S	O	R
29.	Use specific methods to control my stress.	N	S	O	R
30.	Work toward long-term goals in my life.	N	S	O	R
31.	Touch and am touched by people I care about.	N	S	O	R
32.	Eat 2-3 servings of milk, yogurt or cheese each day.	N	S	O	R
33.	Inspect my body at least monthly for physical changes/danger signs.	N	S	O	R
34.	Get exercise during usual daily activities (such as walking during lunch, using stairs instead of elevators, parking car away from destination and walking).	N	S	O	R
35.	Balance time between work and play.	N	S	O	R
36.	Find each day interesting and challenging.	N	S	O	R
37.	Find ways to meet my needs for intimacy.	N	S	O	R
38.	Eat only 2-3 servings from the meat, poultry, fish, dried beans, eggs, and nuts group each day.	N	S	O	R
39.	Ask for information from health professionals about how to take good care of myself.	N	S	O	R
40.	Check my pulse rate when exercising.	N	S	O	R
41.	Practice relaxation or meditation for 15-20 minutes daily.	N	S	O	R
42.	Am aware of what is important to me in life.	N	S	O	R
43.	Get support from a network of caring people.	N	S	O	R

		NEVER	SOMETIMES	OFTEN	ROUTINELY
44.	Read labels to identify nutrients, fats, and sodium content in packaged food.	N	S	O	R
45.	Attend educational programs on personal health care.	N	S	O	R
46.	Reach my target heart rate when exercising.	N	S	O	R
47.	Pace myself to prevent tiredness.	N	S	O	R
48.	Feel connected with some force greater than myself.	N	S	O	R
49.	Settle conflicts with others through discussion and compromise.	N	S	O	R
50.	Eat breakfast.	N	S	O	R
51.	Seek guidance or counseling when necessary.	N	S	O	R
52.	Expose myself to new experiences and challenges.	N	S	O	R

DIRECTIONS: These are additional questions about your *present* way of life or personal habits according to current Canadian recommendations and reports from Statistics Canada. Please respond to each item as accurately as possible. Indicate the frequency with which you engage in each behavior by **circling**:

N for never, **S** for sometimes, **O** for often, or **R** for routinely

		NEVER	SOMETIMES	OFTEN	ROUTINELY
1.	Engage in at least 150 minutes of moderate to vigorous intensity aerobic activity a week, in bouts of 10 minutes or more.	N	S	O	R
2.	Eat 6-8 servings of grain products daily.	N	S	O	R
3.	Eat 5 or more servings of fruits and vegetables daily.	N	S	O	R

Thank you for taking the time to complete this survey and to assist me with my research! Please look over your answers for any missed pages or questions and then send this survey back to me as soon as you can in the envelope provided.

Contact Information Sheet

To thank you for the time that you have put into filling out this survey I would like to enter your name into a draw for one of six cheques for $50. The draw will take place **October 12, 2012,** so it is important that you complete and return your survey as quickly as possible**.**

I will also be doing a telephone interview with a small number of caregivers to explore what helps them to maintain or improve their health and what prevents them from maintaining or improving their health. I may contact you to see if you would be willing to be one of the people that I speak with. If you would like to be interviewed please check the box below. The telephone interview would take approximately 60 minutes. All interview participants will be paid $20 for their participation in the interview; a cheque will be mailed to all interviewees.

Please check all that apply:

☐ I would like my name to be entered into the draw for one of six $50 cash prizes.
☐ I would like to receive a summary of the findings of this study about the health and health promoting behaviors of urban and rural caregivers of children with disabilities living in Central Alberta.
☐ I would like to participate in a telephone interview about what helps me and prevents me from engaging in activities to maintain and improve my health.

If you have checked any of the above, **please complete the information below.**

Please note that all of the information that you provide will remain strictly confidential and that only myself and my supervisor will have access to the information. This piece of paper will be detached immediately and will be stored in a locked filing cabinet in a separate place than the survey so that your name will not be connected with any of the information that you provide on the survey.

Name:
Address:
City:
Province:
Postal Code:

E-mail address:

Home telephone:

Cell phone:

Appendix G

FACULTY OF NURSING
UNIVERSITY OF ALBERTA

Additional Form for Second Child with a Disability

Please fill out this page ONLY if you have more than one child with a disability. I have included this **additional form** for answering questions about your **second** child with a disability. If you have more than two children with a disability then please just answer these questions about your third child on a piece of paper and include that when you return your survey.

