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# Aging with a long-term physical impairment: An ever-changing process

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**Aging with a long-term physical  
impairment:  
An ever-changing process**

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## **Abstract**

The experience of people aging with long-term physical impairments is a relatively new area of research which requires further attention. There will be more people who reach old age who have lived with a long-term physical impairment as the population ages and life expectancy continues to increase. There is a gap in the research that explores life course theory while a person ages with a physical impairment. Using a life course perspective, this thesis examines the aging experiences of eight people between the ages of 50 and 68 who have lived with their physical impairment for more than 10 years. Data were gathered through in-depth, semi-structured interviews. My participants experienced problems in their life as a result of their physical impairment and the stereotypes and barriers constructed by mainstream society. Their impairments have led to physical, emotional and financial problems throughout their lives. They have learned to develop coping mechanisms, mostly on their own, to adjust to these problems and continue participating in society despite initial limitations. My thesis concludes by offering suggestions to improve policies to meet the needs of a large population of people aging with long-term physical impairments.

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## Chapter One – Introduction and Review of Literature

The unique experiences of people who are aging with long-term physical impairments have only recently begun to be examined by researchers. Often, their experiences and needs are subsumed under those of young disabled people, or they are treated as though they are the same as those placed in a homogenous group labeled ‘old’ (Priestley, 2003a: 146). While people aging with long-term physical impairments often have similar needs to those of younger disabled people, particularly because mainstream society is not designed to meet the specific needs of people with impairments, there are also important differences. Similarly, there are important differences between the experiences and needs of those who have reached the magical age of 65 to be catapulted into ‘old age’, and those who are still in the process of approaching ‘old age’. The purpose of this research is to highlight what is unique about the experiences and needs of those aging with long-term physical impairments, and determine what changes need to occur in society to improve their aging process. Ultimately, the research will show that, despite the best intentions of health professionals to help people with impairments, those aging with long-term physical impairments are largely left to their own devices to learn how to accomplish everyday activities while taking impairment into account.

This chapter begins with a discussion of the life course perspective, which frames the present research. It then turns to a review of the relevant literature, highlighting issues and insights that are useful for understanding the experiences and needs of those who are aging with a long-term physical impairment. The chapter concludes with a brief discussion of the need to study aging with a long-term impairment using a life course perspective, and the significance of the present research.

## ***Life Course Perspective***

One way to research the experiences of people aging with long-term physical impairments is to use life course theory. Combining life course theory and disability research is useful because disability can impact a person's life differently depending on where they are situated in the life course (Priestley, 2003a, 2). For example, younger people are not commonly expected to have impairments while older people are typically expected to have impairments.

Bengston and Allen (as cited in Bengston, Burgess, & Parrott 1997: S79) list four things that life course theory is useful in explaining. It can be used to explore the aging process, trajectories that occur at certain ages, how aging is impacted by “social contexts, cultural meanings, and social structural location”, and “how time, period and cohort shape the aging process”. Theoretically, the life course is understood as a constantly changing process where a person learns about him or herself and builds upon past experiences. Life events, such as marriage, children, careers and social interactions all impact how a person experiences the aging process (Elder, 1994: 5).

While life course theory typically does not focus on “illness and disability, this paradigm is often used to examine the effects of normative and non-normative experiences on the life course. As such, life course theory can function as an entry point for examining the impact of illness and disability” (Slota & Martin, 2003: 21).

A special edition of the journal *Disability Studies Quarterly* was created in 2003 to address the growing interest in combining life course theory with disability studies. In an introductory article Priestley (2003b) describes the benefits of using life course theory in disability studies to see how disability impacts an individual's life, or to understand the way society is structured and how barriers impact the lives of people with impairments throughout

their life (2003b: 1). For example, policies are developed with the notion of life course events that people should strive to achieve. These could be goals that some people with impairments are unable to achieve (Priestley, 2000).

### ***Research on Aging with Impairment***

There is a growing literature on the experiences and needs of those aging with long-term physical impairment. Much of this literature is framed by a social model perspective on disability, which essentially argues that disability does not inhere in an individual body but is created by the social and physical environment.

Under the terms of the medical model, which is hegemonic, illness or impairment is viewed as an individual problem and the individual is often blamed for the problem (Estes & Binney, 1989: 588). The person becomes a problem that needs to be treated by the health care system (Oliver, 1993). Many people with impairments are aware of this concept in society and may feel embarrassed and ashamed about their impairments (Winkler, 2004: 285).

In contrast, “social model approaches to disability focus on explaining the social processes and forces that cause people with perceived impairments to become disabled, as a minority group in society” (Priestley, 2003a: 14). People are disabled because mainstream society does not meet their needs rather than because something is inherently wrong with the person. “‘Disability’ is not, therefore, a product of individual failings but is, instead, socially created. Explanations for its changing character are located in the organisation and structures of society” (Barnes, 2002: 314). Disability, from a social model perspective, can be eliminated if society is restructured to meet the needs of all people (*ibid*).

A social model perspective meshes well with a life course perspective, in that it does not conceptualize disability as static and dichotomous. Zola (1993) argues this point by stating, “It is

more fruitful to conceive of disability as fluid, continuous, and holistic ... disability is thus not a fixed state but a continuously changing and evolving set of characteristics” (24). As well, Stone (2003) states that “disability is ubiquitous; it is utopian to imagine that it can be prevented. There always have been and there always will be, variations in what people are able to do, both in that different people have differing abilities and in that a single person has differing abilities over the course of a lifetime” (65).

The following review is organized to draw attention to literature that addresses physical impacts of aging with long-term physical impairments, issues of mainstream attitudes and barriers, the related issues of medical care and financial consequences, and addresses how people cope with the impact of their impairments.

## Physical Impact

### **Premature Aging**

People who are aging with long-term physical impairments often have new experiences and problems linked to the socially constructed concept of old age. Regardless of their chronological age, people who are aging with long-term physical impairments often experience declining physical mobility, fatigue and additional health problems after they have aged with their impairments for several years (Thompson, 2004: 110-118; Zarb, 1993a; Zarb & Oliver, 1993: 59). Research on aging with long-term physical impairments has shown that people with certain types of impairments, such as spinal cord injuries (SCI), cerebral palsy, etc., will age faster and sooner than people who have not aged with long-term physical impairments (Lankasky, 2004; Pentland, Tremblay, Spring & Rosenthal, 1999). This concept is referred to as “premature aging” (Sheets, 2005: 38; Zarb, 1993a).

Based on research completed with people aging with early onset physical impairments, researchers found that an accelerated aging experience occurs fifteen to thirty years after the impairment occurred, regardless of chronological age (Kemp & Mosqueda, 2004; Trieschmann, 1987: 4; Zarb, 1993a). Much of this research involves people aging with spinal cord injuries, cerebral palsy, and polio. However, Kemp and Mosqueda, and Trieschmann suggest that people who are aging with long-term physical impairments, regardless of their physical impairment, will experience this accelerated aging process.

The aging process for those who have aged with long-term physical impairments is often considered to be a second impairment (Zarb, 1993b: 191). Zarb described the changes that occur to people, which are often sudden and unpredictable, as second impairments because the person who is aging with an impairment often experiences a problem or a crisis that is linked to aging or to a personal change. Even if people experience additional problems as they age, the problems may not be permanent and some people are often able to adjust to the new limitations (*ibid*).

Aging faster occurred for the participants in Pentland et al.'s (2002) research. Their participants included 29 women aged 31 to 70 who were interviewed about their experiences of aging with spinal cord injuries. They found that participants were experiencing less mobility, less strength and more pain as they aged. The women identified the physical changes as being related to using a manual wheelchair for a long period of time and the aging process (378). Some of the women reported feeling as though the high levels of pain controlled their life.

Lankasky (2004), who is aging with cerebral palsy, was thirty-five years old when she experienced signs that she was aging faster than her chronological age. She was both relieved and frightened when she learned that the new symptoms she was experiencing, more aches, pains

and tightness, changes in her menstrual cycle, and bladder weakness, were linked to accelerated aging.

Perhaps one problem with researching aging and impairment, which was noted in Pentland, Tremblay, Spring and Rosenthal's (1999) study of disabled women aged 25 to 71, is that participants may not be able to differentiate between the aging process and their impairment (114). Pentland et al. (1999) used interviews to examine how physical impairments impact women's occupational transitions during the aging process. All but one of the participants were aging with various forms of mobility impairments. Their results showed that, despite difficulties with differentiating between impairment and aging, there was a "generalized belief that disability hastens and compounds the ageing process" (*ibid*: 114).

In contrast, other evidence suggests that not everyone experiences "accelerated aging". The case studies included in Gerhart's research (1993) are about people who are aging with spinal cord injuries and the changes they experience in their bodies as they age. One participant does not believe that there is definite proof to show that people with physical impairments age faster than their non-disabled peers. While he recognizes that there is research available that suggests he should age faster, he is not worrying about aging faster until he sees a research study that reports more definite findings.

### **Home Modifications**

Modifications to the home are usually beneficial in helping people who are aging with physical impairments adapt to the changes they experience. Most homes, especially older homes, are not accessible or supportive for people with physical impairments, especially for people who use a wheelchair (Dunn, 1990; Nishita, et al., 2007). Dunn researched how a person's housing environment impacts the ability to live independently. He used a stratified, random sample of

300 people with Cerebral Palsy who were clients of “Project Open House” in New York City (p. 40-41). Dunn used the Barthel score to measure how much assistance participants required for activities of daily living. The findings supported the fact that home environments and home modifications are important in managing independence and improving health for people with impairments.

Homes have many barriers that often impact the accessibility for people with physical impairments and, as a result, are disabling (Heywood, 2004). Homes that are not modified for people with physical impairments can cause pain, accidents, illness and depression (*ibid*). Heywood’s research was completed in England and Wales to determine the effectiveness of home modifications. The research team completed 104 interviews with people who had major adaptations completed in their home and 162 mailed questionnaires were returned by participants who had minor adaptations done to their home. The sample was random and stratified to include participants who had home adaptations completed between the years 1992-1998. The sample was diverse and included participants from a variety of districts, racial/ethnic groups, and age ranges. Findings showed that housing adaptations can improve a person’s health and mental status (*ibid*). People with homes adapted to meet their needs were able to have more control over their actions, worried less about falling, had less frequent incidences of depression, did not have to ask for assistance as often, and were not embarrassed by their living conditions (*ibid*). For example, one participant had a commode in the kitchen and it would often smell. This participant was embarrassed to have company visit because of the smell. Other participants reported feeling depressed because they could not leave their home and had to rely on others to help them complete tasks, such as bathing, dressing, etc. (*ibid*).

Making modifications to a home is often a continual process as a person ages with physical impairments. As a person experiences further physical limitations, more modifications will likely be needed (Trieschmann, 1987). For example, Trieschmann describes how a step that could be negotiated in a manual wheelchair becomes a barrier for an electric wheelchair. The person using an electric wheelchair may need to have a ramp built. When transfers in and out of a bathtub become too challenging, a person may require a roll-in shower (*ibid*).

### **Assistive Devices**

Wheelchairs are the visual symbol associated with disability, which may make it difficult for a person with mobility impairments to accept the benefits of using a power wheelchair. Despite the stigma attached to a power wheelchair, they improve the ability to move without assistance (Pentland et al., 2002).

Using a power wheelchair can reduce the amount of personal assistance required, as Ripat and Booth (2005) found in their research on how assistive technology impacts the lives of people with physical impairments. Ripat and Booth completed semi-structured interviews with three focus groups. There were 18 adults included in the research and the groups consisted of key stakeholders who were either, assistive technology services providers, funders or users. Ripat and Booth argue that as a person ages, their need for assistive devices changes (1469). For example, they describe the process of determining what type of wheelchair a young teenager needs. The type of wheelchair may depend on his/her goals for the future. Clients, they argue, need to be clear about their needs and priorities so that assistive devices can actually match their needs.

While assistive devices or technology can greatly improve a person's ability to accomplish certain tasks, not everyone has access to what they need. Some assistive devices are

too expensive for people with physical impairments to afford, as Verbrugge, Rennert and Madans (1997) found in their analysis of American data.

### **Impact on Employment**

For those who decide to continue working, modifications may be needed to the work environment to accommodate their changing physical abilities. It is common for people with physical impairments to resist asking for modifications to the work place. McMullin and Shuey (2006) found that certain factors are required before a person will ask for modifications. Their research uses data from the Canadian 2001 Participation and Activity Limitation Survey (PALS) to understand why people do or do not ask for workplace accommodations and whether the accommodations are addressed. Their findings suggest that employees who feel their limitations are a result of aging, rather than a physical impairment, are less likely to believe they need modifications. Those who did ask for modifications to assist with their age related limitations were less likely to have their needs addressed. Older workers who were close to retirement age often felt that they did not require accommodations because, as they justified, they would not be working much longer. Lower income earners were less likely to receive modifications, perhaps because they lacked resources. Instead, lower income earners would often hide their limitations for fear of losing their jobs (McMullin & Shuey, 2006).

Dyck's (1999) participants who have multiple sclerosis (MS) experienced problems at work because many had invisible impairments. Most of the participants decided not to disclose their health problems for fear of being fired, not being promoted, and jeopardizing eligibility for disability insurance or pension. Dyck found that women who had higher levels of education and worked as professionals or in managerial positions had more control over their work environment and were able to continue working longer than women who were less educated or

worked at lower paying jobs. The women who worked at jobs involving physical tasks, such as hair dressers, had to reduce their hours or quit working (*ibid*).

### Mainstream Attitudes and Barriers

Mainstream society has linked old age and disability together, and this is problematic for people with physical impairments. Those who are considered to be ‘old’ are devalued in society and considered to be sick (Stahl & Feller, 1990). People who are either older and/or disabled are commonly viewed as dependent (Oldman, 2002) and frail (Grenier, 2005). Because of the strong association between old age and disability “it can be difficult to realize that the two states are not necessarily coterminous. These correlations are, nevertheless, deeply problematic” (Stone, 2003: 59). Stone recommends that “we must demystify the phenomenon of disability, and we need to challenge the myth that disability necessarily entails dependence” (60).

Oldman (2002), in a review of studies focusing on older people and people with disabilities, notes that old age is often associated with impairments, pain, and limitations. Oldman argues that the stigma associated with ageism is much stronger than the stigma associated with disability. People may often feel sympathy for people with impairments, but this sympathy is not always present for older people (804).

Sheets (2005: 38) argues that people aging with long-term physical impairments have no defined location in society where their needs are adequately met. Disability services are focused on the younger, working population. Disability rights activist groups tend to concentrate on independence and work opportunities (Cohen, 1988: 26). In comparison, services for elderly people are geared towards the medical treatment of diseases associated with the aging process (Putnam, 2002: 799). Zarb (1993a) also recognizes the lack of policies and services that meet the needs of people aging with long-term physical impairments. Services are often geared

specifically for younger people or people over 65 years of age. Categorizing people who are aging with long-term physical impairments into a homogenous elderly population does not allow an opportunity for their needs to be adequately addressed as they approach old age (Zarb & Oliver, 1993: 13).

### **The Pressure to Age Successfully**

There is pressure in mainstream society to be able-bodied, given that society is structured to meet the needs of young, able-bodied individuals (Overall, 2006; Wendell, 1996). Both ableism – discrimination based on ability – and ageism – discrimination based on age – pervade society, so that those who are disabled and/or old are viewed negatively (Overall, 2006). Because of these stereotypes, people who are older and disabled are often not treated with respect and dignity (*ibid*).

A way for people to avoid being marginalized based on their advancing age is to age successfully. The recent trend in society is to promote what has variously been termed successful aging, positive aging, normal aging, or the elderly mystique (Cohen, 1988; Katz 2000, 2001; Stone 2003). All promote the idea that to succeed at aging, one has to be eternally young and active (Cohen, 1988: 28). Those who are disabled, dependent, experience a decline in functional ability or show signs of aging are not popularly understood to be aging successfully (Putnam, 2002: 800; Sheets, 2005: 34).

Cohen (1988) stresses the importance of not blaming the individual for showing signs of aging, but rather blames society for the creation of the elderly mystique. Similarly, Katz (2000, 2001) critiques the concept of successful aging, arguing that according to dominant ideas, only people who experience no decline in functional ability and those who do not show the signs of old age are able to age successfully. These ideas pervade contemporary, mainstream society and

make it difficult for people aging with long-term physical impairments to be understood as aging successfully, and thereby be treated with respect and dignity.

## **Barriers**

It can be challenging to socialize outside of the home for people with long-term physical impairments. Many people feel isolated because physical and interpersonal barriers stop them from personally interacting in mainstream society (Pentland, Tremblay, Spring & Rosenthal, 1999; Tighe, 2001). Tighe interviewed eight women, seven with cerebral palsy (CP) and one with a spinal cord injury. While the focus was on health and disability for women with physical impairments, Tighe also wrote about the physical barriers in the lives of her participants that restricted their ability to navigate the environment. An example could be as simple as the lack of a curb cutout which makes it easier for people to cross the street. One of Tighe's participants who uses a wheelchair spends extra time in a grocery store because she cannot reach items on the top shelves. Participants discussed becoming discouraged because they feel society should be barrier-free (*ibid*). When the women face barriers in their everyday life it takes extra time to overcome the barrier or find someone to assist them. This extra time can make them late for appointments or leave them tired and worn out (*ibid*).

Inaccessible environments can make it difficult for people with physical impairments to leave their own home, as Fong, Finlayson and Peacock (2006) found in their study of 27 older adults with MS, who were interviewed about the social experience of aging with MS. The participants were between the ages of 55 to 81 and nine were unable to walk, while five could not get out of bed. Participants reported needing to give up activities such as church, support groups, and visiting friends and family members, because of barriers in society (*ibid*: 702).

The participants included in Grenier's (2005) research, 12 older women living in Montreal, spoke about the barriers they experience when using public transportation. Using the bus seemed to create a situation of frailty for many of the participants because of difficulties with mounting the stairs. The event of using a bus could become a tiring, and sometimes frightening, experience for them. Stairs at subway stations also created barriers for some, and one participant in Grenier's research had to stop using the subway because of the stairs (138).

Interpersonal barriers, as described by Tighe (2001), include intolerant attitudes about people with physical differences. All but one of Tighe's participants, who are aging with either CP or SCI, used a wheelchair for mobility. The participants said that people treated them differently based on their visual differences (517). This was especially evident regarding use of a wheelchair, and participants discussed the negative stigma associated with wheelchairs. Tighe describes a wheelchair as the "visual marker for disability and as proof of "body code" violation" (515). The participants spoke about the perceptions of others that assume walking is the proper way to get places in society, and the perception that wheelchairs are for older people or people who are sick (*ibid*). One participant spoke about children asking her about using a wheelchair while the mothers appear embarrassed by their child's curiosity. Another participant believed that people respond the way they do towards wheelchairs because they lack exposure to them (*ibid*). Overall, the women felt that when they were seen using a wheelchair it became the focus of attention and not the person using the wheelchair. These attitudes have a negative emotional impact on Tighe's participants.

