

THE COPING STRATEGIES OF ADULTS AGING WITH CEREBRAL PALSY

by

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ABSTRACT

Purpose: To investigate the coping strategies of adults with cerebral palsy (CP) who were growing older and experiencing changes in their functional abilities.

Methods: Qualitative descriptive phenomenology was used. Antonovsky's concepts of sense of coherence (SOC) were applied to examine the coping approaches of adults growing older with CP. Data from 12 participants were gathered through in-depth, semi-structured interviews.

Results: Three themes emerged from the analysis: *Awareness, Acceptance and Action* reflects strategies of how participants gain *awareness*, become better able to *accept* what they are experiencing and then position themselves to take appropriate *actions*; *Negotiating One's World* depicts experiences of empowerment, disempowerment and self-responsibility; and *Independence is Everything* portrays what being autonomous means to participants. Despite the fact that their physical abilities seemed to deteriorate as they grew older, most participants described improvements in psychosocial aspects of their lives and were able to maintain SOC while growing older with CP.

Discussion: Based on the interview findings, participants had not been adequately informed of the possibility of experiencing secondary conditions, e.g., pain and fatigue, as they grew older. Pediatric therapy programs have not adequately anticipated challenges that may occur in adulthood. Greater preventive healthcare is called for. All healthcare providers need to be aware of the unique needs of adults with CP. These adults themselves need to be informed what to expect as they grow older and shown ways to take responsibility for their personal health. Programs should be designed to promote

lifetime fitness and prevention where exercise, good nutrition, weight control, stress management and energy conservation are stressed as well as ways to alleviate or manage chronic pain. Adults with CP need to advocate for their health, education, careers, and care, and to better understand an “inter-reliant” sense of independence. Participants want programs that provide options in managing their own care workers. Family support needs to foster independence and inter-reliance. Transition and implementation plans should begin in mid-adolescence and include care coordination of finances and the services of capable adult-centered healthcare providers. Future research could include studies exploring preventive health measures to minimize secondary disabilities and enhanced community accessibility.

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LIST OF ABBREVIATIONS

CP- Cerebral palsy

SOC- Sense of coherence

ICF- International classification of functioning, disability and health

ADL- Activities of daily living

GMFCS- Gross motor function classification system

UBC- University of British Columbia

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DEDICATION

To my mother who was my greatest advocate.

CHAPTER 1

1.1 Introduction

According to the Executive Committee for the Definition of Cerebral Palsy: “Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain”.¹ Even though CP is attributed to non-progressive lesions occurring early in the brain’s development,¹ adults with CP experience changes and loss of functional abilities at younger ages than their able-bodied peers. Moreover, the number of adults with CP is increasing due to medical advances that have improved survival rate of low-birth-weight infants² and increased life expectancy in the general population.³ Because CP affects individuals throughout their lifespan, with increasing numbers of adults who are living longer, studies of the conditions or changes that adults with CP may be experiencing are warranted.

Secondary conditions resulting from living with a lifelong disability, such as CP, may progress subtly, not appearing until late adolescence or adulthood as a result of the aging process.⁴ Some secondary conditions may be preventable and others can be modified by environmental or adaptive measures.⁴ These secondary conditions often contribute to loss of function and deterioration of activities of daily living,⁵⁻⁹ making it important to understand how adults with CP can best cope with these conditions.

1.2 Definition of Terms

The researcher will use the definitions from the International Classification of Functioning, Disability and Health (ICF)¹⁰ for the terms *functioning*, *disability* and

impairments that are commonly associated with adults with CP. Accordingly, *functioning* is an overarching term that includes body functions, activities and participation, whereas *disability* is an umbrella term for impairments, activity limitations or participation restrictions.¹⁰ *Impairments* are problems in body function or structure such as significant difference or losses. *Activity* is defined as the carrying out of a task or action by an individual. *Participation* is when an individual partakes in a life situation. Individuals experience *activity limitations* when they have difficulties executing activities. *Participation restrictions* may occur when an individual experiences problems with their involvement in life situations.¹⁰ These terms are common to many studies involving disability and rehabilitation.

1.3 Coping

Most research on aging with CP has been based on a biomedical focus.^{3-9,11-19} Far fewer researchers²⁰⁻²⁵ have reported on what CP means to the individuals themselves, e.g., the coping potential and psychosocial aspects of aging with CP. Lazarus and Folkman are longtime leaders in the field of coping research.²⁶ Folkman and Moskowitz defined coping as “thoughts and behaviors that people use to manage the internal and external demands of situations that are appraised as stressful.”^{27(p 746-7)} The coping process begins to unfold as an individual appraises a situation or condition as personally significant and taxing, or beyond their individual resources for coping.²⁷ Coping is a complex and multidimensional process that is sensitive to the relationship of the person to their environment. The appraisal of stress and resources is influenced by this relationship between personality dispositions and assessments of the environmental demands and resources.²⁷

Within this theoretical formulation, two separate aspects in the cognitive appraisal process are used for evaluating one's ability to cope with stressful events or conditions. Primary appraisal evaluates the significance of a stressor or specific transaction with regard to the person's well-being. Secondary appraisal evaluates the manageability of the stressor and the resources or options the person may have at their disposal.²⁸ Secondary appraisal occurs after one determines the significance of the event or situation and tries to figure out what can be done about it. Therefore, within the process of coping, a person first determines the meaning of an event or situation and its implications for their well-being. If the person assesses that situation as stressful or a threat to her or his wellbeing, that individual then proceeds to determine what they are able to do about it by assessing their coping resources and then determining which strategies will be most effective.²⁹

Appraisal has been defined as "assessment of the situation by the person facing it and includes an evaluation of both the demands of the situation and the resources the person brings to bear on that situation."^{29(p.138)} At this point, a person evaluates the situation and determines the likelihood that a particular action may have on a desired outcome and the degree to which the person has the ability to carry out the desired action.²⁹ The actual coping efforts are the strategies used to mediate primary and secondary appraisals.

Two major functions of the coping process are problem-focused and emotion-focused.³⁰ The problem-focused function employs strategies directed at changing a stressful situation, e.g., changing the relationship to the troubled environment by acting on the environment or oneself.³¹ The emotion-focused function is used to employ strategies aimed at changing the way one thinks or feels about a stressful situation.

Emotion-focused coping is directed at changing either the way one relates to the stressful environment or the relational meaning of what is happening, which results in alleviating the stress even though there may be no actual change in the conditions that are causing the stress.³⁰

1.4 Sense of Coherence

The sense of coherence (SOC) concept is used to examine the potential for development of coping strategies. Developed as a theoretical model to enhance the understanding of relationships among stressors, Antonovsky introduced the concept of SOC to understand how health is preserved under stressful conditions.³² This model attempts to explain why certain people preserve health and wellbeing while still being able to cope with very difficult life stressors. Antonovsky viewed health within a health-disease continuum, proposing that adaptive coping is key to moving toward the healthy end of the continuum.³² To understand how health is preserved under stressful conditions, Antonovsky focused on the origins of health instead of the origins of disease. He recognized the importance of what he called the general resistance resources - material, ego identity, intelligence, coping strategies, cultural stability, social support and religion/spirituality - in promoting health but was more concerned with a theoretical understanding of why such resources promoted health. He proposed that the concept of SOC provided the answer.³²

Antonovsky developed an SOC scale that focused on SOC and general resistance resources. SOC was defined as:

A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that:

- (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable
- (2) the resources are available to one to meet the demands posed by these stimuli
- (3) these demands are challenges worthy of investment and engagement.^{32 (p.725)}

Antonovsky called these three components comprehensibility (the cognitive component), manageability (the instrumental problem-solving component) and meaningfulness (the emotional/motivation component).^{32,33} SOC is not connected to a certain personality trait or behavior nor to a specific coping skill.³³ General resistance resources are the biological, economic, psychosocial and cultural factors that make life easier to experience as consistent, structured and comprehensible and provide strength to combat stressors.

According to Nilsson and colleagues,³⁴ Antonovsky theorized that individuals who have a strong SOC early in life are better able to activate their general resistance resources later in life. In some individuals, the mobilization of appropriate resources becomes a necessary response as they are exposed to stressors in childhood and adolescence. Antonovsky speculated that an individual's SOC increases to the degree to which the stressors were perceived as comprehensible, manageable and meaningful, thereby reducing the psychological distress.^{35,36} Over time, an individual's SOC is reinforced through repeated and healthful management of stressful situations so that often, by age 40, people will have been exposed to enough significantly stressful situations that their SOC will be established as a stable orientation to the world.³⁶

Studies have been conducted on SOC in the general population^{34,35,37-40} and in specific populations, e.g., persons with Parkinson disease⁴¹ and those with spinal cord

injury.⁴² To date, however, only one published study has investigated SOC in adults with CP.³³ Jahnsen and colleagues investigated SOC in Norwegian adults with CP.³³ Results of Jahnsen and colleagues' study showed that adults with CP had a lower SOC than those in the general population in all three domains but especially in comprehensibility.³³

Experiencing predictability is important to developing SOC. Adults with CP experience many secondary conditions as they age, leading to loss of function.^{3-8,11-15,43} Because CP has been described historically as a non-progressive disorder,⁴⁴ adults with this disability may view these secondary conditions as unexpected and unpredictable, perhaps explaining why the group with CP in the Norwegian study scored especially low in the domain of "comprehensibility". Other explanations for low comprehensibility scores are as follows: 1) results of the Norwegian survey suggested that the daily life of a person with CP is full of unpredictability due to high turnover of staff and caregivers, appointments that are often changed according to the needs of parents and caregivers, as well as having to experience frequent changes in treatment methods;³³ 2) decisions are often made by health professionals or caregivers on behalf of the adult with CP without explanations or without including them in the discussions;⁴⁵ 3) results of two qualitative studies suggest that adults with CP may not understand what is happening to them, reporting that they experience "pain as mystery"^{21 (p233)} and "fear of the unknown."^{22 (p132)}

Because adults with CP experience health problems and secondary musculoskeletal impairments as they age^{3-9,11-19,46,47} they face daily challenges that persons without disability are less apt to experience. A person's coping ability develops through a sense of manageability of balancing their challenges and their personal resources. Loss of function in adults with CP may hinder their sense of manageability.

Interestingly, it has been reported^{5-7,9,14,15,17,18} that adults with CP often experience decline in their functional abilities between ages 25 and 45. Yet Jahnsen et al. found the greatest proportion of high SOC between ages 35-45 and after 55 in adults with CP.³³ These results appear contradictory and warrant further investigation and explanation.

A sense of meaningfulness is enhanced when individuals contribute to their own health outcomes.⁴⁸ For example, adults with CP reported having had many physiotherapy sessions as children but never being provided with attainable short-term goals.³³ Without such goals, children with CP may be confused as to what is expected of them, which may leave them feeling as though they always fall short of what they perceived others expected of them. Because adults with CP did not feel part of their own therapy goals and health outcomes as children, they struggled with whether their efforts were worthwhile.³³ Jahnsen and colleagues suggested that such experiences may explain the differences in SOC between adults with CP and those in the able-bodied reference group.³³ It may be difficult for individuals with CP to have a sense of their own identity when they have been disregarded in goal setting or have not been given a voice to explore their own desired outcomes.

Christiansen⁴⁹ suggested that SOC measures a human dimension that intersects with identity. He linked concepts of SOC, such as agency, competence, meaning and understanding, with those of identity. In other words, a person's SOC reflects her/his sense of agency, meaning and a sense of how events in their lives fit together - which in turn reflects a sense of their personal identity.⁴⁹ Christiansen's essay suggested that the identity of individuals, such as those with CP, may be closely linked to their SOC, thereby emphasizing how important it is for these individuals to have a sense of agency

(e.g., participation in goal setting), a sense of competency, understanding, and meaning in the possible outcomes of their lives.

Antonovsky's SOC provides an understanding of how health is preserved under stressful conditions.³² Adults with CP who experience loss of function due to secondary conditions may be undergoing increased life stress. Therefore, a qualitative study to explore the perspectives of adults with CP on their understanding and anticipation of the age-related changes they were experiencing and the accessibility and adequacy of resources to make their lives meaningful and worthwhile was warranted. Qualitative data may provide knowledge to improve the coping ability and enhance the sense of identity, health and overall wellbeing of adults with CP.

1.5 Purpose and Significance of the Study

The purpose of this study was to investigate the coping strategies of adults with CP as they grow older and experience changes in their functional abilities. Qualitative research procedures based in phenomenology were used to explore experiences of adults with CP as they grew older and to examine what role Antonovsky's concepts of SOC played in the coping strategies used. Whereas quantitative research provides a means for generalizing study results to the population of interest, qualitative research describes the experiences of the group of individuals being studied, in this case adults with CP. This phenomenological study explored the lived experiences of adults with CP in their everyday lives and their meanings of those experiences. In seeking to understand coping strategies in adults with CP, qualitative descriptive data from these adults were obtained.

Hopefully, the data obtained from adults with CP will provide insight into their particular needs during the aging process. Antonovsky's concept of SOC provided the

lens that was used to examine the coping strategies of adults with CP. The present study investigated whether adults aging with CP experienced the changes in their functional abilities as understandable and manageable and whether they experienced their lives as meaningful and worthwhile.

Results of Jahnsen and colleagues' survey³³ guided and informed this qualitative study as to how important predictive factors might influence SOC. For example, Jahnsen et al. reported that marital status, education, life satisfaction and fatigue were predictive of low SOC whereas gender, age, pain and grade of disability were not.³³ However, other literature has indicated that adults with CP lack an understanding of their aging process.²⁰⁻²² Qualitative data collected from adults with CP provide insight and further explanations of the important factors influencing low versus high SOC in this population.

Antonovsky's theory suggests that SOC is stable, except during life-changing events. Jahnsen and colleagues' survey results found that the lowest SOC scores occurred between ages 18-24, a transitional period between adolescence and adulthood. My study focused on adults with CP over age 25 because the literature reviewed reported that adults with CP often begin to experience decline in their functional abilities by age 25.^{5-7,9,18} Developing a strong SOC early in life helps an individual to cope better with challenges that may occur later in life.³⁶ I was interested in examining the coping potential of adults with CP and the role that SOC played as these adults experienced changes that affected their functional abilities. Focusing on adults with CP over age 25 captured a transitional period that these adults experienced while adjusting to changes in their functional levels.

This qualitative (phenomenological) study obtained direct and personal views from adults with CP about their coping strategies and other psychosocial factors

involving growing older with CP. In Jahnsen et al's study of SOC, Norwegian adults with CP were compared to the general Swedish population. Those with CP scored lower in the domains of manageability and meaningfulness than the general Swedish population, and especially low in the domain of comprehensibility.³³ Consequently, the current phenomenological study provided further insight into what information is needed for adults with CP to have a better understanding of growing older with this disability. It was interesting to also explore, from the points of view of adults with CP, how meaningfulness and manageability were related to their experience of coping with secondary conditions resulting from growing older.

Traditionally, health care follow-up programs for adults with CP have focused primarily on development and preservation of functional skills, thus involving the time and resources of physiotherapists, neurologists and orthopedic surgeons, for example.³³ However programs that emphasize coping potential and psychosocial health for persons with developmental disabilities have not been deemed as important.³³ Gaining more in-depth understanding of the role that the concept of SOC plays in adults with CP provides direction for addressing the coping potential of these individuals so that their aging process is comprehensible and manageable and their lives remain meaningful. Knowledge gained from this study may help caregivers and health professionals in their delivery of services to adults with CP.

As Christiansen stated: "Research on sense of coherence during the past 20 years has shown that people with this attribute, or way of viewing the world, are healthier and better adjusted than people without a strong sense of coherence".^{49 (p.555)} Developing SOC is important to adults with CP so that they understand their aging process, are able

to perceive resources as accessible, and can experience their lives as meaningful. Gaining such knowledge and experiences from those individuals themselves could assist healthcare providers and caregivers to develop programs that enhance SOC in these adults.

CHAPTER 2

2.1 Review of the Literature

The purpose of this chapter is to describe relevant research literature on biomedical and psychosocial aspects of aging with cerebral palsy (CP). As defined in Chapter 1, “CP describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain”.¹

As discussed also in Chapter 1, adults with CP are at risk for secondary conditions, such as pain, fatigue and musculoskeletal impairments, that contribute to loss of function, limitation in activities, participation restrictions and deterioration in their quality of life.¹¹ A major concern is whether this loss of function occurs at earlier ages in persons with CP than in the general population.⁵⁰ Adults with CP have fewer opportunities to receive health care support after leaving school than as children and adolescents.⁴⁵ Living with a lifelong disability presents challenges; identifying age-related conditions and changes that occur in adults with CP can provide them with the understanding needed to enhance their ability to cope.

Compared to the wealth of literature on childhood aspects of CP, less attention has been placed on adults and elderly persons with this disability. The published literature regarding adults with CP has been limited to small studies because most longitudinal databases do not include data beyond early adulthood.¹⁸ Adults with CP are asking for more research and information about the aging process in order to know what to expect as they age.⁵⁰⁻⁵²

2.2 Search Strategies

A search of CINAHL (1982 – present), ERIC, PubMed (1950 – present), MEDLINE (Ovid), and Web of Science databases, as well as the American Academy of Cerebral Palsy and Developmental Medicine website was conducted. Key search terms such as “cerebral palsy and aging,” “adults with cerebral palsy,” “secondary conditions,” “functional loss,” “health,” and “psychosocial” were used.

2.2.1 Initial Study Selection Criteria

Included were studies that identified age-related changes or secondary conditions affecting functional loss in adults with CP as well as studies that focused on some of the psychosocial aspects of aging with CP. These studies included adults with CP who did not have intellectual disabilities (as reported in the articles).

2.2.2 Review Criteria

Initially, 79 articles were identified that referred to the aging process in adults with CP. Excluded were studies which stated that the individuals participating had intellectual disabilities, and studies that did not focus on the impact of age-related secondary conditions and changes occurring in adults with CP. Some studies included individuals with other disabilities as well as those with CP. McMaster University’s Guidelines for Critical Review Form - Quantitative and Qualitative Studies⁵³ was used to evaluate the studies.

2.3 Identifying Secondary Conditions

2.3.1 Pain

Pain is a secondary condition commonly identified by adults with CP and reported as a significant concern in a number of studies.^{5,7,9,13,16,22,54} In a paper published in 1999, Schwartz et al.⁵⁴ studied the pain experiences of 93 individuals (48 males, 45 females; mean age = 38 years, range = 18 to 79 years) diagnosed with CP. This prospective exploratory study measured weekly pain intensities, chronic pain grades, interference in daily activities caused by pain, and both pain-exacerbating factors and pain-relieving factors over a three-month period.⁵⁴

Schwartz et al. found a significant but modest correlation between subjects' age and pain intensity ($r = .25$; $p < .05$).⁵⁴ Older subjects had more intense pain, possibly reflecting the impact of the aging process on the experience of pain, either from physiological changes, disuse, or overuse due to the underlying disability.⁵⁴ Factors reported to exacerbate pain were fatigue, stress/depression, overexertion and weather changes. Exercising, stretching, resting, massage, sleeping and staying active were reported to relieve pain. Turk et al. reported that the most common health issues identified by women with CP were pain and musculoskeletal impairments, such as hip and back deformities.⁵⁵

Although more than half of the participants in the Schwartz et al.⁵⁴ study reported pain experiences ranging from moderate to severe, the pain interfered minimally with their activities of daily living (ADL), social or work functioning. However, a limitation of this study was that 95% of the subjects were non-ambulatory, making it difficult to compare these results to those of studies with ambulatory subjects. Similarly, the results

of Turk et al.'s⁴ study of health issues in women with CP suggested that only a modest change in function occurred over the lifetime. However, CP-related pain may have a greater impact on psychological state than on physical status.⁵⁶ Jahnsen et al.¹³ reported immobility as a factor in increasing pain. The conclusions by Turk et al.⁴ and Schwartz et al.⁵⁴ contradict those of other studies^{5-8,13,16} in which fatigue, pain and musculoskeletal impairments led to functional loss.

In 2004, Jahnsen et al.¹³ suggested that when Norwegian adults with CP experienced too high an impact of pain on their daily lives, they tended to change their lifestyle by reducing work hours and beginning to use a wheelchair or other compensatory technical devices. They also applied for more home services. Even though these changes may minimize the pain, they can be perceived as a “defeat”, causing psychological distress^{8,13,33} due to activity and participation restrictions.

Engel and colleagues⁵⁷ interviewed adults with CP (mean age = 38, range = 18-76 years) who had participated also in one of their earlier studies.⁵⁴ In this prospective exploratory study, the authors conducted face-to-face interviews using standardized questionnaires to assess pain experiences, the interference of pain on activities, depressive symptoms, and coping strategies used for pain. Similarities and differences in coping strategies were identified between non-disabled persons with chronic pain and people with CP experiencing chronic pain. Mean scores were compared for the Chronic Strategies Questionnaire (CSQ)⁵⁸ and Chronic Pain Coping Inventory (CPCI)⁵⁹ among two other groups of persons with chronic pain^{59,60} and a group of people with CP experiencing chronic pain⁵⁴ (n = 50, mean age = 36.62, women = 48%). These two other groups consisted of individuals experiencing chronic pain⁵⁹ (n = 78, mean age = 42,

women = 56%) and another group of patients with fibromyalgia⁶⁰ (n= 122, mean age = 52, women = 89%). People with CP tended to use cognitive strategies, such as attention diversions (persisting in tasks), reinterpreting pain sensations, and using prayer/hope to cope with pain rather than physical coping strategies, such as rest or guarding (a physical maneuver to guard against pain). In contrast, able-bodied persons with chronic pain employed more physical coping strategies. Because many of the participants with CP were immobile, the need to rest for pain was a lesser factor than for able-bodied persons who were independent and mobile. The same was true for the use of guarding. The need to guard for pain is limited in persons with disabilities because splints, orthoses and/or wheelchair support may actually prevent postural guarding and restrict movement.⁵⁷

One potential bias in this study was the difference in ambulatory status among the groups. Most in the group with CP were non-ambulatory (94%). This immobility plus a flexible daily routine for the group with CP (versus the comparison group) may have biased the results. High proportions of participants were Caucasian, which may limit generalizability of the results, and the small group of CP participants may not have been representative of all people with CP who experience chronic pain.

Using the same sample as in the previous study,⁵⁷ Jensen et al.⁶¹ examined the experience of pain in adults with CP, change in frequency of use of pain treatments over time, and the association between the use of pain treatment and changes in pain intensity.⁶¹ The adults with CP participating in the study were interviewed five times over 2 years at 6-month intervals. No significant change in pain intensity over the 2-year period was found, although there was an increase in the use of pain treatments between the first and second interviews. However many participants reported moderate relief from

the pain treatments used.⁶¹ These results suggest that adults with CP may not be aware of the availability of possible helpful pain treatments. Adults with CP may benefit from further assessments of their pain experiences so that appropriate pain treatments can be made available.

In 2002, Dudgeon and colleagues²¹ published a qualitative study investigating how people with disability experience pain. Phenomenological methods enabled the researchers to conceptualize the experiences of the participants, using the participants as a source of understanding rather than as subjects being studied. In-depth interviews were conducted with nine participants (three with CP, three with spinal cord injury [SCI] and three with leg amputations; age range = 26 to 55 years) who were asked to describe their experiences of pain and the impact of pain on their ADL, how they managed daily living, and their lifestyles and relationships with others (including health care providers).²¹ Three themes emerged from participants' descriptions of pain experiences: 1) pain as plural (experienced in multiple locations and some predictable and not unpredictable), 2) pain as a mystery (unclear causes and consequences), and 3) pain as personal (difficult to communicate about pain with family, friends and health care providers). Similar to the findings by Engel et al.,⁵⁷ the participants of Dudgeon and colleagues²¹ often used cognitive behaviors to cope with chronic pain, thereby raising important issues as to how pain assessment and intervention are addressed in people with physical disabilities. Even though Schwartz et al.⁵⁴ and Turk et al.⁴ reported little interference of pain on ADL, others have suggested that investigating the impact of pain on the psychological state of adults with CP may be warranted.^{13,21,56} A limitation of the Dudgeon et al.²¹ study was lack of information about the researchers' assumptions and biases.

2.3.2 Fatigue

Based on responses to a mailed, multidimensional survey of 406 Norwegian adults with CP, Jahnsen and colleagues⁸ examined the prevalence of perceived fatigue in comparison to the general Norwegian population. Persons 18 years or older diagnosed with CP and living in Norway were included. The exclusion criterion was intellectual disabilities as documented in medical records. Using linear regression analysis, results of this retrospective study⁸ showed the association of chronic ($p = 0.033$) and substantial fatigue ($p = 0.044$) were significantly related to level of physical function on the SF-36.⁶² The mean scores for total fatigue (13 vs. 12.2) and physical fatigue (8.7 vs. 7.9) were significantly higher in adults with CP as compared to the general Norwegian population ($p < 0.001$).⁸ Scores for mental fatigue did not differ between the two groups.