Your Child with a Disability

1. How old is your child with a disability? ________________

2. Is your child a boy or a girl?
   - 1☐ boy
   - 2☐ girl

3. What is your child's diagnosis(es)? If your child does not have a diagnosis please describe the condition.

   ____

   ____

   ____

4. Overall, how would you rate the severity of your child's disability?
   - 1☐ Mild
   - 2☐ Moderate
   - 3☐ Severe
   - 4☐ Very severe

Appendix H

Permission Letter to Use the Health-Promoting Lifestyle Profile II

UNIVERSITY OF NEBRASKA MEDICAL CENTER
COLLEGE OF NURSING
Community-Based Health Department

985330 Nebraska Medical Center
Omaha, NE 68198-5330
402/559-6382
Fax: 4021559-63

Dear Colleague:

Thank you for your interest in the *Health-Promoting Lifestyle Profile II.* The original *Health-Promoting Lifestyle Profile* became available in 1987 and has been used extensively since that time. Based on our own experience and feedback from multiple users, it was revised to more accurately reflect current literature and practice and to achieve balance among the subscales. The *Health-Promoting Lifestyle Profile II* continues to measure health- promoting behavior, conceptualized as a multidimensional pattern of self-initiated actions and perceptions that serve to maintain or enhance the level of wellness, self-actualization and fulfillment of the individual. The 52-item summated behavior rating scale employs a 4-point response format to measure the frequency of self-reported health-promoting behaviors in the domains of health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations and stress management. It is appropriate for use in research within the framework of the Health Promotion Model (Pender, 1987), as well as for a variety of other purposes.

The development and psychometric evaluation of the English and Spanish language versions of the original instrument have been reported in:

Walker, S. N., Sechrist, K. R., & Pender, N. J. (1987). The Health-Promoting Lifestyle Profile: Development and psychometric characteristics. Nursing Research, 36(2), 76-81.
Walker, S. N., Volkan, K., Sechrist, K. R., & Pender, N. J. (1988). Health-promoting lifestyles of older adults: Comparisons with young and middle-aged adults, correlates and patterns. Advances in Nursing Science, 11(1),76-90.
Walker, S. N., Kerr, M. J., Pender, N. J., & Sechrist, K. R. (1990). A Spanish language version of the Health- Promoting Lifestyle Profile. Nursing Research, 39(5), 268-273.

Copyright of all versions of the instrument is held by Susan Noble Walker, EdD, RN, FAAN, Karen R. Sechrist, PhD, RN, FAAN and Nola J. Pender, PhD, RN, FAAN. The original *Health-Promoting Lifestyle Profile* is no longer available. You have permission to download and use the HPLPII for non-commercial data collection purposes such as research or evaluation projects provided that content is not altered in any way and the copyright/permission statement at the end is retained. The instrument may be reproduced in the appendix of a thesis, dissertation or research grant proposal. Reproduction for any other purpose, including the publication of study results, is prohibited.

A copy of the instrument (English and Spanish versions), scoring instructions, an abstract of the psychometric findings, and a list of publications reporting research using all versions of the instrument are available for download.

Sincerely,

Snwalker

Susan Noble Walker, EdD, RN, FAAN
Professor Emeritus

Appendix I

HEALTH-PROMOTING LIFESTYLE PROFILE II

Scoring Instructions

Items are scored as			
	Never (N)	=	1
	Sometimes (S)	=	2
	Often (O)	=	3
	Routinely (R)	=	4

A score for overall health-promoting lifestyle is obtained by calculating a mean of the individual's responses to all 52 items; six subscale scores are obtained similarly by calculating a mean of the responses to subscale items. The use of means rather than sums of scale items is recommended to retain the 1 to 4 metric of item responses and to allow meaningful comparisons of scores across subscales. The items included on each scale are as follows:

Health-Promoting Lifestyle	1 to 52
Health Responsibility	3, 9, 15, 21, 27, 33, 39, 45, 51
Physical Activity	4, 10, 16, 22, 28, 34, 40, 46
Nutrition	2, 8, 14, 20, 26, 32, 38, 44, 50
Spiritual Growth	6, 12, 18, 24, 30, 36, 42, 48, 52
Interpersonal Relations	1, 7, 13, 19, 25, 31, 37, 43, 49
Stress Management	5, 11, 17, 23, 29, 35, 41, 47

3/95: snw

Appendix J

FACULTY OF NURSING
UNIVERSITY OF ALBERTA

Information Letter for Survey

Title of Research Study: Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Caregivers of Children with Disabilities

Research Investigator:
Brenda Query, RN, MN, PhD student
Red Deer College
100 College Blvd
Box 5005
Red Deer, Alberta T4N 5H5
E-mail: bquery@ualberta.ca
Phone: 403-342-3223

Supervisor:
Lynne Ray, RN, Ph.D.
Level 3 Edmonton Clinic Health Academy
11405 87 Avenue
University of Alberta
Edmonton, AB T6G 1C9
E-mail: Lynne.Ray@ualberta.ca
Phone: 780-492-7558

Background: My name is Brenda Query and I am a PhD student in the Faculty of Nursing at the University of Alberta. As the parent of a disabled child, I know how hard you work taking care of your child, your family, and yourself. I also know how vital it is that you stay healthy so that you can continue to provide this care. You are being asked to be in a research study about your health and what you do to improve or maintain your health.