Similarly, DeSanto-Medeya (2006) interviewed people who had lived with a SCI for five to ten years to examine how they make sense of their experiences. The participants discussed

feeling judged by mainstream society based on their visible differences. One participant spoke about feeling as though people saw her as someone who is scary (*ibid*).

The participants in Gordon, Feldman and Crose's (1998) research, 40 women between the ages of 28 and 79 with various types of progressive chronic illnesses, spoke about how chronic illness impacted their lives. Many felt that they were judged when using the designated parking spots, especially if they had an invisible impairment. Some spoke about feeling as though they had to justify why they were using the parking spot and even started to question their own right to do so. Another common feeling was that others might view them as taking advantage of their impairment by using a parking spot that was much closer to the entrance (*ibid*).

Altogether, the studies by Tighe (2001), DeSanto-Medeya (2006), and Gordon, Feldman and Crose (1998) make it clear that impairment can make people vulnerable to the negative judgments of others, which can lead them to suffer on an emotional level. Participants in these studies were not selected based on whether they were role models for others or appeared to be well integrated into society. However, van de Ven et al. (2005) interviewed four people who were seen to be role models for the disability movement and eleven people with physical impairments who appeared to be well integrated in society. The purpose of their research was to determine what factors influence integration for people with impairments. They found that those who integrated well into mainstream society managed to minimize the impact of their impairment and mimic the actions of able-bodied people (316). Other participants had a difficult time integrating into mainstream society based on the negative stereotypes about disability. The authors argue that mainstream society often views people with impairments as less capable and overemphasizes a person's ability which further oppresses the person with an impairment (320).

In conjunction with other research, van de Ven et al.'s research makes it clear that the problem of stigmatization is pervasive, affecting disabled people with a variety of impairments, from a variety of backgrounds. In other words, a problem for many people with impairments is that they are often judged based on their impairment and not who they perceive themselves to be, and this serves as a barrier to participation in mainstream society.

### **Gendered Stereotypes**

While people with impairments are subject to stereotypes based on disability, they are also subjected to stereotypes based on their gender. The female participants in Harrison's research (2006), which includes 25 women between the ages of 55 to 65 years of age who are aging with polio, spoke about the changes they experience with their bodies. Appearance was important to the participants and many were discouraged when they noticed signs of aging, such as facial lines and darkened skin. While some could laugh about the changes, others were upset (*ibid*). Others became discouraged when they could no longer complete tasks.

The female participants who are aging with SCI included in Pentland et al.'s (2002) research spoke in detail about their gynecological health being ignored by health care professionals. The women noticed that their bodies were changing, such as their menstruation cycles, but their concerns were often ignored by doctors. The women also reported needing more information about sex and that their needs on this topic were often ignored. One participant believed that all the studies about intimacy relate to men, not women (*ibid*).

The female participants included in Pentland, Tremblay, Spring and Rosenthal's (1999) research, reported feeling as though men with impairments have better experiences than women with impairments. Participants reported having two strikes against them based on their gender and their impairment (*ibid*: 115).

In contrast, men who are aging with physical impairments may be judged negatively when they are unable to conform to stereotypes about masculinity. This was what Charmaz (1994) found in her research to understand how chronic illness impacts men. Charmaz interviewed 20 men diagnosed with a serious but not life threatening chronic illness that impacted them on a daily basis (270-271). Some of the men spoke about not wanting to appear disabled by others in order to preserve their masculinity. For example, one man did not use his wheelchair as often as he should because he felt more “manly” when walking (*ibid*: 282).

Charmaz (1994) discussed several examples of men who learned to preserve themselves by adjusting their actions so that others would not see their limitations. One person would limit his socializing so others would not know he had a dietary restriction and a dialysis shunt, another man talked about walking behind people so they would not notice when he had difficulty with stairs (*ibid*). The men were resourceful in finding ways to hide visible signs of impairment.

Shakespeare (1999) interviewed 21 men with impairments about their experiences with sexuality. As Shakespeare argues, “it can be a particular crisis for the able-bodied man when he loses physical prowess, because so much of his identity is constructed on the basis of strength and invulnerability” (1999: 63). Shakespeare also argues that the terms used to describe what it means to be masculine, such as fast cars, violence and war, excessive consumption, recklessness and risk, and sport often contribute to illness and impairment (*ibid*). Therefore, men have a greater risk of experiencing impairment due to the characteristics that define them as masculine. As well, once impaired, the man often feels as though he lost his masculinity (*ibid*).

McVittie and Willock (2006) interviewed 12 men over 65 years of age to discuss issues of health, ill health and the use of personal assistance. They found that the hegemonic form of masculine identity is one of power, control and invulnerability. When talking about the impact of

illness on their life, the men described it as an external factor that they cannot control. One participant only acknowledged that he is ill when he cannot get out of bed. As long as he is able to get up and do things, he does not view himself as sick. The participants spoke about denying the fact that they might be ill because being ill went against the identities of a 'real man' (798).

Rapala and Manderson (2005) developed a case study of one male who is aging with a spinal cord injury. Based on literature reviews and the case study, Rapala and Manderson noted the tendency to describe the male body with an impairment as child-like and feminine. They argued that men with an impairment believe that they can prove their masculinity by participating in physical activity. For those who are unable to prove their masculinity they may worry about others assuming they are feminine (*ibid*).

### Medical Care

The medical system typically plays an important role in the life of a person who is aging with a long-term physical impairment. Health care services in Canada are primarily designed for acute care treatment, not chronic care which is what most people who are aging with long-term physical impairments require (Rioux & Samson, 2006). Negative experiences in the health care system were reported by the participants in Pentland, Tremblay, Spring and Rosenthal's (1999) research to understand how women with physical impairments view their aging experiences. For example, the women could not discuss whether being female had an impact on their health care experiences because they believed health care professionals often only saw the disability (*ibid*).

Shapiro, Mosqueda, and Botros (2003) completed 30 interviews with older adults with different impairments to learn about their experiences with primary care doctors. The research was based in the United States, which has a different health care system than Canada, but some of the experiences of treatment by physicians may be similar in both countries. Their results

suggest that people with long-term physical impairments are more critical of health care professionals than people of the same age who do not have impairments (*ibid*: 637). Many of the respondents reported having been disappointed at some point during their life by a health care professional. Those who were unhappy or dissatisfied reported that the physician variously showed insensitivity toward their impairment, focused primarily on the impairment, was in a hurry, was not thorough, had a patronizing attitude, assumed the person had mental health problems, and appeared to lack the incentive or desire to learn about the aging process for people who have aged with a long-term physical impairment (*ibid*: 638).

Some of the participants in Shapiro, Mosqueda and Bostros' (2003) research spoke about what needs to occur for them to have positive experiences. Physicians who do the following will be received as better physicians by people with impairments: treat the patient as a whole person and not the sum of the impairment, have some knowledge about the impairment and be willing to learn more from the patient and/or other sources (*ibid*).

Krahn et al. (2006) present a literature review to support a national agenda on health and wellness for people with impairments, and argue that the national agenda should focus on a holistic model of health care for people with impairments. As well, Kroll et al. completed five focus group interviews with adults with physical impairments to learn about barriers and strategies when receiving health care services in the United States. The participants spoke about wanting health care professionals to look beyond their impairment and treat their entire body (*ibid*). These findings were similar to those in Thorne and associates' (2004) research. The participants in Thorne et al.'s research, 12 participants who were diagnosed with multiple sclerosis at least five years prior to the interview, reported that physicians should not assume that

impairment is always the problem and instead, treat the whole person and not just symptoms (Thorne et al., 2004).

Another problem in the health care system is that some health care professionals assume that people with the same impairment have the same experiences. Instead, health care professionals need to remember to treat everyone as an individual (DeSanto-Madeya, 2006; Shapiro, Mosqueda & Botros, 2003).

### **Rehabilitation**

Zarb (1993a) states that rehabilitation systems and professionals do not meet the long term needs of people aging with impairments. Most of the rehabilitation services are designed for people who are younger and have recently experienced impairment or have become impaired in old age. People aging with long-term physical impairments need a continuity of support (*ibid*). Rehabilitation services should be offered throughout the aging process because needs change while a person is aging and new technologies may positively impact the lives of people aging with long-term physical impairments (*ibid*). Stone (2007) interviewed long-term survivors of stroke and found that if they received rehabilitation services, it was only for a short-term period immediately following the stroke. Survivors said, however, that their needs changed as they aged, and they would benefit from having access to services on an ongoing basis.

### **Financial Consequences**

Aging with long-term physical impairments can be very expensive. Money is a powerful tool for maintaining autonomy and control of one's life, as Pentland, Tremblay, Spring and Rosenthal found in their research (1999: 118). The participants in Pentland and associates' (2002) study, who are women aging with spinal cord injuries, reported the benefits of money on

their lives. Having access to financial resources helped the women cope with the aging process and their injury (383). Just the security in knowing that they had financial stability was beneficial for the participants.

Although having access to financial resources is important for people aging with long-term physical impairments, it may be difficult to achieve. Many people have financial problems and worry about managing financially in their retirement years (Pentland et al., 2002: 380-381). Financial problems may occur because people may be forced to retire earlier than planned, as Fong, Finlayson and Peacock (2006) found in their research on aging with MS, and as Kemp (2004a: 23) found in his qualitative research with family members of people with impairments who are aging.

The ability to continue working becomes more challenging as the person aging with a long-term physical impairment becomes older, as Mitchell, Adkins and Kemp (2006) found in their research about the impact of aging on employment for people with impairments and people without impairments. Their cross-sectional research included people with a variety of impairments and showed that older people with impairments are more likely to retire earlier than their non-impaired comparison group. Many of the participants with impairments left the workforce at age 40, while the non-impaired comparison group typically left the workforce in their 50s and 60s (*ibid*: 162).

The person with a physical impairment has to struggle with providing for him or herself financially or face being seen as dependent on society (Pentland, Tremblay, Spring & Rosenthal, 1999). Some of the women in Pentland et al.'s study reported feeling forced to retire early and apply for a disability pension because of the limitations they experience. Worrying about poverty

and loss of control and dignity when applying for social assistance led some of them to continue working even when they experienced physical limitations (*ibid*).

Wendell (1996) discusses this issue and points out that a challenge for people with physical impairments is that disability leave and insurance policies assume that people with impairments are not capable of working full-time. This means that people with impairments must struggle to either push themselves to work full-time or, as Wendell says, “dishonestly declare themselves unable to work at all, often when they want very much to continue working” (Wendell, 1996: 20).

In addition to early or forced retirement, many people who have aged with a long-term physical impairment are financially insecure because money is needed to purchase assistive devices, employ personal support workers or homecare workers, or make modifications to the home (Trieschmann, 1987: 117). Therefore, the person with an impairment often has many out-of-pocket expenses and often earns less money than the general population (Furrie, 2006).

### **Personal Support Workers**

Personal support workers may be essential in helping people with physical impairments stay in their own home (Yoshida, Willi, Parker & Locker, 2006). The Ontario government supplies limited funding to assist people to receive care in their own home through a program called “Home and Community Support Services”. Support services are delivered by a variety of groups, including: family and friends, volunteers within the community, provider organizations (i.e. Ministry of Health and Long-Term Care), Community Care Access Centres (CCAC), government or publicly-funded services and provider organizations (examples include: non-profit organization (March of Dimes, Alzheimer’s Society), private corporations, municipal government or aboriginal organizations), commercial retailers and community centers

(MoHLTC, 2007). The services are funded by a variety of sources, including: government (provincial and/or municipal), donations to voluntary organizations, private insurance or benefit plans and the individual.

Unfortunately, some people have to pay for additional personal support, above and beyond what is offered by the government and organizations. Many people cannot afford the extra assistance if they have to pay for it out of pocket (Furrie, 2006). Furrie used data from 2001 PALS to present a profile of Canadians with impairments. According to the results from the 2001 PALS, 22.6% of the respondents reported that they needed more health care or access to social services. Cost was the primary reason for not having as much support as needed. The cost of paying for support was not reimbursed by insurance for 55.1% of the respondents.

### ***Coping Mechanisms***

The discussion of how people living with chronic illness cope with the consequences of their impairments is best developed in the work of Kathy Charmaz (1991; 1995). Charmaz does not focus on the aging process per se and does not indicate use of a social model of disability. Nevertheless, her work is concerned with the experiences of people who live with a variety of chronic illnesses and how they adapt to living with chronic illness, with a particular focus on how this affects sense of self. Her research is based on interviews with adults with serious, intrusive chronic illnesses. She found that, “[A]dapting implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways. Bodily limits and social circumstances often force adapting to loss. Adapting shades into acceptance” (Charmaz, 1995: 657). Adapting, in other words, is a continuous process for her participants and one that is internal. The participants have to learn to accept their limitations as part of themselves and not their body betraying them.

Other research shows that coping with a physical impairment is a complex process (Kemp & Krause, 1999). Kemp and Krause surveyed several hundred people with post-polio syndrome or with SCI, to study the impact of impairment on depression and life satisfaction. They found that coping “involves many elements, including the number and rate of life changes, the person’s attitude concerning these changes, his or her coping methods, their underlying personality, and level of social support he or she receives” (*ibid*: 242).

Pentland, Tremblay, Spring and Rosenthal (1999) note that it is difficult to predict how impairment and aging will affect a person. The impact of age and impairment is difficult to predict as it has only become a recent phenomenon for large numbers of people to experience old age when living with a long-term physical impairment. The results from the participants (women aging with physical impairments) about coping mechanisms were discussed using four categories: “informal supports; participants’ own behavioural and attitudinal adaptations; improved societal attitudes; and environmental supports (technology; social services; and health care) (*ibid*: 118).

### Coping Physically

There is a lack of information available for people aging with long-term physical impairments so coping with unanticipated physical changes can be difficult. Many of the experiences are unexpected, which make it challenging to adapt. DeSanta-Madeya (2006) interviewed 20 people with SCI and their family members to determine what it means to age with SCI, and described aging with a spinal cord injury as “stumbling along an unlit path” (275). Most of the participants and their family members spoke about the uncertainty of their future because of their impairment. In order to cope, the participants have learned to live on a day-to-day basis.

Participants in Plach, Stevens and Moss's (2004) research were aging with rheumatoid arthritis. Twenty women who were middle aged and had aged with their impairment for at least five years were selected to participate in research about their bodily experiences. The participants noticed a decline in their physical abilities and spoke about adjusting their activities. Some of the coping techniques used by the participants included: therapeutic drugs; relying on a sense of spiritual belonging; home modifications; assistive devices/technology; and either modifying, changing or leaving the workforce. The adjustments were a continual process because, as the participants pointed out, as they aged they encountered different changes, pain and discomfort (*ibid*).

The participants in Harrison's (2006) research included 25 women between the ages of 55 and 65 aging with childhood-onset disabilities from paralytic polio. Harrison used qualitative research to learn about the experiences of the participants as they aged with a disability. The women were experiencing changes in their bodies as a result of the impairment and age (E5). They also spoke about their bodies "slowing down" (E6). The participants learned to adapt to changes based on their increasing knowledge of past experiences. By slowing down the participants were able to determine how to maneuver barriers in an inaccessible society (*ibid*). However, it was challenging for the women to accept their limitations and many pushed themselves more than they should have when trying to appear 'normal' or non-disabled. Similarly, the participants in Pentland, Tremblay, Spring and Rosenthal's (1999) research had pushed themselves in the past and were suffering as they got older. Participants in the studies completed by Charmaz (1995), Fong, Finlayson and Peacock (2006), Harrison (2006), and Pentland et al. (1999) had all learned to reduce activities and evaluate whether an activity was worth the possible wear and tear on their bodies. Many of them also reduced the amount of time

they spent on activities to avoid fatigue. Others, especially participants with multiple sclerosis in Fong, Finlayson and Peacock (2006) discussed how they based their activities on a day to day basis because they never knew how they would feel.

### Coping Emotionally

#### **Sense of Humour**

The literature suggests that having a sense of humour can help people to cope with their experiences of change as they age with long-term physical impairments (Fong, Finlayson, and Peacock, 2006; Pentland et al., 2002; Pentland, Tremblay, Spring and Rosenthal, 1999; Stone, 2007). For example, a participant in Pentland et al.'s (1999) research shared an experience with an ostomy bag that did not fit properly. Because she could not do anything about the bag she learned to make jokes about it. Her friend teased her about getting her a Christmas gift, perfume called "Eau de Pooh-Pooh" (119). This participant laughs about this experience because she acknowledges that she has no control over the situation.

#### **Spirituality and Religious Faith**

Participants in DeSanto-Madeya's (2006) research about aging with SCI spoke about placing their faith in God. Both family members and the person with a SCI found comfort in believing that the injury occurred for a reason. By believing that their injury had a purpose, many of the participants wanted to teach others about SCI to prevent more people from becoming injured. Some participants said that since the injury they were less afraid of death.

The female participants in Pentland et al.'s (2002) research who are aging with SCI spoke about inner strength, self-acceptance and a re-evaluation of priorities in coping with their limitations. Some of the participants felt they had become more spiritual since their impairment. Being spiritual assisted the women in accepting their impairment and finding peace within

themselves (*ibid*). At the same time, these participants were more accepting of dying because they had experienced so many different problems relating to their SCI and aging. One participant was quoted saying “I guess before the accident I had some fear of dying and I don’t think I have it nearly as much as I did before, because I was almost dead anyway” (380).

Some of the participants in Fong, Finlayson and Peacock’s (2006) research, who are aging with MS, spoke about the importance of spirituality as a coping mechanism. One woman was quoted as saying, “if you’re going to survive, you have to develop your spirituality...” (701). As well, several of the participants included in Stone’s (2007) research about hemorrhagic stroke spoke about how religious faith helped them accept their impairments and learn to adapt.

### **Family and Friends**

As a person ages with long-term physical impairments, it is often necessary to require assistance with activities of daily living (Pentland, et al., 2002; van de Ven, et al., 2005). The importance of family members and friends providing emotional and physical support to people aging with long-term physical impairments is essential.

Many of the participants in Pentland et al.’s (2002) research rely on their partners for personal care. Some worried that their relationship would change because they relied so heavily on their partner for extra support. The importance of having a family member to offer assistance was so strong that the women who did not have spousal or family members wished they had someone to rely on (*ibid*).

Putnam et al. (2003) interviewed 99 adults between the ages of 22 to 82 with conditions such as cerebral palsy, polio, MS, amputation, and SCI, to determine the way people with impairments discuss health and wellness. The participants spoke broadly about the positive benefits of social support. One participant reported, “If you feel like somebody cares for you, I

think it gives you a reason to give something back, whereas if you don't feel like somebody cares, then, I mean, is there any point in it?" (*ibid*: 41). Support from family and friends helped many participants feel important.