In this survey's results,⁸ the prevalence of fatigue was greater in the group with mild motor disabilities, suggesting that fatigue symptoms result from a certain level of activity, i.e., the group with CP that had more severe motor impairments may have had less opportunity to become fatigued. The group of adults with mild motor impairment may have had to work harder to keep up with the able-bodied population and therefore became fatigued from that extra effort. Whereas the average adult with CP in this study⁸ was 34 (age range: 18 to 72 years), the average age of the general Norwegian population studied⁶³ was 45 (age range 19 to 80 years). This suggests that not only is fatigue a significant problem for adults with CP but it appears at a much earlier age than in the general population. In a univariate linear regression analysis, significant associations ($p < 0.001$) were shown between fatigue and bodily pain, fatigue limitations in physical role

function and emotional role function, fatigue and deterioration of functional skills, and fatigue and lowered life-satisfaction.⁸

One potential limitation of this study is recall bias. Respondents were asked to compare their current fatigue symptoms to when they were last feeling well. This may present a memory problem if respondents had been experiencing fatigue over many years.⁸ Others have reported that persons with CP consume three to five times as much energy (O_2 rate and O_2 cost) during walking than persons without CP.^{15,17}

The Rehabilitation Research and Training Center on Aging with a Disability (RRTC)⁶⁴ reported that the prevalence of fatigue ranged from 62% to 78% in a sample of 1000 persons with CP, rheumatoid arthritis or SCI,⁶⁵ whereas it ranged from 15% to 20% in the general population.⁶⁶ In the RRTC report, 25% of respondents with CP reported fatigue to be a problem by age 35, 50% by age 40 and 75% by age 50.⁶⁵

Pimm hypothesized that adults with CP suffer physiological burnout from systems that are continuously stressed and working near maximal output.¹⁷ Over time, their systems become overburdened and, as a consequence, physical functioning declines. Pimm's¹⁷ hypothesis concurs with the RRTC findings that people with disabilities age 1.5% per year faster than non-disabled people, a direct result of the amount of energy a person with disability expends to carry out their normal ADL.⁶⁵ The articles cited^{8,15,17} suggested the need for further clinical research and follow-up programs for adults with CP that look at balancing personal resources with challenges in daily life.

2.3.3 Musculoskeletal System Complications and Mobility Impairments

In 1995, Murphy et al.⁹ published a study involving 101 adults with CP (53 male, 48 female; aged 19 to 74 years) recruited from those who made contact with the United

Cerebral Palsy Association Affiliate of Alameda-Contra Costa counties in California. Information was gathered about their general health and rehabilitation needs. All participants in this non-random sample lived in the community. Additional bias may have been created by the fact that participants lived in an advantaged area (San Francisco/Oakland) that includes university campuses accessible to people with disabilities, a public transit system and virtually year-round pleasant weather that may contribute to a comfortable lifestyle. In this prospective exploratory study, information was obtained through detailed medical history and physical examinations with emphasis on the musculoskeletal system.

Although acute illnesses were appropriately managed, there appeared to be an absence of preventive medical care compared to that available for an age-matched, able-bodied population.⁹ Attempts to provide preventive care for this population may require greater sensitivity and education of physicians and their staff and include significant modification of examination rooms, tables, equipment and consultation times.⁹ In a later study using the same sample, Murphy et al. reported that adults with CP wished their physicians knew more about this disability.⁶⁷

Musculoskeletal complications included contractures, scoliosis and hip dislocations, conditions found almost exclusively in non-ambulatory individuals with severe physical disabilities.⁹ Other musculoskeletal symptoms and complications were related to physical strain, biomechanical abnormalities and compensatory functional overuse. Cervical spine pain, back pain, pain in the weight-bearing joints and hand paresthesias were reported more frequently in those with CP under age 50 than would be experienced in same-aged, able-bodied persons.⁹

Twenty-six of the participants who were ambulatory as children ceased walking in adulthood, with about 70% stopping by age 25.⁹ Reasons cited were fatigue, feelings of inadequacy and less efficiency in their walking abilities combined with the view that wheelchair mobility offered greater access to a broader range of functional activities. Persistent pain was also cited as a reason for giving up walking. The remainder of the formerly ambulatory participants ceased walking at about 45 years of age, which may have been due to frequent reports of hip and knee pain occurring at around age 40.

Fracture incidence was higher in adults with CP as compared to able-bodied persons matched for sex and age, reflecting increased risks associated with difficulties in balance, gait and mobility as well as disuse osteoporosis. It is difficult to compare a cohort of people with CP to the normal population. Recruitment for the study may not have represented the general population of adults with CP. Although independent living opportunities in this geographic area may represent another bias, results of this study provide some insight into the medical and rehabilitation needs of adults with CP as well as identifying some conditions with which they have to cope.

In examining the progress of 72 individuals with CP (age range = 19 to 65 years) from childhood to adulthood, Bottos and colleagues⁷ collected comprehensive data via case notes and direct assessment of participants from three rehabilitation units in Italy.⁷ This was not a random sample, which may present unexplained bias, i.e., data from participants in rehabilitation centers may not represent adults in the general CP population. Findings from this 2001 prospective exploratory study can be summarized as follows: 1) once individuals reached adulthood, contact with health and rehabilitation services decreased drastically; 2) participants who were integrated into mainstream

schools achieved and maintained literacy better than those who attended special schools; and 3) once into adulthood, motor performance deteriorated in a high number of participants. Of the 40% of participants who had once walked, 16% lost their ability to walk between ages 20 and 40. In those who continued to walk, ability deteriorated in terms of distance.⁷ Mechanisms used by people with CP to continue to walk independently may actually provoke loss of function due to extensive and distorted use of joints which may eventually lead to pain.⁷ As in several other studies,^{9,15-18} the authors concluded that the cumulative stress of repetitive movements and altered body mechanics that accompany physical disabilities often accelerate or intensify the aging process.⁷

It is difficult to compare the results of these two studies because participants from the Italian cohort were from three rehabilitation units with a mean age of 33 years⁷ versus a community-based California sample⁹ with a mean age of 42.6 years. However, in both studies,^{7,9} the authors recommended that services for individuals with CP be planned based on a lifespan approach rather than a child-focused approach.

In a 2001 study involving 221 Swedish adults with CP (age range = 20-58 years), Andersson and Mattsson⁵ examined walking ability and other forms of locomotion. Inclusion criteria were: 1) CP diagnosis; 2) no documented intellectual disability; 3) living in the county of Stockholm and 4) born before 1979. This retrospective study was based on mailed questionnaires that gathered subjective opinions about physical condition and training, with emphasis on locomotion. In this non-random sample, recruitment occurred from medical records of the county archives, various local disability organizations, government departments and hospitals. Most participants lived in their own apartments and only 13% lived with their parents. Of the three categories of CP

participants in the study, spastic diplegia was most frequently reported (35%), followed by dyskinetic CP (22%) and spastic hemiplegia (21%).⁵

Andersson and Mattsson's⁵ sample distribution of types of CP was similar to that of Turk et al.⁵⁵ whereas Murphy and colleagues'⁹ participants had a higher frequency of dyskinetic CP. In Andersson and Mattsson's sample, 64% could ambulate with or without aids but some could walk inside only.⁵ Many in the diplegia group reported that their walking ability had decreased between ages 15 and 34, with 9% reporting a complete loss of walking ability before age 35. Their results suggested also that adults with CP often gain weight from being less mobile, which may contribute also to diminished walking ability. Some participants reported that regular physical training improved their walking ability. The dyskinesia group appeared to experience a decrease in their walking ability later (after age 35) than the diplegia group.

Andersson and Mattsson's⁵ findings agree with those of other researchers,^{7,9,12,14,18,55} i.e., adults with CP experience increased musculoskeletal problems due to joint contractures in knees, hips, and elbows, as well as frequent pain in muscles, joints and other body parts. Walking ability is not necessary for ADL but, for individuals who have been ambulatory, a decrease or cessation in walking ability may be a stressor that affects their sense of well-being. Loss of walking ability may cause limitations in their usual activities as well as creating participation restrictions. Additional stress may be caused by a change in how adults with CP are used to functioning in daily life.

Jahnsen et al.'s 2004 study¹⁴ on self-reported locomotion skills was built on the questionnaire developed by Andersson and Mattsson.⁵ Jahnsen et al. reported changes in the ability to walk in adults with CP. Deterioration of walking ability was significantly

associated with older age.¹⁴ Seventy percent of participants 45 years or older experienced deterioration in their walking ability compared to only 20% of participants younger than 25. Self-reported causes of walking deterioration were pain, fatigue and lack of physical activity. These results concur with those of other studies^{5,7,9,12} in which age was reported to be a factor in change of locomotion skills in adults with CP.

In a 2004 Swedish study, Sandstrom et al.¹⁹ investigated the function and health of a sample of adults with CP by using the Gross Motor Function Classification System (GMFCS). The GMFCS consists of five levels and has been judged as valid and reliable for use in children,¹⁹ and reliable for use in adults with CP.^{12,68} Sandstrom et al.'s aim was to investigate the ability of the GMFCS to identify change in functional ability from adolescence to adulthood, to describe functioning and general health of an adult sample with CP and to investigate the use of the GMFCS in relation to general health, personal activities, motor function and musculoskeletal variables.¹⁹

A cohort of 199 adults (20 years or older) with a CP diagnosis living in a Swedish county were identified retrospectively through medical records from pediatric rehabilitation centers.¹⁹ Forty-eight persons were strategically selected to undergo structured interviews and functional assessments based on age and GMFCS levels noted in their medical records. No significant difference was found between the group studied and the cohort as a whole.¹⁹ One-third of those examined underwent a reclassification of GMFCS level as a result of re-assessment in adulthood. Their deterioration in function concurs with results of other studies.^{5-7,9,12,14,15,18,65,68}

In a 2004 prospective longitudinal study, Strauss and colleagues¹⁸ examined the pattern of functional abilities and decline of skills in adults with CP. The sample was

obtained from the database of persons with disabilities who receive financial services from the state of California and thus may not represent the general adult population with CP. Participants were divided into three different age cohorts and evaluated annually for 15 years. The sample included 8733 persons with CP at age 20 years, 5169 persons with CP at age 40, and 904 persons with CP aged 60 years. Most people with CP eventually declined in gross motor function, consistent with other study findings.^{6,7,9,12,14,15,18,65,68} Strauss and colleagues'¹⁸ study appears to be the first to examine functional patterns of a large sample of adults with CP over a long period of time.

Ando and Ueda⁶ examined functional deterioration in adults with CP working at community workshops throughout Japan. This 2001 study involved: 1) analysis of responses to a survey mailed to 686 individuals; 2) physical examination by a physician for 163 of the participants; and 3) 5-year follow-up of 122 subjects examined by physicians. Approximately 35% of respondents reported overall deterioration in their ability to participate in daily activities.⁶ Deterioration was higher among those with involuntary movements of the head and neck and abnormal movement patterns during walking. Because this study involved participants from community workshops, conditions that affected workers' postures, such as design of workbenches and tools, may have contributed to functional deterioration over time.⁶ A limitation of this study is that it involved only participants who worked at community workshops; thus the conclusions may not apply to all adults with CP.

In summary, the previous studies have indicated that adults with CP experience many secondary impairments and complications in connection to their musculoskeletal system. Pain and fatigue are major contributors to their loss of function. The studies

primarily described the problems adults with CP are experiencing but did not provide information as to how adults with CP are coping with their losses in functioning.

2.4 Psychosocial Aspects of Aging with Cerebral Palsy

In considering the social model of disability, it is important to include studies of the psychological aspects of aging with CP. The social model views disability not as “an attribute of an individual but rather a complex collection of conditions, activities and relationships, many of which are created by the social environment.”^{69 (p.1173)} The following studies will address needs for social support, issues affecting morale, self-efficacy, health attitudes, employment and SOC in adults aging with CP.

A qualitative study by King and colleagues²³ examined the desires and life goals of older adolescents with CP who were at the transition between high school and further education or who were entering the job world. The study involved seven females and three males from 18-20 years of age. Five were nearing the end of high school, two had recently graduated and three had just begun college or university. They were asked what success in life meant to them and what factors they felt helped or hindered them in being successful. The psychosocial theme that emerged was that “success means being happy”; the three factors related to that success were 1) being believed in by others, 2) believing in yourself, and 3) being accepted by others. The findings of this study suggest the need for health service providers to focus on outcomes related to social support, self acceptance and acceptance by others.²³ In another qualitative study,²⁴ King and colleagues examined 15 adults with chronic disabilities (CP, spinal bifida or attention disorder) at turning points in life to find out the nature and meaning of their social support systems. The study revealed that social supports played a significant role in

adaptation of individuals with disabilities to challenging events and experiences.²⁴ The study described three types of support: 1) emotional support (making people feel better about themselves); 2) instrumental support (tools and strategies to address their issues); and 3) cognitive support (being understood - helped them to feel not alone in facing situations and experiences).²⁴ The small samples and qualitative nature of both of King and colleagues' studies limits the generalizability of these results. Nonetheless, each study provides insights into the social needs of adults with CP.

The subjective well-being of 81 adults with CP (age range 26-51 years; mode of locomotion: 39 with independent gait, 20 used crutches for gait, and 22 used a wheelchair) was evaluated using the Philadelphia Geriatric Center Morale Scale (PGC Morale Scale) in a 2001 study by Furukawa and colleagues.⁷⁰ Questionnaires were mailed to former patients of the Philadelphia Geriatric Center with a 47.3% response rate. Results were as follows: 1) former patients with CP who were dependent (requiring help in daily life) scored lower (51% vs. 64%, $p < 0.05$) on the PGC Morale Scale than those who were independent of help; 2) former patients whose physical health was deteriorating due to senile weakness (estimated by rate of appearance of falling stamina or the ability to sustain falling), pain and gait disorders, scored lower than those without the appearance of these symptoms; and 3) the convenience of social environment ($p < 0.05$) and opportunity to go out ($p < 0.01$) positively influenced the subjective well-being of the former patients being studied.

The authors reported that patients scored significantly lower on the PGC Morale Scale with the appearance of senile weakness than those without senile weakness: falling stamina (52% vs. 70%, $p < 0.01$), pain (52% vs. 76%, $p < 0.01$), and gait disorder (58% vs.

64%, $p < 0.05$). Results suggest that the patients with CP were upset when their physical conditions led to limitations of activities and participation restrictions affecting their lifestyle.⁷⁰ The fact that all the participants were recruited from only one center and represented only two types of CP (spastic and athetoid) is a potential study limitation.

Further insights into understanding the experience of aging with a disability were reported in a 2004 qualitative study of women with physical disabilities by Goodwin and Compton.²² In a hermeneutic phenomenological study of six women's experiences of physical activity and aging with a disability, the disabilities included CP ($n = 2$), acquired brain injury ($n = 1$) and SCI ($n = 3$), with ages ranging from 22-37 years. Three themes emerged from the data analysis: 1) experiencing something normal; 2) loss of physical freedom; and 3) maintaining function through physical activity. Aging was expressed as something the women recognized as a normal process. Loss of function, fear of the unknown, and fear of secondary disabilities were perceived threats to these women's physical freedom. The women revealed how important independence was to their quality of life.²² They expressed how their "sense of happiness, freedom and autonomy were all linked to using their body in ways that contributed to their sense of self. Learning, mastering and maintaining independence in their lives was of primary concern."²² (p131) Physical activities were reported as important for maintaining hard-earned lifestyles and levels of physical functioning²² which corresponds with the findings of other studies.^{5,71,72}

In 1992, Whiteneck and colleagues⁷³ noted that people with physical disabilities commonly experience problems associated with aging 10-20 years earlier than persons without disabilities. The mean age (28 years) of the women in the study by Goodwin and Compton²² supports the notion that persons with disabilities may physiologically age

sooner than persons without disabilities, i.e., unexpected changes in functional ability will occur between ages 30 and 50 in people with disabilities.^{73,74} However, given that Goodwin and Compton's sample was small and included only two women with CP, their results are not representative of the entire adult population with CP but do provide information that may apply to the population of adults with CP?

Similarly, in Sweden, Sandstrom examined how adults with CP experience living with a disability and how they manage everyday life.²⁵ The sample included 22 community-living adults ranging from age 35 to 68 years. The author reported two main themes: 1) perceptions of living with a disability that included i) perceptions of a disappearing body, ii) perceptions of a not-appearing body, iii) perceptions of difference, iv) perceptions of being in-between, v) perceptions of normality, vi) perceptions of restricted autonomy and vii) perceptions of autonomy; 2) strategies that included- i) strategies to fight one's way, ii) strategies to plan, iii) strategies to get used to it, iv) strategies to hide and v) strategies to give one's all.²⁵ Data collected in Sandstrom's study²⁵ support some of the data in Goodwin and Compton's study.²² The perceptions of living with a disability were similar across participants in both studies. However the findings of Sandstrom's study²⁵ may be more generalizable to adults with CP than those from Goodwin and Compton's study²² because Sandstrom's sample included only adults with CP (22 adults) whereas Goodwin and Compton's sample had only two women with CP.²²

In 1995, Becker and Schaller⁷⁵ reported on a study of 28 adults with CP (age range 18-49 years) who were living in the community. To examine differences in perceptions of self-efficacy and health attitudes, this group was compared to two other groups: 1) people attending a health fair and 2) people from a statewide disability

advocacy group.⁷⁵ The perceived self-efficacy ratings for the adults with CP were most strongly related ($p < 0.05$) to the nutrition ($r = .68$) and health responsibility ($r = .64$) subscales of the Self-Rated Abilities Scale for Health Practices, followed by the exercise ($r = .50$) and psychological well-being ($r = .46$) subscales.⁷⁵ Interestingly, those who most frequently needed mechanical assistance had significantly higher ($p < 0.05$) self-efficacy perceptions than those who needed personal assistance ($r = .45$ vs. $r = .03$). In fact, the two sets of ratings were at opposite ends of the scale, suggesting that the group who needed mechanical assistance perceived themselves as more independent because they were able to operate their own assistive devices whereas the other group perceived themselves as more dependent because of their reliance on other people for assistance.⁷⁵

Becker and Schaller's⁷⁵ findings showed also that adults with CP scored lower on The Self-Rated Abilities for Health Practices,⁷⁶ especially in the areas of exercise and nutrition, than the two comparison groups. The Self-Rated Abilities scale measured the respondents' abilities to perform health behaviors that promote health. The mean exercise score for the group with CP was 12.36 compared to 19.88 for the health fair group and 16.68 for the disability advocacy group. In the area of nutrition, the group with CP also scored lower (mean = 16.14) than the health fair (mean = 22.15) and disability advocacy groups (mean = 20.59). On the Perceived Health Status Scale, 75% of the group with CP rated their health as good or excellent, which corresponds with findings by Turk et al.,⁵⁵ suggesting that adults with CP perceive themselves as healthy despite their physical impairments. In other words, the CP group perceived their health as separate from their physical impairments.

On the Perceived General Self-Efficacy Scale (measuring beliefs regarding personal abilities to affect outcomes), the average rating of the CP group's perceived ability to perform exercises was much lower than their perceived ability to carry out other health promoting behaviors, (i.e., health responsibility, nutrition, and psychological well-being). These ratings may suggest a need for rehabilitation professionals to facilitate feasible ways for adults with CP to exercise. Other comments by the participants with CP indicated that there are many barriers (e.g., lack of wheelchair accessibility, lack of dentists that specialize in treating persons with CP) that individuals with severe disabilities encounter when they attempt to take care of their health.

It is difficult to generalize these results due to the small convenience sample drawn from one geographic area. Another potential bias was the fact that a number of the questionnaires were completed by someone other than the individual with the disability. Nevertheless, the results provide knowledge of the perceptions that adults with CP have of their health and their abilities to take care of their health. These results provide insight also into the needs of adults with CP and may be beneficial to rehabilitation professionals working with these adults in advising them how to take care of their health as they age.

In a 2006 study, Mitchell and colleagues used a cross-sectional design to investigate the role of both aging and disability on employment status over the lifespan.⁷⁷ Current employment rates were compared between 262 people with disabilities and 115 people without disabilities. The group with disabilities included five different impairment groups: polio (n = 60), CP (n = 60), SCI (n = 59), rheumatoid arthritis (n = 32), stroke (n = 20), and an "other" group (n = 20), i.e., musculoskeletal system, peripheral nervous system, and central nervous system disorders. Mean ages for those with and without

disabilities were 48.9 years (SD=10.7) and 45.8 years (SD=11.7) and mean educational levels were 14.2 years (SD = 3.4) for those with disabilities and 15.9 years (SD = 2.5) for the group without disabilities. The group with disabilities consisted of 61% women versus 75% in the group without disabilities. Using chi-square analyses, there was a significant difference in employment rates for the group with disabilities in relation to having some college education versus those with high school education or less ($p \leq 0.001$). However, for the group without disabilities, college education versus high school education made little difference in employment rates ($p = 0.29$).⁷⁷ Within the group with disabilities, those who had some college education reported a 49% employment rate versus 23% for those with high school or less. There was no significant difference in relation to education and employment rates in the group without disabilities. Within the group with disabilities, employment rate changed significantly over time for the college-educated group ($p \leq .01$) but not for the non-college educated group ($p = .425$).

The group with disabilities reported faster and earlier declines in employment than the group without disabilities. By their 60s, the group with disabilities reported 50% reduction in employment versus 35% in the group without disabilities. The decline began around the 40s age-decade in the group of people with disabilities versus the 50s and 60s age-decades in the group without disabilities.

These results suggest the need for adjustments in the workplace to accommodate for changes experienced by adults with CP during their 40s and later. Workplace accommodations may help to offset early employment loss in people with disabilities. The study also suggested the need for professionals involved in vocational rehabilitation to plan the employment needs and accommodations of individuals with disabilities

throughout their lifespan.⁷⁷ These results concur with the findings of Ando and Ueda⁶ that suggested the need to look at conditions in the workplace that may contribute to functional changes and early employment loss.

A limitation of Mitchell et al.'s study was the failure to include other age-related variables (i.e., age of onset of impairment, duration of impairment and cohort effect) in the analysis. Another limitation is the heterogeneity of impairments in the sample with disabilities.⁷⁷ Even though the group with disabilities included people with impairments other than CP (in addition to those with CP), the data provide information that may be valuable for adults with CP in maintaining long-term employment.

In a 2002 Norwegian study,³³ Jahnsen et al. used the same sample as in their study of fatigue.⁸ In this more recent study, SOC in adults with CP was compared to SOC in the general population.³³ Because no normative Norwegian data on SOC were available, normative data from a Swedish study on SOC were used.³³ A multidimensional questionnaire was sent to a representative sample of adults with CP.³³ The survey results were compared with results from a reference group of Swedish people within the general population.⁷⁸

Participants included persons over age 18 years with CP, but without intellectual disabilities. The response rate was as expected, considering the functional status of the CP population; 406 of 766 eligible persons responded (53%). The gender distribution was 48.5% female and 51.5 % male; age range = 18-72 years (mean = 34 years). Nearly half the respondents needed help completing the questionnaire, which took from 15 minutes to 8 hours.

Jahnsen and colleagues' results showed that Norwegian adults with CP had a lower SOC than that in the general Swedish population⁷⁸ in all three domains: manageability (36% vs. 36.6%), meaningfulness (52% vs. 60.5%), and especially in comprehensibility (43.9% vs. 71.5%).³³ In determining factors that might relate to SOC, socio-demographic and diagnostic variables (i.e., education, marital status, deterioration of functional skills, pain, fatigue, grade of disability and life satisfaction) were investigated as well as gender, age and employment. Based on univariate and multiple logistic regression analysis, results showed that the most important predictive factors of low SOC were educational level ($p < 0.001$), marital status ($p = 0.01$), life satisfaction ($p < 0.001$) and fatigue ($p < 0.001$), whereas gender, age, employment, pain and grade of disability were less important.³³ The variable "sense of coherence" (SOC) differed with age but the difference was not statistically significant.

One potential bias in this study was that nearly half the respondents needed help in completing the questionnaire and the time to complete was extremely long for some respondents. However the data showing that adults with CP experience life as less manageable, less meaningful and especially unpredictable and incomprehensible suggest the need for adult rehabilitation or social programs that include essential aspects of SOC in the socialization process in order to enhance their coping potential.³³

The foregoing studies have reported on some of the psychosocial issues of concern to adults aging with CP, such as the need for social support, self-acceptance, acceptance by others; the need for health care providers to be sensitive to the challenges of adults aging with CP when advising them of health behavior; the concern of adults with CP about physical deterioration that may lead to limitations in their activities and

participation restrictions affecting their lifestyles; the need for accommodations in the workplace and the environment; and their sense of coherence.