Purpose: I am doing this study because I want to find out about your health and what you are able to do to improve or maintain your health. I would also like to see if this is different for city or rural dwelling parents. I am doing this study as part of a thesis requirement for my PhD.

Procedures: The person who takes care of the disabled child most of the time is being asked to fill out this survey. The survey takes about 20 to 30 minutes to do. However, it does not need to be completed all at once. If you prefer, you can do parts of it at different times and then come back to finish it.

You may choose to reply without giving any information that could identify you or your child. However, if you wish any of the following, I will need your name and your contact information at the end of the survey:

1. If you wish to be entered into a draw for a prize to thank you for completing the survey.
2. If you wish to receive a summary of the results of the study.
3. If you wish to take part in a 60 minute telephone interview about what helps and what stops you from doing activities to maintain your health.

A stamped envelope is provided to return your survey.

Please return the survey by September 24, 2012.

Benefits: There are no benefits to you in filling out this survey. However, your answers will provide useful information to me and other health care providers. It will help us better understand the challenges that parents of children with disabilities face and give us ideas for how to help parents stay healthy.

Risks: There are no risks to you in filling out this survey. If you find that a question upsets you, please leave it blank. You can stop filling out the survey at any time. A social worker is available if you would like to speak to someone about feelings that may come up. Just call me at the above number and I will put you in touch with someone.

Confidentiality: Your decision to complete the survey is up to you. All data that you provide will be kept **strictly confidential**. Only my supervisor Dr. Lynne Ray and I will have access to the data that you provide. The Research Ethics Committee at the University of Alberta also has the right to review study data**. *No information that you fill out on the survey will be linked to your name.*** The contact sheet at the end of the survey will be separated from your survey as soon as I receive it. All information that you provide will be given a special number to maintain your privacy. Surveys and contact information sheets will be kept in separate locked filing cabinets in locked rooms that only I and my supervisor can access. During the study, all study data will be kept in locked filing cabinets in a locked office at Red Deer College. All study data will be securely stored at the University of Alberta for five years after the study is over, at which time it will be destroyed. All computers used in this study will be password protected. Any files stored on a computer will be encrypted. The information for this study may be looked at again in the future to help answer other questions. If this happens, the University of Alberta Research Ethics Board will first review the study to ensure that the data is used ethically. *Your name, the place where you live, and other information that could identify you will never be reported*.

Voluntary Participation: *Your participation in this study is completely voluntary and you may choose not to answer any of the questions on the survey.* However, your opinions are important to the success of this study. By filling out and mailing the survey you are giving consent to be in the study.

Reimbursement of Expenses: There is no cost to you for filling out the survey. Please mail the completed survey in the stamped self-addressed envelope that was included in your package.
To thank you for the time that you took to complete and mail this survey I would like to enter your name in a draw for one of six $50 cash prizes. Your odds of winning are about 1 in 90. At the end of the survey you can choose to give information about yourself so that I may contact you if you win a prize. You will be told by phone if you are a winner and you will be asked to answer a simple skill testing questions (e.g. what is 2 + 2?). All winners will receive a cheque in the mail for $50. **The draw will be made on October 12, 2012.**

Contact Names and Telephone Numbers:

If at any time you have questions about this study you may contact me or my supervisor at the numbers on the first page of this letter. The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. If you have concerns about this study, you may contact the Research Ethics Office at (780) 492-2615. This office has no direct involvement with this project.

Note: Please keep this information letter for your reference.

Appendix K

Information Letter for the Pilot Telephone Interview

Title of Research Study: Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban and Rural Caregivers of Children with Disabilities

Research Investigator:
Brenda Query, RN, MN, PhD student
Red Deer College
100 College Blvd
Box 5005
Red Deer, Alberta T4N 5H5
E-mail: bquery@ualberta.ca
Phone: 403-342-3223

Supervisor:
Lynne Ray, RN, Ph.D.
Level 3 Edmonton Clinic Health Academy
11405 87 Avenue
University of Alberta
Edmonton, AB T6G 1C9
E-mail: Lynne.Ray@ualberta.ca
Phone: 780-492-7558

My name is Brenda Query and I am a PhD student at the University of Alberta. Thank you for agreeing to allow me to contact you about completing a pilot of my survey. I am doing this survey to help me learn about the health of caregivers of children with disabilities. I am doing this study as part of a thesis requirement for my PhD.