Interestingly, findings from Pentland et al.'s (1999) research with women with physical impairments suggests that there is a gender difference in terms of who people turn to for emotional support. Pentland et al.'s (1999) participants spoke about relying on friends for emotional support. While spouses were important in assisting with physical and homemaking support, most of the women did not rely on them for emotional support. This is in contrast to research about men with chronic illness, which shows that men are likely to turn to family members rather than friends for emotional support. Male participants in Charmaz's (1994) research, for example, spoke about the importance of their partners' support and being there for them emotionally.

Another issue is that those who are aging with a long-term physical impairment often do not want to be a burden on their spouses and family members. Fong, Finlayson and Peacock (2006), for example, interviewed a woman aging with MS who spoke about her husband having his own health problems. She worried that he may not always be able to help her as much as she needs and he may need his own help (*ibid*). Similarly, participants in Pentland, Tremblay, Spring and Rosenthal's (1999) and Putnam et al.'s (2003) studies are also concerned about being a burden on their spouses. Worrying about being a burden creates stress and anxiety for people aging with physical impairments.

### **Support Groups**

There is a rich literature showing that support groups can be beneficial for improving a sense of wellbeing for people with chronic illnesses or impairments and allowing people to help

each other cope with their difficulties (e.g., Cohen, Underwood, and Gottlieb, 2000; King, Willoughby, Specht, and Brown, 2006; Schwartz and Sendor, 1999; Stone et al., 2002). The benefits of support groups have also been noted in studies of the experience of aging with a long-term physical impairment.

Fong, Finlayson and Peacock (2006), for example, found in their research with people who are aging with MS that support groups provide a place for people to laugh and learn more about their impairment or chronic illness. Not all of their participants, however, belonged to a support group for people with MS. As well, Pentland et al. (2002) found in their research with women aging with spinal cord injury that peer support was beneficial in reducing loneliness and isolation. Many of the participants in Pentland, Tremblay, Spring and Rosenthal's (1999) study talked about the importance of social networks with other women with impairments. Having a strong sense of community made it easier for the participants, all women with physical impairments, cope with their physical limitations.

A few of the participants in Stone's (2007) interviews with women who experienced a hemorrhagic stroke shared their experiences with support groups specifically designed for people who had a stroke. Jean enjoyed being able to share her experiences with people who have similar experiences. Another participant, Katherine, attended several support groups but was not satisfied with them. She stopped going to support groups but did not regret the times she went in the past.

A growing body of research focuses on the benefits of on-line support groups for people, especially for people with impairments, chronic illnesses, and older people, as a way to learn from each other, learn about health problems and treatments, and form social networks (Braithwaite, Waldron & Finn, 1999; Turner, Grube & Myers, 2001; White & Dorman, 2001;

Wright & Bell, 2003). For example, Braithwaite, Waldron and Finn (1999) found in their content analysis of an on-line support site for people with disabilities that contributors would reassure each other and boost each other's self-esteem. They showed empathy, sympathy, and understanding towards others in the group.

While on-line support requires access to a computer and internet connection, and so is not an option for everyone, it may be beneficial when face-to-face interactions in support groups are not possible or even desirable. People who may not be able to participate in face-to-face interactions include people with impairments, people without access to transportation or the ability to verbally communicate (Braithwaite, Waldron & Finn, 1999; White & Dorman, 2001). A benefit to online support groups is that people who have an internet connection can have access to support anytime and when it is convenient to the user (White & Dorman, 2001).

### **Working to Ensure that Health Care Needs are Met**

A subject that comes up time and again in the literature on aging with physical impairment is that interactions with physicians are not always satisfactory. People need to develop strategies to ensure that their needs will be met in a medical encounter.

Many of the participants in Pentland, Tremblay, Spring and Rosenthal's study of women aging with SCI (1999; 2002), discussed the importance of speaking up for themselves. Similarly, participants in Shapiro, Mosqueda and Botros' (2003) research, people over the age of 50 who have lived with their impairment for at least 10 years, discussed the need to be forceful and confront physicians if their needs were not being met. They wanted to be taken seriously and with respect. Many of the older participants who had aged with their impairment for longer periods of time (those with post-polio syndrome and SCI) reported that they avoided physicians

and took care of themselves rather than seek medical attention (Shapiro, Mosqueda & Botros, 2003).

Thorne et al.'s (2004) research participants with MS also spoke about taking charge of their experiences and not relying on health care professionals. Many of the participants carried out their own research by asking a variety of health care professionals their opinions, or searching medical journals and the Internet. One participant reported that a health care professional told her that "It's [MS] a mystery. You are on your own. Call me when you need a wheelchair" (*ibid*: 14). Most of the participants wanted a health care professional who would recognize their expertise and learn from them (*ibid*).

## **Conclusion**

Studying aging with a long-term physical impairment is challenging as it incorporates many different aspects that continuously change and develop throughout the life course. Therefore, life course theory is useful when exploring how people aging with long-term physical impairments learn how to accomplish everyday activities while taking impairment into account. The ability to develop coping mechanisms is a process that occurs throughout the life course.

People who are aging with long-term physical impairments have different experiences than people who are not aging with long-term physical impairments. The literature provides an in-depth view of the changes that occur to people as they age with long-term physical impairments. They typically feel as though they are aging faster, have more limitations which may result in giving up activities, require assistance in completing tasks, experience barriers in mainstream society and may have a limited income due to early retirement and extra expenses.

People with long-term physical impairments are able to accommodate their limitations by making home modifications, purchasing assistive devices and asking for accommodations in the

workplace. However, when these types of coping mechanisms are not possible they may have to rely on support networks, sense of humour, religious faith and speaking up to health care professionals. Developing coping mechanisms is an important part of aging with long-term physical impairments. Coping mechanisms are used to adapt to the changes that are occurring based on the impairment and the aging process. Although there are many changes that occur when people age with long-term physical impairments, most learn ways to accommodate their impairment and still attempt to participate in mainstream society despite barriers.

The next chapter of this thesis will explain the methods used to research the experiences of eight people who are aging with long-term physical impairments for over ten years. Following the methods section will be an analysis of the results from the eight participants.

## Chapter Two – Methods

Qualitative researchers seek answers to their questions in the real world. They gather what they see, hear, and read from people and places and from events and activities. They do research in natural settings rather than in laboratories or through written surveys. Their purpose is to learn about some aspect of the social world and to generate new understandings that can then be used (Rossman & Rallis, 2003: 4-5).

My goal in this research was to expand and fill a gap in the literature focusing on how people aging with long-term physical impairments make sense of their lives. Therefore, a qualitative method was appropriate for this research. This method allowed me to capture the rich details of a person's life as he or she ages with a physical impairment, and draw attention to the intimate details of a small group of people who are aging with long-term physical impairments.

Researchers use qualitative research to understand the lived experiences of the participants (Novak & Campbell, 2006). Learning the lived experience is important because it provides detailed examples of how the participants interact in the social world. Qualitative research is useful in “understanding how individuals subjectively see the world and how they make sense of their lives” (*ibid*: 247).

I determined that in-depth interviews would be an ideal method to collect data from the participants. Rossman and Rallis (2003) describe in-depth interviewing as “the hallmark of qualitative research” (180). Interviews are a useful way to collect rich and detailed personal information from participants, allowing them to answer in their own words. “Interviewing takes you into participants' worlds, at least as far as they can (or choose to) verbally relate what is in their minds” (*ibid*). The researcher can learn what is important to the participant by listening to the details described or not described.

## ***The Interview Guide***

Semi-structured interview schedules were used for this research in order to ensure that certain common themes were addressed. “Semi-structured interviews are designed ahead of time but are modified as appropriate for each participant. They begin either with an interview guide, which is a list of topics to cover and the order in which to cover them, or an interview schedule, a set of specified, preformulated questions that can be modified” (Adler & Clark, 1999: 248).

Most questions in a semi-structured interview are open ended to allow discussion from the participant and are flexible enough so that probing can be used. Using open ended questions allows the participants to respond in their own way and to add comments that may not have been expected or to follow the interview schedule. While some of the information may not seem applicable to the research topic, it may add a dimension to the research that was otherwise unexpected. There is no right or wrong answer when answering open ended questions which allows participants to have some control over the interview by answering questions in a manner with which they feel comfortable.

The design of the interview guide was exploratory. “In research with an exploratory purpose, the investigator works on a relatively unstudied topic or in a new area” (Adler & Clark, 1999: 9). Palys (1997) expands further on the definition of exploratory research by stating that its purpose is to “gain familiarity with or to achieve new insights into a phenomenon, often in order to formulate a more precise research question or to develop hypotheses” (77). The experiences of people aging with a long-term physical impairment are under researched from a qualitative perspective. More research is needed on this topic as more people are approaching old age with a long-term physical impairment.

The interview questions were developed to focus on a life course perspective after completing a thorough literature search. One goal of the interview guide was to learn about the transitions in the participants' lives as they age with a long-term physical impairment. The interview questions focused on five main issues: demographics, questions regarding age and impairment-related experiences, health status, social support and assistance, and modifications required (See Appendix A for complete interview guide). These areas were selected because evidence suggests that they have an impact on the experiences of someone who is aging with a long-term physical impairment.

The last question asked participants to describe a photograph or image that would illustrate what it means to age with a long-term physical impairment – a modification of the photovoice method used by Wang (1999). Instead of describing an image, many of the participants expanded on a particular incident in their life that was greatly influenced by the fact that they have a physical impairment. This question was a useful way of asking the participants to sum up their experiences.

### Reflexivity

Knowledge is subjective and interpretive because the researcher makes meaning using what is learned during the research (Rossman & Rallis, 2003). When completing research, the researcher needs to be aware of his/her identity, the identity of the participant and how the two interact. The different identities have an impact on “the data we gather and do not gather, the questions we ask and do not ask, and the interpretations we make and do not make” (Pini, 2004: 176). It is important to recognize these identities because participants know more than they are telling us and the stories they share are a reflection of the way they perceive the researcher and the research (Altheide & Johnson, 1994).

The researcher is a part of producing knowledge and his/her personal characteristics must be considered when reflecting on how knowledge is created. Factors that influence the relationship between researcher and participants include: age, sex/gender, and class (Manderson, Bennett & Andajani-Sutjahjo, 2006). Prior to completing research, the researcher needs to be aware of his or her own interests, biases, opinions and prejudices. Rossman and Rallis (2003) recommend that researchers “make clear who you are and what assumptions drive the study” rather than pretend that research is objective (36). They further argue that researchers need to be aware of how participants view them (*ibid*: 50).

I am a young, able-bodied woman whose social location is very different than that of the older participants experiencing disability who I interviewed. I must be reflexive about how my social location may have positively and/or negatively influenced the interviews and the knowledge produced. My gender had an impact on the type of questions I asked, how I probed the participants and how the participants responded to me. As a woman, I have been socialized to develop an emotional and caring role, and I projected this during interviews. As well, being a female may have made male participants feel more comfortable sharing information about their physical inabilities because they saw me as an emotional and caring woman who might not fully understand their situation, but who would not compare their experiences to her own. Initially, most of my male participants did not speak about activities that they can no longer complete. After probing, a few male participants talked about feeling inadequate when they were unable to complete tasks that were expected of them because of their gender. However, given the pressures around masculinity it may have made them less comfortable to talk to me about their inabilities.

My age is another personal characteristic that impacts my social location. How can I understand what it is like to be fifty years old and have aged with a physical impairment for

almost as long as I have been alive? I believe that my age helps me to be genuinely interested and open-minded during the interviews because I have so much more to learn about life.

Unfortunately, the participants in my research might not be as willing to share experiences with me because I am so much younger. However, to contradict this statement, participants might think that I need to know their stories so I can personally learn from them. They might have been less likely to assume that I already know what they were talking about, and so might have been more willing to explain their experiences in detail. As well, participants appeared to enjoy talking about their experiences with someone of a different generation.

My lack of physical impairment may also have impacted the research. While the participants in my research did not ask about my experiences or lack of experiences with impairment, this may have been an issue. A goal prior to completing the research was to ensure that participants did not feel I was being voyeuristic in asking about their experiences. While I may never know whether the participants felt this way about me, I hope that they felt comfortable with my presence and interest in their lives.

Prior to researching the topic of aging with long-term physical impairments, my experience with impairment was very limited. More specifically, I had not thought about what it would be like to age with physical impairments. Thus, I approached the research without making prior assumptions about the lives of my participants. That is, I was slightly naïve, but very open minded about the topic.

### ***The Process of Recruiting Participants***

I decided that a small sample would provide enough detail about the lives of people aging with physical impairments to make general comparisons and comments in a timely fashion. A large sample may have created more variety in responses but I had to consider the amount of

time it would take to complete the research using a larger sample. My goal was to have an equal representation of males and females and to include participants who had different impairments.

I used a purposive sampling approach to recruit eight participants. Adler and Clark (1999) argue that purposive sampling in qualitative research is a desirable method. Participants are selected based on specific characteristics that are deemed important to the research based on a literature search. “Purposive or theoretical sampling thus merely extends the admonition that researchers should be guided by the objectives of the study and should recognize that while “representativeness” may at times be a crucial requirement, at other times kneeling before the gods of randomness impedes rather than facilitates understanding” (Palys, 1997: 139).

The amount of time spent living with a physical impairment was a specific characteristic that needed to be incorporated into the sampling approach. Participants needed to be between the ages of fifty and sixty-five, have lived with a physical impairment for over ten years, and live in their own home. The length of time is important because the purpose of the research is to learn how people experience the aging process when they have a long-term physical impairment. For the purposes of information gathering, all participants had to be able to speak English.

Ethics approval from the Lakehead University Research and Review Board was gained in July 2006. After receiving ethics approval, I asked family members, friends, classmates and colleagues in July, August and September whether they knew someone who fit the criteria of my research. I hoped to schedule interviews during August 2006 with the goal of finishing the interviews by September 2006. This process allowed me to find only two participants, who were both interviewed in August. Their names were provided to me by mutual acquaintances. Once I knew they were interested in participating, I telephoned them to schedule a meeting.

When my initial method of recruiting participants did not seem to be yielding a large enough sample, I asked friends, classmates and colleagues a second time and contacted an organization in southwestern Ontario that offers assistance to people with physical impairments to ask if they could help recruit participants. The contact with these groups occurred during the first few weeks of August. Although the organization was able to provide four names of people who met the criteria of the study, it took approximately one month to make the necessary arrangements and sign the appropriate paperwork that would enable me to have access to their clients. I met with two people selected by the organization. The contact person at the agency mailed copies of the consent form and information sheet to their clients who volunteered to participate in the study so they were aware of my research before I arrived at their homes to conduct the interview. I was also able to recruit two other people in September who were recommended by my friends. These participants were initially contacted by the person who knew them and once their approval was gained, I was notified and given their phone number.

The third phase of the recruitment occurred when I returned to Lakehead University in September 2006. One participant was recommended by a professor and another participant was recommended by a fellow classmate. Additionally, a group of professors who teach gerontology courses were asked to assist me in recruiting participants at one of their meetings. There was no follow-up from this meeting and no participants were recruited. The interviews with the participants who were recommended by a professor and a fellow classmate occurred in October 2006 and the other occurred in December 2006.

Ideally, I hoped for a group of individuals with a variety of impairments. Most of the literature I read focused on the aging experiences of people who became physically impaired as a result of an injury. I anticipated that most of my participants would fit into this category. As

much of the current literature discusses the aging experiences of people with spinal cord injuries, I expected, and hoped, to include someone in my research who met this description. However, recruiting participants, especially participants with injury related physical impairments, was more challenging than first expected. The majority of my participants have been diagnosed with chronic, degenerative illnesses that have resulted in a physical impairment.

### ***Participant Characteristics***

The sample consisted of four women and four men who have aged with a long-term physical impairment for more than ten years. Pseudonyms are used in the text to replace the participants' real names. Participant profiles can be found in Appendix D, and here I discuss their general characteristics. Five of the eight participants were between fifty-four and sixty years of age. The oldest participant was sixty-eight and the youngest was fifty-one. Six of the eight participants have lived with their physical impairment for over twenty-five years. They are variously impaired due to: multiple sclerosis (MS), muscular dystrophy (MD), rheumatoid arthritis (RA), polycystic kidney disease (PKD), Legg-Calvé Perthes Syndrome and an amputated arm. Two female participants have multiple sclerosis and two female participants have rheumatoid arthritis. One female participant has aged with her impairment for approximately eleven years while on the opposite spectrum, one participant was diagnosed at birth with polycystic kidney disease which resulted in a loss of kidney function.

Although one participant, at age sixty-eight, was slightly older than the age group I sought to recruit, he was interested in participating in the research and I felt that his experiences should be included for two reasons. First, I was having difficulty finding participants who exactly fit my sampling criteria, yet this person was close enough in age to make his experiences relevant to my research. Second, I was aware that his health was quickly deteriorating and I felt

that his experiences were important and should be shared before he was no longer able to share them.

Only one identified as non-Canadian. This participant is American and immigrated to Canada after she married. All of the participants are currently living in their own home. They all talked about living in the same home for a long period of time and one had lived in his house for over forty years. One participant is single, another is a widow and the remaining six are married. The two single participants are both women. Five of the six married participants have been married for over twenty years and one has been in a long-term relationship that recently resulted in marriage.

Most of the participants had a difficult time approximating their financial situation. One participant does not earn her own money because, as she told me, she is not a Canadian citizen and she has never worked in Canada. She told me that she is not eligible for a disability pension plan but “when I get to be 65, I guess I might get something. If I am still alive.” Two participants are single and could only talk about their own income, while the others lived in families with two earners. These factors make it difficult to determine the average income for the participants because the responses varied depending on their living situation. However, on average, most participants responded that their income level was between \$20,000 and \$30,000. One participant’s personal income was lower than \$20,000 and at least four participants have a combined family income of over \$40,000.

Four participants have education past high school, and one completed up to grade ten and the others found jobs after graduating high school. All of the participants were satisfied with their level of education. Two of the eight participants are currently employed. One of these participants has changed occupations to accommodate his impairment while the other participant

has learned to pace herself to accommodate her impairment. The participants who are currently unemployed commented that the decision to quit their job was their own decision and was based on their limitations and physical differences. Only one participant spoke about accommodations to the workplace, but he decided to quit working because he experienced a lot of pain and was worried about the possibility of needing to use a wheelchair. Another participant, who lost her job when the company went bankrupt, would have preferred to continue working but felt no one would hire her because she has RA.

The female participants who have been employed outside the home worked in occupations such as salesclerks, secretaries and housecleaning. The male participants were employed in a variety of jobs. One male participant was a police officer until he was no longer able to work. Another male participant was a veterinarian and then worked for the federal government until he was urged to retire. After his retirement he was active with the municipal government at several agencies and organizations. Another male participant worked in construction for many years. He is now working as an advocate for injured workers and jokes that he is using his “brain muscles” now. One male participant worked at a variety of jobs when he was physically able. He has long lapses in his employment history because of the multiple surgeries and pain related to his hip problems.