2.5 Summary

Given the various secondary health conditions experienced by adults with CP, it seemed prudent to explore the coping strategies that these adults use. Coping is defined as thoughts and behaviors used by people to deal with the demands of internal and external situations that they assess as stressful.²⁷ Antonovsky's³² concept of SOC is one approach to investigate a means for understanding the relationships that exist among stressors, coping and health. His model attempts to explain why certain people preserve health and well-being while still being able to cope with very difficult life stressors. Many of the studies reviewed have revealed that secondary conditions, such as pain, fatigue, and musculoskeletal impairments, were not anticipated in adults with CP and appropriate or adequate resources needed to cope have not been available. Previous research suggests that a lack of contact with health services by adults with CP may result in deterioration in their quality of life. Several studies in this review concluded that adults with CP need greater knowledge and understanding to enhance their decision-making processes about their health.^{22,33,67,75} The information obtained may also provide knowledge to health care providers who care for adults with CP so that they better understand how health can be preserved during the aging process.

The main limitations of the studies cited in this chapter were that most involved small samples, selection was not random and the cohorts were not homogeneous. Even though most of the study samples were small and not necessarily representative of the population of adults with CP as a whole, they do provide some insights into the health

and rehabilitation needs of this population. These findings may, in the future, advance some theories in approaching the needs of adults aging with CP.

CHAPTER 3

3.1 Methodology

The purpose of this chapter is to explain the methodological background for this study, to justify the rationale and the design of the study, to address issues of rigor and to describe the research process, data collection and analysis.

3.1.1 Qualitative Research Background

As a field of inquiry that crosses multiple disciplines, fields, and subject matters,⁷⁹ qualitative research is an umbrella term encompassing many different approaches and traditions.⁸⁰ Qualitative research is often described, and justified, by contrasting it to quantitative research, another established and accepted approach to research. As a word, “qualitative” implies an importance of the quality of entries on processes and meanings that are not experimentally examined or measured in terms of quantity, amount, intensity or frequency.⁷⁹ Rather than testing existing theories or hypotheses, qualitative research is aimed at producing descriptions and explanations of particular phenomena or experiences from the perspective of the individuals being studied.⁸¹ According to Denzin and Lincoln: “Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry.... They seek answers to questions that stress how social experience is created and given meaning”.^{79 (p.13)} The quality of the research depends on the quality of entries and the process used by the researcher to capture the meaning of the experiences of the phenomenon being studied.

There are a number of different approaches to qualitative research that are viewed and evaluated by different criteria, yet there are common characteristics among the various approaches. Phenomenology, the method used in this study, was developed about 100 years ago by philosopher Edmund Husserl who struggled with the experience that science was preoccupied with explaining natural objects or events but that the understandable meaning of those objects or events were taken for granted and given little consideration within the framework of natural science.⁸²

American phenomenologist, Amedeo Giorgi, explained four distinctive features of qualitative science to engender it as phenomenological in a descriptive, Husserlian sense.⁸³ First, Giorgi described consciousness as “the medium of access to whatever is given to awareness”,^{83 (p.2)} because consciousness has a presence whether one acknowledges it or not. Nothing can be spoken about or referred to without consciousness being implicitly included in whatever is presented to awareness.⁸³ What Giorgi was saying is that once a person brings something into their awareness, consciousness is automatically present. Secondly, he defined experience as consciousness’ presentation of objects to the self. In other words, the focus of human science is not so much on the real character of the object but instead on how such objects are perceived or what they mean.⁸³ Thirdly, a “phenomenon” in phenomenology means the presence of any given (object) exactly as it is given or experienced by the self.⁸³ In analysis of a phenomenon, the focus is always on the meaning of the object precisely as given, rather than trying to relate the phenomenon to an “objective meaning”.⁸³ Fourth, according to Husserl,⁸⁴ intentionality is the essential feature of consciousness, implying that consciousness does not exist by itself, but is always directed toward something.⁸³ As Giorgi stated: “To say the intentionality is the essence of consciousness thus means that consciousness is

intrinsically relational--open to that which is not consciousness itself, but also to itself".^{83(p.3)} Object and subject are two separate entities: "the very meaning of subject implies a relationship to an object, and to be an object intrinsically implies being related to subjectivity."^{83 (p.3)} According to Giorgi, consciousness always has a presence and, in phenomenology, focuses on how the object is perceived or what it means, rather than its real objective character.⁸³ The focus of analysis in phenomenology is on the meaning of an object precisely as it is presented rather than its objective reality. By its very nature, consciousness is relational because when a person is conscious, he or she is always conscious to something.

While Husserl is considered the father of phenomenology, philosopher Martin Heidegger advanced the science by developing phenomenological hermeneutics. For clarification, descriptive phenomenology is juxtaposed with hermeneutics below.

According to Bergum, phenomenological hermeneutic research is a human science that strives to "interpret and understand" rather than to "observe and explain", the latter being more the focus of natural science.⁸⁵ Husserlian phenomenology has to do with the *description* of experience, whereas Heideggerian phenomenology has to do with the *interpretation* of experience.⁸⁵ To present the perspective of participants in the study of a phenomenon, Husserlian phenomenology claims that descriptive analysis can be done effectively so findings are solidly based and less dependent on assumptive, hypothetical or theoretical factors.⁸⁶ Descriptive researchers derive meaning from the data and argue against any need to go beyond the data, claiming that the evidence is sustained in the data.

3.1.2 Rationale for Phenomenological Research

In developing a phenomenological framework to support an exploration of how adults with CP cope with their aging process, Husserlian descriptive phenomenology seems more suited than Heideggerian interpretative phenomenology, even though, according to Stubblefield and Murray, “both approaches support the development of understanding of what the experience means to persons living within it.”^{86p.(150)} Interpretive phenomenology requires reinterpretation of one’s prejudgments or presuppositions in view of the data present in a given study.⁸⁶ Descriptive phenomenology, however, asks for the suspension or bracketing of the researcher’s own presuppositions of reality so as to hear and understand more clearly the reality of others (those individuals being studied).⁸⁶

The descriptive approach seemed well-suited to developing an understanding of the unique, lived experience of adults growing older with CP. Descriptive phenomenological study discovers and explores the depth and richness of the lived experiences in a person’s everyday life and the meanings of those experiences. As described by Giorgi, the key point of the descriptive methodological approach to human science is that one describes what is present precisely as it presents itself, neither adding nor subtracting from it.⁸⁷ The researcher attempts to let the data speak for themselves, while bracketing or suspending past knowledge about the phenomenon being experienced.

Therefore, this study encouraged adults with CP to describe their own aging process and their experiences in coping with age-related changes in their functional abilities. This approach captured an authentic presentation of the participants’

experiences with getting older because it presented their descriptions as they themselves articulated them. The researcher sought meanings in their descriptions as presented in the data rather than interpreting the data for the meanings.

Descriptive phenomenology was chosen over alternative qualitative methods because the researcher was most interested in giving voice to adults growing older with CP and their experiences of coping with changes in their functional abilities. A phenomenological approach presented the perspective of the experience of getting older with CP by adults with CP as they themselves experienced it, giving meaning to their everyday lived experience.

3.2 Rigor

Qualitative research has been criticized by empirical researchers for its lack of control over validity and reliability of the findings.⁸⁸ Mays and Pope explained that all research involves subjective perspectives and that different methods produce different perspectives: “The philosophy of qualitative and quantitative researchers should be one of ‘subtle reality’ - an attempt to represent that reality rather than to attain ‘the truth.’”^{89(p51)} From this stance, it is possible to assess the different perspectives offered by different research processes and compare quality criteria common to both.⁸⁹ However there may be a need to modify the means of assessment to account for the different goals of qualitative research.⁸⁹ As a result, attention has shifted more to concerns of trustworthiness.

The following criteria were used in this study to ensure trustworthiness, even though the criteria require some judgment to be exercised by both the researcher and the reader. The first criterion is triangulation, which compares the results of two or more

different methods of data collection (interviews, field notes, memos, observation) by looking for patterns of convergence to develop or corroborate the overall interpretation.⁸⁹ Controversy exists over whether or not triangulation assures validity because interpretive research often focuses on the context through which alternative meanings are derived. Triangulation is just as likely to result in inconsistent or contradictory evidence as in convergent findings.⁸⁹ Therefore “triangulation is seen more as a way of ensuring comprehensiveness and encouraging a more reflexive analysis of the data than a pure test of validity.”^{89 (p.51)} Triangulation was carried out through the following methods: 1) interviews of the participants, 2) field notes on my observations of the interviews (i.e., setting, description of participants, nonverbal gestures and expressions), 3) memos (my reflexive process of the interview), 4) member checking, 5) use of negative cases and 6) by checking the relevant literature. As part of my data analysis, I used and compared the data received from the interviews with my notes and memos. In developing themes, I looked to see how the data from other sources converged or corroborated with the overall interpretation. I also incorporated data that were not necessarily in consensus with the overall experience of the participants, yet often these negative cases added to the richness of the explanations provided by the participants.

The second criterion is respondent validation or member checking, which is the process of returning analyses to the participant for confirmation that their experiences were reflected in the analysis.⁸⁹ There are criticisms of this strategy as well because sometimes the interview process may have influenced a change in the participant’s original assessment of what is being studied or new experiences may have occurred and the participants may disagree with the researcher’s interpretations.⁹⁰ The problem with respondent validation lies in the perspective that there is one fixed reality instead of an

understanding that meanings are co-created through dialogue.⁹⁰ Respondents' validation is best seen as a process of error reduction which may encourage an ongoing process that may lead to further data which in turn require interpretation.⁸⁹ Upon completing the thematic analysis, I sent a brief summary of the themes to the participants to confirm whether the themes reflected their experiences. I received responses from seven of the 12 participants. All seven participants responded favorably to the findings. I provide a more extensive report of participants' feedback in Chapter 4.

The third criterion is to present a clear account of the process of data collection and analysis, often referred to as an audit trail. An audit trail clearly documents the process or system used by the researcher in his/her decisions, choices and insights. As the researcher, I wrote a diary account of my research process. In the applicable sections, I have explained and accounted for all decisions made throughout the interview process and data analysis. An audit trail was used to enhance confirmability and includes enough data to allow the reader to evaluate if the interpretations are adequately supported by the data.⁸⁹

The fourth criterion, reflexivity, is the means by which the researcher clarifies his or her biases in order to identify the ways in which she/he may have influenced or shaped the whole research process including the choice of topic, the research question, data collection and analysis. Personal and intellectual bias, as well as prior assumptions and experiences, all need to be stated clearly up front in the research report to enhance credibility of the findings.⁸⁹

With phenomenology, the researcher brackets his/her biases, views, and assumptions. Although reflexivity is important to the interpretive process, it does not encourage an objective, distant position. Instead, interpretative research values the

contribution of the researcher to the understanding of the topic and encourages the researcher to express how his/her original sense of the topic may have changed over the course of the research. Bergum stated the need for the researcher to keep a written record of their own transformations throughout the process.⁸⁵ According to Angen: “Interpretative research depends on the inter-subjective creation of meaning and understanding.”⁹⁰ (p.383)

I chose the topic of adults growing older with CP because I am a woman getting older with CP. It was important to suspend my personal experience of aging with CP so I was present and heard the experiences of those I interviewed. I have included a section on my reflexivity that acknowledges my own experiences, assumptions and biases from the beginning and during the research process. My reflexivity was informed by the memos I wrote of my ongoing process with the data, acknowledging the influence of the data on my own views. I recorded any changes in my views that I experienced during the data collection and analysis.

The fifth criterion uses negative cases as a way of exploring alternative explanations for data collection.⁸⁹ Negative cases are used as a means of improving the quality of explanations in qualitative research. The researcher searches for and discusses elements of the data that contradict or seem to contradict the explanations of the phenomenon being studied.⁸⁹ During the analysis, I acknowledged elements of the data that did not quite fit so as to enhance and enrich the depth of the descriptions. This process is referred to as “deviant case analysis” which helps refine the analysis until all or the majority of cases under analysis can be explained.⁸⁹

Sixth was the technique of “fair dealing” that ensures the research design clearly incorporates a wide range of different perspectives so that the standpoint of one group

does not represent the sole truth about any situation.⁸⁹ To broaden the context of perspectives that were shared by adults aging with CP, the sample included six men and six women; some participants lived in British Columbia and some lived in Alberta. The findings of this phenomenological study provide insight into the topic being studied while acknowledging that they do not necessarily represent the whole truth or the last and only words on the topic for adults aging with CP.

In my study, I applied the following seven principles of Angen:⁹⁰ 1) the researcher is ultimately responsible for choosing and creating the inquiry process; 2) the researcher must take this responsibility seriously and choose topics that are practical, relevant and beneficial to those concerned; 3) the whole research process (questions and answers) must involve the complexity of the human experience and address a shared humanity; 4) the researcher's position needs to be clearly stated; 6) the work needs to be made visible through substantive documentation and made public or the research becomes meaningless; and 7) the conclusions need to always be open to alternative broad interpretations and new possibilities. In evaluating interpretive inquiry, the objective is more about validation than validity.⁹⁰ Interpretive inquiry is about validation of people's lived experience rather than presenting a single truth.

3.3 Process for Phenomenological Research

3.3.1 Framing the Question

Phenomenological research is guided by the research question. The research questions for this study were: 1) How do adults with CP experience getting older and coping with unanticipated changes in their functional abilities? and 2) What role does sense of coherence (SOC) play in their coping strategies? The phenomenon of interest to this

researcher was coping strategies of adults getting older with CP. Participants were asked to describe their experiences of getting older and to describe any changes they were undergoing in their functional abilities. They were then asked how they were coping with these changes.

“With questions that search for understanding there can be no separation of the knowledge of the experience from the meaning of the experience.”^{85 (p.57)} Reflecting on the context of the situation is what gives understanding to the meaning of the experience.⁸⁵ We start from our own lived experience, and in order to become aware of its meaning, we have to express it. Often this awareness leads to improvements in our understanding of a phenomenon (in context of the lived experience) that is being studied.⁸² By giving voice to the lived experience of adults getting older with CP, the hope was that more understanding and insight into their experiences would be gained as to how they cope with changes in their functional abilities. The strength of this approach was the assumption that the participants’ perspectives were fundamental to the understanding of their lived experience.

3.3.2 Ethical Approval, Selection, and Recruitment

Ethics approval for this study was received from the University of British Columbia’s (UBC) Behavioral Research Ethics Board. Informed written and verbal consent were obtained prior to beginning the interviews. Participants were given a consent form (Appendix A) explaining that they were able to decline participating in any aspect of the study and could extract or remove any data they provided at any time throughout the study.

Participants for this study were selected by purposeful and convenience sampling, based on their knowledge of the phenomenon being studied. The researcher was interested in investigating the coping strategies used to deal with the changes these adults might be experiencing in their functional abilities as they grew older. Therefore, the researcher chose participants who were experiencing age-related changes in their functional abilities in order to explore the coping strategies they might be utilizing. The researcher informed administrative staff of the Cerebral Palsy Association of Alberta and the British Columbia Cerebral Palsy Association, as well as the Special Needs Coordinator of the Jewish Family Service Agency in Vancouver about the criteria for the study. They in turn distributed the letter of initial contact (approved by UBC Behavioral Research Ethics Board) (Appendix B) to candidates who qualified for the study.

According to Morse and Field, the two principal guides to qualitative sampling are appropriateness and adequacy.⁸⁸ Appropriateness is derived from those participants who can best identify and inform the theoretical requirements of the study. Adequacy involves acquiring enough data to develop a full and rich description of the phenomenon being studied. Therefore, the selection criteria were adults over 25 years of age who: 1) had been diagnosed with CP; 2) had not been diagnosed with any other chronic disability or illness but were experiencing changes in their functional abilities as they had gotten older; 3) had at least a high school diploma from a regular curriculum (not special education); and 4) were able to articulate and describe their experiences in a coherent manner during interviews by the researcher. The researcher focused on adults over age 25 because the literature^{5-7,9,18} suggests that adults with CP often begin to experience changes in their functional abilities by that age. Morse has recommended phenomenologies that are focused on the essence of experiences to include about six

participants.⁹¹ A principle of establishing an adequate sample size in qualitative research is one that is not too large so as to permit in-depth analysis which is central to qualitative research and a sample not too small so to permit new and richly textural understanding of the experience.⁹² My committee suggested a sample size of 10-12 participants in order for me to acquire enough rich data of the experience of adults with CP coping with growing older and yet not to take away from the ability to provide an in-depth analysis of this phenomenon. Sandelowski wrote that the adequacy of sample size in qualitative research is relative. It is a matter of judging whether a sample is too small or too large in accordance with the purpose of the sample and for the qualitative product.⁹² Smaller samples are recommended when one uses studies involving phenomenology because they are directed towards finding the essence of experiences and in-depth, detailed analysis is required.⁹¹ I anticipated that a sample of 12 participants would provide enough information redundancy but would not be too large to complete an in-depth detailed analysis.

Volunteer candidates from the Cerebral Palsy Association of Alberta, the British Columbia Cerebral Palsy Association, and Vancouver's Jewish Family Service Agency were interviewed as well as other participants that heard about the study through professional acquaintances familiar with the study criteria. All participants were given the letter of initial contact (Appendix B) by a third party and then contacted me on their own initiative.

3.3.3 Data Collection

Data were gathered through in-depth, semi-structured interviews in settings that were most convenient to the candidates and the researcher. All interviews were audio taped.

Open-ended questions were asked about what it was like to age with CP, with particular attention to how symptoms were experienced, how these experiences were understood, strategies used to cope with the changes, and the meaning of these experiences to them. A pilot interview was conducted to ensure that the proposed questions elicited appropriate data on the phenomenon being studied. The participant for the pilot interview was a 58-year-old man with CP interviewed at his home. My supervisory committee reviewed the transcribed interview and made suggestions to improve the interview process for further interviews. However, they all agreed that the data collected were valuable to the study. The data from this pilot interview were included in the final analyses.

I continued to collect data through semi-structured interviews with 11 other participants. Each participant was interviewed twice. The first interview lasted 60-90 minutes and the second interview 45-70 minutes. All interviews were conducted in person by me as the researcher with the exception of one participant for whom I gained permission from UBC's Behavioral Research Ethics Board to use email for the second interview due to her articulation difficulties. The second interview allowed the participants to reflect on their experiences and to clarify and validate the information provided in the first interview. The second interview also allowed participants, after reflection, to expand on aspects of the data they had provided in the first interview. Prior to the second interview, I reviewed the data from the first interview and prepared questions that helped clarify or elaborate various parts of the data. Often the mere interview process produces new insights to participants on the phenomenon being studied, which was true for a few participants in my study.

Building rapport is important in setting the stage for the interview process. I used techniques suggested by Morse and Field⁸⁸ for building rapport with the participants and

tried to create a comfortable atmosphere. I allowed the participants to choose the setting where the interview took place. Some participants chose to do the interview in their home, others chose an office at their place of employment and one participant requested meeting in a room in the researcher's home department at UBC. Ten of the interviews were done privately with just the participant and me present. One participant with speech difficulty requested that her husband be present to help translate and another participant, during his second interview, had his assistant in the same room working on a computer (she was not involved in the interview process). I was able to build a sense of trust with all of the candidates because they acknowledged that, as a middle-aged woman with CP myself, I identified with their experiences of getting older with this disability. One participant began her first interview appearing quite guarded towards me but, as the interview progressed, I was able to build trust through my sincerity. I believe I was able to create an atmosphere of safety and comfort by being sincere and empathetic. I showed genuine interest in the participants.

I began data collection by asking each participant to provide background information in order to gain a holistic perspective of their experiences. Then I asked a few probing questions (Appendix C). I allowed the participants to lead the interview as much as possible. Other questions were asked as needed to gain a richer description of how adults with CP cope with growing older. Most of the participants began speaking freely about their experience of growing older with CP. I needed to probe some participants more than others. The interviews were conducted with as few interruptions as possible so the participants felt encouraged to present their own story or experiences in their own words.

In the second interview, I used data from the first interview as a source to probe deeper into the experiences of the participants. As a result, the second interviews captured further reflections on their experiences of coping with age-related changes. I was able to gather rich data from all 12 participants. I chose not to take notes during the interview process although I did write notes as soon as possible after completion of each interview. My memos included descriptions of the participants' surroundings, my impressions, any other non-verbal cues or observations. I conducted all the interviews myself but the transcription was done by someone who had been recommended to me through a contact in the UBC School of Nursing. A verbal agreement of confidentiality between the transcriber and me was made. Alphabetical initials were used to label the transcripts as well as the use of pseudonyms within the transcripts. To ensure accuracy, I then listened to the tapes, compared them to the written transcripts and edited them to better match audio-recordings.

3.3.4 Role and Impressions of the Researcher

Researchers using a qualitative approach are interested in the different ways people make sense of events or situations that impact their lives.⁹³ In a phenomenological approach, the researcher is trying to understand the meanings people create around these situations. The goal of a qualitative approach is to understand the participants from their own 'point of view' and to interfere as little as possible on that point of view, while at the same time realizing that it is impossible to eliminate the effects of the researcher. In fact, the researcher in a qualitative approach is an active participant in the research process and does not set himself or herself outside the problem they have formulated.⁸⁵ However, it was important to identify and understand the effects of the researcher.

As a researcher who is also aging with CP, the questions I posed originated from some of my own experiences. However, using a phenomenological approach, my critical reflections helped to increase awareness of my assumptions and ideas of the research question such that I could bracket or suspend them in order to hear the participants' worldviews. As an added way of increasing my awareness of my pre-understanding, another graduate student interviewed me teasing out my experiences, assumptions and beliefs about the phenomenon being researched. Upon reading the transcribed interview, I noted any assumptions that I felt might bias the interview process. My experiences, assumptions, and beliefs are presented in a summary of the bracketing interview (Appendix D). Bracketing does not eliminate biases but brings them into awareness so that they can be judged appropriately. For example, it was important that I did not impose my experience of aging with CP but rather that I try to use my experience as a way of understanding the complexities of the participants' experiences and their perspectives on those experiences.

As a result of my reflexive process, I observed that all participants had a desire to be accepted as men and women in their own right. They did not want to be defined by their disability. They wanted to be perceived as whole human beings, like everyone else. In reviewing my own interview with the other graduate student (Appendix D), I expressed thoughts similar to those of many of the participants, e.g., I recognized that having CP is part of who I am. I agree with how one participant explained that living with CP, in many ways, shapes and forms who we are but that our own personhood goes beyond having CP. However in reflecting on my own experience, I realized that I have been socialized primarily in an able-bodied world and am not socially familiar with the disabled community. I was raised in a family that had the means to pay for private

therapy and private education so I was never dependent on or vulnerable to the support of government agencies or non-profit organizations. However, I still struggled with the perceptions of others and had discriminatory experiences. I recognized the advantages of being raised in a family with means and position but nevertheless the means and position did not entirely erase the conditions presented by my disability.

My experience of rehabilitation therapies as a child cannot help but influence my view or understanding of rehabilitation therapies. One of the participants expressed her disregard for all types of therapy, believing that “all the therapy in the world” would not change that fact that a person has CP. After the interview with her, I shared in conversation how I believed therapy had made a big difference in my life, recognizing how I was privileged to have had one therapist throughout my childhood who treated me as if I was his daughter. We continued a friendship throughout his lifetime. However, in my adult life, I sought out alternative therapies and have developed a bit of a bias against mainstream medicine as expressed in my bracketing interview (Appendix D).

My bias against ever having to use a wheelchair or powered chair was revealed in my own interview with the other graduate student. However, after interviewing the participants, I softened my views a little about possibly having to use a manual wheelchair or powered chair in the future. I realized that the decision to use a wheelchair or powered chair can be based on a need for safety and can enhance the independence of adults with CP. I have become more open to the possibility of my own need to some day use a powered chair. Those participants who shared their experiences in using powered chairs helped me realize other possibilities. In recent years, I have experienced walking on the concrete floors of large stores to be very painful and tiring. Many of these stores

offer powered chairs as a courtesy to their customers. After conducting the interviews, I am more open to the use of a powered chair when shopping.

I found myself quite amazed by the lives of the participants I interviewed. I was in awe of how they were able to create the lives they had for themselves and how positive and optimistic many of them were. Based on my own background, I asked a couple of the participants whether or not there was a spiritual component to their lives. I stated up front that that question came from my own bias because my faith and spiritual path are central to who I am and how I view the world.

The themes that developed from my data analysis may have been influenced by my experience of aging with CP. Although the data clearly lent itself to the themes presented, they were influenced also by my own experience of aging with CP. For example *Awareness, Acceptance and Action*, is a process I use in my own life. I realize that I am unable to make necessary changes until I am aware of what needs to be changed; I then need to accept what may need to be changed before I am able to take the necessary action. As an adult aging with CP, part of my motivation as the researcher was to become more aware of the conditions adults with CP experience growing older and to hear how others are coping.