Purpose: You are being asked to be in this pilot because you care for a child with a disability. I am doing this study because I want to pilot a survey that I am sending out to caregivers in Central Alberta. It is hoped that your answers will help make the survey better.

Procedures: This survey will take about 30 to 40 minutes to complete. **Please record the actual time that it took you to complete the survey at the end of the survey.** After you have completed the survey, please contact me at work at 403-342-3223 and give me your contact information. I will then contact you to set an appointment for me to call you about what it was like for you to do the survey. This phone interview will take about 30 minutes. I will ask the following questions:

1. How long did it take for you to fill out the survey?
2. Did you find any of the questions confusing? Which ones?
3. Was the purpose of each question clear? Which ones were not clear?
4. Have I missed asking any questions on the survey that you think are important?
5. Do you have any concerns about the order in which the questions were asked?
6. Was the survey easy to fill out?
7. What about the layout of the survey? Do you have any suggestions?
8. Do you have any other comments about the survey?

Benefits: There are no benefits to you for doing this interview. However, your answers will help make this survey better for others.

Risks: There are no risks to you in doing this interview. If you feel that any of the questions are too hard or if they upset you, please do not answer them. I can arrange for you to speak with someone if you have feelings that upset you.

Confidentiality: All data that you provide will be kept **strictly confidential**. None of the information that you provide will be linked with your name. A special number will be placed on all of your data and that number will be put on notes from our talk. All papers that have your name on them will be kept in locked cabinets in locked rooms away from the results of this interview. Only my supervisor and I will see your answers. Your name, where you live, and other information that could identify you will never be reported in any presentations or publications of the study results.

During the study, all data will be kept in locked filing cabinets in a locked office at Red Deer College. After the study is completed, all study data, including the consent, audio tapes, interview notes, transcripts, and notes from this interview will be kept for five years. They will be kept at the University of Alberta in locked filing cabinets in a locked room that only I and my supervisor can access. After five years all data from the study will be destroyed. Computers used in the study will have passwords. Any files stored on a computer will be encrypted. The Research Ethics Committee also has the right to review study data.

Voluntary Participation: It is your choice to take part in this study. Your participation is completely voluntary. You can refuse to answer any questions.

Freedom to Withdraw: Even if you agree to be in the study, you can change your mind and withdraw at any time prior to or during data collection without any consequences. Just call me at the number listed above. You can stop the interview at any time. Just tell me to stop.

Reimbursement of Expenses: There should be no cost to you in completing this interview. However, if you have an increased cost on your cell phone bill as a result of roaming charges that occurred during the interview, then please call me as soon as you receive your bill. Your costs will be paid back to you in the form of a cheque that will be sent to you in the mail.

Compensation: I would like to thank you for the time that will be required to do this interview. I will send you a cheque for $20 whether or not you answer all of the questions that I intend to ask. The cheque will be mailed to you using the contact information that you provided for the survey.

Contact Names and Telephone Numbers:
If at any time you have questions about this study you may contact me or my supervisor at the numbers on the first page of this letter. The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. If you have concerns about this study, you may contact the Research Ethics Office at (780) 492-2615. This office has no direct involvement with this project.

Appendix L

FACULTY OF
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Title of Research Study: Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Caregivers of Children with Disabilities

Reminder Letter for Survey

September 12, 2012

Dear Parent/Caregiver,

About ten days ago you were sent a survey asking about your health and what you to do maintain and improve your health. This survey is part of a research study that I am doing at the University of Alberta about the health of caregivers of children with disabilities. Your response is important in helping me to complete this research. Thank you for your time as I know how busy your life is caring for yourself and your family.

- If you have mailed in the survey, I want to thank you for doing so. Your input will help me to learn about your health and health promoting behaviors.
- If you are interested in participating in the study but have not returned the survey yet, please do so when you can. However, I would appreciate it being returned to me by **September 28, 2012.** You are eligible to win one of six cheques for $50 if the survey is received by **October 12, 2012.**
- Please contact me if you did not receive the survey, need another copy of the survey, or have any questions. You can call me at work at 403-342-3223 or e-mail me at bquery@ualberta.ca

Sincerely,

Brenda Query, RN, MN, PhD student

Appendix M

Script for the Telephone Interview

Question: Hello. My name is Brenda Query. You agreed to participate in an interview about what helps you to and what prevents you from improving your health. Thank you for agreeing to be part of this study. Is this still a good time to go ahead with the interview? Is your family experiencing a crisis at this time?
[If the caregiver replies that it is not a good time then alternate arrangements will be made for another time to do the interview. If the family is experiencing a crisis at this time the interview will not continue and the caregiver will be excluded from the study].