All four female participants were living in southwestern Ontario, two of the four male participants were living in southwestern Ontario and the other two were living in northwestern Ontario. Four participants live in small rural communities, three live in small urban communities and one lives close to a large urban community.

Two participants required the use of a wheelchair on a regular basis. Only one was using a wheelchair during the interview. The other woman was researching which type of wheelchair would best suit her needs.

### ***Interview Process***

The interviews were completed between August 6th, 2006 and December 13th, 2006. In preparation for each interview, I first spoke with participants on the telephone to review the purpose of my research and to establish a time and place for the interview. I believe that allowing the participants to decide on the time and location made them feel more comfortable during the interview because it shifted control and power to them. As Manderson, Bennett and Andajani-Sutjahjo (2006) discuss, participants who are interviewed in their own home may be in a more powerful position because the setting is a private space under their control. In contrast, choosing a “coffee shop or park provides a relatively anonymous space, less formal but still public, influencing confidentiality, informing perceptions of what may or may not be discussed, and potentially inhibiting the introduction of private and potentially emotive topics” (*ibid*: 1318). However, this did not appear to be the case for the participants in my research who chose to be interviewed in public spaces, as explained later.

One interview occurred in the morning and all others were completed in the early to late afternoon, at the request of the participants. Six of the eight interviews were completed in the participants' homes. Conducting interviews at the participant's home was beneficial to this study because, as I learned during the interviews, home modification was an important factor conditioning the experiences of participants, and they had quite a bit to say about the subject. They offered discussions about modifications to the home that were often quite detailed and lengthy, and they were pleased to be able to show me the modifications in person. Interviewing

the participant in his or her own home enabled me to gain an impression of the resources and social status of the participant based on the location and type of house and its contents (Manderson, Bennett & Andajani-Sutjahjo, 2006). Most of the interviews completed at the participants' homes were interrupted by family members contacting the participant, either in person or by telephone. These were short interruptions and did not noticeably distract from the interview.

One interview was completed at a hospital while the participant received dialysis treatment. The participant decided on the location because he spends a lot of time there and his home is several hundred kilometers from the hospital. I would not have been able to interview him in his home, as he lives too far away for me to be able to get there. The hospital, however, was convenient for me to get to. Initially I was worried about interviewing him at the hospital because I have never been in a dialysis unit before and was not sure what to expect. I was worried about how the nursing staff would feel about the interview. However, my initial fears were diminished when I arrived at the dialysis unit and met staff who appeared to be very friendly. They appeared to know the participant very well and told me how to find him. Although the dialysis room was quite large and included probably fifteen or more spots for people to receive their treatment, it was relatively quiet with very few interruptions. There were only a few other people receiving dialysis treatment and none were sitting near us. Interviewing in the dialysis unit was interesting because I could observe his surroundings and the way the nurses interacted with him. The hospital is like a second home to him as he is there three times a week and spends the better part of a day receiving the treatment. Initially I felt awkward asking this participant about his health care experiences, but he appeared comfortable to talk about them, even though he was in a hospital with nursing staff likely within hearing distance.

Another interview was completed at a coffee shop at the participant's request. He selected this location because he had an appointment in the area prior to the interview and another meeting nearby after the interview. The area was also convenient to me because I did not have access to a vehicle to allow me to visit his out-of-town home. Prior to our meeting we had to discuss how we would recognize each other. I had a difficult time describing myself to him, whereas he told me that he'd be the 'good-looking guy with only one arm'. There was some background noise, but it was still a comfortable setting. We were not interrupted and he appeared comfortable to talk in this environment. I was also able to observe his interactions with other customers and servers.

Prior to each interview, I described the research and provided the participants with the cover letter (Appendix B) and consent form (Appendix C) to be signed, if it had not already been completed. Some had received the information prior to the interview. The participants provided consent when I asked if they objected to me recording the interview. I explained that I would fully transcribe the interviews once they were completed. Many of the participants were interested in the recording device as it is a small digital recorder. A few expressed an interest in owning one so they could record some of their own stories for family members to enjoy later. Before starting the interview I reminded the participants that the information they provided would be confidential and that they could withdraw from participating at anytime. I also told the participants that if they were tired or needed a break that we could stop and start again at a later time.

The time between my initial contact and the actual interview, which ranged from one day to a few weeks, allowed participants time to think about their life with a physical impairment. Some of the participants told me in the interview that they thought about the types of questions

that I might ask and tried to think of answers in advance. One participant told me that she expected me to ask her more personal questions and she was prepared to tell me the answers for no reason other than to shock me. Thus, the participants shaped what was discussed in each interview as much as I did with my prepared list of questions.

Each interview lasted between one hour to four and a half hours, with the average being an hour and a half. The use of a recording device may have helped develop rapport because I could listen and engage more with the participants when I was not taking detailed notes. At the beginning of each interview, I talked to the participants about topics not related to the interview in order to create a sense of comfortableness and ease for both the participants and myself. This conversation prior to the interview helped me to feel more comfortable interviewing people, especially the participants who I had not met before. I believe it also made the participants feel as though they as people mattered and not just their experiences for the sake of research. We often talked about the weather and other background information. I was open and honest with the participants when they asked me questions because I wanted them to feel comfortable during the interview. Many of them were interested in my plans after school.

Although there was some small chat before the interviews, most of the informal conversation occurred after the interview was completed. There were occasions when the participant and I continued talking for over an hour after the formal interview was completed. Conversation following the interview created a strong bond between me and the participants, making me more aware of the responsibility I held in retelling their stories.

One interview lasted over four hours and this participant talked freely about her life so the interview did not follow the set list of questions. After four hours I had to apologize because I only had half an hour left before I had to leave. During this half hour I rushed through what I

thought were the more important questions to ensure that I had enough data to compare with the other participants. This participant was very excited to show me how her computer works and walked me through the process of message boards, email, and ordering books on tape from the library and the Canadian National Institute for the Blind (CNIB).

Another interview was an hour and a half, but the participant had to leave for another appointment before all the questions could be answered. The last half of the interview questions were quickly completed in the last twenty minutes of the interview. Due to the time constraints, not all of the questions were asked and some of the questions may have been expanded if there had been more time. This participant was energized to talk about the way society disables people with impairments and expanded a great detail during some of the first questions on the interview guide. We also went off topic a few times when talking about his family. These conversations, although they were not included in the interview guide, were still important because it allowed him to feel comfortable and willing to share more details with me. As well, his comments gave me additional insight into the context that conditions his experiences.

Two participants asked their spouses for help when answering certain questions. Another participant wanted her husband's assistance with answering questions about finances but this was the interview that ended early and I was not able to ask him the questions. I did not follow up with this participant to learn more about finances. Consent forms were signed by both spouses after they agreed to contribute to the interview. The wife of a participant with MD provided translation assistance when her husband was not able to clearly verbalize what he wanted to say. She also contributed to the conversations about how the family copes with finances. A husband of one of the participants who is aging with RA also contributed to the interview at the request of his wife. She had difficulty summing up her experiences and asked her husband to help.

The use of in-depth interviews was beneficial in gathering detailed information from the participants. Prior to completing the interviews, I reviewed an article by Glesne and Peshkin (1992) that describes participants as the “processors of information” (64). It is the researcher’s responsibility to ask questions in a manner to seek information from the participants. The researcher is referred to as the “seeker of knowledge” (*ibid*: 79). Responses from the participants vary depending on motives, values, concerns and needs (*ibid*: 64). These were things that I needed to remember when completing my own research. I tried to ensure that the participants held the power during the interview, to make them feel more comfortable sharing their experiences with me.

My use of a semi-structured interview guide allowed for the “collection of rich, person-centered, contextualized data through a collaborative participant-researcher effort based on good rapport” (Schoenberg, 2002: 130). Additionally, using a semi-structured interview guide allowed me some flexibility in the sequence of questions which was important for maintaining a smooth flow during the interview (Adler & Clark, 1999). Adler and Clark argue that having a smooth flow will lead to more detailed responses. While I tried to ensure that all questions were answered, they did not always occur in the same sequence.

Some questions seemed repetitive during the interview based on previous conversations with the participants. Some participants just jumped into explaining their history so questions about their health care were answered at the beginning of the interview and not near the end, as it was structured in the interview guide. I had to be careful to ensure that the same questions were not asked during the interview. This could have broken down any pre-established rapport if the participant feels as though I was not listening. If I felt that the question was answered previously,

I might skip the question or rephrase it to show the participant that I have been listening but asking if they have anything more to expand since our previous discussion on that topic.

Because I used probing, the participants could provide more information and the format was flexible enough to encourage digression from specific topics. Probing also meant that the interviews did not all proceed in a uniform manner. Rather, participants were encouraged to talk about experiences that they felt were important, and I frequently encouraged them to elaborate upon points. There was great variation in terms of what participants told me, which is illustrated by the variation in the length of the interviews.

During the interviews I paid attention to non-verbal communication and the setting. I observed the set-up of the house and how the participants moved around. All but three participants moved around during the interview, either to answer the phone, let a cat into the house, stretch, or relocate to a different room. This movement allowed me to observe the way they moved and evaluate them on visual signs of physical impairment. In fact, I was likely judging them the same way they are often judged by mainstream society. I was looking to see if they needed assistive devices or appeared in pain when moving. I only noticed two participants who appeared in pain when they moved and they were the ones aging with rheumatoid arthritis. The pain could be seen in their facial expressions and verbal comments such as grunts and moans and confirmed by them telling me how sitting for too long makes their muscles seize and results in pain. During the interview I noted when there were hand gestures and silence or long pauses.

I wrote up my thoughts and impressions of the interview after the interview when I was at home at my computer. I wrote about how I was feeling during and after the interview and my impressions about how the interview progressed. Suggestions on how to improve the next interview were also documented. Throughout the data collection process, I kept a small diary

where I would document my thoughts about how I should write up my thesis and noted significant themes.

Participants seemed to benefit from sharing their stories with an active listener. They seemed to enjoy telling me stories about their lives, but at the same time, made it clear that there are 'other people' that are 'worse off' than them. Some even commented that other people questioned them on why I would be interested in their life. They seemed disgruntled by this comment but seemed proud in a sense that they could contribute to my research. Arthur Frank (1995) discusses the benefits of sharing stories of sickness and illness. Reliving experiences through narrative has a positive impact on both storytellers and listeners. My participants seemed to benefit from telling their experiences to me, a captive audience interested in what many of them considered an uneventful life. Many of the participants expressed some anxiety about their stories and experiences not being that important, or not important enough to document. I told them that I was interested in their life and that there were no right or wrong answers. Learning their stories changed me and made me more aware about what it truly means to age with long-term physical impairments. While some of the participants expressed different emotions during the interview, most seemed to benefit from telling their story to an active listener. It was common for many of the participants to express agitation and frustration when discussing experiences where they were treated differently by members of society because of their physical differences.

At first I was skeptical about how much information would be provided during the interviews because of the vast differences between me and the participants. Schoenberg (2002) uses work completed by other researchers to discuss whether commonalities between the participant and the interviewer are beneficial or problematic. Problems associated with lack of

commonalities can be reduced if the interviewer is able to create and maintain rapport with the participant. There were many differences between me and the participants but it did not appear to impact the research. However, perhaps the responses from the participants were ones that they thought I wanted to hear, based on my age, gender and what they believed to be the purpose of the research. I think the differences between me and the participants had both a positive and a negative impact on the responses to the research questions.

Being able-bodied and lacking prior knowledge about the physical impairments had an impact on the type of information that was shared with me and how I interpreted the shared information. A major problem for me was to sift through the vast amount of information to determine which information was most important to my research. The ease of conversation and the vast amount of knowledge produced during the interviews made my task of organizing the data more challenging. The openness of the participants made me feel a special connection to them, creating a strong desire to ensure that their true experiences were honoured. Their experiences should not make the reader pity the participants, but rather appreciate their experiences as they exist and adapt to a world that is designed for the able-bodied.

I thanked the participants after the interview for their participation. Unfortunately one of the participants passed away before I could mail his thank-you. I sent a sympathy card to the family to thank them on his behalf.

### ***Approach to Data Analysis***

Once the interviews were transcribed, I re-read the transcripts without taking any notes. Throughout this process I visualized the interview and tried to remember all the non-verbal gestures that occurred. By not taking notes I was able to focus more on the details in the interview. The second time I reread the interviews I made rough notes about my thoughts on

similar themes that could be drawn out from the interviews. I was also looking for “naturally occurring classes of things, persons, and events, and important characteristics of these items. In other words, looking for similarities and dissimilarities – patterns – in the data” (Berg, 1995: 60).

The interview transcripts were read and reread and I was looking for predominant themes and links between themes. Listening to the language and framing of my interviewees helped to rethink some of the fundamental assumptions of the literature and to come up with a different coding scheme than anticipated.

Initially, after completing my first version of the literature review, I wanted to look at the inequalities that people aging with long-term physical impairments experience during their life course. The interview guide was structured around areas where inequalities might occur, such as: health experiences, physical limitations, social experiences and modifications, but did not specifically state that I was looking at inequalities. I believed that people with physical impairments would have a difficult time functioning in mainstream society and their problems would result in inequalities. While not all literature focused on inequalities or used the term inequality, there was enough information to suggest that this was a common experience for people aging with long-term physical impairments.

However, after meeting my participants and hearing about their experiences I realized that describing their experiences as inequalities would not be a true reflection of their lives. It was not until I met more people with long-term physical impairments and informally talked to them about their experiences that I realized that there had to be a more accurate way to portray the lives of my participants. Some of these conversations helped me make sense of the data and create a new coding scheme.

I decided that the new focus of my thesis should be to show that people with impairments are no different than people without impairments but need to develop coping mechanisms to live in a world structured around the needs of non-impaired people. I wanted to illustrate the way mainstream society is not structured to meet the needs of people aging with long-term physical impairments and how they need to create coping mechanisms on their own to adapt to the changes they are experiencing as a result of the aging process and their initial impairment.

Once I knew what I wanted to focus on, I had to reorganize my data into main themes and reduce the information into a manageable form. Qualitative data reduction refers to “the various ways in which a researcher orders collected and transcribed data” (Adler & Clark, 1999, 438). To assist with data management, I imported the interview transcripts into the qualitative computer program N-Vivo. N-Vivo enabled me to code the contents from the interviews into specific themes. Each interview was coded in whole before moving on to the next interview. This seemed to be the most logical way of doing it at the time as the purpose was not to compare the results question by question but to look at the interviews as a whole process.

I decided the best way to reduce and make sense of my data was to use open coding. This appears to be a common method used by other qualitative researchers. Strauss (1987) provides a very detailed description of open coding that I used as a guide when coding my interviews. Strauss describes the open coding procedure as, “an unrestricted coding of the data. With open coding, you carefully and minutely read the document line by line and word by word to determine the concepts and categories that fit the data. These concepts, once uncovered, are entirely tentative” (p. 28). The first time I coded the interviews, I had over forty different themes because I coded everything in the interviews. I created the themes throughout the coding experience, which meant I had to go back to the first ones and make sure the content from them

was coded using the newer themes that were created after the first few interviews were coded. I stopped adding themes after the fourth interview because I did not find any new information that needed its own code. The initial coding process was very broad and time consuming. However, upon reviewing these themes, I found that many were not relevant or overlapped. I realized that I needed to recode the data another time to reduce the data to a more manageable size.

Strauss (1987) expands further on the process of open coding by saying:

As you continue working with and thinking about the data, questions and even some plausible answers also begin to emerge. These questions and answers should lead you to other issues and further questions concerning “conditions, strategies, interactions and consequences”. (p. 28)

The second time I coded the interviews I knew what codes I wanted to use and I collapsed several of the themes to generalize the data. I was still not happy with this coding scheme and decided that I needed something even more specific. It was during this time that I realized that I needed to focus more on coping mechanisms and how participants develop them on their own.

Once I had a more specific topic, I was able to code the data into six themes. The six themes were: coping with finances, emotional coping, physical coping, social coping, knowing what to expect and medical experiences. After I developed these six themes I realized that it would make more sense to organize the data into two separate chapters. I used one chapter to highlight coping processes and in another chapter I reorganized my themes again to reflect different experiences and areas of life (i.e. physical, finances and mainstream society). I still read the interviews line by line, but not all lines were coded in the final coding scheme. I only coded the information that was relevant to my topic. However, I saved my first and second coding schemes so I was able to refer back to them if I needed more specific information that may not have been coded in the last coding scheme. Although it was time consuming to code the

transcripts three different times, the process was invaluable because it allowed me to not only become intimately familiar with my data, but also to organize it such that I am confident that my analysis reflects the purpose of my research.

#### A Note on Data Limitations

I interviewed each participant only once; therefore, I gained only a limited appreciation for their experiences. Although it is often better to interview people more than once, in order that detailed information can be gathered, Rubinstein (2002) states that “short-interviews (e.g., one or two sessions) can be extremely worthwhile, as long as they involve the collection of biographical and other necessary background information, are focused on a specific topic or area, and can expand in new or interesting directions if necessary” (140). All of these components were incorporated into my interviews. A downfall of interviewing participants only once is that it seems likely that participants were most interested in discussing experiences that had the most impact on them, or were most recent. Additional interviews may have captured experiences that did not immediately come to mind in the first interview.

The sample is a very small and not representative. My participants have very diverse experiences with disability making the group very heterogeneous. I cannot generalize my findings based on these reasons but I will focus on elaborating the experiences of this small case study.

### **Conclusion**

Disability is socially constructed and the participants’ responses are a reflection of the way mainstream society views disability and people with physical impairments. The responses were made based on the participants’ experience. The next two chapters present a review of what participants had to say on the subject of aging with a long-term physical impairment.

## **Chapter Three – Aging with Long-Term Physical Impairments**

This chapter examines themes that emerged through analysis of the interview transcripts, focusing on challenges and difficult situations that research participants encounter on a regular basis. Three main themes emerged: physical challenges, finances, and mainstream attitudes and barriers. The section focusing on physical challenges describes the experiences of the participants as they age with long-term physical impairments. As their bodies change, due to both impairment and the aging process, they experience different challenges. Most also deal with questions about how long they will be able to live with a body that is progressively deteriorating. Regarding finances, most of the participants in my research found that purchasing what they needed to help them adapt to their physical limitations was expensive, yet their income was reduced due to early retirement. Finally, participants discussed the discriminatory attitudes and barriers to participation that they face in mainstream society, including difficulties they face when dealing with the medical system. The participants are referred to by pseudonyms to ensure anonymity, but more information about the participants is available in Appendix D.

### ***Physical Challenges***

#### Loss of Activities

All the participants in my research used to be physically active when they were younger, but many are now unable to complete the same tasks that they used to enjoy. Physical activity is something they all miss and they often wish they were still able to participate in all of the activities that they previously enjoyed. A few of the participants continue to push themselves to complete tasks even though they know the extra strain may damage their bodies.