I also identified with the ways the participants described experiences that enhanced their lives in the theme *Negotiating One's World*. In my experience, education, supportive relationships (family, friends, caregivers and mentors), and self-improvement initiatives (alternative therapies, support groups, education/new learning courses) have played a significant role in how I have coped with growing older with CP. I recognized the importance of including disempowering experiences as well as empowering

experiences because I understand the meaning of those disempowering experiences described by participants as I have had similar experiences.

Independence is Everything especially resonated with me because, as a person with a disability, the importance of independence from an early age was stressed by my family and health care professionals. I recognized how important it was to present how each participant defined what independence meant to them and I appreciated the variations of those experiences. My perspective of independence was enlarged by those definitions. In particular, I revered those participants whose experience of independence was not necessarily having to do everything themselves. These participants' experiences of independence affirmed what I have come to realize in my own adult life, i.e., that accepting help from others does not take away from my independence but instead, in many circumstances, enhances it.

As a woman growing older with CP (an “insider”), I identified with much of the data and understood their meanings differently, perhaps, than a researcher without CP. As previously explained, it was impossible to have my own experiences of aging with CP not enter into the research process. However, rather than influencing the data, I used my experience and knowledge of the topic to enhance both the data collection and analysis.

3.3.5 Data Analysis

Between interviews, I analyzed the data being collected in order to enrich the interview process. As a result, I was able to use data from the first interview to stimulate questions and probe deeper into the experiences of the participants during the second interview.

Data analysis followed the steps presented by Giorgi.⁸³

Step 1: After the interviews were transcribed, I read through all the data within each transcript several times. The phenomenological approach was holistic, so I could maintain a global perspective of the data in order to determine how the parts were constituted.⁸³ Upon reading the transcripts, notes were made of any impressions or insights that were triggered by the participants' reflections.

Step 2: The data were divided into meaning units. Each meaning unit contains a complete thought relevant to the phenomenon of interest, i.e., coping strategies of adults growing older with CP. The meaning units were formed by rereading slowly the description given; each time I discovered a transition in the data, the analysis continued until the next meaning unit was discriminated and so on,⁸³ resulting in a series of meaning units expressed in the participants' everyday language.

My first analysis resulted in 48 topics. The guiding principle of this step was that the parts were determined by the criteria that were consistent with the lens (scientific discipline) used in the study. As Giorgi stated: "The phenomenological approach is 'discovery-oriented' and in order to discover meanings in the data, one needs an attitude open enough to let unexpected meanings to emerge."^{83(p.8)} I approached the data with an openness of discovery but I also remained sensitive to theoretic assumptions of the study when determining meanings in the data relevant to the phenomenon of interest. As I viewed the data, I used Lazarus and Folkman's²⁶ concepts of coping and Antonovsky's SOC concepts as guides to enhance my understanding of what was being reflected by adults aging with CP.

Step 3: As the researcher, I organized and transformed the meaning units into the language that expressed the values of the scientific discipline being utilized, i.e., a psychosocial perspective using Lazarus and Folkman's²⁶ concepts on coping as a lens for

understanding the data. Although the participants described their concrete experiences in their everyday language of everyday life, it was important to have their experiences expressed in terms relevant to the discipline being utilized.⁸³ This process helped transform the participants' language of everyday life into the meaning behind the language within the psychosocial perspective in which it was being studied.

Step 4: After another full read of the data, I organized the 48 topics or meaning units into clusters of five themes that appeared to reflect the data. These clusters of themes represented broader categories or structures. I, as the researcher, determined what was essential for the phenomenon under study and what was not. After further contemplation, I then organized the data further into three themes instead of five. Ideally, as the researcher, I tried to synthesize the clusters of themes into the structures to which the data lent themselves, being careful not to force the data into a predetermined number of themes or structures. Structures are to be understood as essences and their relationships, and not ends unto themselves but rather 'measures of central tendency'.⁸³ I was able to categorize the 48 topics (meaning units) under three themes. I then color-coded each meaning unit according to the applicable theme and placed the data in files in accordance with the represented theme. After a period of time, however, I reviewed my analysis and was concerned whether or not the themes I had chosen truly captured the essence of the data. So I then decided to spend some time reviewing the summary notes I had made of the data representing the participants' reflections. Three modified themes emerged that seemed to capture more of the essence or lived experience of the participants than the previous three themes. For example, one of the previous themes was *Awareness*, which I realized was perhaps too vague or general. So, after looking at the meaning units categorized under *Awareness*, I was able to expand this theme to

Awareness, Acceptance, and Action, which is more representative of some of the coping strategies that I was trying to encompass in the original theme.

Enhancing Experience was another original theme that I believed fell short of capturing the essence of what was represented by the data. As I was reading over my summary notes, a new theme emerged: *Negotiating One's World*. That theme encompassed three sub-themes: *experiences of empowerment*, *experiences of disempowerment* and *experiences of self-responsibility*. The original theme, *Enhancing Experiences*, did not capture enough of the essence of the data, such as those experiences that were not empowering or those experiences that reflected the participant's own sense of agency. The third theme remained the same: *Independence is Everything*.

The goal of this analysis was to integrate the results into a succinct shared story that reflects the meaning and experiences of adults aging with CP who were participants in this study. These three themes are presented and discussed in the next chapter.

CHAPTER 4

4.1 Presentation of Findings

This chapter presents participants' demographic data and the analysis of in-depth interviews of 12 adults with CP. The presentation is congruent with the purpose of the study related to the coping strategies of these adults as they grow older with CP. The theoretical assumptions outlined in Chapters 1 and 3 are used as a framework for discussion of the data. Examples are illustrated with quotations from the adults with CP who participated in the interviews. The researcher assumes each participant is an expert informant for the study.

The participants comprised a purposeful sample. After providing the three agencies in British Columbia and Alberta with a letter of initial contact, they distributed the letters to participants who qualified for the study. The response was immediate with 13 volunteers willing to participate in the study. I chose 12 participants who met the study criteria in the order in which they contacted me. One person was eliminated for not meeting the inclusion criteria. Due to limited time and resources in conducting this master's thesis, I decided that 12 participants interviewed twice would likely provide me with adequate data to describe the essences of the experience of adults growing older with CP. I realized I needed to limit the amount of data in order to be able to conduct an in-depth detailed analysis that was consistent with the objectives of a qualitative study. Although not deliberate, the sample ended up with 6 men and 6 women, 4 from Alberta and 8 from British Columbia.

The participants ranged in age from 25-58 years (median = 41 years). The type of CP varied among the participants. Six participants were diagnosed as having spastic

diplegia, two with spastic quadriplegia, two with ataxia, one with spastic double hemiplegia and one with athetoid quadriplegia. Five participants were able to walk independently or with ambulatory devices. Five participants had articulation difficulties. Seven were single and five were married or had live-in partners. All participants were living independently in the community with or without paid support workers (not living in an institution or group home). Six participants were employed by others, four were self-employed, one was retired and one participant had a volunteer position. For further information about the participants, refer to Table 4.1.

Table 4.1 Participants' Information

Name¹	Age & Gender	Education²	Employment Status	Marital Status³	Type of CP	Mobility Status⁴
Alan	58 (M)	BSc in EE	Retired	M	Ataxia	Able to walk
Nina	25 (F)	HS, CC diploma	Employed	S	Spastic diplegia	WCH/ PCH
Barbra	37 (F)	HS, some CC courses	Employed	S	Spastic diplegia	Able to Walk
Gary	33 (M)	HS, 2-yr diploma, Level 1 - Securities	Self-employed	S	Ataxia	Able to Walk
Kate	43 (F)	BSW	Employed	S	Spastic diplegia	Able to Walk
Tom	48 (M)	LL.B	Employed	M	Spastic diplegia	Able to Walk

Name ¹	Age & Gender	Education ²	Employment Status	Marital Status ³	Type of CP	Mobility Status ⁴
Sara	39 (F)	2-yr certificate in social work	Employed	S	Spastic quadriplegia	WCH/PCH
Wendy	40 (F)	BA	Self-employed	M	Athetoid quadriplegia	WCH/PCH
Sheila	46 (F)	BA	Volunteer position	S	Spastic double hemiplegia, ataxia	WCH/PCH
Keith	38 (M)	Two diplomas	Self-employed	S	Spastic diplegia	WCH/PCH
Ted	36 (M)	HS, CC business courses	Volunteer	M	Spastic quadriplegia	WCH/PCH
David	48 (M)	2-yr diploma	Self-employed	M	Spastic diplegia	WCH/PCH

¹Pseudonyms

²Marital status: married = M, single = S

³Education: HS = high school, BA= Bachelor of Arts, BSW = Bachelor of Social Work, CC = community college, LL.B = law degree, BSc in EE = Electrical engineering

⁴Mobility status: wheelchair = WCH, power-chair = PCH

Each participant was interviewed twice, with 6 to 8 weeks between the two interviews. As mentioned in Chapter 3, one participant's second interview was done through email. A few of the interviews began with the participants appearing a little "stiff" or guarded. However, by the end of the first interview, I had strived to build rapport and generally the second interview proceeded very comfortably. With greater understanding of the study and a sense of who I was, all the participants seemed to

develop a trust in me and were enthused to share their stories. I enjoyed meeting all of the participants and was amazed and empowered by many of their stories.

In the course of conducting this study, I found that the interviews were a unique and intense learning experience for me, as a researcher living with CP, as well as for the participants. The participants were enthusiastic that someone was studying the process of coping with growing older with CP and especially encouraged by the fact that the researcher had CP herself. I was careful not to impose my own experience of growing older with CP on the participants but, in qualitative research, the influence of the researcher is acknowledged (by bracketing or suspending my understandings, assumptions, or bias). So, as a researcher with CP, it was impossible not to influence the interviews and data analysis process. In many cases, I was perceived as a peer providing hope because I was broaching a subject that was dear to them and that they felt no one was speaking about.

My objective was to analyze the data so I could give voice to the participants' stories and concerns. I have summarized the data into three themes as a way of telling their stories. I tried to represent all the participants in the creation of these themes.

4.1 Themes

The themes are *Awareness, Acceptance and Action, Negotiating One's World* and *Independence is Everything*. The themes are not presented in any particular order and there is no clear distinction among the themes but rather an interweaving of different elements of the themes unique to each individual's experience.

4.1.1 Awareness, Acceptance and Action

“Awareness, Acceptance and Action” is a theme that captures some of the coping strategies used by adults with CP as they grow older and experience age-related changes. This theme reflects acknowledgement by the study’s participants of what might be happening to them in regards to their physical condition and subsequent changes in their functional abilities. The first component of this theme is awareness, which leads to a certain amount of acceptance before action takes place. The action may be just a change of attitude or it may involve changes in habits or behaviors. Descriptions will begin with participants’ awareness of their experiences of pain, stiffness, and fatigue, followed by their need for therapy and availability of funded services, lack of information amongst medical professionals and how perceptions of other people affect them. Following their experiences of awareness, participants describe experiences of acceptance and action.

4.1.1.1 Awareness

As they grow older with CP, many participants become aware of physical changes through experiences of pain, stiffness and fatigue. They recognize how their bodies are deteriorating at a faster rate than those of their able-bodied peers. One participant described feeling like a 65-year-old even though she was only 37.

Participants described how their experiences of pain and stiffness affected abilities such as balance. One participant described her balance as “unpredictable,” suggesting that she could no longer trust a sense of her own balance ability. Even though falling was a major issue among the participants, of equal concern was their declining ability to get up on their own when they did fall. Participants were aware that not being

able to get up on their own threatened their sense of independence. Balance is often linked to stability and feeling stable is often linked to feeling secure or safe. Awareness of instability and lack of balance seemed to undermine the participants' sense of security or safety.

Many participants also reported experiencing fatigue, creating a consciousness of the need to alter their activities. They realized that they could not keep up the same pace as when they were younger. Participants described fatigue as an experience that can suddenly overwhelm them in the middle of the day, forcing them to quit whatever activity they may be doing. As Alan explains:

Basically...like I wake up in the morning feeling really, really good. I feel lots of energy and then, by the time noon hour comes along, I feel a loss of energy. Not exactly sure how that happens but it...even though I haven't really done anything, it seems to happen. ... I can't do anything. I can't do the things that I normally do. I have to basically call it quits, whatever I'm doing, and go have a nap.

In order to function in their everyday lives, the participants were aware of the need for more rest, whether it was a nap during the day or making sure they got a minimum of eight hours of sleep at night. Participants were aware of having to manage their lives differently than when they were younger because of the fatigue they now experience.

Experiences of pain, stiffness and fatigue also made participants aware of their need for physical or occupational therapy. Even though participants recognized their need for continued therapy services, many of them complained about the lack of funded services available after they reached the age of 18. As Barbra stated, "They pretty much let you go with pretty much no resources ... once I was 18 ... they cut you loose and said 'we can't do anything for you now, and you're on your own,' and that was it..." Most

participants believed that they would maintain their abilities longer if they had more access to therapies. As expressed by Gary, “I still think right now if I went back to therapy I could still learn a lot and improve on different things.” What was perhaps more bothersome to the participants was the lack of knowledge amongst medical professionals about conditions related to growing old with CP. Participants struggled to gain information or answers to their concerns from medical professionals. They explained that often their family doctor did not seem to know anything about CP. As articulated by Sara,

There’s very limited information; there’s not too many people I can turn to for advice. The medical personnel don’t seem to know whether they’re coming or going half the time – they don’t know enough. They can’t tell you what to expect. The medical expertise drops when you’re 19. Like there doesn’t seem to be anyone that carries through from childhood to beyond childhood, so expertise totally drops...

Female participants were especially aware of how they, as women with a disability, have special issues that are not getting addressed. Participants expressed fear and frustration, stating that information about what to expect as they grow older with CP would be helpful. As Barbra said, “ And the doctors don’t have a clue so I guess as far as aging with CP, it would help if somebody could say this is aging with CP and this is what’s not...” Individuals’ experiences of seeking information about aging with CP have made them acutely aware of the lack of such knowledge amongst medical professionals.

Until recently, research on CP has focused almost exclusively on the childhood and adolescent years. One 36-year-old participant commented how she was part of the first wave of people with CP who were not institutionalized at birth or shortly thereafter. Being part of the community at large provides opportunities to participate fully in life,

such as having careers, marriage, and children. However these opportunities tended to increase the participants' own expectations of themselves. As Wendy stated, "So we expect more of ourselves in ways of working and going to school." Participants expressed concern that CP becomes a forgotten disability after age 18.

Five participants expressed how limitations in their physical abilities led to isolation and loneliness, often resulting in bouts of depression. Four of the five participants were conscious of the need for professional counseling. The one participant who expressed strong opinions *against* professional counseling explained that her loneliness and depression were due to the circumstances of living with a disability and that all the "counseling in world" would not change those circumstances. However, she agreed with the other participants of the need for peer support.

Participants were aware of the need to talk to other adults with CP who might be experiencing similar struggles. During the interview process, many participants enjoyed speaking with me about their struggles of growing old with CP because they sensed that I understood what they were describing. Although participants acknowledged support from family, friends and co-workers, they yearned for more peer support.

Participants were conscious of how other people's perceptions tended to affect them. As Gary stated, "The only reason I know I'm disabled is by the way other people treat me ...". Participants described experiences of being treated either in a condescending or patronizing way – feeling dismissed or infantilized. As Nina explained:

I mean when you're unsure and you're faced with a world of able-bodied people and a world where most people are able-bodied, they look at you and their mind automatically goes to what you can't do. 'That poor person...what could she do.'
Or, my personal favorite [is] when you're in the grocery store, bagging your

groceries and somebody comes up to you... [and says] 'It's so nice that your kind can get out.' Like 'my kind'...okay! I'm not sure what that is but [okay].

The participants realized that people may be well-meaning but are nevertheless condescending. Another participant described his experiences with able-bodied people whereby they assume that people with a disability are amazing if they get out of bed and show up for anything. Keith called it the 'disability wowzer factor' explaining,

[T]he 'disability wowzer factor' is that attitude that people have about people with disabilities that they think it's like 'amazing' that you got out of bed and showed up at all. It's like 'WOW, you know, you're really doing it if you can do anything at all!'. . . .

Participants experienced themselves as minorities in an able-bodied world, who are often perceived as helpless and are aware of their need to be accepted for who they are as human beings. They are disturbed when other people are more interested in their disability than their personhood. They wish that people would see beyond the disability to the people they are, and focus on their abilities rather than their disability.

Yet, as Tom explained, it is important to accept one's disability,

There's nothing worse, I think, than having a disability and being so arrogant about it, that you're basically having this attitude of, you know, certainly their service was something that might have been needed but you don't want to acknowledge it because you're acknowledging that you might be disabled. Of course you're disabled! I know I'm disabled but not sorry about that and trying to hide that. It doesn't worry me; I've got a better life than a majority of people I know.

4.1.1.2 Acceptance and Action

Acceptance and action seemed to follow awareness. Each participant described coming to some level of acceptance that hastened actions or decisions towards improving their well-being or quality of life. As examples of action, some participants altered their lifestyles; others made decisions about the use of adaptive equipment, such as a wheelchair or scooter; others sought out various kinds of therapy and others just worked on changing their attitude about or outlook on their challenges.

Participants were aware that their stiffness, pain and fatigue often adversely affected their balance -- leading them to strategize on how to prevent themselves from falling and how to address their personal safety. In accepting their increased risk of falling and decreased ability to get back up, some participants realized that the best strategy for safety was to use a wheelchair or scooter as a means of mobility on a long-term basis. Nina explained, "... I made the decision that because I'm on my own 23 hours a day, it's safer for me to be using the chair more often." Another participant expressed how her scooter is faster and saves her energy. Conversely, other participants were diligently seeking ways to stay ambulatory in order to avoid the use of such equipment because, for them, wheelchairs or scooters were not currently acceptable solutions. Interestingly, for those who accepted the use of wheelchairs or scooters, they saw the mobility device as a practical solution providing them with more independence. On the other hand, those opposed to using a wheelchair or scooter viewed their use as a major compromise to their independence. All participants accepted their need to address difficulties with their balance as they grow older with CP.

Each participant accepted the need for support, whether from family members, friends or hired caregivers. In accepting his balance limitations and decreased ability to get up after a fall, one participant developed a strategy to always attend public events with either his wife or daughter. He also makes sure he is seated near an exit with easy access to a handrail. When by himself, he never attempts stairs without handrails. Five of the 12 participants needed hired caregivers for their personal care (e.g., dressing, bathing, and eating). The level of care needed by each participant varied according to that individual's functional capacities.

For participants needing hired caregivers for their personal needs, proper assessment of their functional limitations was required in order to acknowledge the level of care they felt was necessary. However each of these five participants struggled to attain adequate funds for the number of hours they felt that they needed. One participant commented that the problem resided in whether assessments were viewed through a medical model or a participation model. Most of the participants' assessments of themselves included being able to participate in activities that were of interest to them (participation model) whereas most social service agencies' assessments only consider what was needed for their basic health (medical model).

British Columbia has a social service program entitled Choices and Support for Independent Living (CSIL). Once a person with a disability is assessed for attendant hours, he or she can choose to go through an agency (where the agency sets up the allotted hours for the person and provides the staff), or they can choose to receive a dollar allotment for care and are free to interview and select caregivers of their choice. Four of the five participants who needed hired caregivers chose to receive a dollar allotment and

select their own caregivers. Ted explained the advantage of the CSIL program for people with disabilities.

So...yeah, this program is...to me it's a model program through this country; it is making a difference for people to be able to go to work, to be able to go to school, be involved in recreational activities and be able to socialize...you know. It really is a program that is dynamite...it just needs to be tweaked a bit to be more ...the assessment of hours need to be based on participation, not on the medical model because that's really what the assessment process part is based on.

One of the five participants chose to use an agency to hire her caregivers, saying she did not want the responsibility -- even though she was quite dissatisfied with the care she was receiving. Most of these participants were in favor of funding programs whereby they would have their own individual responsibility for the allocation of funds.

In *accepting* an increased level of fatigue, participants acknowledged the need to seek alternative ways of managing their lives and initiating changes, i.e., taking *action*. Realizing needs for more rest, they often have had to alter the level of activities in which they were involved. Sheila explained, "When one gets older, one learns to accept a lot of things. Then that makes it easier and your energy is used toward more useful and practical things." Some participants needed to take actions to acquire flexibility in regard to their employment. Alan took early retirement whereas others were self-employed, providing the flexibility needed to care for themselves. Gary described the difficulties he experienced in a regular job but said being self-employed provides him with the flexibility to rest and work within his own schedule according to his personal needs. For most interviewees, flexibility was an important factor in managing their lives.

Experiencing increasing pain, stiffness and fatigue appeared to motivate participants to undertake various *actions* as coping strategies. Exercise and diet were commonly mentioned strategies to manage the changes they were experiencing in growing older with CP. Tom realized how increased body weight negatively affected his abilities, changed his diet and incorporated a more rigorous regime of stretching and exercise. He explained, “I have to do what I have to do. And I feel healthier for it ... I either stretch or I get too stiff.” Tom also commented that perhaps some of the changes he was experiencing were part of the normal process of growing old but, for people with CP, the magnitude of stiffness is often a lot more significant,

I don't contribute that (stiffness) necessarily to having cerebral palsy; I contribute the magnitude of the stiffness is a lot more significant for me as it would be for someone else. Maybe really not, but again, I would tend to think it probably is.

Some participants sought out alternative therapies such as massage, hydrotherapy, hypnosis, nutritional counseling and chiropractic services whereas others paid for services such as physiotherapy and exercise coaches. Gary described his experience with massage: “[with] massages and a little bit of therapy sessions, I should be able to take my disability and even take it to the next level where probably... I'll be walking a lot better and be able to move a lot better.”

Keith also talked about the benefits of using alternative therapies such as massage, hydrotherapy and chiropractic treatments. At one point, he asked a massage therapist to develop a case study of him and measure the before and after effects of the alternative treatments in which he was partaking and said “what she found out was that I had improved substantially through these other methods...” Diet, exercise and alternative therapies were reported as helpful *actions* in dealing with pain, stiffness and fatigue.

Some participants spoke of a change in attitude as a result of coming to accept having CP. Alan stated, “I think the biggest understanding that I’ve had to ... that I’ve gained over the years is learning to accept my CP.” The awareness of other people’s perceptions led some participants to a sense of responsibility to educate people on what CP is and what CP is not, recognizing there is a certain amount of ignorance about CP, especially if a person with CP has speech articulation difficulty. Tom stated, “There’s an obligation on us to make those around us understand our situation, learn from us and feel comfortable around us.” Another participant said that it is important to transcend how society sees you. They realize that their CP is a part of “who they are”. Tom explained, “I have understood how CP has really shaped the way that I think and behave and how I react to certain situations.” The participants came to understand that their disability is not separate from their personhood and yet recognized that they are more than their disability. Gary explained, “I tell people when people are born with cerebral palsy, they’re born completely normal [for them] because they’re never going to be able to change it.” As they grew older with their CP, many participants were better able to accept their condition and that acceptance facilitated changes in their attitude that seemed to provide them with a more positive way of viewing their lives.

In summary, as participants were able to accept changes in their physical abilities they made decisions to address the adverse effects these changes were eliciting. The participants accepted the need to address safety issues and their increased need for support. Some participants took actions toward increased uses of mobility devices whereas others moved toward more support of family and friends and others increased their use of hired caregivers. Alternative therapies, exercise programs, diets and changes in levels of activities were some of the actions used by the interviewees in addressing

changes in their physical abilities. The participants' decisions on how to view growing older with CP also seemed to make a significant difference in their approach to the changes they were experiencing. The theme *Awareness, Acceptance and Action* illuminated some of the coping strategies used by adults growing older with CP.

4.1.2 Negotiating One's World

Negotiating one's world depicts some strategies used by people with CP to navigate their lives, especially as they grow older and experience age-related changes. This theme describes participants' sense of agency that things are not just happening to them but that they are able to take certain actions and effect change. This theme comprises three types of experiences: those that empower, those that diminish or disempower, and experiences of self-responsibility.

4.1.2.1 Empowering Experiences

Empowering experiences are those experiences that have enhanced the participants' lives, such as education, employment, supportive relationships (family, friends, caregivers and mentors), and self-improvement initiatives (alternative therapies, support groups, education/new learning courses). These experiences have helped participants to navigate through their lives and, in many cases, reach certain goals or aspirations. The descriptions will begin with interviewees' educational experiences.

Participants' school experiences were not uniformly empowering but, when they were given support and encouragement, they felt confident and were able to complete their educational goals. One inclusion criterion for this study was that all participants had attained at least a high school diploma; in fact, all 12 participants also had some post-

secondary education. Most participants received some support throughout their elementary school, high school and post-secondary education, whether through assistive technology, teaching assistants, or accommodations to course loads and time constraints that helped them complete various educational goals.