Question: Will it be possible for you to talk for up to 60 minutes?
[Note: if less than 60 minutes determine if it is possible to reschedule the interview. Depending on the time available, a timer will be set at the start of the interview to ensure that we stay within the time limits].

Question: Is it okay for me to tape this interview? [If the caregiver states that it is okay then turn on the tape recorder. If it is not okay to tape the interview then start taking detailed notes].

[START THE TIMER AND ENSURE THAT THE TAPE RECORDER HAS ALSO BEEN STARTED IF PERMISSION TO TAPE THE INTERVIEW HAS BEEN GRANTED]

Question: You were sent an information letter in the mail about this interview and your rights as a person who is in a research project. Do you have any questions at this time?
[Answer all questions in lay terms].

Before we begin I need to record your consent to be in this study.
[Go over the consent, fill out, date, and sign]

Question: Is the contact information that I have for you still correct?
[Make changes to contact information if needed]

Start of the Interview:
Now that you have given your consent to participate in this interview, I would like to get started. I will now ask you some questions about what helps you to maintain and improve your health as well as some questions about what prevents you from maintaining and improving your health. Please be assured that there are no right or wrong answers. The questions that I ask are based on the answers that you provided on your survey about what you think is important to do to improve or maintain your health.

Semi-structured Interview Questions:

First, can you tell me what factors you considered when you were asked to rate your health?

Now, I see that one of the things that you want to do to improve or maintain your health is to __*insert topic here*____.

Possible topic options (at least three will be chosen but the exact number will depend on the amount of time spent on each response. They will be prioritized based on their answers regarding their health):

1. *Get regular checkups (medical, dental, etc.)*
2. *Increase physical activity*
3. *Improve eating habits*
4. *Strive for a positive attitude*
5. *Increase support from family, friends, and neighbors*
6. *Reduce stress levels*
7. *Engage in activities that enhance my personal growth*
8. *Get more sleep*
9. *Lose weight*
10. *Quit smoking/reduce the amount smoked*
11. *Drink less alcohol*
12. *Other (refer to individual's responses on survey)*

Facilitators:

1. **Broad Question**: Can you describe what will help you to ___*insert topic here*_____?

    Probes:

    a. What about yourself (knowledge, skills, attitudes, values) will help you to ___*insert topic here*_____?
    b. How will members of your family, friends, neighbors, or co-workers help you to ___*insert topic here*_____?
    c. How will work or school help you to ___*insert topic here*_____?
    d. What factors in your community (e.g. recreational facilities, grocery stores, public transportation, safe neighborhoods, or weather) will help you to ___*insert topic here*_____?
    e. What health promotion policy factors (e.g. municipal, provincial, or national policies, procedures, and laws) will help you to ___*insert topic here*_____?

Barriers:

1. **Broad Question**: Can you describe what will prevent you from ___*insert topic here*_____?

Probes:

a. What about yourself (knowledge, skills, attitudes, values) will prevent you from ___*insert topic here*_____?
b. How will members of your family, friends, neighbors, or co-workers prevent you from ___*insert topic here*_____?
c. How will work or school prevent you from ___*insert topic here*_____?
d. What factors in your community (e.g. recreational facilities, grocery stores, public transportation, safe neighborhoods, or weather) will prevent you from ___*insert topic here*_____?
e. What health promotion policy factors (e.g. municipal, provincial, or national policies, procedures, and laws) will prevent you from ___*insert topic here*_____?

End of the Interview:

Okay, that is the end of my prepared questions.

or According to the timer our time is up. Would you like to continue or are we out of time?

I would like to briefly summarize what you have told me [Briefly summarize comments].

Is this summary correct?

Do you have any further comments that you would like to make?

Do you have any questions?

Thank you very much for your time - I know how busy you are and I appreciate the time you have taken to answer my questions. You have been very helpful in providing me with information to use for my dissertation. You will receive your cheque in the mail shortly.

If I have any questions during my review of the results from this interview, would you be open to me calling you back if I need further clarification about anything? *(check response)*

1☐ Yes
2☐ No

Thank you again for participating in this interview. If you have any questions about the study, please feel free to contact me or my supervisor at the numbers that I have given you. Have a wonderful day!