Victoria, who lives with rheumatoid arthritis (RA), continues to push herself to work as a housecleaner even though she is often in pain and has difficulty moving. She told me, “I had

several professionals tell me that I shouldn't be working. I am still working. [determination in her voice] I said, 'I ain't gonna let this thing beat me.' But some days I think it beats me." She recognizes that she cannot clean as fast as she was able to in the past, but she still works long days regardless of her pain levels. Victoria acknowledges that she needs to take breaks between jobs if the pain is too much to tolerate. When I asked her how she manages to work between six to eight hours a day on average, she told me "stupidity."

Dorothy was active prior to being diagnosed with RA and enjoyed going for bicycle rides and long walks. She has, however, noticed a steady decline in her ability to walk long distances. She told me "like up until about like 3 or 4 years ago I was walking maybe a mile and a mile and a half a day. But now, going to the mailbox is hard work."

Mark, who experiences pain and limited function of his right hip as a result of Legg-Calvé-Perthes syndrome, prides himself on keeping in shape and told me "keeping fit was the key, I think." Mark's limited mobility is a result of a prosthetic hip that does not work as naturally as his real one. Instead of playing baseball and soccer, which were his favourite sports, Mark was satisfied being able to umpire baseball and coach his children's soccer teams. He reflects back on these activities and questions whether they may have caused more damage to his hip. He questions the impact that coaching had on his hip because as he told me,

I probably overextended myself in the soccer because I wanted to teach them and by teaching them you had to do a little bit of running and by teaching you had to use your legs and by teaching them you sometimes overextended yourself. So that, probably, I shouldn't have, you know, I probably could have got probably 1, 2 or 3 years out of my hip, but who knows, right? Because nothing happened when I was doing it but it was just general wear and tear.

The other participants also talked about how aging with a physical impairment can be very challenging and physically exhausting. For example, Jake's body is worn out by the many

years of dialysis treatment. It is not uncommon for Jake to return home from his dialysis treatment exhausted.

Karli, who has multiple sclerosis (MS), knows that the best time of day for her to communicate on the computer (a favourite activity) is during the morning before she becomes too tired. She does most of the tasks that involve fine motor skills, such as typing on message boards and searching the internet for images to use as an electronic signature on her message board submissions in the morning when she has more movement in her hand. Karli is also dealing with the fact that she can no longer use the washroom in her home. She told me she “had to give up on showers and go to bed baths”. Karli seems upset that she can no longer have a shower. She reflected back on her life and said:

I never thought I would live in the world where I couldn't jump out of bed in the morning, hop in the shower, do my hair and be dressed and up and doing whatever. And now I lay in bed and wait for someone to get my lift to get me out of bed. Put me on my commode. That first and get my food for me, help me eat it. You know, I mean, those are all things that I think, I mean people take for granted, you know.

David, who is aging with muscular dystrophy, does not move around much and hardly leaves his house. The family was having supper following my interview and one of David's children assisted him with walking to the kitchen. He was also aided by the use of a rollaidier. Similarly, Carol, who is aging with multiple sclerosis, cannot walk and without a wheelchair she spends most of her days sitting in a chair watching television. She finds it challenging to find activities to do everyday without becoming bored.

Finally, John, whose arm has been amputated, has noticed a decrease in his physical activity. He has had to limit some of his activities because he has started experiencing back pain which he believes is related to overusing his prosthetic arm.

## Transportation

### **Wheelchair Use**

Of my participants, only Karli uses a wheelchair on a regular basis. Karli, who is aging with MS, is thankful for her wheelchair because it allows her the ability to move around in her house and use her computer. Carol, meanwhile, does not currently have a wheelchair that she can use without help. She is looking forward to having a power wheelchair because she will have more flexibility in her movements and not have to rely on her sons or support workers to move her as much. She currently has a manual wheelchair that she uses when she leaves her house but she needs someone to push it. David, who has weakened muscles due to Muscular Dystrophy and has trouble walking, is not concerned about possibly needing to use a wheelchair on a regular basis. There is a wheelchair at his house but it does not seem like he uses it very often.

Other participants are hoping to avoid using a wheelchair. Victoria told me, “that’s one thing that I worry about is ending up in a wheelchair. Rheumatoid arthritis is one that will cripple a small number of people.” Dorothy, also aging with RA, realizes that she will need more modifications to her house if she has to start using a wheelchair on a regular basis. Mark, who has needed several operations on his right hip, told me that he quit working because “you just reach that point, and walking, you know, I don’t want to end up in a wheelchair so that’s one of the reasons, one of the bigger reasons, because I thought I would end up in one the last time.”

Jake, who has no kidney function, is also concerned about needing to use a wheelchair. He told his wife and son that “if something happens that I have to end up in a wheelchair and you have to look after me, then that’s the end. No more dialysis.” Jake associates using a wheelchair with having no control over his life and needing others to help him. Finally, John did not discuss

needing to use a wheelchair, because his impairment (amputated arm) does not compromise his ability to walk.

### **Transportation Outside the Home**

All except for Karli and David discussed problems with transportation outside the home. The participants who are still able to drive told me they had to change the type of vehicle they were accustomed to driving. Mark had to sell his motorcycle because it was difficult to ride with his hip problems. He is still able to drive a car but is used to taking a passenger role when traveling. When I asked him if getting into a higher vehicle, such as a van compared to a car, was easier, he told me that he does not notice a difference. Victoria, who has experienced some physical limitations as a result of RA, has found that a van is much easier to get in and out of than a car.

John had to trade his standard truck for an automatic when his arm was amputated. He said, "I prefer a standard, but whatever, it's just one less thing to worry about." Jake has also had to purchase a different vehicle to accommodate his disability. He has to travel over four hours a day, three times a week for dialysis treatment, and it is expensive for him to travel back and forth. Although Jake receives a travel allowance for his dialysis treatments, driving a standard four-cylinder car was using up all the money. He now drives a Smart car and told me "I am saving so much money on fuel. The car is actually paying for itself and it's also paying for the insurance. So that makes a big difference."

Dorothy, meanwhile, wishes that she had purchased a larger car or a van instead of a small car because she found it was too difficult to get in and out of the low car. She had to give up driving her car when she could no longer get in and out of it. She told me:

The last time I drove my car [pause] I came home and no one was home on the other side [of the house] and I couldn't get up from of my car. I had a Cavalier and it was low and I couldn't get to my feet. And so finally, by somehow getting one arm in the steering wheel, and I put the automatic window down and was hanging out the door [I got out of the car], I thought that was the last time you can, you can drive.

Dorothy now relies on family members and volunteers from Seniors' Support for transportation, and this limits the activities in which she can participate. She must rely on others as there is not a public transportation system in her small rural community [none of my participants have access public transportation from their homes because they live in rural or small urban areas]. Sometimes she needs to use a wheelchair to get to her medical appointments, but because family members and volunteers are not designed for wheelchairs she relies on an ambulance to take her. Dorothy commented on needing to use an ambulance: "if you have got to be at the pre-op and the ambulance is called to an accident then that's their priority." Her most recent ride in an ambulance "must have cost them three or four hundred dollars and riding in it, I had no idea how bad a ride in an ambulance is." For these reasons Dorothy tries to avoid traveling by ambulance. She prefers to travel in vehicles that are higher off the ground than a car because she is able to get in and out of them easier.

Carol, who is aging with MS, does not leave her home very often because of her lack of transportation. If she needs to go somewhere further than the hospital, which is located across the street, she borrows her neighbour's wheelchair van. She told me that, "I can use that when I go to the doctor in [another city]. And my doctor here in town, I just get in the wheelchair and my sister just pushes me down the street."

### Thoughts of the Future

Some of the participants are living with illnesses that are commonly expected to shorten one's life span. This is true for Karli and Carol who live with MS, David who lives with MD, and Jake who lives with polycystic kidney disease. Each seems to have accepted this knowledge and copes primarily by not dwelling on the future.

Jake talked about the people who are living on dialysis as having the power to determine when they will die, by deciding to stop their treatments. Jake told me:

But we all have an advantage down here. If we want to, we can pick when we want to die. All I have to say is no more dialysis and that's my decision and the doctors will not interfere with those decisions because that's what you decide. And they'll just, they are with you all the way to the end, they keep you comfortable but it's your decision so, I mean, I have often told my wife and son, if something happens that I have to end up in a wheelchair and you have to look after me, then that's the end. No more dialysis. I don't want you to spend the rest of your life looking after me because I can't look after myself. So [pause] that's the way it's going to be. I think more people are so afraid to die that they will do anything they can not to. But let's face it, dying is a part of life, everybody is going to die. So you just have to come to terms with it.

For Jake, becoming a burden on his family is something more fearful than death. Therefore, Jake has decided that if he cannot continue to drive himself to dialysis treatments he will stop them.

He is so dependent on dialysis that he told me,

if I took Friday off, now I'd probably be coming in by ambulance on Monday. I don't have any kidneys at all, so I have no kidney function, so I would live any place from 7-10 days and then I would be done, a goner. And I am not ready to go yet.

David has also accepted that his death could be near. He talks about it openly and without any noticeable fear. I asked him if he had any concerns about the future and he said he does not. He told me, "well if I get sick and die then I die, eh?" Karli also talks about the possibility of her dying in the near future. She tries not to look too far into the future but takes each day at a time. I

interviewed Karli in September and she mentioned that her support worker recently asked her about her plans for Christmas. She told her,

I don't know if I will be here. We'll just wait and see if I make it through Halloween. Well, my, my theory on life [pause] and how I have lived my life, it's just you, you just live each day, one day at a time. [pause] Don't procrastinate, get it all done. Because you might [pause] because they might not check on it or come around again.

Carol's thoughts about the future are similar to Karli's. When we were talking about the Old Age Pension plan she told me that she had fifteen years to go before she was eligible. She was not going to think about that because as she told me, "I might not be here at that time."

Victoria, meanwhile, does not live with a life-threatening illness, but nevertheless avoids looking into the future. She had to ask her husband about his opinion on what it is like aging with a long-term physical impairment. His comments about her life were accepted by her as being exactly the way she feels. Her husband told me:

the future? Trying to live ... Well it would be a person walking down the road with Dr. Death walking behind her. How's that? That's the best I can describe her [pause] somebody with her physical disabilities is just a walking time bomb waiting for the grave. That's all she can do.

Victoria told me, "I figured he could describe it better than me. Sometimes there is so much pain involved you just want to lay down and die."

## **Finances**

Aging with a long-term physical impairment often creates economic hardship, especially for people who need to purchase assistive devices or make home modifications to limit the impact of their impairments or difficulties on activities of daily living. Purchasing assistive devices, such as wheelchairs, crutches, prosthetic arms, grabbing sticks, and other useful tools,

can improve the efficiency of tasks that many people take for granted. For example, getting dressed in the morning is something taken for granted by most people in society, but many people need to learn how to do this to take impairment into account. Most of my participants have experienced some economic hardship based on their need to adapt their ability to perform what many consider ‘normal’ activities.

The economic problems associated with aging with long-term physical impairments are continuous and as Dorothy pointed out, “it is amazing how many thousands of dollars you can spend in a few years. And you get to a point where you start to worry, how am I going to do this?” The more resources a person has, especially economic resources, the easier it seems to age with a long-term physical impairment. Victoria told me that “finances are going to play a big role in getting assistance”.

Fortunately, most of the participants in my research do not have serious money concerns at the moment, although some are limited in what they can do because of inadequate finances. As well, because the economic costs associated with aging with a physical impairment cannot be predetermined, the economic status of the participants could change at any time. The participants, overall, try to avoid thinking about the future and their economic situation.

#### Canadian Pension Plan Disability Benefits (CPP)

Many of the participants who are unable to continue working are eligible to receive Canadian Pension Plan Disability Benefits (CPP). Eligibility for CPP is determined by the government and, in part, is based on the type of limitations a person experiences. Dorothy had no trouble applying for and receiving CPP. Although she tries to survive on her CPP income, she often has to cash in her investments for extra income. She is surviving financially for the time being but does have concerns about the future.

In contrast, Mark had a lot of difficulty proving his eligibility for CPP. It took Mark several years of legal fighting to become eligible. He was turned down three times and finally won his case after attending a tribunal. This process of appealing the rejection decision had a negative emotional impact on Mark and his family. He seemed to learn a lot during his fight for CPP and I asked him if he had any words of wisdom to pass to other people applying for CPP. Mark laughed and said,

There is no easy way. They make it as difficult as *possible* (emphasis on this word) for every individual. They turn you down. [pause] They turn everybody down. You have to fight tooth and nail. ... You have to fight and the minute you give up, is the minute that they win. Because there is no turn back there. If you, if you let the system beat you then you have no recourse because they will say why? Because you turned it down or whatever or you tried this. And I wasn't going to let that happen this time. I said that there is no way I am doing this, [pause and continue with determination in his voice] I am going to fight until the end.

Although the CPP battle has been won, life has not improved economically for Mark. He is concerned because his long-term disability income that he received from the company he worked for was tax free. He was no longer eligible for a long-term disability income from the employer after he was granted eligibility for CPP. While money earned from a long-term disability income is tax-free, income earned on CPP is taxable so Mark told me,

I am stuck at the end of the year trying to figure out where I am going to get \$7000 of taxable income to pay for the CPP. [pause] See, so I fought the system to lose. I fought the system to lose. It's a no win situation. People don't realize this is the way the system works.

Victoria has been encouraged by her physician to apply for CPP so she can stop working. She believes the process will take her six months to complete and she cannot financially afford to stop working for six months. She also worries that if she stops working her muscles will seize

and she will be in worse pain than she is now. She hopes to continue working for a few more years before she has to worry about applying for CPP.

### Modifications to the home

Modifying the home was an issue for David, Dorothy, Carol and Karli, who have to make sacrifices in order to maintain living in their own home. David's wife is worried about what will happen when he can no longer live in his own home. His health is deteriorating and he finds it more difficult to walk and talk. Many of his deteriorations can be linked to aging with MD for over twenty-eight years. After he had a few tumbles down the stairs, a single bed was moved to the living room and he was only able to use the main floor of the house. Instead of relocating to a new home where everything was on one level, David and his wife decided to stay in their home of over forty years and modify the entranceway to include a wheelchair accessible bathroom. The remodeling of the bathroom was expected to cost between twelve to fourteen thousand dollars. David's wife is hoping to have some of the money reimbursed; however, she is skeptical that this will actually happen. She hopes he will continue living in the home for a long time because it will be expensive to have one spouse in a nursing home and the other living at home.

Dorothy and Carol also made extensive home modifications. Dorothy is not happy with her modifications and dreams of how they can be improved. She believes that more modifications will be needed within the next few years. Her next modification will be a chairlift. Dorothy paid for all the modifications and did not seek financial assistance. Carol, on the other hand, was fortunate to have some funding available to help pay for the modifications to her bathroom. Most of Carol's respite care at the local hospital while she waited for the renovations to be completed was paid for with the funding. She was in the hospital for almost a month during the renovations.

Karli has a wheelchair ramp attached to her front porch, but has not been able to make any major modifications inside her home. She did not explain why she has not modified the home and when asked questions about finances she did not know the answers. Instead of modifying the home, the doors have been taken off most of the rooms to allow room for her to maneuver her wheelchair.

Home modifications are often too costly for people to afford without some financial assistance. My participants, especially those who did not receive any financial assistance, had to determine whether the benefits of accessibility were worth the cost of the modifications, or whether they should relocate. Unfortunately, relocation would likely mean moving to a long-term care facility. Participants avoided talking about this.

### Assistive Devices

One of the issues referenced most often by my participants was the need or desire to purchase products that improve their ability to do things. All of them have purchased something for the purpose of accommodating their impairment. The types of purchases range from something considered the icon of disability, a wheelchair, to something unrelated, such as a flat bottom boat to replace a canoe when stability and mobility became an issue for John who has an amputated arm. The conversations with participants ranged from some people talking openly about various assistive devices to other participants talking about changes in their behaviours to accommodate their impairment.

Purchasing assistive devices is not a common experience for John, Mark, David or Victoria. They did not discuss assistive devices as much as the other participants. John has learned to adapt items to make them easier to use with only one arm. Mark relies on his crutches when he has difficulty with mobility. This is the only assistive device that he talked about during

the interviews. Jake bought a Smart car to reduce his expenses because of the distance he drives for dialysis treatment. This was the only item he talked about that helps him adjust to his physical limitations. David uses a rollaider and a wheelchair but he did not discuss these items in great length. The only assistive device that Victoria talked about was the installation of grab bars in her bathroom.

Spending money on assistive devices has become a significant aspect of Dorothy's life while she ages with rheumatoid arthritis. She openly discussed the amount of money that she has spent on assistive devices over the last ten years. While she has been satisfied with many of the devices, others have been given away when she found they did not meet her needs.

Unfortunately for Dorothy, as with many of the other participants, she did not have anyone to advise her on what products would be most useful. Without much assistance from a physician or therapist, Dorothy is required to make her own decisions on what types of products would be best in helping accommodate her impairment. Personally testing assistive devices has become an expensive task for Dorothy who told me:

you don't realize how expensive it is being disabled [pause]. It's not only the modifications. It's trying, I bought a special pillow from the Arthritis society and it, well it helped my shoulders but it bothered my neck. So you end up giving it away. So you buy various gadgets that don't work and then you end up giving it away [pause] so it's all money wasted because you buy things and then give them away. [pause] Well, I have probably wasted about \$1500 on shoes that I would buy and then they weren't comfortable and then I would end up giving them away.

There are a few assistive devices that Dorothy acknowledges play an important role in her ability to perform everyday tasks such as dressing herself. During the interview, Dorothy told me "and then I have to use a grabber stick to pick things up off the floor and I have to use a dressing stick to put my nightgown on and take my clothes off." She demonstrated how she uses

the grabbing stick, which she keeps conveniently located near her chair. She went on to explain how she uses it to reach clothes in her closet and to pick up things from the floor. Although the dressing stick is useful, it does not solve all her problems. A grabbing stick was not useful when a bag of milk dropped from her hands and landed on the kitchen floor. Dorothy had to leave the milk on the floor until a homecare worker arrived. Another task Dorothy has trouble with is opening water bottles. None of the products that she currently owns help her complete this task. To solve this problem, Dorothy asks a homecare worker to open several bottles at a time because it is easier to open the bottles once the seal is broken.

I asked Dorothy about renting equipment because I thought it might be cheaper than buying products that you later find are not beneficial. Dorothy has rented some products, such as a bedrail, and later purchased the product. She told me about the bedrail experience, “I rented it for one month because I thought I’d only keep it [while] my hip was bad and I needed help getting out of bed. I was only going to keep it for a few weeks but when I realized how expensive it was to rent, I ended up buying it.” Dorothy is very conscientious about the needs of other people and worries about using a device for too long. She told me, “I had a commode from a service club and I realized that other people would need it so I ended up buying my own too.”