Nina found “virtual” high school (classes taught on-line) to be more empowering than mainstream high school because she received more one-on-one time from her teachers and was able to develop friendships with them. Gary described how the high school resources counselor made it his goal to get Gary through high school. Because Gary was being raised by a single mother, he viewed his counselor as a surrogate father. Sheila described the support she received while attending university as empowering: “I found it ironic one year I was in university, I was able to take three courses at once which was full-time and I was getting more hours per unit for help with my university than I was my personal care at that time.” The amount of post-secondary education varied; some participants attained a certificate/diploma, some a university bachelor’s degree and two achieved professional (lawyer and engineer) degrees. All participants described ways that their education facilitated employment opportunities.

The two participants who achieved professional degrees were able to establish long and stable careers. One worked for the same company for 26 years before taking early retirement. The other has worked in the same office for 17 years and hopes to remain in his job for another 7 years before retiring. Five participants who were self-employed described the advantages of being able to set their own schedules to work at their own pace. They all enjoy their work and appreciate the flexibility of self-employment. As Gary explained,

Well, I've experienced the difference in careers because I'm running my own business. I have the flexibility that I need throughout the day because if I get tired or I'm not having a good day, I have the ability of either go have a nap or go somewhere else whereas when I'm in a job, there's not that flexibility and it causes ... stress for myself so ...

Gary loves his work and feels a sense of fulfillment because he believes he is truly achieving his purpose. Similarly, all self-employed participants felt empowered by the work they do and valued having autonomy.

Sara, Barbra, Nina and Kate described themselves as working in supportive environments and enjoying what they do. However, a common complaint among most participants was that often the only types of work opportunities open to them involved dealing with people with disabilities and some of them would like opportunities to work in fields other than those solely connected to people with disabilities. Sara explained:

Well...the disability doesn't define me as a person and I think it's important as somebody who works in the field could do something totally separate from... I eat, breathe my cerebral palsy, I work in the field, work for ... [an organization that works with people with disabilities], so it's really important to set aside some time where you're not totally focused on that... [and that] part... is put aside and you do something unrelated to your disability, whether that be some leisure thing or...I don't know."

Although Kate enjoys her job, she had hoped after earning her university degree that there would be more opportunities to work with able-bodied populations. She stated "...the fact that I've been here so long that I hate to see my life go by and not having the opportunity to work in different areas of the field." Conversely, Ted loves working in

areas that are improving programs for people with disabilities. He finds it exciting and meaningful. Previously he worked in the private sector at a job where he made good money but he did not find it as rewarding. Ted explained,

I ended up just not wanting to do it anymore ... with the experience of moving out on my own and going through the process of red tape and stuff, it was what I learned that I could really benefit other people with disabilities, to help them to be able to move out on their own and go through the process. So I ended up by getting a contract with [an organization] where they were starting a training program for a [social service] program...”

Sheila has a volunteer position which she enjoys because it gets her out of her apartment to interact with people and that adds a sense of purpose to her life. Some participants had more difficulty than others finding jobs that they enjoyed and experienced as worthwhile. As described in Kate’s example,

[that was] what I had originally wanted to do ... to work with people with disabilities. But as the time passed and because of all my struggles, I realized that I really didn’t want to work with people with disabilities but I still wanted to be able to assist people to be able to achieve what they wanted in life, but somehow I got myself stuck here [in the job she is presently in] and ... I can’t seem to be able to get out. I’m stuck.... I’ve applied to a couple of other disability organizations but I’ve also applied with non-disability organizations.”

Despite the challenges, having a job and the opportunity to use their skills seemed to be important to the participants. This being whether they were employed by others, self-employed, or volunteering. Gary stated,

What keeps me going and what keeps me running my business is knowing [that] my purpose in life is to inspire others to see the possibilities within themselves and each other, so by knowing that purpose statement, I'm better able to find... a good career fit for what I do and I'm able to know when I'm on [fulfilling] my purpose and when I'm off, so when I'm doing my business I'm doing what I need to be doing in life... so that ...gives me a focus for just about every aspect of my life.

Being employed was empowering for the participants. Work seemed to provide them with a sense of worth and those who were in paid positions enjoyed having financial independence. Even though employment played an important role in each participant's life, many expressed how family, friends, mentors and caregivers also influenced their lives.

Family, friends, mentors and caregivers played significant roles in the lives of the participants. They described how it had often been their mothers who had encouraged them and, when possible, involved them in activities in which non-disabled children might be involved, that helped them have a sense of normality. Alan expressed, "My mother taught me that I was the same as everybody else". Only three of the 12 participants had driver's licenses so most needed help within the community to shop for groceries and other needs. Often family members, friends or caregivers would help them. Three participants were raised in foster care homes, two of whom felt very supported by their foster families throughout their lives. However, the third participant thought his foster mother was great until he was 12 years old; after that, he felt she could no longer handle him. At age 12, he elected to be placed in a group home.

As adults, many participants had significant others in their lives providing

support. Five were married and described their spouses as providing companionship, emotional support, encouragement and in some cases serving as back-ups to hired caregivers. Alan stated, “I’m a lot happier with J__ in my life”. Only one participant, Tom, had his own child and expressed how thrilled he was with this role. “I think the big thing I wanted to do was to be a dad. I think that’s my biggest achievement.” His daughter is a big part of his support system. Four of these five participants had non-disabled spouses. All reported that their marriage relationships enhanced their lives.

All participants mentioned having supportive friends. Alan talked of a friend who provides him with guidance. Tom expressed how lucky he was to have a large group of friends from his childhood who support each other and still gather together on special occasions.

Now, beyond my family, my big support group was my friends and I’ve been really blessed and I say that sincerely. I think I’m one of the luckiest guys in the world to have as many good friends for as long as I have.

David also spoke of how he was grateful to have friends he could count on, describing them as loyal and reliable.

Besides having friends, most participants also had people in their lives that had mentored them in some capacity. For some participants, mentors were described as professionals who worked in the same career as they did. Professional mentors often provided support and guidance to the participants throughout their careers. Others described mentors as people who were peers and exemplified ways of living with a disability that they admired and learned from. Nina befriended a woman with disabilities who is a little older than her; Nina admires how this woman has a full life. Her friend is in a wheelchair/scooter, she is married, has raised a child and is employed. Some

participants described being mentored by a family member. Keith talked about his grandfather as a mentor, who showed him how to behave as a man,

In my grandpa's case,...it was a very strong but gentlemanly servitude ['sic'] of how to carry yourself in the world and how to treat people and how to think about your problems and how to pick yourself up, dust yourself off and start all over again when necessary ... That kind of resilience that we all need when life gives us its knocks and stuff ... I think there's some kids, particularly some kids with disabilities, that aren't necessarily given a very positive possibility kind of picture, even by their own families of what they [are] ... capable of."

Keith described how he felt being around his grandfather, "I never felt like less because I had a disability, I never felt like I didn't belong." Mentors were people who usually exemplified a way of being and provided less direct support than friends or caregivers.

Empowering experiences occurred through interactions with caregivers. The care needs amongst the participants varied; four had extensive care needs and required a considerable number of paid caregiver hours. For example, Ted described needing assistance with all his personal care; he needs to be fed, he needs to use a powered wheelchair to get around and requires someone to physically help him with most things. The funding that Ted receives allows him to choose and hire his own caregivers, and to allocate and assign hours according to his needs. He has been able to find people to support him with his personal needs so that he can participate in activities of his own choosing. Two other participants are served by the same funding program as Ted and also feel supported with the care they are receiving. The participants who choose their own caregivers often described their relationship with their caregivers as one of friendship. Two participants also use service dogs to help them get dressed, pick up things, open and

close doors, turn on and off lights, activate elevators, hand their bank card to cashiers, and to provide companionship and safety. All participants acknowledged and valued the support they were given but also recognized the need to use their own initiative in seeking ways to improve their lives.

Many participants sought out alternative therapies, attended support groups or enrolled in courses or classes (e.g., continuing education courses, self-improvement courses, exercise classes) as ways to improve their lives. Most of the participants described massage therapy as helping to improve their stiff muscles. Alan and Keith especially found alternative therapies such as massage, hydrotherapy, and chiropractic helpful. Keith made a proposal to a massage school to provide massages to him as a way of seeing what a difference massage could make to a person with CP as well as providing practice to new massage therapists. They agreed and he received a combination of hydrotherapy and massage three times a week for two years. He commented that this experience made “an unbelievable difference.” Gary also described his experiences with massage therapy,

So, I recently volunteered for some massage therapy classes and I've been learning a lot about how my position is out and how I walk and how, because of the tight arm and tight shoulder, how it affects my motor skills and my walking ...

Barbra made use of a fitness program that included weight training and aquatics.

Wendy and David found a martial arts course for people with disabilities a helpful form of exercise and self-defense. Tom hired a personal trainer for encouragement and to have an exercise program set up for him. He also made use of two physiotherapists with different approaches that he felt helped him to stay ambulatory. Massage, hydrotherapy,

and the services of chiropractors, personal trainers and physiotherapists were reported as making a positive difference in addressing age-related physical changes.

Several participants also found psychological therapies and other self-improvement courses helpful. Sheila explained how art therapy was helping her to work through her psychological problems. Sara described how hypnosis therapy helped her manage her pain whereas Alan used visualization techniques to overcome his fears connected to his disability. A few participants enrolled in continuing education classes or self-improvement courses, such as “Toastmasters” and “Choices” as ways to enhance themselves and their professional careers. Two participants undertook training courses on how to handle their own services dogs.

4.1.2.2 Disempowering Experiences

Unfortunately, many participants reported disempowering as well as empowering experiences. Participants defined disempowering experiences as those that were dismissive and diminished their rights as adult citizens. They often described these experiences as making them feel discounted or infantilized. As an example, Keith and Kate were told as young adults that the careers in which they were interested were not suitable for a person with a disability and were banned access to any educational funding in their areas of interest. Ted was told he would not amount to anything and should be happy to just rely on his disability check. Keith pursued the career of his choice despite the obstacles he encountered; eventually, he was able to succeed in his field of interest. On the other hand, Kate was redirected to an entirely different field in which she had no interest. Because it was the only area for which she was able to receive funding, she completed the recommended program. However, she was unable to find employment and

eventually was accepted and funded for a program closer to her interest. Kate felt discriminated against and resented the fact that she was over 30 years old before she finished her university degree.

Alan and Gary experienced disempowerment in the work place. After working for a company for many years, Alan lost interest in his work because he was demoted after the company went through a merger whereas Gary completed a 10-month training program and then was placed in a position in which his needs were not accommodated. He became frustrated because he was not able to keep up.

Not being treated as an autonomous adult is a disempowering experience. As an example, one female participant described not being able to convince her doctor to give her a Pap test even though there was evidence that she needed one. Another participant, Sara, described disappointing health care interactions, “I’ve gone into emergency where they won’t even take me out of my chair to do a proper exam”. Incidents like these often made participants feel disempowered and less deserving as human beings. Service people often seemed unwilling to make eye contact or address them directly. Sara stated, “Some people, you know, they don’t give you eye contact”. Often, when seeking medical attention, health personnel addressed the attendant accompanying the participant rather than the participant directly. Sara explained, “...first of all they usually want to talk to the attendant. I tell the attendant to leave so the doctor can’t keep looking at them...” Gary described a story of being completely infantilized while at a restaurant,

. . . the waitress was walking by and I turn to her and said, “Can I get an orange juice?” And she turned to me and said, “Well, you need to ask your friends if you’re allowed to have an orange juice.” She came back a few minutes later and I

called her over and said, ‘Madam, I can drive my own car, I can run my own business, do you think maybe one day I can order my own orange juice?’

All participants seemed to feel disempowered when they were not treated like autonomous adults who had a sense of their own needs and wants, capable of making their own decisions. These incidences of disempowerment often warranted participants to become more active and forceful advocates for themselves.

4.1.2.3 Self-Responsibility Experiences

Experiences of self-responsibility were those in which participants acted as their own advocates, often defending against disempowering experiences. For example, many participants sought out government agencies to help them with funding and guidance.

Those participants who attended college or university advocated with teaching assistants and professors for whatever accommodations they required. In the case in which funding was denied for the university degree desired, that participant was able to advocate eventually through an employment agency for the funds required. As described above, self-improvement initiatives sought out by the participants also represented ways in which they were taking responsibility for their own well-being.

Sometimes, experiences of self-responsibility involved recognizing when a situation was not working and taking care of themselves, as in the two employment situations. For example when Alan was demoted, he took early retirement with a buy-out package rather than stay at his job. Gary left his job because the company for which he worked was unwilling to make any accommodations for him; he went on to start his own business, which he is finding more fulfilling. In situations where participants experienced being treated as helpless or like a child, they demonstrated agency by voicing their own

wants and needs. These experiences often required educating others as to how the participant wished to be treated. As Tom explained,

...certainly in my life I never liked people being patronizing or being helpful because they thought I needed help. It's when people fall over themselves, thinking that they're helping you ... You know there's a difference between providing support and making a nuisance out of yourself... Don't assume what I need. Ask what I need, but don't assume. Because you don't know who I am and you don't know where I come from and what I do and all those things. And that's a basic rule for all of us, I think. I mean it doesn't take a lot of work to ask and communicate and find out rather than coming to the table and bringing your own preconceived ideas to help people ... To me it's a little disrespectful to deal with people who have a disability based upon what you think and what you have in your own mind as their needs. You should take the time to learn from them because they're the ones who really know ... you don't."

Sara advised taking responsibility for obtaining adequate health care through the way one chooses a primary care physician,

"You interview them! You find out what they know about CP and what their connections are with medical community. You find out whether they have hospital privileges. You find out, you know, what they are comfortable with doing, you find out what they are able to offer you."

Experiences of self-responsibility were ways in which the participants acted on their own behalf in situations that negated them as adults and, in some cases, violated their rights as citizens.

In summary, *Negotiating One's World* describes ways in which the participants

moved through their lives. Education, employment, supportive relationships (family, friends, caregivers and mentors), and self-improvement initiatives (alternative therapies, support groups, courses or classes) were some of the means by which the participants' lives were improved and enhanced. Each participant described experiences of self-responsibility whereby they dealt with disempowering experiences and overcame barriers placed before them.

4.1.3 Independence is Everything

Independence is Everything represents the participants' notions of what independence is and what it means to them. Gaining and maintaining independence are essential to the participants as they cope with growing older with CP. However, how independence is defined varied substantially among the participants. Individuals' views of independence ranged from being able to do everything oneself (being self-reliant) to having the support one needs to live the life one wants to live (being inter-reliant).

4.1.3.1 Self-Reliance

Eight of the 12 participants defined independence in terms of being self-reliant. In this theme, self-reliance is defined in accordance with the Oxford English Dictionary as "reliance on one's own powers and resources rather than those of others".⁹⁴ Gary, who is self-supported through his own business, offered these thoughts on independence:

Independence means to me, not having to count on anyone to do the things I need to do in life [as an example] driving, being at home alone, in charge of my own money, making any decisions myself and not answering to anybody about my decisions.

As Gary further explained,

Well, I guess I got to where I am by being resourceful and being able to adapt to different situations. I just felt like from my upbringing, I really didn't have a family that ever thought that I had a disability; like that was never in the back of their mind. They just knew that if I had to get from point A to point B, well...I had to get there somehow. Either I'm way behind or I go with them. So I never really grew up with this idea that I have a disability.... Being resourceful ... [is] I think one of the best things that people with cerebral palsy can do.

Gary claimed to be self-reliant; he lives in a house with three able-bodied men. He believed that it was important that he looked after himself and be resourceful because he grew up with a single mother who had to raise four children on her own. He also explained that his measure of 'how to be' was his able-bodied peers, "Yeah. But what I found is that I've always lived my life like kind of trying to keep up to a person who doesn't have cerebral palsy, so my measurement has always been a normal bodied person..."

Tom stated that "independence is everything" and emphasized how he has always been independent. He moved out on his own at an early age, got his driver's license, chose his profession and put himself through a university degree program. For Tom, independence means,

[B]eing able to live the life I want to live without the need to rely on others. And when you don't have to rely upon others, you take away the uncertainty of whether the others will be there for you. You've got control. You've got control of the situation, certainly to the extent that people have control.

Tom stated that his independence has made him who he is, and desires to maintain his independence as long as possible, “and not infringe on the independence of others.”

Presently, Tom has a real fear of falling in public. He knows that he would have to depend on someone else to help him up and that really bothers him. He also has very strong feelings against ever having to use a manual wheelchair or scooter:

I have no desire to be in a wheelchair or a scooter. I think that would make me angry...I really don't want a scooter. I don't want one. I think they're a hassle. I don't want to be scooting because it becomes a whole different view.

Tom believes that using a scooter would curtail his lifestyle quite a bit. He hopes to travel in retirement and stated, “I don't want to be scooting up the stairs to see the Coliseum in Rome! That would be a hell of a problem! It limits our access tremendously.” He talked about how it was a bit of a balancing act between insuring he could live independently and doing what is needed to stay on track with what he wants to do with his life. Tom indicated that sometimes, in order to keep going, one needs to prioritize what is most important. Further, Tom expounded on his belief that people with disabilities may not know their potential unless they push themselves a little.

I think we're running this great race called life and we're all kind of in there doing what we can do and trying to keep up and you had to do what you had to do and there's a real uncertainty how far you can really go. I think the potential of all of us [is unknown] and so I know until you give yourself a little push ...you really don't know how far you can climb until you give yourself that kick.

For Tom, there is always a bit of a tension between taking care of himself and the need to push himself. He currently prides himself on relying mainly on his own endeavors in maintaining his independence.

Offering a slightly different perspective of independence, Kate described herself as not needing anything and being able to do everything herself. Kate recognizes that her disability is a part of her but believes that the focus should be on who she is as a person and what she may want to do. Kate indicated that the priority should be on what is needed for her to achieve what she wants in order to stay in control of her life, so that she has choices and is able to make her own decisions. She does not want to be viewed as if she were a helpless child needing to be being told what to do.

Barbra described independence as, “Doing normal things...everyday things without asking for assistance ... [or] needing assistance. That to me is independence.” She explained, “I grew up being independent. ... my parents basically taught me ... independence is the number one key.” She presently works full-time and lives with a roommate, but is disturbed about the fact that she has to count on other people to support her more than before. Self-reliance is very important to Barbra; she fears having to rely on other people as she grows older. She admitted, “Maybe I put too much emphasis on independence, so when I see it decreasing ... my disability increasing, it means my independence is decreasing.” Barbra fears losing her independence and appreciates whatever independence she does still have: “It means that whatever independence I have is more valuable to me now.” Barbra is reluctant to ask for help from family and friends, “... they don’t mind. It’s just that my view on it is ... if I don’t need it, I don’t want it, and don’t help me.” Barbra does not want to worry her family and friends so she does not ask for help unless it is absolutely necessary. When I asked her about using a wheelchair, her response was similar to Tom’s views, “I’m pretty adamant ... It’s more like I’m already limited in my ability to do things. Being in a wheelchair only limits it more ...”

In contrast, Sheila and Nina believe their use of powered wheelchairs has given them more independence. Sheila stated,

I almost feel like what I've lost I've gained in other abilities.... Going into the [powered] wheelchair has brought about more independence for me, even though I'm not as mobile as I was. I can do things without asking for help; I'm not as exhausted and all the rest of it.

Nina described how using her powered chair allows her to get out on her own, use the bus, and not have to depend on para-transit (transportation for people with disabilities).

She has affordable housing in an area that has access to many attractions, like the zoo, parks and museums, and lives a short distance from downtown. She stated,

“Independence is doing everything you can for yourself.” Presently, Social Services have assessed Nina as needing one hour of care in the morning, seven days a week. However, the agency that provides her with support cannot find people to work for her on weekends so, for that time, she is on her own. She is, however, grateful to have support-care five days a week versus none at all. On weekends, Nina manages to dress and shower herself but describes it as being very difficult. Fortunately, she lives in a duplex and her neighbor is willing to help her if needed. Nina is forced to be self-reliant due to lack of funding but is presently looking for employment so that she can have more financial independence in the future.

Sheila lives alone and partakes in a government program that provides funds to hire and schedule her own caregivers. She recognizes that with autonomy there is responsibility and sometimes it is not easy to hire the staff she needs. Overall, however, she enjoys having more flexibility and is able to accomplish what she needs to do. Sheila defines independence as,

Being able to live my life the fullest I can. Able to have the choices everybody else has. Not having those limitations because of my disability. I mean I do accept the limitations of my disability but not to be told that you can't do something because of your disability.

Sheila accepts some limitations connected to her disability but wants to be able to explore other options that interest her:

I mean ... some things I don't want to do because I just do not want to, but if it's something that I want to explore, I don't want you to say I can't do it because of my disability and I've always challenged something like that. And over time I've usually found that if you want to do something, there is a way you can do it ... maybe not the way the average, normal able-bodied person does it, but you can do it such as disabled sailing. ... with certain adaptations or whatever, most things can be achieved.

She believes that if a person with a disability wants to try something, there is usually a way to do it; however, there may be consequences. Sheila explained that most of her injuries were due to being forced to do things on her own, either because the government representative said she could do it, or should do it, or other people thought she should be able to do it. Because of this kind of pressure, Sheila had often overexerted and overused her body, resulting in injuries.

Participants Wendy and David are married and live on their own in an apartment. Wendy is a self-published author and David is also self-employed. Wendy defined independence as, "To do what I am able to do and have the support with what I want help with ... Help in a way that I'm still in control." She does not want to be second-guessed and told by others what she needs. David defined independence as, "Independence to me

means being able to do what I want, when I want, the way I want. Being able to say ‘I’m going to go and do something’ and being able to do that on my schedule ...”

Transportation is one of the biggest hindrances to David’s independence. When he was younger, one of his greatest struggles was accepting that he would not be able to have a driver’s license and own a car. He does not like being dependent on the schedules of transportation systems such as para-transit. What is most frustrating is that when he and Wendy want to go out, there are no taxis that can accommodate two wheelchairs. Living near the sky train, however, contributes to their participation in the community.

Presently, Wendy and David do not have any paid caregivers. David said, “I’m ... as much as possible an independent individual ... That’s the way my parents raised me and that just works.” He described growing up with normal expectations of having to get a job and move out on his own. His family raised him doing all the typical things that other members of his family did, such as camping, swimming and boating. David was never excluded because of his disability. Wendy had a very similar upbringing. So the two of them stressed the importance of making their own decisions about what they do, when they want to do it, and how they want to do it.

Gary, Tom, Kate and Barbra are all still able to walk, which seems to allow them to function at a level that requires less need for assistance. Nina, Sheila, Wendy and David use manual wheelchairs and/or powered wheelchairs as their main source of mobility but still approach independence with a self-reliant attitude. The remaining four participants (Alan, Sara, Keith and Ted) approached independence from a more interdependent outlook.

4.1.3.2 Interdependence

Within this theme, interdependence is defined as being mutually reliant on one another.

Alan is still ambulant and lived most of his life without paid support. Even though he sometimes struggles with asking people for help, Alan prefers to use the term interdependent stating, “I mean I recognize how I’m interdependent on the love [of] my family; I have friends ... I’m not needy but I love them being part of my life ...”

Although he is proud of the independence he acquired by going to university and working 26 years in the same career, he also acknowledges the inter-reliant relationship he has with family and friends.

Sara lives on her own in an apartment and relies on use of a powered wheelchair; however, she also prefers to use the term interdependence.

I don’t like the word ‘independent’; I like interdependent. No one’s totally independent. We rely on the grocery store...the middle man at the grocery store ... those types of things. Being interdependent is being able to function at your full potential and pursuing your interests to the best of your ability with a support system.

She accepts having mutual support in order to be able to pursue her interests and attain goals she may desire. Sara stated how it is important to her that she is interdependent, not just with her family members but that her support system extends beyond them.

In high school, as a student with a disability, Sara felt she was never encouraged to strive towards independence such as going on to university or pursuing work opportunities like her able-bodied friends. She was never informed about options or of what community resources might be available to her so she envisioned a future of just

sitting at home. Sara is currently employed as a resource person for people with disabilities. She is supported by a program with the Ministry of Health where she is able to manage her own attendant care, which helps her to be able to live the life she wants.

Keith lives alone and is self-employed. For him independence implies, “I think that means being able to have ... enough control and influence over your own circumstances. To at least be able to do most of what you want to do.” He does, however, support the idea of interdependence,

I don't think that it's particularly useful anymore to think that ... the only way to get somewhere is totally by your efforts because after a certain point of life, I realized that everybody who's ever been able to do anything in life had somebody somewhere who helped them along the way.

He acknowledged that generally everyone tends to use some kind of help or support throughout their lives. This point was demonstrated by an incident when Keith woke up one morning with a dislocated shoulder. He realized he needed help,

[A]fter I dislocated my shoulder, I made a decision that ‘okay ... now is the time to arrange for somebody ... to hire somebody or something to do the things that I can hire somebody to do so that my body parts are preserved to be able to better do those things that I can't hire somebody else to do.