Appendix N

FACULTY OF
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UNIVERSITY OF ALBERTA

Information Letter for the Telephone Interview

Title of Research Study: Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Caregivers of Children with Disabilities

Research Investigator:
Brenda Query, RN, MN, PhD student
Red Deer College
100 College Blvd
Box 5005
Red Deer, Alberta T4N 5H5
E-mail: bquery@ualberta.ca
Phone: 403-342-3223

Supervisor:
Lynne Ray, RN, Ph.D.
Level 3 Edmonton Clinic Health Academy
11405 87 Avenue
University of Alberta
Edmonton, AB T6G 1C9
E-mail: Lynne.Ray@ualberta.ca
Phone: 780-492-7558

My name is Brenda Query and I am a PhD student at the University of Alberta. You just filled out a survey for me about what you do to improve your health. At the end of the survey you agreed to talk to me about what you would like to do to stay healthy.

Purpose: You are being asked to be in this research study because you care for a child with a disability. I am doing this study because I want to hear from you about what helps you and what prevents you from improving your health. I also want to see if there is any difference depending on where you live. I am doing this study as part of a thesis requirement for my PhD.

Procedures: This interview will take about an hour. However, you may choose to talk longer if you would like to do so. We will talk about what helps you and what stops you from doing the things you would like to do to promote your health. If you have questions at any time during the interview, please ask them.

Benefits: There are no benefits to you for doing this interview. However, your answers will provide useful information to me and other health professionals. It will help us to understand what helps you to and what prevents you from improving your health.

Risks: There are no risks to you in doing this interview. If you feel that any of the questions are too hard or if they upset you, please do not answer them. I can arrange for you to speak with someone if you have feelings that upset you.

Title of Research Study: Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Caregivers of Children with Disabilities

Confidentiality: All data that you provide will be kept **strictly confidential**. None of the information that you provide will be linked with your name. A special number will be placed on all of your data and that number will be put on tapes and notes from our talk. All papers that have your name on them will be kept in locked cabinets in locked rooms away from the results of this interview. Only my supervisor, a person who will transcribe the interview, and I will see your answers. The transcriptionist will sign a confidentiality agreement. A code number will be used to identify the tapes. Your name, where you live, and other information that could identify you will never be reported in any presentations or publications. If quotes are used from our talk, you will be given an alias so that no one can identify you.

During the study, all data will be kept in locked filing cabinets in a locked office at Red Deer College. After the study is completed, all study data, including the consent, audio tapes, interview notes, transcripts, and notes from this interview will be kept for five years. They will be kept at the University of Alberta in locked filing cabinets in a locked room that only I and my supervisor can access. After five years all data from the study will be destroyed. Computers and files used in the study will have passwords. Any files stored on a computer will be encrypted. The Research Ethics Committee also has the right to review study data.

Voluntary Participation: It is your choice to take part in this study. Your participation is completely voluntary. You can refuse to answer any question and you may ask for the tape recorder to be turned off at any time.

Freedom to Withdraw: Even if you agree to be in the study, you can change your mind and withdraw at any time prior to or during data collection without any consequences. Just call me at the number listed above. You can stop the interview at any time. Just tell me to stop.

Reimbursement of Expenses: There should be no cost to you in completing this interview. However, if you have an increased cost on your cell phone bill as a result of roaming charges that occurred during the interview, then please call me as soon as you receive your bill. Your costs will be paid back to you in the form of a cheque that will be sent to you in the mail.

Compensation: I would like to thank you for the time that will be required to do this interview. I will send you a cheque for $20 whether or not you answer all of the questions that I intend to ask. The cheque will be mailed to you using the contact information that you provided in the survey.

Contact Names and Telephone Numbers:
If at any time you have questions about this study you may contact me or my supervisor at the numbers on the first page of this letter. The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. If you have concerns about this study, you may contact the Research Ethics Office at (780) 492-2615. This office has no direct involvement with this project.