Wheelchairs are one of the more expensive assistive devices that might be needed for someone aging with a long-term physical impairment. Carol, who has recently experienced more physical limitations as a result of MS, is in the process of purchasing her first power wheelchair. She cannot move anywhere without assistance and spends the day sitting in the living room watching television. A power wheelchair will enable her to move around her house without assistance. This will greatly improve Carol’s mobility because she currently relies on personal support workers and family members to move her from her bedroom to the bathroom, to the

living room, to the kitchen and back again. Fortunately, Carol's previous employer will pay eighty percent of the cost of the wheelchair.

Karli, who also experiences physical limitations as a result of MS and requires the use of a wheelchair, did not mention any economic problems associated with purchasing a wheelchair. She has had at least two different wheelchairs since being diagnosed with MS. Her first wheelchair was given to her. Her current power wheelchair enables her to sit at her computer and spend most of the day 'chatting' on the Internet or searching for books and videos to borrow from the library and the Canadian Institute for the Blind (CNIB).

### Personal Support Workers

While assistive devices can improve the process of adapting to aging with an impairment, the assistance of a personal support worker is often required to improve or maintain quality of life. Karli, Carol, Dorothy, and David all received support from either the March of Dimes or a nursing support agency, and sometimes both. Each of them has a case manager who determines the type of care they require and how many hours they are allowed to receive each week. They have all reached the maximum number of hours allowed, but Karli, Carol and David mentioned the need for more care hours. Karli's husband would benefit from more hours because he is currently helping her get ready for bed each night. This nightly ritual is difficult for her husband because he has a bad back. David's wife appreciates the extra support because David cannot be left alone. However, she wishes she had more time because they live in the country and she uses a portion of her support time to travel to the nearest town.

Fortunately for the participants, most of the expense of these support workers is funded through the government, which they greatly appreciate. Carol has used more nursing hours through the support agency than she was allocated, and she had to pay for the extra time.

Fortunately, she only needed a few additional hours and the cost was approximately \$16.00.

David's wife receives respite care for David, but she has to pay three dollars for every hour of service used. David also participates in a day away program hosted by the Seniors' Support which costs \$29 per day.

Karli, Carol and Dorothy have experienced problems with personal support workers. Karli and Dorothy have had at least one personal support worker or nurse who they did not like. Dorothy talked about an experience where a personal support worker would not place items in convenient places. She asked the support worker not to put a dish towel on the handle of the stove or refrigerator because she did not want it there. The support worker responded that she puts it there at her own house. Dorothy told me that she told the support worker, "I don't care where you keep it at your house." She continued after by saying, "but, I think a lot of people think they are helping you but they are not. Because I am still capable of knowing how I want things done in my own house."

Karli did not like one of the nurses who came to her house to provide care and refused to allow her back. Unfortunately, the woman is now working in a local hospital so Karli may see her at the hospital. Carol initially had trouble finding a suitable time for a support worker to come to her house to get her ready for bed at night. Initially, the company wanted to send someone at eight o'clock, which was too early. She did not want to go to bed early because she feels she does not do enough during the day to make her tired. The company finally agreed that someone would help get her ready for bed at ten o'clock but they had to wait until a new staff member was hired.

## Medical Expenses

Many of my participants have several physicians treating their various physical impairments, and some must occasionally be hospitalized, so they are fortunate that they do not need to pay for physician visits or hospital stays. They do, however, have to pay for medications and other health care services.

For some, the cost of medication to control symptoms related to their physical impairment can become a huge economic burden. Some have drug plans provided through their previous employers or their spouses' employers that pay the costs of these medications. Those who do not have drug plans have been encouraged to apply for the Trillium Drug Plan which is offered through the provincial government. Karli uses the Trillium Drug plan to help her pay for her medications. However, she told me "they're making [the medication] harder to acquire ... sometimes I have to change my medication because they will pull out, think it's too expensive. Go for generic, generic is not bad."

Dorothy's medications are expensive. She told me,

I have been on one drug that is \$169 for two months' supply and the Celebrex, I use to spend 100 bucks a month but it was bothering my stomach so now I only take 1 pill a day so that's \$100 for two months. And the Actine ... a 3 month supply is over \$100 so it is expensive.

In spite of these costs, Dorothy initially resisted applying to the Trillium Drug Plan. Ideally Dorothy would prefer to be treated and advised by a homeopathic doctor, but this is not economically feasible for her. When she was employed she relied on information provided by a homeopathic doctor trained in herbology. Now that she cannot afford to see the homeopathic doctor, Dorothy makes up her own mind about what types of medications she should be taking.

Mark needed physiotherapy after his first surgery and his fifth (or second to last) hip surgery. At the time, the cost of a limited amount of physiotherapy was covered by the Ontario Health Insurance Plan (OHIP). Mark, however, was told he needed two more sessions than OHIP would pay for, and he had to pay \$50 per session. By the time of his last surgery, physiotherapy had been completely de-listed as an insurable service. Mark could have used physiotherapy again, but he decided that he would rely on what he had learned from his previous sessions and complete the therapy at home, by himself. Mark does not agree with having to pay for therapy sessions. He told me, “people with disabilities don’t have the money that regular people have made over their years. ... the system now doesn’t pay for any of those extras. So you have to pay for yourself, so I daresay they go without. They just don’t do it”.

John actively participates in different types of therapies. He regularly goes for massage therapy and will occasionally see a physiotherapist. A session with a therapist who focuses on his back costs \$60.00. In addition to visiting therapists for sessions, John does an hour of exercises each morning at the recommendation of his therapists. John recognizes that many people cannot afford to see a therapist and he told me that he has been “lobbying for 10 years or more for people who have a permanent disability to have access to on-going care.” While there has been some change in the access to on-going medical care for people with permanent impairments, John is not satisfied and continues to lobby for more rights. John continued by saying:

Certainly OHIP doesn’t fund chiropractic, physiotherapy, either so there’s your sorta backup, where do you end up getting therapy? So, really most of the people are left with their workplace insurance.

Victoria wishes that OHIP would provide financial coverage for therapy. She thinks having access to free therapy sessions would make aging with a long-term physical impairment easier.

Karli appreciates having her eye examinations paid for by the government because her blood sugar level measures low. She told me that it was:

not a giant panic but, [the optometrist] said that I am riding the line ... He said, 'well you will get an eye exam every two years for free.' So I went and got my eyes [examined] and then spent my money on glasses. And then I got a refund. I don't know how I got a refund, but I got some money back.

Karli also receives funding from the CNIB because of her blood sugar levels and a floater in her eye. This funding helped her purchase an audio device to listen to books and videos on DVD.

## ***Mainstream Attitudes and Barriers***

### Encountering Mainstream Attitudes

Many of my participants reported that there is not enough awareness about disability. Almost every participant had an experience where they were treated differently, looked at differently or ignored because of their physical impairments. Dorothy, who has been ignored in retail stores when purchasing products for herself, became agitated when she talked about the way salespeople address her companion for information and not her. Dorothy told me "the one pet peeve that I have is the way people treat you by not talking to you as a person and dealing with the person with you." When Dorothy purchased a Rollaidler from a store that sells products for people with disabilities she became frustrated when the salesclerk continued to speak to her companion instead of her. She told me that she felt like saying:

"Lady, I am right here, I can hear you". She [the clerk] would say, "how does she find the height of the walker, or do you think she finds it comfortable?" And I thought, I am not mentally disabled, do I look deranged. And I should have said something but you were taught when I was young that you don't cause problems and you didn't make waves. But I should have said "Lady, I am right here and I can hear you and why are you talking to her when I am the one who's buying it".

Although Dorothy wishes she could stand up for herself, she still did not say anything to the salesclerk.

Based on her treatment by members of mainstream society, Dorothy believes that people need to be educated on what it means to be disabled. She offered a few suggestions for educating people about disabilities. She thinks that more television advertisements should be directed towards people with disabilities. An advertisement that had an impact on her was one produced for the CNIB. She told me,

so, one of the ads shows a guy with a cane and there is a guy in front of him waving his hand so when this young guy turns his back [pause] the guy with the cane starts waving his hands and behind this guy's back because he saw what he was doing.

Dorothy found this advertisement interesting because:

just because you have a white cane doesn't mean you are totally blind. They might have some vision, but people don't think of that. I thought what an effective ad because that might sink in to people because while they are doing hand gestures and things they can do it back to me.

Dorothy thinks that children need to be educated in school. She believes children need to learn about disability even if there is no one in their class with a physical impairment. Her experience has shown that children exposed to people with impairments do not see it as anything different. Her great-nephew is comfortable approaching people using canes. Dorothy has a friend who has both legs amputated. His young granddaughter will bring him his prosthetic legs and it appears she has become desensitized to the issue of missing limbs and prosthetic limbs.

John believes that children need to be educated that people with impairments are not different and should not be avoided. Avoidance of people with impairments was something reinforced by his mother when he was a child. He retold a story to me about his mother. His experience went like this:

I mean I just know, you know, from when I was a little kid, you know, from walking with my mom no matter where I was I must have been about five or six years old, I don't know [pause] see someone in a wheelchair and she'd say, "don't look, don't stare, don't stare" (he leans forward and changes his voice – like he's mimicking his mom) "what do you mean. I've never seen this, of course I want to have a look." "Don't stare". Well right away it made me understand that there is something wrong. I mean my mom's real nice and, you know, so, there must be something unfortunate, something bad, you know, and not even know it, really. You start getting these values and umm you see how our society is umm is umm set up so that it's harder for our part of our population's approach.

John is aware of people's reactions to someone who looks different so he makes an effort to teach people, especially young children, about the way his prosthetic arm works. His prosthetic arm has a hook on the end and he finds it draws a lot of attention because it is shiny.

I try to show them how it works and, you know, and you do it in a friendly way and they're [pause] especially kids are *always* curious, adults are afraid to ask mostly. They have gotten to a point where you know they have already been told don't look, don't stare. You know, whatever, so the kids, it's great because they are curious and they want to know and they want to find out. And I try to show whatever I can and just kinda [pause] not have it feel like it's weird.

Jake, Mark and Victoria notice that stigma attached to disability makes it difficult for people with impairments to function without feeling uncomfortable. Jake and Victoria talked about the mean and judging looks they receive from people when using wheelchair accessible parking spots. Victoria uses wheelchair accessible parking spots because she finds it difficult to walk after sitting in a car. She recognizes that she does not always look "disabled", especially when she leaves the store because walking in the store helps her ability to move. Victoria explained to me that,

Well, I know there have been times when I have used the wheelchair [parking spot] and people look at me as if to say, why

are you parking in there. Sometimes I think people think I am using a permit just so I don't have to walk far.

This feeling of judgment is familiar for Victoria and Jake. Jake told me,

you know when I get out of the car I look 'normal' and a lot of people don't realize that I am missing kidneys, that my body is deteriorating. So, there is, there is a big stigma attached to that. People just don't understand.

Despite the judging looks, Jake and Victoria continue to use parking spots reserved for people with impairments.

Being a man with an impairment can be challenging because of the emasculating effects of disability. A disabled woman is not a contradiction in terms because of the stereotypes that both entail, but the same is not true for the concept of a disabled man. Jake, who has no kidney function, feels restricted because of the stereotypes linked to masculinity. He often requires assistance opening a bottle of tomato juice at the hospital cafeteria. Jake told me, "there are a number of times I have to ask the guy to open it for me because I just don't have the strength. And that, you know, that makes you feel like a wimp." Feeling weak is difficult for Jake since he always took his strength for granted. Throughout the interview, Jake talked about all the physical tasks he has completed and at one point he mentioned how much muscle mass he has lost. He said that his arms are half the size they used to be. His body weight is a concern to him and he misses being able to complete physical labour without much effort. Even though he is unemployable, engaging in physical labour appears to be Jake's way of proving his masculinity. This helps Jake to feel better about his life and makes coping with his limitations easier.

Mark, who has hip problems which impact his strength and mobility, has experienced problems relating to mainstream society believing that males are strong and should be offering assistance rather than accepting assistance. Mark and I discussed how people with visible

impairments are treated differently than people with invisible impairments. A problem with invisible impairments, in Mark's opinion, is that the person looks fine even though he or she may have limitations. Braces, crutches and wheelchairs are visual triggers that show people that the person is disabled. Since Mark avoids using his crutches, he often has no visual trigger to show other people that he has limited strength and mobility. I asked Mark if he has to prove himself to people because he has an invisible impairment. He told me,

Yes, all the time. All, all the time before, no matter what, [pause] "what do you mean, you can't do that?" [pause] "what's wrong with you?" [pause] just because you limp a little, so what, big deal, get over it. [pause] Right, yeah, it was always there, [pause] that was always a pinpoint of, [pause] "come over here and do this or get that." "I can't do that" [pause] "what do you mean can't do that?" I mean, trying, [pause] there is no sense in explaining to them because they wouldn't understand, especially people who don't know you.

He often has to turn people down when they ask for help. This is difficult for Mark because he knows people are judging him on the basis of his able-bodied appearance.

### Attitudes Towards Old Age

The participants in my research were all over fifty years of age. All but David, who was already sixty-eight, were approaching the stereotypical age of sixty-five that marks the entrance to old age in mainstream society. Nevertheless, many talked about feeling and looking younger than their chronological age. Very few described themselves as old. Dorothy told me:

it is difficult for me to differentiate the difference between the old age and the disability. Like even with my disability and at this age, I don't really consider myself, I don't know how to put it, but old old. But I don't feel that old.

Although the participants do not distinguish themselves as old, there are markers in society that make them realize that they are, in fact, getting older. Mark talked about his experiences when he looks in the mirror. He said:

I think we don't realize one day you are 30 and the next day you look you are 50. I get that when I, when every morning when I look the mirror I say I didn't invite you, who are you? I don't see the person I am seeing, I see the person I was.

Jake has only recently noticed and decided that he is getting older. He accepted his increasing age when he was watching television and noticed that new people were playing the roles of his favourite actors and actresses. The new person is much younger than the one he or she replaced. Jake also realizes that he is getting older when he looks at his son. He told me, "he will be 20 in June, but it feels like he is only about [pause] like he was just born yesterday. So where did that 20 years go?"

Karli, although she wanted to look old for the interview, told me, "I couldn't get the grey hair, it just hasn't come yet. I don't have a lot of wrinkles. Some would say that I don't have any. But I am not going to look for them." Very few people would believe that Karli is approaching sixty years of age based on her physical appearance.

Only two participants explained how the impairment made them appear visibly older than they were. Mark said,

there are people out there that that the impairment has aged them ... more quickly. I got grey hair really early because of all of my medications and the number of times I was under the [anesthetic] [pause] that gave me premature grey hair so I looked older than what I really was.

Even though Mark might look older than his chronological age, he told me: "I'm almost 60 but I don't feel ... I feel like I am 40. Other than my leg. I am in good physical shape." Victoria was the one participant that felt that her physical impairment has made her look older than many of her friends who are the same age. She complained that, "like with me with rheumatoid arthritis, you look a lot older because you are in pain and you can't sleep and you can't cover that stuff up. No matter how much makeup and stuff you put on."

The comments about feeling old were triggered when I asked the participants if they had heard of the term ‘successful aging’. Most of them had not heard this term but had some strong opinions of it when I described the concepts of the term as depicted by mainstream media. I explained that successful aging meant people who were able to look younger than their chronological age either by acting younger or changing their physical appearance, such as hair dyes and face lifts. Although the participants agreed that it would be nice to ‘age successfully’, they did not like this term because it further stigmatized them and their experiences. Mark thinks the term is a joke because:

This plastic surgery and the health clubs and you know what's all a fantasy for all the baby boomers to try to jump in on the bandwagon and say that try to keep their youth. But it's not going to happen. [pause] You look back at your family history did they die young?, did they die old?, did they die under circumstances? [pause] it's like a gambling game out there, it's a guessing game. When your time is up, it's done.

Jake also disagrees with successful aging because he thinks “you may be able to avoid it [aging] in your own mind but your body is still going to age.” David, who is aging with MD, agrees with the comments by Mark and Jake and thinks that you cannot avoid getting older and that eventually your body will wear out.

#### In/accessibility of the Physical Environment

Physical barriers can prevent people aging with a long-term physical impairment from socializing outside of their home. Three of my participants were especially concerned about the inaccessibility of public and private bathrooms, and/or the existence of automatic doors.

Washrooms are a problem for Karli and she has helped a local businesswoman design the store's bathrooms so they “wouldn't be a handicapped bathroom, but, a bathroom for

handicapped people to use. Because sometimes those handicapped johns are not the greatest in the world. You can't shut the door or go in pairs."

Whenever Dorothy leaves her home she worries about how she will use the bathroom.

She told me:

I think even with these wheelchair accessible bathrooms I don't find them that great. I mean, maybe in a wheelchair they are great, but I find for me they have a low toilet and the grab bar is off to the side too far that it doesn't help me. Like the part that I have to grab is too low so it doesn't do me any good. So, well, I don't think they consult the right people when they do a lot of these things. I don't know who they consult. But that was one of the gripes my therapist had from the Arthritis Society that she had [pause] that they don't consult the right people.

Another concern for Dorothy is how quickly automatic doors close on her. Her biggest fear is the doors at a local Zeller's store. When explaining why she is worried about them, Dorothy told me:

Because they start to close on me when I am partially through. Now they probably wouldn't close on you but it scares you to see those doors coming towards you until they open back up again and I don't know why they got the timing set that they don't give you well, well that people with disabilities don't move too fast ... I am really afraid of those doors. Because I was there a couple of weeks ago and they started to shut on me because I was that slow [pause] and so I imagine if someone took a picture of my face when those doors started to close then they would have seen sheer panic.

Victoria also discussed the problem of opening doors. In her case, the lack of automatic doors creates a problem because she finds many of them too heavy to open. She told me "usually when I come out I am using my butt to open the door (laughs) it's a lot easier or if they have buttons I push them."

### Dealing with the Medical System

Most of the participants expressed satisfaction with the medical care they have received and the health care system in general. While many of the participants discussed at least one

negative medical experience, they summed up their overall experiences as positive. Additionally, not many offered suggestions for improvements but the changes that were suggested were directed towards long wait lists and lack of nurses and doctors. Although some participants experienced negative treatment from nurses or doctors, these experiences were blamed on the lack of funding and staffing issues.

Nevertheless, the participants have specific concerns about the health care that is available to them. Most of the participants are worried about the shortage of physicians, especially those living in rural Southwestern Ontario. Although all of the participants in Southwestern Ontario have a family physician, many of their physicians are approaching retirement age. There was a common concern about replacing their physician when he or she retires. Mark is satisfied with the care he receives from his family physician but told me,

I hope I am still with him for another at least five to six years. Because he's almost at the point of retiring and getting another doctor is, oh boy, a challenge. There are not many doctors around here and there's another [pause] well my wife says there's another one going to retire in January. So that'll be two gone outta the clinic. Then they'll be down by two doctors. Well that's [pause] two doctors, that's like seven thousand patients, so I don't know what they are going to do.