Even though he only needed someone to do basic housecleaning, he said he did not qualify for government support. Keith primarily needs to use a powered wheelchair; yet he said the rules had changed and, for some reason, he was not disabled enough to qualify for funding. He was not the only participant to comment on how some people with disabilities are assessed as too disabled for certain supports and yet not disabled enough to qualify for other support programs.

Ted lives on his own, even though he requires support with all his personal and functional needs, e.g., feeding, dressing, and bathing; his only source of mobility is a powered wheelchair. Ted's definition of independence is,

Independence means full citizenship to me. Independence means having the choice to decide what you're going to do in life and what you're not ... independence means that you also have the necessary supports to be able to actually ... live life to the fullest that you would like to live. ... I think that full participation is huge and goes right with the citizenship aspect, too, and I really don't agree that independence means that you ... you have to be able to do everything for yourself and ... something that has been hammered into me from when I was young that if you're going to be independent, you have to be able to dress yourself ... do this and this and this. For me that's not independence because even if I could ... and I can't ... but even if I could, it would take me two or three hours to get dressed on my own, and I know people that do that and ... to them, they believe that is independence and if that's what makes them happy, that's great but for me it's about wanting to be with my family, being able to enjoy the activities with my family, be able to earn income, to be able to support the kinds of activities that I like to do, you know....

Ted accepts the need to be interdependent or inter-reliant in order to be independent. He acknowledged from a young age his need for support if he was going to have the freedom to participate in activities in which he was interested. Ted moved out of a group home to be on his own for the first time at age 19. To do so, he had to fight for the kind of support he needed. The government agency with which he was working told him it was impossible for him to live on his own because they would only allot four care hours per

day, even though he had 24-hour care living in a group home. The four hours allotted were for specific times which he said would not work for him. The agency informed him that he had to get up at 6:00 AM every day of the week, be home in the afternoon by 4:00 PM and go to bed at 7:00 PM. Ted's response was, "that's not independence"! He viewed group homes as mini-institutions and was determined to live on his own. Fortunately, by chance, he heard about a program the government was introducing that allocated a certain amount of funding to the person with the disability so that he could manage his own care needs (e.g., staffing, scheduling). Ted demanded to be allowed to partake in such a program. He fought to receive enough funds to pay for six care hours instead of four. He hired someone he knew would be flexible about working with him so that he could participate in the activities in which he wanted to participate. Ted is now married, fosters a child, works full-time and participates in a Paralympics sport.

Independence is everything to each of the participants, even though each has his or her own view of what independence means. Basically, all of the participants viewed independence as being able to live one's life in the manner that one desired. Whether they are able to achieve their goals by relying mainly on their own abilities or whether they are in need of natural supports or hired assistance, the participants all believe that they are entitled to create their own sense of autonomy.

4.2 Respondents' Validation or Member Checking

Respondents' validation or member checking is a process where the researcher returns to the participants with a summary of his/her analyses in order to confirm whether the analysis reflects the experience of the participants.⁸⁹ It is a way of comparing the researcher's findings with the experiences of the participants of the study. I contacted all

12 participants and received responses from seven. I sent a summary of the themes to the seven participants who responded. Alan, Tom and Sheila were available to discuss the themes over the phone whereas David, Ted, Wendy and Sara commented via email.

Alan, Tom, Sheila, Ted and David identified with the themes, especially *Independence is Everything*, finding them very interesting. While reading the theme *Independence is Everything*, Alan was saying to himself “that is me ... that’s me.” Tom enjoyed Keith’s expression of the “disability wowzer factor”, identifying with having those kinds of experiences. He was surprised by the similar views of all the participants. The data also affirmed Tom’s belief that it is the responsibility of people with CP or any type of disability to educate others and recognizes that there is a lot of ignorance around disabilities. Sheila especially liked the theme, *Independence is Everything*, commenting that it does not matter if someone is self-reliant or interdependent but what matters is their perception of their own autonomy.

As a researcher, my notions of what it means to be independent were expanded after hearing the participants’ views on what independence meant to them. I realized that being independent does not necessarily mean doing everything yourself. I was amazed that one of the most disabled participants interviewed lived one of the fullest lives. He was married, fostered a child, had a full time job and competed in Paralympics sports, but could not dress or feed himself.

In the theme entitled *Awareness, Acceptance and Action*, Tom and Alan resonated with the process of first needing to become *aware* and then having to *accept* before they are able to take necessary actions. Alan suggested I add “feeling safe” to feeling secure because he relates feelings of security with feeling safe. Alan especially related to my discussion on fatigue, commenting that the description accurately portrays his own

fatigue experiences. He agreed with emphasizing the need for adults with CP to take their own initiative. Alan and Tom both expressed how much they resonated with the data in all three themes. Ted was pleased with the themes saying that my summary reported most of what he wanted to say and what he wanted to hear from others. However, he suggested that the section on disempowerment could be expanded. I added a comment in the section on disempowering experience about Ted being told, “he would never amount to anything and should rely on his disability check.” This was a disempowering experience that he had not expressed in his interview. David’s comment was brief, just stating that he thought the content of my summary was accurate.

Wendy responded via email commenting that my themes were “great” and that they probably applied to many age groups and across other disabilities. Nevertheless, she brought to my attention that I was incorrect in reporting that people in wheelchairs were more dependent. I appreciated her comment because I was not intentionally saying that people using wheelchairs/power-chairs were more dependent but she read it that way. Perhaps my wording came from my own bias of viewing my (eventually) having to use a wheelchair as being more dependent, which is contrary to Wendy’s experience. Her comment gave me an opportunity to change the wording to state more accurately what I was meaning to say.

Sara responded via email and also identified with the findings. She thought that overall the themes resonated with her experiences. However she was hoping to see a more in-depth look at the foundational issues underlying the themes. Sara raised a couple of questions that addressed issues that need further discussion and research. These will be addressed in Chapter 5. Overall, the seven participants that responded to the request for member checking resonated with all three themes.

I do believe that some candidates seemed to benefit from the interview process because many expressed how much they enjoyed talking to someone who they believed understood what they were experiencing as they grew older with CP. As an interviewer with CP myself, I had the advantage of establishing trust with the participants. The participants appeared to be more comfortable during the second interview than the first, perhaps because I was able to establish a deeper rapport with some participants in the second interview. Some participants' lives had improved in between the interviews, or at least their perspectives on their lives had changed some.

4.3 Summary

The meanings attributed by the participants to their experiences of coping as they grow older with CP were expressed as three themes: *Awareness, Acceptance and Action, Negotiating One's World* and *Independence is Everything*. As the participants cope with growing older with CP, the first theme reflects their strategies of gaining *awareness* so that they are better able to *accept* what is happening to them physically and then positioning themselves to be better able to take appropriate *actions*. The second theme of negotiating one's world depicts the participants' experiences of both empowerment and disempowerment as well as their experiences of self-responsibility. This theme acknowledges those experiences that enhanced their lives and those that diminished their lives but also recognizes where they have been able to effect change by acting on their own behalf. In the third theme, the participants described what being autonomous means to them. *Awareness, acceptance* and *action* as well as how to *negotiate one's world* through education, employment, support and self-improvement initiatives are all ways by

which the participants have coped and have strived to live independent lives as defined in the third and final theme, *Independence is Everything*.

As mentioned in Chapter 1, Antonovsky's³² SOC concept is used to examine the potential for development of coping strategies. SOC consists of three components -- comprehensibility, manageability and meaningfulness. I believe each of the participants encompassed a sense of coherence to some degree. The results of this study supported Jahnsen et al.'s³³ study where adults with CP scored lowest in the domain of comprehensibility. Most participants reported experiencing unexpected secondary conditions as they grew older. Many participants also complained of a lack of understanding or knowledge from the medical community of what was happening to them as adults growing older with CP. Participants reported their struggle to obtain adequate resources that affects the manageability of growing older with CP. In the domain of meaningfulness, all the participants had a clear sense of what independence meant to them and what was needed to acquire and sustain their independence. The findings of this qualitative study of the coping strategies used by adults with CP as they grow older and how SOC concept took part in their coping potential will be discussed further in the next chapter.

CHAPTER 5

5.1 Discussion and Implications

Using a descriptive and interpretive approach to gather and analyze narrative data, this study sought to explore how adults growing older with CP view and understand their experiences. The focus of this research, revealed through the language of the participants' descriptions, was to understand the meanings attributed to the experiences of adults growing older with CP. As described earlier, the data were collected through semi-structured interviews with adults with CP over the age of 25 who were experiencing changes in their functional abilities.

The purpose of this chapter is to integrate and compare the findings of this qualitative study to Antonovsky's sense of coherence (SOC) concepts and existing literature on aging with CP. The implications of these findings will be discussed within the context of current health care services and the need for further research, limitations of the study will be presented as well.

5.1.1 Appraisal, Coping Strategies and Sense of Coherence (SOC)

Lazarus and Folkman define coping "as thoughts and behaviors that people use to manage the internal and external demands that are appraised as stressful."^{26(p.746-7)}

Lazarus and Folkman's theoretical formulation entails two separate aspects of the cognitive process people use to cope with stressful events or conditions. The primary appraisal evaluates the significance of the stressor or transaction in relation to the person's well-being. The secondary appraisal evaluates the manageability of the stressor and the resources or options available to the person. According to Folkman and

Moskowitz, the coping process begins to unfold as an individual appraises a situation or condition as personally important, trying, or beyond the individual's current resources for coping.²⁷ Two major functions of the coping process are described as problem-focused and emotion-focused.³⁰ Problem-focused function employs strategies directed at making changes to the environment or making changes to oneself. The emotion-focus uses strategies aimed at changing the way one thinks or feels about stressful situations. Additionally, Antonovsky's SOC concept (comprehensibility, manageability and meaningfulness) is used to examine the potential for development of coping strategies. The SOC model provides an understanding of how health is preserved under stressful conditions.³² All the adults who participated in this study were experiencing some secondary conditions as they aged. Even though all were living independently in the community, most viewed their lives at times as less comprehensible, manageable, and meaningful than the lives of their peers without disabilities. These findings are similar to quantitative results reported by Jahnsen et al³³ regarding coping challenges experienced by adults with CP.

In the current study, the participants reported experiencing secondary conditions, such as pain, stiffness and fatigue, which lead to changes in their functional abilities. These changes appeared to be happening at younger ages than in their able-bodied peers. The participants had never been informed of these possible secondary conditions and struggled to acquire knowledge and understanding of these conditions from medical professionals. Therefore, the unpredictability and lack of understanding of these secondary conditions seemed to undermine their sense of comprehensibility.

Participants described times in their lives when physical and social challenges seemed to be beyond their own capabilities. Contributing to the unmanageability in their

lives was the lack of funded services beyond the age of 18. Several participants believed that their loss of abilities as they grew older could have been prevented or minimized if access to rehabilitation therapies had continued into and throughout their adulthood.

Furthermore, participants were aware of their increased need for help as they grew older. Generally, help came from family members, friends, and or hired caregivers. The level of care needed varied among the participants, depending on their functional capacity. Some participants struggled to receive the amount of care hours they needed to live independent lives and participate in desired activities; however, some participants joined programs where they managed their own care. The latter group hired their own attendants and arranged care hours to enable their participation in meaningful activities of their choice.

5.1.2 Themes and Sense of Coherence

The themes developed in this research describe strategies used by participants to cope with daily life, although the strategies differed among them. In realizing that they needed to address physical safety issues, a number of participants made decisions to increase their use of mobility devices. Others recognized their increased need for support and were able to turn to family and friends for more help. Still other participants were able to hire caregivers or increase their care hours.

The theme *Awareness, Acceptance and Action*, reflects both emotion-focused and problem-focused strategies. *Awareness* was the first step in the coping process. Many participants were able to access coping strategies by acknowledging the difficulties they were experiencing with secondary conditions and then assessing their situations and the resources available. *Acceptance* and *action* employed strategies that included changes in

both attitude and environment. As participants embraced a more accepting attitude of themselves, they were better able to make appropriate decisions. Altering their lifestyles was a strategy used by those experiencing fatigue. Participants who were struggling with their balance abilities due to stiffness and pain made decisions about the use of mobility devices whereas others sought out various kinds of therapy. Most participants had not expected to be experiencing these changes at such young ages and wished they had been informed sooner so that they might have been able to take more preventative measures. In regard to their health and well-being as they grew older, all the participants seemed to be proactive, altering their lifestyles, seeking out alternative therapies or counseling, changing their diets and doing exercises. The theme *Awareness, Acceptance and Action* also reveals the participants' SOC as the strategies describe the participants' sense of comprehensibility and manageability.

The theme *Negotiating One's World* reflects the use of general resistance resources described by Antonovsky in the SOC model.³² Antonovsky identified the general resistance resources as biological, economic, psychosocial and cultural factors (material, ego identity, intelligence, coping strategies, cultural stability, social support and religion/spirituality) that make life easier to experience as consistent, structured and comprehensible. In his SOC model, Antonovsky claimed that these resources provide strength to combat stressors. The participants in the current study described how education, employment, supportive relationships (family, friends, caregivers and mentors) and self-improvement initiatives (alternative therapies, support groups, education/new learning courses) helped them to navigate through their lives. These were some of the resources that provided the participants with a sense of coherence as they coped with growing older with CP. Although many participants did not take part in

making decisions about therapies as children, they were actively involved as adults in their healthcare and well-being. Participants sought out alternative therapies as adults, learning more about their bodies and how they work through massage therapists, chiropractors and personal training coaches, which helped them understand and in some ways deal with the secondary conditions they were experiencing.

Independence is Everything revealed the participants' views of independence and what they believed they needed to live meaningful lives. Many participants reported times in their lives where they faced barriers or obstacles that prevented opportunities for success. Regarding educational and employment barriers, participants described experiences of discrimination and institutional unwillingness to accommodate their special needs. These barriers often interfered with the participants' abilities to create the lives they desired. Despite many of these challenges, participants often overcome obstacles and persevered to construct lives that they believed to be meaningful and worthwhile.

Regardless of the fact that their physical abilities seemed to deteriorate as they grew older, most participants described improvements in psychosocial aspects of their lives. As a result of accepting themselves and their CP, actively engaging in their own therapies, managing to find support, and being able to achieve education and/or employment goals, participants reported improvement in self-esteem, and social relationships as they grew older. The participants seemed to be able to maintain SOC in their lives as they grew older with CP.

5.1.3 Comparison of Study Findings with Other Literature

As described above, participants reported experiencing many of the same age-related biomedical and psychosocial conditions reported in other studies. Descriptions of increased pain with increasing age in the current study coincide with findings in other studies.^{13,21,54,56,57,61} As reported by Schwartz et al.⁵⁴ in a study using survey methods, stress/depression, overexertion and weather changes were factors that exacerbated pain, whereas exercising, stretching, resting, massage, and staying active seemed to relieve pain. These same strategies aimed at pain relief were used by participants in the current study.

Jahnsen et al.'s quantitative study¹³ reported that adults with CP who experience too high an impact of pain in their daily life coped by changing their lifestyle through reduced work hours, beginning to use a wheelchair or other compensatory technical devices, or applying for more home services. Jahnsen and colleagues' findings were mirrored by findings in the current study. Even though such changes may minimize pain, Jahnsen et al.⁸ and others^{13,33} have suggested that these measures can be perceived as a "defeat", leading to psychological distress because of accompanying activity and participation restrictions. Some participants in the current study described psychological adjustments when having to alter their lifestyle, use mobility devices or request more help. With few exceptions, however, most participants were accepting of the changes they needed to make as they grew older with CP.

Rapp and Torres² reported increasing numbers of adults with CP due to medical advances and de-institutionalization. Being part of a wider community provides opportunities for adults with CP to participate fully in life activities, such as careers,

marriage and children, while also increasing their expectations of themselves. In the past, there has been a lack of viewing individuals with CP and their possibilities throughout their lives (lifespan perspective) when planning programs.^{8,13,33} Participants in the current study believed in preventative measures and thought that ongoing therapies would improve or halt conditions contributing to their declining abilities. In terms of support from social and medical services, the current participants felt as though they were “forgotten” after turning 18 years of age.

Participants in the current study described personal and environmental factors that sometimes promoted but could also restrict their abilities to control their lives. Community and life participation were restricted not just by their physical impairments (biomedical) but also by environmental factors. For example, inadequate means of transportation and dependency on para-transit systems were environmental factors that at times restricted many participants’ sense of autonomy.

King and colleagues^{23,24} qualitative studies reported on social support needed by adults with CP. In the current study, peer support and companionship were important to the participants who desired support beyond their families and caregivers. They especially appreciated the support of peers who shared similar struggles of living with a disability. They desired to have someone in their lives who understood their struggles and provided hope and encouragement, similar to the findings by King and colleagues.

Furukawa and colleagues⁷⁰ quantitative study reported that the morale of adults with CP tended to be lower in those who were more dependent (requiring help every day), and also in those who were declining in their physical abilities. This finding was not supported in the current study. For example, morale seemed strong in the participant who required help with all his personal care. This participant was married, fostered a child,

worked full-time and participated in a Paralympic sport. In fact, the morale of most participants interviewed in my study appeared to be good and did not seem to be related to their functional capacity. They described feeling well-supported by family, friends and caregivers, although those participants who strived to be totally self-reliant seemed to struggle more with having to rely on others. Perhaps morale is linked more to a person's sense of autonomy and attitude than to their functional abilities.

As in Goodwin and Compton's qualitative study,²² participants in the current study recognized the need for physical activity in order to maintain hard-earned lifestyles and levels of functioning. Other previous studies^{75,76} found that adults with CP scored lower when rating themselves on their ability to perform behaviors that promote health because they found these behaviors difficult. In the current study, participants were actively engaged in the responsibility for their physical and psychological health. They described various ways in which they participated in health-promoting behaviors such as good nutrition, exercise and counseling. However, for those participants in the current study who used mobility devices (wheelchairs/power chair), prior study findings^{75,76} that adults with CP experience more difficulty exercising were supported. Those participants with greater need for adapted mobility devices require more access to rehabilitation therapists and exercise programs designed to address their functional needs.

Some participants in my study reported struggles with attaining education and employment opportunities. They had been discouraged from pursuing careers of their own interest because they had been told that they were unsuited for these careers. Others were forced to leave jobs or retire because of unaccommodating work environments. These findings are supported by those of previous studies^{6,77} that found that people with disabilities experienced decline in employment at a faster rate and at earlier times in their

lives than people without disabilities. These participants may have benefited from vocational rehabilitation counselors trained in working with adults with CP so their employment goals might have been met.

The participants' descriptions in the present study indicated that educational level, marital status, life satisfaction and fatigue were significant factors in SOC, in agreement with Jahnsen and colleagues' findings.³³ However, employment and gender also seemed to play an important role in SOC for the participants in my study, thus differing from results by Jahnsen et al.³³ Participants in the current study described employment as playing a significant role in enabling them to have meaningful lives. Descriptions of loneliness and depression seemed to be more prevalent in the female participants in my study. One could speculate that women with disabilities experience more discrimination that then restricts both their social and employment opportunities.

5.1.4 Implications of the Current Study's Findings

Therapy programs beginning in childhood have not adequately anticipated future challenges that may occur in adulthood. CP is a lifespan condition that manifests itself in many physical, intellectual, cognitive, and psychological ways.⁹⁵ Campbell recommended programs that are effective over the lifetime of individuals living with CP.⁹⁶ Both Svien et al.⁹⁵ and Campbell⁹⁶ stressed the need to improve clinical practices for adults with CP. Participants in the current study voiced similar concerns. Svien et al. and Campbell also recommended that service providers need to plan interventions, services and supports to enhance participation of adults with CP⁹⁵ and improve clinical practice to aim at prevention of secondary disabilities.⁹⁶

5.1.4.1 Implications for Health Care Practitioners

The findings of the current study support the establishment of therapy programs that focus on a lifespan perspective for individuals with CP. Physical therapy that puts an emphasis on participation in functional activities helps children to set appropriate goals that include participation in activities of their own interest and in their own environments. The current study suggests the need for practitioners to aid children in understanding how their therapy program may help them to attain their own unique goals. Mobility goals should promote independence, socialization and interaction with family and peers, but not at the expense of creating further musculoskeletal impairments. Therapists should promote participation in desired activities while at the same time encouraging awareness of energy conservation so that children and adults with CP are not over-stressing themselves to achieve independence at all costs. For example, therapists need to assess children for age-appropriate and socially-appropriate mobility, not ambulation at any cost.⁹⁶ As Campbell suggested, these goals should include keeping up with peers and opportunities for learning and pleasure. However, these goals should consider also the prevention of future musculoskeletal impairments that may result in later functional limitations or produce secondary conditions, such as pain or contractures, and the need for possible surgeries.⁹⁶

Antonovsky theorized that individuals who developed a sense of coherence early in life are better able later in life to activate the general resistance resources described in his SOC model.³⁴ Many participants in my study did not speak favorably of their childhood rehabilitation therapy experiences. Some did not remember much about their therapies and others spoke negatively of their experiences or felt that they were pushed

and given messages to be independent at all costs. Unfortunately, messages to be independent at all costs can result in children pushing themselves and perhaps causing musculoskeletal impairments that may later result in functional limitations.^{18,47,96} Current child-centered therapy practices that are designed to integrate therapy goals within the child's daily life are perhaps more enjoyable and hopefully have more lasting effects than the childhood experiences of the participants in the present study. Therapy practices where rehabilitation professionals address children's innate need to explore, learn, and seek pleasure may become more long-lasting.⁹⁶ Children need to feel a sense of control over their world. Current programs that are designed to provide children with an understanding of the role of therapy and attainable goals may enable children with CP to feel their efforts are worthwhile and may build a better foundation for SOC in these children than was the case for the participants in my study.

Preventive health care is important. Practitioners need to create programs promoting lifetime fitness and prevention where exercise, good nutrition, weight control, and stress management are included, as well as energy conservation, so that individuals with CP are not compromising their abilities. One way of conserving energy mentioned by participants in the current study was to prioritize activities so they were able to partake in those they most enjoy. Programs that help adults to alleviate or manage chronic pain are also needed. Campbell suggested interventions that improve range of motion, reduce spasticity and improve function and thereby perhaps delay chronic, CP-related pain.⁹⁵

Women with disabilities have special issues that are not getting addressed.⁴ Participants' experiences suggest the need for improved access so woman with CP are encouraged to have regular breast and pelvic examinations by healthcare practitioners who are trained in positioning adaptation. This practice should be available to all women

with CP. Emergency rooms need to have equipment that is adaptable to individuals with disabilities, making all emergency rooms accessible. Continual monitoring of the slow progression of changes in strength and range of motion and assessment of fitness and appropriateness of equipment is essential because often deterioration is slow and seemingly insignificant but decline becomes notable over time.^{18,95}

Health care providers need more sensitivity and greater expertise. When approaching the medical system, participants in the current study want to be addressed directly and to be heard. Training of healthcare providers and/or caregivers in how to listen and be sensitive to the needs and goals of adults with CP is required. All healthcare providers need to be aware of the unique healthcare needs of adults with CP.⁴⁷ Moreover, rehabilitation specialists are often in the best position to advocate for accessibility in healthcare and encourage preventative and routine examination for their clients with CP.⁹⁵

5.1.4.2 Implications for the Need for Independence or for Supportive Care

Individuals with CP need to better understand an inter-reliant sense of independence. Inter-reliant views of independence need to be supported so that children with CP grow up learning healthy ways of being supported, thus dispelling beliefs that independence means doing everything for one's self. Consequently, when these children reach adulthood, they may be better able to accept support that enhances independence rather than perceiving help as a loss of independence. Encouraging and valuing interdependence or inter-reliance during childhood may be helpful in later life in viewing the need for support as a means of empowerment rather than as a "loss" or "defeat".

There is a need for transition and implementation plans beginning in mid-adolescence that includes care coordination of finances and capable, adult-centered healthcare providers. Those working with individuals with CP (social service workers or/and healthcare providers) need to be particularly aware of the needs of these individuals during times of transition, such as adolescence to adulthood. These transition plans need to address moving away from child-centered to adult-oriented health care, from child-centered to adult-oriented activities, from school to work and from living with family to community living.^{45,97} Accordingly, Liptak suggests that transition planning include assessment of individual, family, and community beginning in adolescence, concurrent with findings in the present study. Participants would support the idea of developing transition and implementation plans that include care coordination, ensuring availability of finances for care and having interested and capable adult-centered healthcare providers to ensure success of the transition from adolescence to adulthood.⁹⁷

Participants desire the option to manage their own care workers. Programs that allocate funding directly to the person with the disability to manage their own care needs (e.g., staffing, scheduling) provide these adults with their own sense of agency, as described in the words of the participants. Participants spoke also of the need to improve the delivery of these programs. In some cases, the responsibility of hiring and scheduling their own home care was overwhelming. Finding innovative ways to facilitate adults with CP to manage their own care could be advantageous.