Appendix O

FACULTY OF
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Consent Form for the Telephone Interview

Part 1 (to be completed by the Principal Investigator and verbally reviewed with the informant):

Title of Project: Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Caregivers of Children with Disabilities

Principal Investigator: Brenda Query Phone Number: 403-342-3223
Supervisor: Dr. Lynne Ray Phone Number: 780-492-7558

Part 2 (to be completed by the researcher based on responses by the informant):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you been read information about the research study?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without consequences to you?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to the information that you share?	☐	☐
Do you know how the information that you share will be used?	☐	☐

Who explained this study to you? ____

Do you agree to take part in this study: YES ☐ NO ☐

Do you agree to have this interview tape recorded: YES ☐ NO ☐

Printed Name of Research Subject: ____________________________________

Date:____

I believe that the person who has been read this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator:__________________________________ Date ________________________

Appendix P

FACULTY OF
NURSING
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Confidentiality Agreement for Transcriber

Title of Research Study: Health Status, Health Promoting Behaviors, and Facilitators and Barriers to Health Promoting Behaviors of Urban versus Rural Caregivers of Children with Disabilities

Research Investigator:	**Supervisor:**
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The plan for this study has been reviewed for its adherence to ethical guidelines and approved by Research Ethics Board 2 at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Appendix Q

‘Other’ Caregiver Medical Problems Expected to Last 6 Months or More

Table 12

‘Other’ Caregiver Medical Problems Expected to Last 6 Months or More

Medical Problem	Number of Caregivers Reporting
Alopecia	1
Anemia	1
Bipolar	1
Celiac Disease	3
Cold Sores	1
COPD	1
Fibromyalgia	2
Interstitial Cystitis	1
Hypotension	1
Kidney stones	2
Learning Disability	2
Lactose Intolerance	2
Leg Cramps	1
Metabolic Disorder	1
Myotonic Dystrophy	1
Osteopenia	1
Pancreatitis	1
Parasthesia	1
Planter’s fasciitis	2
Sleep apnea	1
Social Isolation	1
Stroke	2
Thoracic outlet syndrome	1
Vocal Cord Injury	1

Appendix R

Facilitators and Barriers to the Top Three Health Promoting Behaviors and to Getting Checkups

Table 18

Facilitators and Barriers to the Top Three Health Promoting Behaviors and to Getting Checkups

Integrated Social Ecology Model	Increasing Physical Activity	Eating Healthy	Healthy Weight	Regular Checkups
Intrapersonal Factors	**Facilitators:** knowledge of health benefits of physical activity, feeling safe being outside, making exercise a priority, owning a dog **Barriers:** lack of knowledge about the amount of exercise recommended, lack of motivation, personal health issues	**Facilitators:** knowledge of the benefits of healthy eating, nutrition knowledge, motivation and prioritizing healthy eating, planning meals, using a phone application to make healthy food choices **Barriers:** lack of motivation, not prioritizing own need to eat healthy, a lack of knowledge about what was in a healthy diet	**Facilitators:** monitoring weight, eating smaller and more frequent meals, limiting portion sizes **Barriers:** frustration with unsuccessful attempts at weight loss or lack of progress, depression, feeling hungry while dieting, lack of motivation, overeating	**Facilitators:** using birthdays as reminders, having another health concern **Barriers:** lack of motivation, previous unpleasant experiences

Table 18 (continued)

Facilitators and Barriers to the Top Three Health Promoting Behaviors and to Getting Checkups

Integrated Social Ecology Model	Increasing Physical Activity	Eating Healthy	Healthy Weight	Regular Checkups
Interpersonal Factors	**Facilitators:** activities with children, spouse providing respite and a workout partner, family outings ***-related to caring for a child with a disability:*** decreasing stress related to caring for child, needing to stay fit to be able to continue to physically care for child, needing to participate in special activities with child, physical demands of caring for child **Barriers:** no time due to after school activities, spouses who worked away, lack of a partner ***-related to caring for a child with a disability:*** lack of time due to special care needs of child (therapies, feeding, bathing, etc.), inability to alter routine without behaviors occurring, inability to get respite for child, inability to push wheelchairs due to snow and ice, interruptions from school to help with child's behaviors, inability to work and to afford activities due to child's care needs and unreliable respite	**Facilitators:** role modeling healthy eating for their children, feeding their children healthy food, friends as sources of information and support, family gardens, being responsible for family's well-being, having a partner who provided a 2^{nd} income and was motivated to eat healthy ***-related to caring for a child with a disability:*** needing to stay healthy due to the long-term care needs of their child, child's special diets **Barriers:** children who were picky eaters, no time due to after school activities, loneliness, exposure to unhealthy foods from family and friends ***-related to caring for a child with a disability:*** eating unhealthy 'comfort' foods due to stress related to care needs of child, no time to eat or garden due to care needs of child, child's ritualistic behaviors	**Facilitators:** role modeling healthy weight for children, spousal encouragement, information from colleagues, parents who were good role models and sources of information ***-related to caring for a child with a disability:*** need to stay a healthy weight in order to be able to continue to provide care for their child over the long-term **Barriers:** none reported	**Facilitators:** family history of health concerns prompting from family members ***-related to caring for a child with a disability:*** wanting to stay healthy due to concerns of who would be able to provide the complex care needed by their child **Barriers:** lack of social support ***-related to caring for a child with a disability***: their child`s special care needs resulted in them having no time and forgetting about their own needs, unable to take time from work due to numerous appointments for their child, a lack of respite, disruptive child behaviors