Dorothy expressed her concern about the lack of doctors in her community, especially because she lives in a rural area. During the interview Dorothy told me:

we certainly need more family doctors because, I mean, my family doctor is at an age where he wants to retire and they can't find a doctor to come to this area and they've been trying for 3 or 4 years now. Because they needed a second doctor because the other doctor took ill when this doctor came and there were supposed to be 2 doctors, but he ended up with all the patient load and like he wanted to be semi-retired and he like never took hospital privileges because he didn't want that big of work load. So there has to be something done to entice doctors to come to smaller towns.

The participants in Northwestern Ontario did not complain as much about the lack of physicians, but talked about the lack of choice in their physicians and being frustrated with wrong diagnoses. Jake talked about moving to Southwestern Ontario to be closer to physicians. He felt he would greatly benefit from being located closer to the hospital. In contrast, John lives closer to the hospital in Northwestern Ontario, but he still has complaints about the type of care he receives, or does not receive, from his family physician. His family physician failed to diagnose a hyperthyroid condition and John did not receive treatment until his wife researched his symptoms on the Internet.

When I asked Dorothy if she ever has accessibility problems with visiting her family doctor she replied,

No, not really [pause] nope, like my family doctor is really good, like last year when my left hip got really bad he came to the house and after my knee surgery when my legs were really swollen he came to the house the day before Christmas. So I think he's marvelous.

Similarly, when I asked Karli about her family doctor she told me "mine is great [pause] he stops and makes house calls." Karli has a good rapport with her current physician and affectionately refers to him as Mr. Walking Prescription Pad because she only really uses him to manage her pain and symptoms relating to MS.

Negative experiences with the health care system, on the other hand, led most participants to talk about not trusting the doctors' opinions and using their voice to speak up when necessary. They do not always take the doctor's opinions at face value and like to do their own research before making decisions. David did not have much to say about his health care experiences. Victoria was the only participant who appeared satisfied with her doctors, especially the rheumatologist, and was not as quick to second guess their opinions.

Despite Karli's satisfaction with her family physician, she has had some bad experiences with other doctors. When she experienced problems with her ovaries and needed surgery, she was not satisfied with the first doctor she visited. She told me,

I couldn't find a doctor that would put me to sleep for the surgery. Because they were afraid of my MS. [pause] You know putting you out and then you didn't know if I would wake up. Right, so I, I found a doctor that had said he'd done it before and he felt pretty confident and I, and I found a book where there was an asthmatic woman who couldn't take the umm, [pause] I had an epidural and I was the first epidural that they did in Ottawa. And then they, they changed the whole [pause] proceedings you know. They are doing epidurals on other operations now.

Unfortunately, Karli experienced some serious complications after the surgery. She told me:

It was pretty scary. It took them about a week of me projectile vomiting ... before they decided that I had a, I had a problem ... That hospital, I would have wanted to sue them but, but people don't do that. But I would have liked to have got the news media in on it [pause] it was kinda a nightmare experience.

Jake also has reason for not trusting the doctors to know best. His second kidney transplant was not successful and he told me that "the second one I lost over the doctors' mistakes, just call them mistakes." Jake talked about this transplant surgery in detail. Basically, he believes the problem was that doctors gave him too many immunosuppressant drugs, even though he had told the doctors beforehand that he would not need as many drugs as they were suggesting. He said:

So they put the kidney in and it worked right away, within 3 days the reactants were back to normal, I was feeling great. But then they started giving me the immunization drugs, they screwed up the kidney.

More recently, Jake hurt his leg and does not believe his physician's explanation that he had torn a tendon. Based on his own research, he is convinced that he had a leaking blood vessel, but the doctor discounted this possibility. Jake told me:

I think that there is a point [pause] or rather there is a point where I think they are getting placid about me being here because I have been here for so long and they almost take you for granted.

## ***Conclusion***

The experiences of my participants show that aging with long-term physical impairments is not easy. My participants spoke about their physical challenges, financial challenges, and problems interacting with mainstream society. Their experiences continue to change and evolve throughout their life course. Many of the changes that occur were unexpected and continuous. My participants struggle to deal with the loss of activities and push themselves to continue some activities so they do not feel completely powerless to their impairment.

While my participants learn to deal with their changing bodies and decreasing income, they must learn to live in a society that is designed to meet the needs of a younger, able-bodied population. Most of my participants deal with stereotypes and stigma on a daily basis based on their physical differences and limitations.

As my participants learn to adapt and adjust to personal changes and attitudes and barriers in mainstream society they must develop coping mechanisms to help them meet these challenges. The following chapter focuses on the ways they have learned to cope with aging with long-term physical impairments.

## Chapter Four – Developing Coping Mechanisms

This chapter examines the themes that emerged through analysis of the interview transcripts, with a focus on coping mechanisms used to help participants adjust and adapt to aging with physical impairments. Coping mechanisms can be grouped thematically as related to: coping physically, coping with finances, and coping emotionally. Each of these themes is also broken into related sub-themes. Although all themes are discussed here separately, they are not in practice isolated from each other; there is overlap between them.

### ***Coping Physically***

People aging with long-term physical impairments must learn techniques to accomplish everyday activities while taking impairment into account. Under the umbrella of this theme, participants discussed assistive devices, home modifications, physical activity, and the use of therapeutic services. Most of the participants in my research learned techniques on their own by trial and error or by analyzing what they need assistance with and finding or creating a tool to help. Although there are many different types of assistive devices available to people with physical impairments, my participants typically designed or adapted items to better suit their needs. As people with physical impairments age, they are likely to need modifications done in their house so they can maintain living there throughout old age. Regarding current levels of activity, many believe that having been active in the past or continuing to be active has played an important role in helping to maintain their functional abilities. Some participants also discussed the use of rehabilitation or other therapy services to help them maintain abilities.

### Assistive devices

Unfortunately, many of the assistive devices that are available in stores are not always useful for the participants in my study. Most of the participants commented on the need to develop personalized assistive devices based on their specialized needs. For example, while many people only think of using a straw for drinking beverages, some participants have found other uses for a straw. Three of them discussed using a straw to drink coffee, soup, yogurt and other liquid type foods. While most people are familiar with using a straw for cold drinks, Victoria needs one to drink coffee. She told me,

There are days when I can't even lift a cup of coffee. I have to drink coffee from a straw because I can't even lift the cup. I haven't had too many of those days, but man do I hate those days. When you can't lift anything in your hands, that's the days that really get to you.

Karli uses a straw to help her eat products such as yogurt and apple sauce. It is for this reason that she avoids going out in public because she cannot feed herself without making a mess.

Dorothy also has a different use for a drinking straw. She told me,

You have to kinda figure out on your own what you need. Because I have come up with things to do to aid me, not that someone told me. Like, umm for instance, I cut my leg and I needed Polysporin on. I couldn't reach so I took a drinking straw and put some Polysporin on it to reach the cut.

This new device has been helpful and she uses it on a regular basis.

Some of the participants have been able to adapt items they have around the house to make completing tasks easier. Dorothy, when told the personal support workers could not put medicated cream on a sore on her leg, created a device using a doweling rod and a cotton swab. She uses this device to put cream on her leg but told me,

it's a pain to cut the tape or take the duct tape off everyday but that's how I figured out how to do it myself. So I think a lot of

devices, assistive devices, have been thought of by people at home who had to think up a way to do something.

John has experienced problems as he has learned to adapt with a prosthetic arm. When John first received his prosthetic arm he wore it all the time because he found it useful. He has recently, in the past few years, noticed that the strap from the prosthetic arm has been rubbing and pinching his other arm resulting in pain and a loss of feeling. He wore the prosthetic arm most of the time for twenty-five years. Because he has noticed the impact on his existing arm, John tries to avoid wearing the prosthetic arm unless he needs it for certain activities. John was not wearing his prosthetic arm when I met him for the interview. He told me,

this weekend I was working in the garden a lot and I was wearing it most of the time and it does kinda hurt. So [pause] it was just as well today not to wear it. I wore it for a bit today when I needed to lift some stuff.

Even when John wears his prosthetic arm, he still requires modifications in how he completes certain tasks. Instead of using a one-wheeled wheelbarrow, John purchased a garden cart with two wheels that is easier to maneuver. He also uses a restaurant style can opener that only requires one hand. His comment about assistive devices was that “some of the tools that I use, I adjust them a little bit.” He modestly told me that his ability to figure out how to adapt is just “luck”. John believes that he was “was born with the good physical sense and problem solving and figuring stuff out.”

John thought about some of the tasks he had to relearn so he could complete them with one arm. He spoke about how he is not always open to learning about new ways of completing tasks, especially if the way he currently does it works. He told me,

I think a lot of us are creatures of habit. So, for instance, my shoes. I found a way that works, and I have never thought about it again. I am not sure that it's the best way [and] there may be other ways that are better but I stopped thinking about it.

Asking for help is not always easy for John who tries to complete activities using his prosthetic arm. Prior to his accident, he was used to doing things for himself and he now finds it challenging to adjust to needing others to complete tasks. When I asked how he felt about asking for help, he told me “sometimes it’s okay and sometimes, I just, I just find a way trying to do it myself [pause] get more clamps. I’ve got seven arms now!”

Aging with a long-term physical impairment requires a person to be resourceful and adaptable. The participants in my research have found ways to accommodate their impairments by designing assistive devices that are not often for sale.

### Home Modifications

When people with long-term physical impairments age, they often have to make a decision about whether they should continue to remain in their current home and make modifications, relocate to a house already modified, or relocate to a long-term care home or retirement home. Stairs were a problem for most of the participants, but Jake and Mark were fortunate to already own homes on one level, so they did not need to make modifications. John did not mention whether his house was on one level and did not mention having trouble with stairs. Another three participants, David, Carol, and Dorothy, made extensive renovations to their homes, especially the bathrooms, so they could continue to live at home. The other two, Karli and Victoria, have made relatively minor home modifications.

Karli has made some minor modifications to her house, but the most useful modification was the installation of an outside ramp. Instead of modifying the washroom to accommodate her wheelchair, Karli and her husband decided that she would no longer use the washroom but would use a catheter. The other doors in the house have been removed which allow Karli to move around in her wheelchair.

Victoria, although she would prefer her laundry to be on the main floor of her house, has only made a few modifications. Her husband installed grab bars in the bathroom to help her get on and off the toilet. Although this grab bar is helpful, Victoria worries that when she uses the grab bar and the edge of the sink she might pull “the sink off the wall when using it.”

David, Carol and Dorothy have made significant modifications to their washrooms. The washrooms are now wheelchair accessible and all three can have a shower. The renovations were completed without consultations with professionals who are skilled in renovations for people with physical impairments. The participants had to determine on their own what type of modifications would best suit their needs. None of these participants were aware of trained people who could help them with their modifications.

Dorothy mentioned that she would have preferred a bathtub over the walk-in shower that was installed. She told me:

I looked into a lift for there but it was nearly \$2000 and well [pause] the bathtub wasn't long enough so I would have to sit with my knees drawn up so the girl said how long could you sit like that? I said about 5 minutes and she said, “you want to spend \$2000 to sit 5 minutes in your bathtub?” I said, “well I don't.” So that's when we decided to throw the tub out and get a big shower stall.

David's new washroom, which was being completed while I was there for the interview, had a walk-in shower/tub installed. Although the washroom was not quite completed, David was still able to shower and use the toilet. I did not see Carol's washroom but she told me,

I just had my bathroom renovated so I have a shower and everything in it. I used to have an old claw foot bathtub so I couldn't step up to get into the tub so, so I needed a new bathroom with a new shower in there.

The newly renovated bathrooms for Carol and David are on the main floor, which makes them more convenient to use. Unfortunately, Dorothy's washroom is located on a higher level

than the rest of the rooms in her house. Dorothy contemplated making a new bathroom which would be on the same level as the other rooms but realized it would cost too much money.

If Dorothy requires the use of a wheelchair she will need a wheelchair lift installed on the stairs leading to the washroom. Although the current stairs were not completed to her satisfaction, Dorothy will be able to install a small chair lift that will not be in the way for the personal support workers. Dorothy's opinions about how to design the bathroom, and most specifically the stairs, were not considered when the contractor made the renovations. Her request to put the toilet on a two inch base was ignored by the contractor. She told me,

when I looked up there the toilet was sitting on the floor. So I said, "where is the base?" "Well we decided that you would fall so we are not going to do that." I said, "the base wasn't for me to climb up on, it was for the toilet to sit on." "Oh well, we didn't understand that." So finally, [pause] well you see it's really hard to get contractors to do what you want them to do, you see they don't understand. Well he said that he didn't understand what two inches would make. Well when you are disabled an inch can keep you from going up the steps.

Dorothy learned a lot from this experience and knows what she will do differently if she has to make any more modifications in the future.

### Physical Activity

Adapting to a physical impairment may be easier if people were physically active prior to the impairment or continue some form of physical activity that takes impairment into account.

Victoria and Dorothy are both aging with rheumatoid arthritis. Dorothy, after reflecting about missing long walks and bicycle rides, told me that she thinks that her previous physical activities made her stronger and made it easier for her to cope with her declining physical abilities.

Victoria still pushes herself to clean houses because she told me that it is best to keep moving even when you are in a lot of pain. She told me:

Well it would probably help if I slowed down working. But, see I know a lot of people make their mistake when they have arthritis and they hurt and they sit and that's the worse thing you can do. Because what happens is that your muscles shortens and that puts you in more pain. So you have to keep mobile. That's one thing you have to do.

Both John and Victoria stressed the importance of pacing themselves in their activities.

Victoria is able to continue cleaning houses because she has learned to pace herself. John told me that maybe the secret to aging successfully was pacing. He is able to do a lot of things but he has to pace himself so he does not overdo it. After he started experiencing numbness in his arm three years ago, John also began to pay more attention to how he does things. He was worried that the years of overusing his arm and the strain of the strap from the prosthetic arm would leave his good arm useless. He told me, "you know I worry about [pause] really my existing arm more than anything. I think, I feel like I've got it more in balance now."

When Jake feels his body is letting him down, he often tests himself by completing home renovation projects. These projects make him feel better and his health improves. After his second kidney transplant in southern Ontario failed, Jake saw himself as going home to die. However, he found some strength to continue living when he tackled a new addition to his house. Once he returned home he sold his boat and:

decided that I am going to put a new room up in the back of the house. So I started building that and the first day I worked at it, I worked 2 hours and I was beat. I was done. Next day I worked 4 hours, the next day I worked 6 hours and after that I worked everyday. Just getting back up here and getting out of that crap down there, the fresh air and being active, it brought me back. So I have learned from that, that I have to keep active and the same thing with this new addition, before we put it up, I was feeling pretty crappy, and then [pause] I had somebody build the shell for me because I couldn't do that, so, well I am doing the inside. And that's keeping me active so now I am feeling better. So that's just it, I gotta to keep moving, I gotta keep working all the time. I can't think about being an old person. I haven't got the time anymore.

Even though he is unemployable, engaging in physical labour helps Jake to feel better about his life and makes coping with his limitations easier.

### Rehabilitation/Therapy Services

Some participants discussed the usefulness of rehabilitation or therapy services. Mark needed the services of physiotherapy after his hip replacement operations. Although he found them useful the first time, he did not go back after his other operations. He told me, “once you get the routine you don’t need their assistance to know what you should and shouldn’t do. That’s my theory on it anyways.”

Dorothy found the services provided by a therapist through the Arthritis society to be very useful. However, the therapist retired a few years ago and Dorothy is unaware of another therapist being hired.

John received information and rehabilitation services when his arm was amputated, but he cannot remember everything he was told after his accident because it did not seem relevant at the time. As he ages, however, he finds himself experiencing new problems and thinks it would be nice to have someone to talk to about them. John is fortunate because he can afford to pay for physiotherapy and massage therapy sessions, which help him to cope with new physical problems. These sessions that John pays for himself help him to maintain flexibility and mobility as he accommodates to aging with one arm.

## ***Coping with Finances***

### Employment and Unplanned Early Retirement

Financial constraints appear to be a major problem for the participants as they age with long-term physical impairments. Many of the participants had to change jobs or quit working

earlier than expected. Others experienced long lapses of unemployment because of health problems. The costs of living with a physical impairment and lack of employment can create many financial difficulties for people aging with a physical impairment.

The employment transitions of the participants are very diverse. David has worked at several different jobs because of the limitations he experiences relating to MD. When realizing that he could no longer work at his veterinary practice, he was not content to stay home once he was unable to perform surgical duties. Instead of staying home and being eligible for disability pay, David decided to work for the government doing analysis on animals. This job was not as strenuous being a veterinarian and he was able to continue working for ten years. After being convinced that he should retire from this position, David continued working at paid positions within the community. He tried to continue working as long as he was physically able.

Dorothy, Carol, Jake and Mark all stopped working when they felt they could no longer continue because of their limitations. Most of them made the decision to quit so they could preserve their functioning as long as possible. Dorothy's decision to quit working was determined for her when the company she worked for went bankrupt. In her words, "then I tried to find a job but you know when you are disfigured and you know people don't want to, you know, take a chance on you." RA has made it difficult for Dorothy to move her hands and feet.

Carol, who is aging with MS, made the decision to quit working when she noticed that she was no longer physically able to continue. Jake's decision was forced on him when he required dialysis treatment three times a week because he has polycystic kidney disease. He now treats his dialysis treatments as a job. He told me,

Okay, I have to get up in the morning and when I was a cop, I was driving all the time. So my job now is to drive to the hospital, get my blood clean and then drive home and I think if I hadn't looked at it that way, I wouldn't be here now. So I get paid to go back and

forth. So, it's not much but I get paid. I got \$180.92 for each trip so that pays for itself.

Jake also had to leave work to receive a kidney transplant. He was on long-term disability from his employer when he relocated to southern Ontario for the transplant. It was difficult for his family to survive on the long-term disability payment while he waited for the surgery so Jake felt forced to find work. Jake became employed as the head of security at a local attraction park. His previous employers did not approve of him working and attempted to cut off his long-term disability income. Fortunately, Jake was able to fight them and win. However, the kidney transplant was not successful and Jake has not worked for the past fourteen years.

Mark, after switching jobs several times to accommodate his hip surgeries, realized four years ago that if he did not stop working then he might need to use a wheelchair. He is very fearful of having to use a wheelchair. During his employment history he rotated between jobs that were more physical to more sedentary. There were long periods in his adult life where he was unable to work because his hip stopped functioning and he needed an operation. Mark told me,

I made do, I sacrificed and I, I knew that I had limitations. But, but the limitations [pause] I don't know how to put it, the dollars and cents still had to come in to pay the bills. So you, you overrode your limitations to a point where you probably shouldn't have done it. But what are you going to do?

Finally, Mark realized that he was unable to keep up with the physical components of a job because "I could feel that there was something with my leg, I couldn't keep up, the physical part. I made do, I sacrificed and I knew that I had limitations." Ultimately Mark made the decision to quit working because he did not want to end up using a wheelchair for the rest of his life. The decision to leave work was not an easy decision for the participants and many wished they could have continued working longer.