According to the participants in the current study, adults with CP need to be encouraged and supported to make their own choices about their lives. They want the freedom and support to be able to participate in activities they desire and be allowed to make decisions about their own lives. Beginning in childhood, active participation and

choice of meaningful activities are important in encouraging a sense of autonomy in individuals with CP so as to build self-esteem and provide them with a sense of their own agency in adulthood. For those who require assistance in their everyday lives, managing their own care workers provides them with freedom to choose how they may want to participate. Adults with CP should be encouraged in how to be assertive so they can address their own needs.⁵⁰

5.1.4.3 Implications of Study Findings on the Need for Client-centered Resource

Centers

Programs are needed that inform and promote ways for adults with CP to take responsibility for their personal health and to be informed and know what to expect as they grow older with CP. As the participants in this study stressed, health care and social service providers need to make more substantial information available so adults with CP are able to become informed consumers of health and social services.⁵⁰

Individuals with CP or other disabilities need to have a resource center where they can gain all different types of information, i.e., a center that people can easily access that does not require special skills to acquire information they need. Through continual input from adults with CP, local facilities such as CP agencies, independent living centers or wellness centers, should also help to facilitate dissemination of information, provide exchange of self-help information and offer support.⁵⁰ As expressed by participants in the current study, adults with CP desire to have access to information on optimal ways of maintaining their health and well-being. Adult-centered healthcare programs are needed that foster health and well-being in adults with CP.^{50,97}

5.1.4.4 Implications for Individuals with CP and Their Families

Adults with CP and their families need to advocate for health, education, careers, and care; they need also to recognize the implications of living with a lifelong disability. Participants in this study believed that it was important to be aware of the age-related changes they were experiencing as they grew older. Many of these changes occurred subtly over time. However, by being aware of and acknowledging these conditions when they begin to occur, and by taking advantage of rehabilitation, massage or alternative therapies, the progression of these conditions could potentially be better managed.

Adults with CP should be encouraged to advocate for greater access to medical services beyond just acute care services. Participants in this study desired a “one-stop shop” (central facility) where an occupational therapist, a physical therapist, a recreation therapist and support groups would be available as well as opportunities to attend workshops on aging issues and coping with change in their lives. Adults with CP appear to need and desire continued therapy that addresses issues such as range of motion, pain, stiffness, fatigue, and transferring skills. They need to learn how to access the healthcare system so that they are able to get their medical and therapeutic needs met.⁹⁵ Participants recognized the necessity of advocating for funded services beyond age 18 and believed that continued therapy beyond the childhood years might have delayed or prevented some of the secondary conditions they were experiencing. Adults with CP need to inform themselves and continue to advocate for research into ways to optimize function and participate in life activities.

Adults with CP should take responsibility for their own health and well-being by seeking out information from medical professionals in order to become informed

consumers.⁵⁰ The present study findings show the need for individuals with CP to take initiative to learn optimal ways of coping with the onset of secondary conditions they may be experiencing. They should seek out community programs and funding opportunities that may be available to them.

In taking responsibility for their own health, adults with CP need to know what their physician will do for them. One participant suggested that adults with CP need to interview their family physician and find out what the physician knows about CP. They should find out what connections the physician has to the medical community (i.e., other specialists, rehabilitation therapists) and whether or not the physician has hospital privileges. Often adults with CP require extra time and special equipment for proper examinations.⁴ The findings of this study suggest that adults with CP, especially women, find out up front whether a physician is equipped to handle any special needs or adaptations required for care and if the physician is willing to take the extra time that may be needed for examinations.

The present study's findings encourage adults with CP to gather for peer support so that common struggles may be shared, and support provided for problem-solving. However, peer support should not be exclusively from other people with disabilities. Individuals with CP also need able-bodied peers so they feel an integrated part of a community. This study's participants suggested that adults with CP need to accept responsibility for educating non-disabled people on what CP is and what it is not, recognizing that there is a certain amount of ignorance about CP. Understanding and information may help non-disabled people feel more comfortable and learn how people with CP or other disabilities wish to be treated.

Family members need to foster independence and inter-reliance. King et al²³ found that adults with CP need “to be believed in” by families and friends. Participants in the current study were raised in families that included them and allowed them to participate in activities similar to those of other children (e.g., camping, swimming, sports). This participation seemed to nurture a sense of normalcy in the present participants. Most of the participants in the current study participated in numerous activities (e.g. sports and fitness programs, travel, attended entertainment events) as adults.

Many participants’ descriptions portrayed positive potential for adults with CP, and this may be a source of hope for families who have children with CP. Families of adolescents with CP need to begin planning for transitions to adulthood when their children are in their mid-teens.⁹⁷ Families need to investigate services in the community that may facilitate transitions such as from home to community and from school to work. In planning for these transitions, families need to be informed of the financial and social resources available to individuals with CP. Participants in this study appreciated the support of their families but also expressed not wanting to be too reliant or dependent on them.

Adolescents with CP should be encouraged by their families to pursue advanced opportunities in education and employment, provided they are given the support needed, i.e., family, friends, professionals, attendants and assistive technologies. In planning the transition from school to work, vocational counseling may be helpful to individuals with CP and their families to develop employment strategies that include adaptations in work environments to ensure equal opportunities. Counseling may also be helpful in determining solutions that are suitable to both the adult with CP and the employer.

Professionals involved in vocational rehabilitation need to plan for the employment needs and accommodations with individuals who have disabilities that may aid them throughout their lives.⁷⁷

In conclusion, adults with CP need to work on their own behalf for health, education, and careers, as well as care needs. Family support that fosters independence and inter-reliance rather than dependence is important. Families may need to help access financial and social services for family members with CP, ensuring equal opportunities for full citizenship.

5.1.5 Future Research

More research is needed on what adults with CP are to expect as they grow older and what preventive measures can be taken to avoid or minimize the effects of musculoskeletal impairments, such as contractures, and pain. Studies are needed to address how to minimize excessive wear and tear on joints and muscles from overuse and spasticity, how to promote relaxation, reduce stress, and how to conserve energy during mobility.⁹⁶ New research could positively influence the development of programs for both children and adults to minimize the risk and impact of secondary conditions on the aging process.

More studies describing experiences of what independence means to adults with CP would be prudent. Further qualitative research may enhance adults' views of independence by exploring healthy ways to support independence through an interdependent or inter-reliant strategy. Examining different ways of describing supportive relationships that do not include the term "dependence" may be helpful.

Further studies exploring accessibility to healthcare services and the need for greater sensitivity and expertise on the part of healthcare providers might improve the ability of adults with CP to take care of their health. In particular, research into health issues faced by women with CP as they grow older is needed.^{4,55} Female participants in this study described how their healthcare needs as women with disabilities were not being met. They believed that there are unique health concerns of women aging with disabilities that are not being addressed.

Participants experienced various alternative therapies as helpful; however, studies⁹⁸⁻¹⁰⁰ have reported a lack of evidence as to the credence of claims about the efficacy of alternative therapies. Authors of these studies state that individuals with CP should not be discouraged from exploring alternative therapies but stress the need for sound scientific inquiry about the benefits and side effects of alternative therapies and possible new therapies of the future.⁹⁸⁻¹⁰⁰ Further evidence-based research of alternative therapies is warranted.

One participant stated that her struggle with loneliness and depression was not clinical but situational. Investigating factors experienced by participants in this study that contribute to isolation and depression, such as premature losses in areas of employment, health, function, mobility or independent living, would be beneficial. Continued research into underlying factors leading to lack of access to transportation, occupations and social activities is important.

This study's findings reflect the importance of adults with CP having opportunities for success and their need to be part of a community. A major access issue for the present study's participants was transportation. Investigating ways to improve means of transportation for individuals with disabilities is warranted. Research is required

into the accessibility of work environments and ways to optimize opportunities for adults with CP to pursue meaningful employment. Previous studies^{67,77} have suggested that future research should explore workplace conditions that contribute to changes in their functional abilities that may lead to early loss of employment.

Participants of the present study described experiencing being stereotyped as either “helpless or heroic”. Research that focuses on underlying assumptions that still operationalize these perceptions of people with disabilities has been called for by these participants. More research might help to dispel these unfounded or inappropriate perceptions of people with CP.

5.1.6 Limitations of the Study

The findings of this study are specific to the participants and do not necessarily reflect or describe the experiences of all adults who are coping and growing older with CP. This sample of adults with CP did, however, include participants from two Canadian provinces (where socialized healthcare is available) and represented community-living adults.

Another limitation may be that the inclusion criteria for this study limited the sample to those with CP aged 25 years or older who had achieved at least grade 12 in a regular high school curriculum (not special education).

Although there was merit in using a phenomenological approach in this study to describe the experiences of growing older with CP, this approach has limitations. The focus was on only a few individuals and interpretations of their experiences were done by only one researcher. Even though the findings were reviewed by three thesis committee members and credibility of findings was checked with participants, the analysis was

conducted solely by the author. Nevertheless, the findings provide important insights into coping strategies used by individuals growing older with CP.

REFERENCES

1. Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N. Proposed definition and classification of cerebral palsy. *Dev Med Child Neurol.* 2005;47:571-576.
2. Rapp CE, Jr., Torres MM. The adult with cerebral palsy. *Arch Fam Med.* 2000;9:466-472.
3. Zaffuto-Sforza CD. Aging with cerebral palsy. *Phys Med Rehabil Clin N Am.* 2005;16:235-249.
4. Turk MA, Scandale J, Rosenbaum PF, Weber RJ. The health of women with cerebral palsy. *Phys Med Rehabil Clin N Am.* 2001;12:153-168.
5. Andersson C, Mattsson E. Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Dev Med Child Neurol.* 2001;43:76-82.
6. Ando N, Ueda S. Functional deterioration in adults with cerebral palsy. *Clin Rehabil.* 2000;14:300-306.
7. Bottos M, Feliciangeli A, Sciuto L, Gericke C, Vianello A. Functional status of adults with cerebral palsy and implications for treatment of children. *Dev Med Child Neurol.* 2001;43:516-528.
8. Jahnsen R, Villien L, Stanghelle JK, Holm I. Fatigue in adults with cerebral palsy in Norway compared with the general population. *Dev Med Child Neurol.* 2003;45:296-303.
9. Murphy KP, Molnar GE, Lankasky K. Medical and functional status of adults with cerebral palsy. *Dev Med Child Neurol.* 1995;37:1075-1084.
10. International classification of functioning, disability and health: ICF. World Health Organization. Geneva, 2001;1-298.
11. Gajdosik CG, Cicirello N. Secondary conditions of the musculoskeletal system in adolescents and adults with cerebral palsy. *Phys Occup Ther Pediatr.* 2001;21:49-68.

- 12.** Jahnsen R, Aamodt G, Rosenbaum P. Gross Motor Function Classification System used in adults with cerebral palsy: agreement of self-reported versus professional rating. *Dev Med Child Neurol.* 2006;48:734-738.
- 13.** Jahnsen R, Villien L, Aamodt G, Stanghelle J, Holm I. Musculoskeletal pain in adults with cerebral palsy compared with the general population. *J Rehabil Med.* 2004;36:78-84.
- 14.** Jahnsen R, Villien L, Egeland T, Stanghelle J. Locomotion skills in adults with cerebral palsy. *Clin Rehabil.* 2004;309-316.
- 15.** Kemp B. What the rehabilitation professional and the consumer need to know. *Phys Med Rehabil Clin N Am.* 2005;16:1-18.
- 16.** Murphy KP. Medical problems in adults with cerebral palsy: case examples. *Assist Technol.* 1999;11:97-104.
- 17.** Pimm P. Cerebral palsy: non progressive disorder? *Educational and Child Psychology.* 1992;9:27-33.
- 18.** Strauss D, Ojdana K, Shavelle R, Rosenbloom L. Decline in function and life expectancy of older persons with cerebral palsy. *NeuroRehabilitation.* 2004;19:69-78.
- 19.** Sandstrom K, Alinder J, Oberg B. Description of functioning and health and relations to a gross motor classification in adults with cerebral palsy. *Disabil Rehabil.* 2004;1023-1031.
- 20.** Crawford C; The Ontario Federation for Cerebral Palsy. Aging, well-being and cerebral palsy. www.ofcp.on.ca/aging.html Published October 1996. Updated August 6, 2002. Accessed March 1, 2005
- 21.** Dudgeon B, Gerrard B, Jensen M, Rhodes L, Tyler E. Physical disability and the experience of chronic pain. *Arch Phys Med Rehabil.* 2002;83:229-235.
- 22.** Goodwin DL, Compton SG. Physical activity experiences of women aging with disabilities. *Adapted Physical Activity Quarterly.* 2004;21:122-138.
- 23.** King GA, Cathers T, Polgar JM, MacKinnon E, Havens L. Success in life for older adolescents with cerebral palsy. *Qual Health Res.* 2000;10:734-49.

- 24.** King G, Willoughby C, Specht JA, Brown E. Social support process and the adaptation of individuals with chronic disabilities. *Qual Health Res.* 2006;16:902-925.
- 25.** Sandstrom K. The lived body- experiences from adults with cerebral palsy. *Clin Rehabil.* 2007;21:432-441.
- 26.** Lazarus R, Folkman S. *Stress, appraisal, and coping.* New York: McGraw-Hill; 1984.
- 27.** Folkman S, Moskowitz T. Coping: pitfalls and promise. *Ann Rev Psychol.* 2004;55:745-774.
- 28.** Folkman S. Personal control and stress and coping processes: a theoretical analysis. *J Personal Soc Psychol.* 1984;46:839-852.
- 29.** Hood C, Carruthers C. Coping skills theory as an underlying framework for therapeutic recreation services. *Therapeutic Recreation Journal.* 2002;36:137-153.
- 30.** Lazarus R. Coping theory and research: past, present and future. *Psychosom Med.* 1993;55:234-247.
- 31.** University of Twente. Transactional model of stress and coping. http://www.tcw.utwente.nl/theorieenoverzicht/Theory%20clusters/Health%20Communication/transactional_model_of_stress_and_coping.doc/ Accessed December 9, 2006
- 32.** Antonovsky A. The structure and properties of the sense of coherence scale. *Soc Sci Med.* 1993;36:725-733.
- 33.** Jahnsen R, Villien L, Stanghelle JK, Holm I. Coping potential and disability--sense of coherence in adults with cerebral palsy. *Disabil Rehabil.* 2002;24:511-518.
- 34.** Nilsson B, Holmgren L, Stegmayr B, Westman G. Sense of coherence- stability over time and relation to health, disease and psychosocial changes in a general population: a longitudinal study. *Scand J Public Health.* 2003;31:297-304.
- 35.** Richardson C, Ratner P. Sense of coherence as a moderator of the effects of stressful life events of health. *J Epidemiol Community Health.* 2005;59:979-984.
- 36.** Antonovsky A. The sense of coherence: an historical and future perspective. *Isr J Med Sci.* 1996;32:170-178.

- 37.** Malterud K, Hollnagel H. Positive self-assessed general health in patients with medical problems. *Scand J Prim Health Care.* 2004;22:11-15.
- 38.** Lundberg O, Nystrom P. A simple way of measuring sense of coherence: experiences from a survey in Sweden. *Eur J Public Health* 1995;5:56-59.
- 39.** Lundberg O, Peck M. Sense of coherence, social structure and health. *Eur J Public Health.* 1994;4:252-257.
- 40.** Schumann A, Hapke U, Meyer C, Rumpf H, John U. Measuring sense of coherence with only three items: a useful tool for population surveys. *Brit J Health Psychol.* 2003;8:409-421.
- 41.** Caap-Ahlgren M, Dehlin O. Sense of coherence is a sensitive measure for changes in subject with Parkinson's disease during 1 year. *Scand J Caring Sci.* 2004;18:154-159.
- 42.** O'Carroll R, Ayling R, O'Reilly M, North N. Alexithymia and sense of coherence in patients with total spinal cord transection. *Psychosom Med.* 2003;65:151-155.
- 43.** The Rehabilitation Research and Training Center on Aging with a Disability. *Natural Course Study of Aging with a Disability.* Downey, CA, 2001.
- 44.** Fox MA. *A guide to cerebral palsy.* 3rd ed. Toronto, Ontario: Canadian Cerebral Palsy Association; 1991.
- 45.** Stevenson CJ, Pharoah PO, Stevenson R. Cerebral palsy--the transition from youth to adulthood. *Dev Med Child Neurol.* 1997;39:336-42.
- 46.** Kemp B. *Functional Change in Adults with Cerebral Palsy.* 58th Annual Meeting of Cerebral Palsy and Developmental Medicine, Los Angeles, CA, Sept 29, 2004.
- 47.** Murphy K, Molnar G, Lankasky K. Medical and functional status of adults with cerebral palsy. *Dev Med Child Neurol.* 1995;37:1075-1084.
- 48.** Antonovsky A. *Health, stress and coping.* San Francisco: Jossey-Bass; 1979.
- 49.** Christiansen C. Defining lives: occupation as identity: an essay on competence, coherence, and the creation of meaning. *Am J Occup Ther.* 1999;53:547-558.

- 50.** Overeinder JC, Turk MA. Cerebral palsy and aging: a framework for promoting the health of older persons with cerebral palsy. *Topics in Geriatric Rehabilitation*. 1998;13:19-24.
- 51.** Malraison P; Cerebral palsy and aging <http://www.geocities.com/Tokyo/7970/cpage.htm>. Accessed January 15th, 2003.
- 52.** The Round Table on Aging and Cerebral Palsy. <http://www.jik.com/awcp.html>. Updated March 6-7, 1997. Accessed Jan 29, 2003.
- 53.** Law M, Stewart D, Letts L, Pollock N, Bosh J, Westmorland M. McMaster University's Guidelines for Critical Review Form - Quantitative and Qualitative Studies McMaster University. Hamilton, On, 1998;
- 54.** Schwartz L, Engel JM, Jensen MP. Pain in persons with cerebral palsy. *Arch Phys Med Rehabil*. 1999;80:1243-1246.
- 55.** Turk MA, Geremski CA, Rosenbaum PF, Weber RJ. The health status of women with cerebral palsy. *Arch Phys Med Rehabil*. 1997;78:S10-17.
- 56.** Ehde DM, Jensen MP, Engel JM, Turner JA, Hoffman AJ, Cardenas DD. Chronic pain secondary to disability: review. *Clin J Pain*. 2003;19:3-17.
- 57.** Engel JM, Schwartz L, Jensen MP, Johnson DR. Pain in cerebral palsy: the relation of coping strategies to adjustment. *Pain*. 2000;88:225-230.
- 58.** Rosenstiel A, Keefe F. The use of coping strategies in chronic low back pain patients: relationship to patient characteristics and current adjustment. *Pain*. 1983;17:33-44.
- 59.** Jensen M, Turner J, Romano J, Strom S. The Pain Coping Inventory: development and preliminary validation. *Pain*. 1995;60:203-216.
- 60.** Nicassio P, Schoenfeild-Smith K, Radojevic V, Schuman C. Pain coping mechanisms in fibromyalgia: relationship to pain and functional outcomes. *J Rheumatol*. 1995;22:1552-1558.
- 61.** Jensen M, Engel J, Hoffman A, Schwartz L. Natural history of chronic pain and pain treatment in adults with cerebral palsy. *Am J Phys Med Rehabil*. 2004;83:439-445.

- 62.** Loge J, Kaasa S. Short Form 36 (SF36) health survey: normative data from the general Norwegian population. *Scand J Soc Med*. 1998;26:250-257.
- 63.** Loge J, Ekeberg, Kaasa S. Fatigue in the general Norwegian population: normative data and associations. *J Psychosom Res*. 1998;65:53-65.
- 64.** Mayston MJ. People with cerebral palsy: effects of and perspectives for therapy. *Neural Plast*. 2001;8:51-69.
- 65.** Thompson L. Functional changes affecting people aging with disabilities. In: Kemp B, Mosqueda L, ed. *Aging with a disability: What the clinician needs to know*. Baltimore, Maryland: John Hopkins University Press; 2004:102-128.
- 66.** Price R, North C, Wessely S, Fraser V. Estimating the prevalence of chronic fatigue and associated symptoms in the community. *Public Health Report*. 1992;107:514-522.
- 67.** Murphy K, Molnar G, Lankasky K. Employment and social issues in adults with cerebral palsy. *Arch Phys Med Rehabil*. 2000;81:807-811.
- 68.** McCormick A, Brien M, Plourde J, Wood E, Rosenbaum P, McLean J. Stability of the Gross Motor Function Classification System in adults with cerebral palsy. *Dev Med Child Neurol*. 2007;49:265-269.
- 69.** Bickenbach J, Chatterji S, Badley E, Ustin T. Models of disablement, universalism and the international classification of impairment, disabilities and handicaps. *Soc Sci Med*. 1999;48:1173-1187.
- 70.** Furukawa A, Iwatsuki H, Nishiyama M, Nii E, Uchida A. A study on the subjective well-being of adult patients with cerebral palsy. *J Phys Ther Sci*. 2001;13:31-35.
- 71.** Allen J, Dodd K, Taylor N, McBurney H, Larkin H. Strength training can be enjoyable and beneficial for adults with cerebral palsy. *Disabil Rehabil*. 2004;26:1121-1127.
- 72.** Jahnsen R, Villien L, Aamodt G, Stanghelle J, Holm I. Physiotherapy and physical activity-experiences of adults with cerebral palsy with implications for children. *Adv Physio*. 2003;5:21-23.

- 73.** Whiteneck G, Charlifue S, Frankel H, Fraser M, Garder B, Gerhart K. Mortality, morbidity, and psychosocial outcomes of persons spinal cord injured more than 20 years ago. *Paraplegia*. 1992;30:617- 630.
- 74.** Vandenakkler C, Glass D. Menopause and aging with a disability. *Phys Med Rehabil Clin N Am*. 2001;12:133-151.
- 75.** Becker H, Schaller J. Perceived health and self-efficacy among adults with cerebral palsy. *J Rehab*. 1995;61:36-42.
- 76.** Becker H, Stuifbergen A. Self-rated abilities for health practices: a health self-efficacy measure. *Health Values*. 1993;17:42-50.
- 77.** Mitchell J, Adkins R, Kemp B. The effects of aging on employment of people with and without disabilities. *Rehabil Couns Bull*. 2006;49:157-165.
- 78.** Lundberg O. 'Sense of coherence' from the general population's point of view. Swedish Council for Planning and Coordination of Research Report 98:9. Uppsala: Ord & Form 1998;42-53.
- 79.** Denzin N, Lincoln Y. The discipline and practice of qualitative research. In: Denzin NK, Lincoln YS, ed. *The landscape of qualitative research: theories and issues*. Thousand Oaks, CA: Sage; 2003:1-45.
- 80.** Hasselkus B. Beyond ethnography: expanding our understanding and criteria for qualitative research. *Occup Ther J Res*. 1995;15:75-83.
- 81.** Hammersley M, Atkinson P. *Ethnography: principles in practice*. London: Routledge; 1995.
- 82.** Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci*. 2004;18:145-153.
- 83.** Giorgi A. The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *J of Phenomenological Psychol*. 1997;28:235-261 Online 1-18.
- 84.** Husserl E. *Phenomenological psychology* (Trans. J. Scanlon). The Hague:Nijhoff; (1962/1977).

- 85.** Bergum V. Being a phenomenological researcher. In: Morse J, ed. *Qualitative nursing research: a contemporary dialogue*. Newbury Park: Sage; 1991:55-71.
- 86.** Stubblefield C, Murray R. A phenomenological framework for psychiatric nursing research. *Arch Psychiatri Nurs*. 2002;15:149-155.
- 87.** Giorgi A. Description versus interpretation: competing alternative strategies for qualitative research. *J of Phenomenological Psychol*. 1992;23:119-135.
- 88.** Morse J, Field P. *Qualitative research methods for health professionals*. 2nd ed. Thousand Oaks, CA: Sage; 1995.
- 89.** Mays N, Pope C. Qualitative research in health care. Assessing quality research in health care. *BMJ*. 2000;320:50-52.
- 90.** Angen M. Pearls, pith and provocation. Evaluating interpretive inquiry: reviewing the validity debate and opening the dialogue. *Qual Health Res*. 2000;10:378-395.
- 91.** Morse J. Designing funded qualitative research. In: Denzin NK, Lincoln YS, ed. *Handbook of qualitative research*. Thousand Oaks, CA: Sage; 1994:
- 92.** Sandelowski M. Focus on qualitative methods: sample size in qualitative research. *Res Nurs & Health*. 1995;18:179-183.
- 93.** Bogdan R, Biklen S. *Qualitative research for education. An introduction to theory and methods*. Boston: Allyn and Bacon; 1982.
- 94.** J Pearsall, ed. *Concise Oxford English Dictionary*. 10th ed. New York, NY: Oxford University Press; 2002.
- 95.** Svien LR, Berg P, Stephenson C. Issues in aging with cerebral palsy. *Top Geriatr Rehabil*. 2008;24:26-44.
- 96.** Campbell S. Therapy programs for children that last a lifetime. *Phys Occup Ther Pediatr*. 1997;17:1-15.
- 97.** Liptak GS. Health and well being of adults with cerebral palsy. *Current Opinion in Neurology*. 2008;21:136-142.