Table 18 (continued)

Facilitators and Barriers to the Top Three Health Promoting Behaviors and to Getting Checkups

Integrated Social Ecology Model	Increasing Physical Activity	Eating Healthy	Healthy Weight	Regular Checkups
Organizational Factors	**Facilitators:** bringing children to and from school, information about benefits of physical activity from school, school provided them with respite, sufficient income to pay for activities, flexible work hours, physically demanding jobs, employer wellness programs -***unique to rural:*** physical activity required to maintain animals and property **Barriers:** children being out of school, no time due to work demands, lack of monetary resources -***unique to rural:*** time required to maintain property	**Facilitators:** information from school, reminders when preparing healthy food for children, having enough income to be able to afford healthy food, scheduled work breaks **Barriers:** no time due to need to study, children in school so no reminder to eat, unhealthy snacks in workplace, eating due to work stress, not enough income to afford produce, too busy due to work demands	**Facilitators:** employer's programs on how to lose weight and eat healthy, overweight or obese colleagues **Barriers:** overeating due to missing meals as a result of work demands, lack of income to afford special foods recommended by some weight loss programs	**Facilitators:** school providing respite to be able to go to appointments, requirements for post-secondary education and employment, having health care coverage **Barriers:** unwilling to take time off of work

Table 18 (continued)

Facilitators and Barriers to the Top Three Health Promoting Behaviors and to Getting Checkups

Integrated Social Ecology Model	Increasing Physical Activity	Eating Healthy	Healthy Weight	Regular Checkups
Community Factors	**Facilitators:** warm weather conditions, safe neighborhoods ***-unique to urban:*** convenient access to available and affordable facilities, walking and biking trails ***-unique to rural:*** walking long driveways, limited access to facilities and activities, businesses within walking distance, time traveling **Barriers:** inclement or cold weather conditions ***-unique to urban:*** length of time spent on public transportation ***-unique to rural:*** lack of access to and no available facilities and services, lack of trails that was further impaired with inclement weather, no street lights, problems with animals, distance to activities and respite, time traveling	**Facilitators:** available healthy food, food clubs, farmer's markets in their community, being able to buy food in bulk ***-unique to urban:*** good selection of available and affordable quality produce, public transportation, farmer's markets, information from trainers ***-unique to rural:*** limited access to local grocery stores, gardens, easy access to fresh food from farmers, no fast food restaurants in community **Barriers:** none reported ***-unique to urban:*** no room for a garden, no available bulk food stores (for urban caregivers outside of a large city), ease of access to fast food ***-unique to rural:*** unable to get to grocery stores in inclement weather, lack of access to affordable and quality food, distance to access food, travel time conflicting with meals	**Facilitators:** access to and available resources and programs to help with weight loss, physicians who provided medications and advice ***-unique to urban:*** ease of access to a large variety of available weight loss programs ***-unique to rural:*** none reported **Barriers:** none reported ***-unique to urban:*** none reported ***-unique to rural:*** limited or no access to weight loss programs/ services in their community	**Facilitators:** physician offices sending reminders ***-unique to urban:*** ease of access to and available walk-in clinics, public transportation ***-unique to rural:*** rural physician initiatives **Barriers:** physicians being overbooked ***-unique to urban:*** none reported ***-unique to rural:*** length of contracts for rural physician initiatives, no available physicians, long distances to get to physicians on poor roads further hampered by inclement weather, lack of housing for single physicians

Table 18 (continued)

Facilitators and Barriers to the Top Three Health Promoting Behaviors and to Getting Checkups

Integrated Social Ecology Model	Increasing Physical Activity	Eating Healthy	Healthy Weight	Regular Checkups
Policy Factors	**Facilitators:** government funded facilities and trails, ParticipACTION, discounts for memberships, government subsidies **Barriers:** No tax breaks for adults who exercised	**Facilitators:** regulations regarding standardized food labelling of the nutrient content of food, Canada Food Guide, Body Break ©, ParticipACTION, some restaurants posting nutrition information of their food **Barriers:** lack of a regulations requiring chain restaurants to list nutrient content of food	**Facilitators:** none reported **Barriers:** none reported	**Facilitators:** government subsidies for rural physician initiatives **Barriers:** none reported