98. Rosenbaum P. Controversial treatment of spasticity: exploring alternative therapies for motor function in children with cerebral palsy. *J Child Neurol.* 2003;18:S89-S94.

99. Liptak GS. Complementary and alternative therapies for cerebral palsy. *MRDD Research Reviews.* 2005;11:156-163.

100. Hurvitz EA, Leonard C, Ayyangar R, Nelson VS. Complementary and alternative medicine use in families of children with cerebral palsy. *Dev Med Child Neurol.* 2003;45:364-370.

APPENDICES

Appendix A Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA



Department of Physical Therapy
Faculty of Medicine
T325-2211 Wesbrook Mall
Vancouver, British Columbia V6T 2B5
Phone: 604.822.7392
Fax: 604.822.7624
Web: www.rehab.ubc.ca

Consent Form

Coping Strategies of Adults Aging with Cerebral Palsy

Principal Investigator: Susan Harris, PT, PhD. Department of Physical Therapy, Faculty of Medicine, University of British Columbia (604 822-7944)

Co- Investigator: Marylyn Horsman, BGS, Master's Student (research for master's thesis), Research Graduate Programs in Rehabilitation Sciences, University of British Columbia (604 888-0611).

Purpose:

The purpose of this study is to investigate the coping strategies of adults with CP as they experience changes in their functional abilities due to getting older. In seeking to understand coping strategies in adults with CP, Ms Horsman will have adults with CP describe their experiences of getting older through audio-taped semi-structured interviews.

Study Procedures:

You will be asked to take part in two audio taped, semi-structured interview sessions. If you have difficulty speaking clearly due to your cerebral palsy, it is possible that the interview could be conducted by email instead of orally. Ms Horsman will ask the participants questions pertaining to their experience of getting older with CP. The first interview is anticipated to be 60 to 90 minutes followed by a second interview of 30-45 minutes. The second interview will be conducted after a few weeks so that you will have time to reflect on the questions raised in the first interview. You will be shown the transcript (written record of the audiotape or email correspondence) of the first interview. For the second interview participants who have significant difficulty with their speech may choose to compose written responses by email. After Ms. Horsman has analyzed your transcripts, she will check with you to see if her findings are representative of your experiences. Upon completion of the study, she will mail the results to each candidate if requested.

Potential Risks: Potential risks may involve the inconvenience of taking 2-3 hours of your time and the fact that you may become frustrated or upset about the changes you are experiencing in

function. In order to minimize these effects, the interviewer (Ms. Horsman) will: 1) create a comfortable atmosphere; 2) allow you to choose the setting where the interview will take place; 3) allow to choose whether you prefer to be interviewed in person or by email; 4) assure that the setting is private with little opportunity for interruptions; and 5) be empathetic and genuine to create an atmosphere of safety and comfort.

Potential Benefits:

The interview may provide you with a clearer understanding of your experience of getting older with cerebral palsy by talking about it. There are often psychological benefits from being able to talk about what a person is experiencing and to feel they are being listened to. By “giving voice” to the lived experience of adults aging with CP, we hope you will gain more understanding of your experiences and gain insight into coping with any changes in your functional abilities. The strength of this study’s approach is our assumption that your perspectives are fundamental to the understanding of your “lived experience”. Several previous studies have reported that adults with CP need greater knowledge and understanding to enhance their decision-making processes about their health. Further research investigating how adults with CP cope with stressors in their lives may serve to enhance your wellbeing and quality of life. Knowledge gained from this study may also help caregivers and health professionals in their delivery of services to adults with CP.

Confidentiality:

Your confidentiality will be respected. Ms. Horsman will use a coding system rather than your names or initials and will have the audiotape transcriber sign a letter of confidentiality as well. Your name will not be used in the transcripts. Your identity will only be known by Ms. Horsman who will ensure that your identity will not be disclosed through any of the information secured. However, the information itself may be available to the public through publication of the study results (but your identity will not be part of that). UBC policy requires that all research data be saved for five years. The audiotapes and transcripts will be saved in a locked file that only Ms. Horsman will have access to. At the end of five years, she will shred all transcripts and all audio tapes will be destroyed.

Contact Information:

If you have any other questions you may contact Marylyn Horsman 604 888-0611 or Dr. Susan Harris 604 822-7944.

Contact for information about the right of research subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-882-8598.

Consent:

Your participation in the study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without any consequence. You may withdraw or extract any data given at any time.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature below indicates also that you consent to participate in this study.

Print name of participant

Signature

Date

Appendix B Letter of Initial Contact

THE UNIVERSITY OF BRITISH COLUMBIA



Department of Physical Therapy
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T325-2211 Wesbrook Mall
Vancouver, British Columbia V6T 2B5
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Initial Letter of Contact

Title of Study: Coping Strategies of Adults Aging with Cerebral Palsy

Principal Investigator: Susan Harris, PT, PhD. Department of Physical Therapy, Faculty of Medicine, University of British Columbia (604 822-7944)

Co- Investigator: Marylyn Horsman, BGS, Master's Student (research for master's thesis), Research Graduate Programs in Rehabilitation Sciences, University of British Columbia (604 888-0611).

Invitation to participate

You are being invited to participate in this study because you are over age 25 years and have been diagnosed with cerebral palsy (CP) but have not been diagnosed with any other chronic illness. However, you may be experiencing changes in your functional abilities as you have gotten older and therefore are invited to participate in this study. You will need to be able to articulate and describe your experiences in a coherent manner during interviews by the researcher.

Purpose:

The purpose of this study is to investigate the coping strategies of adults with CP as they experience changes in their functional abilities due to getting older. In seeking to understand coping strategies in adults with CP, Ms Horsman will have adults with CP describe their experiences of getting older through audio-taped semi-structured interviews.

Who should not participate?

The study will focus on adults with CP over the age of 25 because results of other studies show that many adults with CP begin to experience change in their functional abilities after that age. The study is excluding persons who have been diagnosed with another chronic illness, in addition to CP, because the focus of the study is on the effects of living with CP only. The design

of the study requires participants who have achieved at least a high school diploma from a regular curriculum (not a special education program).

Study Procedures:

You will be asked to take part in two audio taped, semi-structured interview sessions. If you have difficulty speaking clearly due to cerebral palsy, it is possible that the interviews could be conducted by email instead of orally. Ms Horsman will ask the participants questions pertaining to their experience of getting older with CP. The first interview is anticipated to be 60 to 90 minutes followed by a second interview of 30-45 minutes. The second interview will be conducted after a few weeks so that you will have time to reflect on the questions raised in the first interview. You will be shown the transcript (written record of the audiotape or email correspondence) of the first interview. After Ms. Horsman has analyzed your transcripts, she will check with you to see if her findings are representative of your experiences. Upon completion of the study, she will mail the results to each candidate if requested.

Potential Risks: Potential risks may involve the inconvenience of taking 2-3 hours of your time and the fact that you may become frustrated or upset about the changes you are experiencing in function. In order to minimize these effects, the interviewer (Ms. Horsman) will: 1) create a comfortable atmosphere; 2) allow you to choose the setting where the interview will take place; 3) allow you to choose to be interviewed in person or by email; 4) assure that the setting is private with little opportunity for interruptions; and 5) be empathetic and genuine to create an atmosphere of safety and comfort.

Potential Benefits:

The interview may provide you with a clearer understanding of your experience of getting older with cerebral palsy by talking about it. There are often psychological benefits from being able to talk about what a person is experiencing and to feel they are being listened to. By “giving voice” to the lived experience of adults aging with CP, we hope you will gain more understanding of your experiences and gain insight into coping with any changes in your functional abilities. The strength of this study’s approach is our assumption that your perspectives are fundamental to the understanding of your “lived experience”. Several previous studies have reported that adults with CP need greater knowledge and understanding to enhance their decision-making processes about their health. Further research investigating how adults with CP cope with stressors in their lives may serve to enhance your wellbeing and quality of life. Knowledge gained from this study may also help caregivers and health professionals in their delivery of services to adults with CP.

Confidentiality:

Your confidentiality will be respected. Ms. Horsman will use a coding system rather than your names or initials and will have the audiotape transcriber sign a letter of confidentiality as well. Your name will not be used in the transcripts. Your identity will only be known by Ms. Horsman who will ensure that your identity will be not be disclosed through any of the information secured. However, the information itself may be available to the public through publication of the study results (but your identity will not be part of that). UBC policy requires that all research data be saved for five years. The audiotapes and transcripts will be saved in a locked container that only Ms. Horsman will have access to. At the end of five years, she will shred all transcripts and all audio tapes will be destroyed.

Contact Information:

If you have any other questions you may contact Marylyn Horsman 604 888-0611 email marylynhorsman@yahoo.com or Dr. Susan Harris 604 822-7944 email shar@interchange.ubc.ca.

Contact for information about the right of research subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-882-8598.

Consent:

Your participation in the study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without any consequence. You may withdraw or extract any data given at any time.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature below indicates also that you consent to participate in this study.

Print name of participant Signature Date

Print name of Co-Investigator Signature Date

Print name of Signature Date
Principal Investigator

Appendix C Guiding Questions for Interviews with Participants

I began by asking each participant their age, type of CP, education, employment, living status, and mobility status (Table 4.1).

1. Tell me a little about your background.

- Tell me about your childhood.
- Tell me about your teenage years.

2. Describe what were the things you enjoyed doing.

- Describe activities you partook in high school.
- Describe the types of relationships you had in high school.
- Describe what kinds of therapies you received as a child.

3. Describe your experience of aging with CP.

4. Describe any changes you maybe experiencing in your functional ability as you have become older.

- Describe how these changes may affect your life.

5. Were you informed that these changes may occur and, if so, describe how you were informed and what was your understanding of these changes?

6. Describe what you are doing to cope with these changes. What do you find helpful? Describe what adaptations you have had to use. What has helped make your life more manageable?

7. Describe what has been helpful versus what has not been helpful.

8. Describe your relationships with others.

- What kind of support system do you have?
- Describe how they help you.

- Have these relationships changed and, if so, describe how.

9. Describe how your life is different.

10. What are some of the things you enjoy about your life?

11. Have the changes in your functional abilities interfered with activities you enjoy doing? If so, describe.

12. Have you had to give up some activities and, if so, describe what other activities you enjoy.

Please describe.

13. What kinds of adjustments have you had to make in your lifestyle?

14. Do you feel seasonal changes? If so, what are some of the coping strategies you may use?

15. Tell me what independence means to you.

* The above questions were only used as a guideline. Not all questions needed to be asked because participants often volunteered the information that may have been solicited from the questions.

Appendix D Bracketing Interview

Interview with Researcher and a UBC graduate student

1. What were your experiences growing older and living with cerebral palsy?

MH: Well, cerebral palsy is something that I've had all my life so its part of who I am but I first starting getting some total back pain in my late 20's and surgery was recommended – a bone fusion. I had four young kids and they told me I'd be in a body cast for six months and I said there's no way. I can't do that. At that point I didn't relate to my CP.

2. Can I just go back to the very first thing you mentioned to me that it's part of whom you are? What do you mean by that?

MH: Well, I don't know life without CP, so it has formed and shaped who I am in the world, and how I relate to the world for the most part. Actually as I've gotten older I'm more aware of my CP because of it becoming more evident. I mean in the way that when I'm tired, I know my speech is more difficult and the way I walk is more difficult because I have more pain. I think I show my disability a lot more. I know from the responses of other people that it's more noticeable and that has been more evident.

3. So when you were in your sort of early 20's, what definition did you have for your CP? Like what things would you call CP?

MH: Well, up to that point, I don't recall being told much except that physiotherapy was recommended until I was 18. Beyond that there's not much you can do because CP is based on developmental movement. I mean it's like status quo...I no longer agree with

that, especially since doing my research. But, you know, I didn't have much limitation in my life. I mean I did whatever. I've always been part of an able-bodied world. I've probably done more than most people. I mean I've hiked, had four kids, learned to water ski after my third child was born. I knew my CP was there but when I say it was a part of me, I can't separate CP from me. I've been fortunate to have been able to do most of the activities I have wanted to partake in. It might take me longer to learn something but generally have I been able to learn. I no longer feel that that is true.

4. What do you think now of the experience of getting older?

MH: Well, you know, this is how I came about acquiring or getting into this research because I did, at first, separate the back pain from CP and other pains but then one day I looked up on the Internet a site called CP and Aging, and started reading people's stories and began to identify with their stories and realized that that was what I'm experiencing. I began to acknowledge that my pain and the fatigue were increasing.

6. So you mentioned pain and fatigue. Can you speak more about those two things? Maybe give me some examples.

MH: Last year especially, I was suffering a lot of pain at night so I wasn't sleeping well, so naturally I was tired during the day. So I don't know whether the fatigue is from that or fatigue because of my activities.

7. You mentioned back pain and neck pain. What are the other pains involved.

MH: Well, now I'm having pain from this hip. I don't know whether it's the hip joint but last year I was suffering a lot. I found relief by working with a Feldenkrais practitioner (alternative movement therapy) whom I've known for 14 years.

8. So how has this Feldenkrais practitioner explained to you, to help you understand aging with CP? Has he been part of that process?

MH: Feldenkrais focuses on a sense of how we use ourselves, so it makes sense that someone with CP would have more wear and tear on our joints. We create habits and patterns of movement, so one of the things he explained to me is when people are compensating for their balance they put their knees together, right, so I have that habit and have throughout my life so when I do that I'm popping out my hipbone so those muscles are having to work all day to keep that bone in place while at night, of course, the muscles tend to scream. Even sitting at the computer I was doing that same pattern so just being conscious of doing that and not doing that has made a difference.

9. This is an alternative way of dealing with it or dealing with pain. Have you tried mainstreamed medicine (western traditional medicine) and has that helped...is there an understanding there of what you're going through? Can you tell me some of those experiences?

MH: I did try mainstream medical. It's my own bias! What I get from mainstream medical, generally is a surgical solution or medical prescription and neither of those work for me. I'm sensitive to drugs. I don't necessarily say that is true for anyone else.

10. What about rehabilitation? Mainstream rehabilitation (e.g. physiotherapy, occupational therapy).

MH: I expect physiotherapy may help but I have a strong belief in the benefits of Feldenkrais. It really has made a difference.

11. You mentioned earlier that you don't do hiking anymore. Are there any other activities, as you've aged, you've had to reduce or discontinue.

MH: I water skied up to 50 and realized I better not do that anymore because I probably was going to hurt myself. I still am able to go for walks but I certainly have a limitation of how far I go. I'm trying to walk more because I'm starting to gain weight. I

have a bunch of grandkids and I'm very, very cautious of holding them or walking with them because I fell with one of them...

12. So, would you say that caution is something that has increased?

MH: Yeah! I'm more strategic in what I do, I guess, I'm just cautious because my balance isn't as good. I never hesitated with my own kids. Other people, I realize now, thought I was going to trip or fall or whatever with my kids, but I'm aware of myself now and I know I don't have the same kind of balance.

13. And so, that sounds like that answers something that has also deteriorated for you. And is impacting you.

MH: After the Feldenkrais session last year I've been better again. I was falling a lot last year before the work done by the Feldenkrais practitioner and my balance has improved but I'm still compromised. I've lost some balance ability.

14. And so how do you cope with these things that you're noticing? Are there any things other than this alternative therapy that you sought that you've found is helpful?

MH: I have some spiritual beliefs that I'm trying to practice. I think last year I was really getting pretty discouraged and one of the things that I think that helped me was sort of taking things day by day. Each day I optimized that tomorrow would be different, so that kind of kept me going...that tomorrow I might not feel this pain...I might feel better so I worked with myself, trying not to mentally and emotionally get discouraged and look for the things that are working and the things that I can still do, instead of things that I can't do and I try to be okay with who I am.

15. Do you find that categorizing things in your mind, having some kind of way of explaining things is helpful for you...to cope?

MH: I do find having an understanding helps me.

16. You said something earlier that just sort of tweaked my attention about what is normal aging and in a sense that in normal aging you deteriorate too, so how do you navigate that?

MH: Well, I guess we all have limits. Limitations are in context with one's own life, so maybe I'm still more capable than lots of people my age, but I'm less capable than I was. ... most of my life I know I've been blessed most of my life in that I've been able to do most of what I've wanted to do.

17. Do you compare...is there some kind of comparison that goes on?

MH: Well...somewhat...sure. I can't do what I used to be able to do. I can't keep up the same. It's interesting because some studies are showing that people with a disability often burn out trying to keep up and so part of my awareness has me trying to not overly push myself. That, too, may be a coping mechanism because I realize it's okay. It's okay if I can't do everything so I'm in touch with limits where maybe a lot of my life I would keep plowing through, so in that way I'm taking care of myself as I age.

18. Are you finding enjoyment?

MH: Oh, yeah. I am. I mean my kids are great and they are supportive and I'm learning how to be with the grandchildren; my husband can rough play and do things with them and I can't but I'm learning how to have a relationship with them in different ways. And my children are good about that and encourage that. So...yeah, it's just learning to be in the world differently...

19. And is that differently to how you pictured yourself being a grandmother?

MH: Probably not...yeah. I think I can do what I used to be able to do but I can't. So there are two voices going on but it's okay. I think I've made a mental adjustment.

20. And tell me about that process of making the mental adjustment. Was it over a

significant period of time?

MH: Yeah. I think doing this research has influenced me. I'm still working with myself but I'm accepting. I don't know what I'm going to have to accept in the future maybe being in a wheelchair or something but I'm not there yet so I don't have to go there.

21. The idea of being in a wheelchair...can you tell me a little bit about what that does for you?

MH: That's a pretty frightening prospect. I think if it comes to that I'll have to accept but I'm a long ways from accepting that prospect. Because I see it as being very, very limiting and yet, in some of my research I read, people choose that because it actually gives them more access but I can't see that. At this point I don't see that.

22. Right. Is there a fear?

MH: Oh...sure. And I think there will be a day when that will come about, but I'm not there yet and hopefully I'll get to a place where I will choose to do that for whatever reason.

23. What happens when some of these alternatives means of coping no longer help? Is surgery the last resort or will you consider perhaps going on to some kind of medication? Will you look ahead to that? What do you think about those things?

MH: I mean I don't know but I don't think so. Well...I don't know. With medication I'm always going to be very cautious of. I've acquired a way of dealing with pain. If they can give me something that won't affect me...I would rather live with pain than be living in that fog.

24. You said you found a way to cope with the pain. Can you enlarge a little bit on that?

MH: Keeping optimistic helps and I do some meditative practice. Pain's something that comes and goes. However when I was in chronic pain for six months, it did wear me

down. I also felt it did take a lot of mental energy and it took me out of social balance as well because a lot goes into dealing with chronic pain.

25. Can you communicate the journey that you're on with your CP to some of your friends? You mentioned that during that time of chronic pain, it affected you socially.

How has this journey affected you socially?

MH: Well it's not that I want to be a martyr but when someone's dealing with chronic pain, it's different than breaking something and you have a period of time and you're going to get over it, but with chronic pain it's different. One of the most profound studies that I've read was by Brian Dudgeon, (thesis committee member) on pain with people with disabilities because with chronic pain, the reason you don't talk about it is because it's so ongoing and to me receiving understanding and compassion is fine but when you have pain day after day after day. What's there to talk about? It's not being stoic but for me it's not always that helpful. I mean after reading that article I realized it was good for me to tell people in a general way that something was painful but to talk about it on an ongoing basis. What's the point? Now my husband, my children living with me know when I'm in pain because they observe when I'm suffering.

26. Now what do they do that's helpful and what do they do that's not helpful?

MH: I don't know. I guess I've set myself up as a pretty independent person. Sometimes I get after my husband because I think he should know that I need more help. I think he's willing but he's not a person that notices, you know, he's been so used to me being independent that he has gotten unaware of my CP. There's a lot of little things that he misses.

27. Tell me a little bit more about this value of independence.

MH: I'm working on that too ...that's a hard one to talk about. I realize to be too caught into independence for independence's sake is not healthy but I was raised in an environment

where...the people around me were not available so I think I acquired a sense that, I had to do everything myself because when I asked for help they were not available to help so I as a child I interpreted that as not deserving of help. It was like a rejection... So...that lingered with me, but in my adult life I've learned to choose people that can support me but I don't want anyone to carry me. I want to be an equal among my peers. I have people who are willing to help. I have begun to hire someone to come in and clean because I can't do it myself and when my children were still living at home they helped with cleaning but they are gone.

28. The steps to ask somebody to come and help clean – was that a difficult process?

MH: Well, to justify paying for someone...yeah, but now that I've got her, it's great.

29. Who suggested it? Was it your idea...your husband's idea...your family?

P: Yeah...kind of my family. It's always been out there; as an option, but yeah, rather than nag when it's time to vacuum and all that kinds of stuff, you know, we are at a stage where we can afford to hire someone, so I accept that.

30. Do you anticipate giving up some of your roles in the home?

MH: I'm not stuck on those roles. I mean my husband went to school for a long time and when I went back to school to finish my degree, he asked me "what do you need" and I said "I need a wife."

31. Has the aging process with CP affected your marriage in any way, would you say?

MH: Hmm...well, it depends what's what. We've had to go through a real re-evaluation of a lot of things, which I think a lot of people do if they're married long-term. I would say we had to re-negotiate the terms and there was a lot of past history that we had to get through, so I don't feel is just my CP per se has...I think really in my marriage, up to a certain point, I think I compensated for my disability because of my lack self-esteem. I would overkill and was negative on myself and my self-image and probably tolerated

things that I shouldn't have tolerated. And so, all that had to be worked through at a certain point in our marriage and gratefully we've done that and now, I'm okay with who I am. Sometimes the outside world would perceive my husband heroically because he lived with someone with a disability and when he was younger he would play that up but today he's done a lot of his own personal work; he sees those perceptions as false and we laugh about it because he knows how sick that is ... that people have those false perceptions. However it's difficult to change people's perceptions. For many years, I know the world gave him extra brownie points for living with a woman with a disability.

32. In this new research area of yours...in starting to think through aging with CP...has he entered into that with you? Do you feel like he's informing himself with you?

MH: Yeah, because I call him my in-home professor, so he's read all of my thesis; so when he read the research on functional loss. I think it hit him, but he knows that I'll find whatever there's to be found to help myself .

33. So ... if you did go to see someone ... say, ask a question of the physical therapist about this CP stuff. Would that not even enter into what you're researching ...?

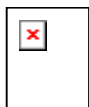
MH: It's not in their realm generally and that's why I haven't pursued it. Even my GP... my family doctor is fascinated with my research, but he doesn't know anything about how CP has affected my adult life.

34. You said, 'I had a hunch that I needed to anticipate aging; I anticipate something different for me in aging.' Is that a coping strategy?

MH: Yes and no. I can't know what's to come ... a year ago the chronic pain I was experiencing had me anticipating a wheelchair in two or three years but now it's better, so I think it's a mixed thing. Anticipation can put me places that I don't want to be so I ... actually I think more about coping strategies in the present to what I'm dealing with

today and try not to anticipate what may negatively affect me in the future.

Appendix E UBC Ethics Certificate



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road,
Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL- MINIMAL RISK RENEWAL

PRINCIPAL INVESTIGATOR: Susan R. Harris	DEPARTMENT: UBC/Medicine, Faculty of/Physical Therapy	UBC BREB NUMBER: H07-01672
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution	Site	
N/A		
Other locations where the research will be conducted: The site will be chosen that is most convenient to the participants. I am willing to interview in their home if that is the most convenient location. I will be interviewing candidates involved with the Cerebral Palsy Association in Alberta. I will most likely use a room in their facility to interview the candidate involved with their association if that is convenient to the candidates.		
CO-INVESTIGATOR(S): Melinda Suto Marylyn A Horsman		
SPONSORING AGENCIES: N/A		
PROJECT TITLE: The Coping Strategies of Adults Aging with Cerebral Palsy		

EXPIRY DATE OF THIS APPROVAL: July 28, 2009

APPROVAL DATE: July 28, 2008

The Annual Renewal for Study have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board

Dr. M. Judith Lynam, Chair
Dr. Ken Craig, Chair
Dr. Jim Rupert, Associate Chair
Dr. Laurie Ford, Associate Chair
Dr. Daniel Salhani, Associate Chair
Dr. Anita Ho, Associate Chair