John, although he is still employed, is no longer working in construction, his preferred employment. John attempted to stay employed in the construction business after losing his arm by starting his own company.

The option that I saw in terms of employment again, I didn't really think anywhere was going to hire me. So I started up my own construction company. And [pause] that also gave me a lot of control. And the people that I hired were people I had worked with or my friends. I got along with, we worked well together. So it was fairly easy to talk about how we divide up the work that needs to be done. And my arm, umm really doesn't work really well really above this level [*his middle area of the chest*]. So anything up above here [above his torso] is more difficult and time consuming and slow. And the stuff that is, you know, waist level or below would be the stuff I'd focus on. And the overhead stuff I wouldn't. And that worked out fine but, you don't, it had to be accommodated. And like I said being the boss you know meant that I had the power and the control over making sure that it was accommodated and [pause] accommodating a disability, the two key issues are communication and control. So, if I have control over the work that I am doing, it's not hard to accommodate. It's when someone else has control and won't allow me to do the things that, [pause] or do it my way that seems to be where the barriers are. Which fits into well with my understanding of disability rights and then and then the definition of disability which is more mental not physical.

Unfortunately, John had to quit working when he realized how the physical work was affecting his body. He told me,

giving up construction was hard. [pause] But I gave it up because, umm, the rest of my body was at risk. My back, I figured was the next thing to go and I've seen too many people with back, serious back injuries that I thought that would be the end of it for me, you know, at least now I can still do all kinds of stuff I just can't do it a lot. You know, so I quit soon enough so that I never ended up with any real significant back disabilities.

John receives an income from his part-time job and a pension from the Workers Compensation Board. He says he is fortunate because his pension earnings are quite high compared to other pensioners. He believes he would be able to support himself and his wife on the amount of

income he receives from his pension and part-time employment. Because his wife is employed they are able to afford luxuries, such as happily spending money on their children and grandchildren, which they would not be able to do if they were only surviving on the pension.

Victoria continues her job cleaning homes and businesses despite constant pain and physical limitations. She and her husband benefit from the extra income she receives from cleaning. Her husband is employed and his income and benefits are important in sustaining the household. Applying for CPP disability is an option and Victoria almost applied until she realized how long it would take before she would be accepted and receive money. It was not economically feasible for her to stop working, especially when she was not certain she would be accepted by CPP disability.

Karli has never been employed outside of the home, except for when she sold Avon and Regal products. She did some book-keeping for her husband's job, on a casual basis, until the company expanded so much that they needed to hire someone on a regular basis. Her husband recently convinced her to stop selling Regal products when it became difficult for her to leave home and people would have to deliver the products for her. Karli did not have much to say about finances and did not know how she and her husband have coped financially with her impairment. Coping financially might become more challenging because her husband is currently unable to work because of an impairment.

### ***Coping Emotionally***

Adapting to a society where independence, mobility, and youthfulness are deemed highly desirable can be difficult for people aging with a physical impairment. Although some of the participants may be able to hide their impairments, the internal struggle of trying to fit in and adapt to what is considered 'normal' in mainstream society can be challenging and impact a

person emotionally. Participants use a variety of strategies to cope with everyday life, their own fears, and the attitudes that are part of mainstream society.

### Religious Faith

Religion was a very important part of life for some of the participants, who attribute some of their ability to cope with aging with a long-term physical impairment to their religious beliefs. Those who were religious appeared to accept their impairments and not question why they were chosen to live life with an impairment. Karli, who attributes her coping mechanisms to her faith, told me,

my theory on life, and how I have lived my life, it's just you, you just live each day, one day at a time. Yesterday is gone, so I thought, God left you here, and nice song about it, and now, and now you live one day at a time and that's all [pause] it is the first day of the rest of your life and you are beginning every morning.

Adapting to life with multiple sclerosis has not been easy for Karli but her faith allows her to accept her life. Karli told me,

I missed a lot of the, of the ummm, [pause] the outings that I did. That's why ... I became a Mormon. And I found that you can be busy twenty-four hours a day, seven days a week just being, well I gave the missionaries a hard time.

She volunteered through the church, which made her feel useful even though she was not able to help on the farm that her husband was running. Joining the church may also have provided Karli with companionship and a sense of feeling useful.

While Mark acknowledges that his wife and children have given him “the strength and the motivation to [pause] seek out and keep going”, his faith also plays an important role in his life. His theory is “I just thought I knew that there was something out there for me. It was just a matter of not only finding it, but allowing [pause] the structure to work.” Dorothy's family was religious and she still carries the values and traditions from her grandparents. When I asked her

whether it would be easier or more difficult to receive assistance in old age, she told me “well, my grandmother always said that God gives a helping hand to those who seek help on their own. But if you sit and wait for God to save you, then it’s not going to happen.” Dorothy has used this philosophy in her own life because she takes an active approach in understanding and treating her symptoms relating to Rheumatoid Arthritis.

### Sense of Humour

All of the participants have a sense of humour and laughter was found within each transcript. The participants seemed to feel secure enough during the interview to make joking comments about themselves and their limitations. Some of them felt comfortable even to joke around and tease me during the interviews. Making light of and laughing about physical impairments seemed to be an important coping mechanism.

When I asked Mark about his coping mechanisms he told me that his wife says his sense of humour keeps him going. Mark is able to laugh about the problems he has experienced during his life while learning to live with a long-term physical impairment. Mark told me that he joked around at the hospital while he was being prepped for his second or third hip replacement surgery. He said that “I joked when at the hospital. I said, can I have a grease fitting or a zipper or, you know, to make it easier for you. They always say, geessh shut up.” Being able to laugh about the situation makes it easier for Mark to accept that although he has certain limitations he is still a person.

Another participant, Karli, retold stories about conversations she had with a man who works with the CNIB. They became friends over telephone conversations when he assisted her in selecting movies and books on compact discs to borrow from the CNIB library. She retold this experience with me:

He did go to England and his wife – he was meeting her there because she had been working – and they spent two weeks there. And I said, “was it nice?” He said, “I didn’t get to see nearly enough”. And I said, “you got on a plane and you could see? That’s the trip to take.” He said, “I’ve got to be careful with you.”

Karli enjoys making people laugh and told a few jokes during the interview. Her ability to laugh and joke makes it easy for her to make friends.

### Social Support

A recurring theme that emerged during the interviews was the importance of social networks. Coping with a long-term physical impairment can be a lonely experience unless the person has a strong network of family and friends to help cope with the constant changes that occur. Having a strong network of friends and family can help to feel less ostracized and feel important and valuable. My participants feel that their experiences of aging with long-term physical impairments are improved when they can share their thoughts, feelings and problems with someone. The stigma attached to disability often results in people with physical impairments feeling like outsiders. This stigma also makes them disappointed when they are unable to fully integrate themselves into a world that is designed for people without physical impairments. This section examines the benefits of creating and maintaining relationships, thoughts of being a burden to family members, and explores why the participants did or did not participate in support groups specifically designed for their disability.

### **Family and Friends**

All of my participants except Victoria attribute most of their ability to cope with a physical impairment to having supportive family and friends. Although Victoria appreciates her family she does not go to them for emotional support. All of my participants acknowledge that without strong networks of social support it would be extremely difficult to age with a physical

impairment. Only one participant, Dorothy, had never married or had children; the rest were either married or widowed, but all had at least one child. Dorothy has close connections with her brother's family, while the other participants rely on their spouses and/or children for emotional and physical support.

Dorothy relies on her sister-in-law and her family for support. Fortunately, she lives next door to her nephew and his family. Dorothy attributes her high quality of life to having many supportive friends and family members. She told me,

as in my case now, you know, I guess having supportive friends and family which I mean I have right now, friends that help me, certainly my niece helps me you know a lot. My sister-in-law's sister, she's wonderful. She comes in and trims shrubs and takes me to town when she's not working.

Her sister-in-law also helps whenever possible, such as driving her to doctor's appointments and inviting her for meals, but her sister-in-law lives about forty minutes away so Dorothy worries about being an inconvenience. Dorothy used to help her nephew and his family by doing laundry, but now that she is unable to maneuver the stairs, her niece is returning the favour. Dorothy is very thankful to her family and friends for their continuous support.

Carol's husband passed away two years prior to our interview. She now relies on her two adult sons, who live with her, to help care for the home and carry her from her living room chair to the table each night. Her sons have assistance from personal support workers who take care of some of the cleaning tasks and Carol's personal tasks such as bathing and dressing. Carol's mother comes to visit every afternoon with a coffee from Tim Hortons. Her siblings, but especially her one sister, offer support whenever needed. Most of her family members live in the same town. The others live about thirty minutes away, but still maintain regular contact. Carol's

sister takes her to doctor appointments and organized the renovations to her bathroom. Her sister provides a lot of physical and emotional support.

David believes that people with high quality of life have a strong network of family, friends and neighbours. David's family has been very supportive during his experiences of aging with MD. His wife has taken on a lot of the responsibilities around the home and David mentioned that he worries about her because there is a lot of pressure on her. David relies primarily on his family for support because it is difficult for him to leave the house. His wife receives help from home care workers, nursing staff, their adult children and grandchildren.

Similarly to David, Mark worries about the strain of his physical impairment on his wife. Mark attributes most of his ability to cope with a long-term physical impairment on his family and friends. However, when I asked him if his physical impairment has impacted his family he told me "my wife, she was [pause] always been strong but I could tell there were times when emotionally she was drained to the max." He worries about his wife because as he told me,

I've heard it said before, a lot of people well, if you have one person ailing and they come up to you and you are together they say, "how are you today?" "Fine, I am doing alright". But they never extend that to the other side. "How are YOU feeling, how are YOU coping? How are you mentally capable of handling what's going on?" Just because I have a physical ailment the mental capabilities of the other person should be taken in as much as the person with the disability because it takes, because the two are really, if you can't harmonize the two you get friction.

Part of John's ability to cope is his family and close friends. John recently married a woman he has been with for sixteen years. He told me:

I have good friends, I mean, look at this marriage this summer. And umm it was a real high point, our ceremony we wrote [pause] and we had our five kids stand up and speak. And they were all just like awesome. You kinda go, how can it be any better than this? [pause] I was like, life's good.

Although John tries to complete most activities on his own, he does need to rely on others for some assistance. He often relies on his wife for emotional and physical support. However, John realizes that his wife has her own life and he tries not to take up too much of her time. In order to maintain as much physical function as possible, John completes an exercise routine every morning. His therapist recommended an activity that involves his wife helping him. But, John told me,

well [pause] it didn't work, you know. It's just, she's doing other stuff, you know. [pause] I don't feel like I can say, you know, come here and do this with me every morning, you know. So on the one hand you go geeze I really wish she would because this would be good for me but, she is not here just to serve my needs.

Karli also tries to avoid relying too much on her family. She told me that she raised her children "to be independent, so they don't need to rely on me. So, they can talk to me, can ask my opinion on something but we are not living each other's lives." Karli also prides herself on being independent and told me, "I am pretty independent for somebody who can't work their chair properly." She acknowledges that she can only continue living in her own home because her husband helps her, but she still tries to hide her problems from him. Karli speaks affectionately about her relationship with her husband and mentioned that although their relationship is not always perfect, she is happy. She told me that he:

puts a roof over our head, clothes, food to eat, the bills keep getting paid, everything just keeps coming. We eat. [pause] He provides for all my needs to survive. And on top of it all, he loves me and every now and then reminds me that I am his princess. [pause] I don't need to be cuddled by people. I wouldn't have wanted that. I think I would have felt smothered.

Karli would benefit from a hospital bed at home but this would not be suitable for two people to sleep together. In the meantime "we did what needed to be done. We don't have a

hospital bed. But my husband has [pause] propped up what he can. That's the way it's gonna be. We do sleep in the same bed together" (She giggles at this comment).

Karli is able to make friends easily. She makes friends with people that she has never met in person, either on the telephone or on e-mail and electronic discussion boards. Karli spends a lot of time in her 'office', which is setup so she can easily access her computer, television and CD/DVD player that was purchased from the CNIB. When talking about her ability to make friends with people she has never met, Karli told me:

But, I make friends with people that I never did meet, that I just talked on the phone. That girl from the library [who called during the interview], if she came to the door I wouldn't know her.

While Jake tries his best to avoid relying on his family, he acknowledges that his family is what has kept him going. Jake's willpower to continue living is based on the fact that he has a son. Jake's second kidney transplant occurred when his son was five years old. When this transplant failed, Jake was sure he was going to go home to die. But, he told me that he could not just die because of his son and that "he's the reason that I am still here, if you really want to know. I just, I just put all my energy into raising him." Jake told me that aging without kidneys:

takes away from my, [pause] you know, what you want to get accomplished. What you can do [pause] it's, I know it's been hard on my wife. And umm as far as my son, well about all he knows is about me being in the hospital [pause] so I don't think it's as hard on him as you would think it would be. Because this is all that he knows.

Instead of relying on his family for physical support, Jake often reaches out to the community for help. While he may not want the help because it makes him recognize his limitations, he is thankful that people are willing to help him. The local hardware store is aware of Jake's limitations and offers carry-out for his heavy items, such as a bag of cement. The community that Jake lives in is very small and appears to have strong personal relationships.

When Jake lost his sight and required cataract surgery he needed someone to drive him to his dialysis treatments. He told me,

well, at one time I was declared legally blind because my eyes were going and I put an ad in the paper to get some help to get back and forth and I got all kinds of drivers. So, but then again I come from a small town so everybody pitches in and helps.

Although Jake may wish he did not need assistance, he appears to be very thankful for the support he continues to receive from the community.

Victoria was the one participant who mentioned feeling alone at times. When I asked her about her support network and who listens to her problems, she said “really, I have nobody.”

After some discussion about needing assistance with physical tasks, Victoria mentioned that her family members are helpful with physical tasks but she really has no one to talk to about her feelings and experiences. One person that Victoria feels comfortable talking to is her internist.

She told me:

he listens to what you have to say. But to just sit and talk to somebody, I don't talk really to anyone about my health. People say “how are you?” And I could be having a real bad day and I tell them I am doing good. That's one thing I read in the book, a book that says that people with Rheumatoid Arthritis will say that they are doing good even when they aren't and boy that's me.

Victoria likes to keep her personal struggles to herself and tries to hide her limitations because she does not want others to feel sorry for her.

## **Support Groups**

There are many different support groups available in communities that connect people with similar physical impairments. Many of my participants were aware of support groups but not many utilized their services. Some of them have used support groups in the past, but only one is currently involved in a support group. A major problem with support groups is that they are

not always convenient to attend. Another problem expressed by the participants was that each person has different experiences and therefore, the support group may not be beneficial. Other participants did not want to hear about others' problems because they have enough to deal with on their own.

Dorothy, Karli and John were the only three participants who talked about being members of a support group. John is the only one currently involved in a support group. Dorothy was a member of the Arthritis group but she quit going because, as she told me: "I found it a hassle in the winter time, it was more of a hassle to attend than what you got out of it. I find that what works for one person doesn't work for someone else." The one thing that Dorothy enjoyed about the support groups was hearing other people with similar impairments complain about able-bodied people offering suggestions on how to improve their life. Dorothy retold a story about an older woman who became angry with her daughter for always providing unsolicited help. The woman at the support group told them how:

I held up my cane and I said to her, "you see this cane, the next time a person who isn't disabled with arthritis gives me advice", she said, "I am going to shove this cane up their you know where." And my daughter said, "MOTHER I am just trying to help." "Well you are not. You are always telling me in the house that you should do this or to try this [pause] and when you get as disabled as I am that's when you can give me advice.

Hearing this story was useful for Dorothy because she told me,

people want to give you advice, "well it's easier to do it this way". Well when you are not disabled how do you know that it's easier for me to do it this way. So I think sometimes unsolicited advice really bugs me.

Dorothy contemplates returning to the group but feels the challenge of leaving her home will not make it worth the effort of going.

Karli is aware that support groups can be very beneficial for people, especially for people with physical impairments. Karli started a support group in a small town where she used to live.

Karli told me:

that town is the most unsuited for handicapped people. I did a lot of the social activists' things, get ramps, stuff you know. I had articles in the paper and [pause] I turned two restaurants into what I said user 'friendlies'. I mean [pause] there wasn't a place that you could go out except Burger King, that you could get in. And umm, I just really [pause] I got involved with those kinds of things and I had an endless support group going there. We didn't have one. And I got involved with the groups.

However, now that Karli has difficulty leaving her home, she is no longer involved in support groups.

John is involved in a support group for injured workers. He is often the one offering advice and support but he also benefits from his conversations with other injured workers. John strongly believes that support groups are beneficial for people.

Carol is aware that there groups in her community and through her former workplace that offer support for people with physical impairments. Despite her knowledge of their existence, she has never joined one. When I asked her why she has not joined a support group she told me "I don't want to sit and talk about it all day."

### Taking Charge of their Own Health

Dorothy argues with her doctors about the types of medications she should be taking. During the interview Dorothy told me, "years ago people treated doctors like God they didn't question anything but now people more people speak up to their doctor."

When I asked Dorothy about problems using equipment at the doctor's office, such as examining tables being too high, she told me that it has never been an issue for her. But, she told me, "if you don't speak up and tell them that you need it at a certain height and then say that she

didn't lower it for me, well excuse me, these people aren't mind readers." Dorothy seems to think she has earned a reputation for speaking her mind. She is not embarrassed by this and actually seems impressed that she has some power and control over her body and her symptoms.

Dorothy told me about an experience she has had with her doctor. She reported,

I mean, I always argue with my doctors, I mean, I am sure [in] my file they must have a quotation that says 'a patient that doesn't believe or questions everything' ... The doctor told me I had to take estrogen. I said I didn't have to do anything but die.

This does not mean that Dorothy does not trust her doctor, in fact, she told me "I think the doctors are knowledgeable but you have to have knowledge yourself to know that you don't have to do what they tell you if you don't want to." Dorothy told me about an argument she had with her rheumatologist. She told me,

like my rheumatologist, like for years I fought him taking Myochrysine but finally I have been on it for 2 or 3 years. I gave up on that. But he wanted me on a trial for Enbrel and I said NO, I said, these new drugs like Remicade and Enbrel they are not going to know the side effects 'til ten or fifteen years down the road. I still think that I am in good enough shape that I am not going to take this.

Because of her experiences, Karli takes her medical care into her own hands. She relies on her pharmacist for advice. When I asked Karli about coping advice for people aging with a physical impairment she told me,

I think that they need to [pause] read about it and become educated. I think that knowledge is not a dangerous thing, it's a good thing. I need, I know through taking medications that you should, you should be aware of what of what they do. Don't, umm, just take something because somebody gives it to you. Investigate it. But, better friends than your doctor, would be your pharmacist. Because they know, they know more about drugs. I am always close to the pharmacist.

Similar to Dorothy and Karli, Jake does not take everything the doctors tell him at face value. He told me that he often goes home after a dialysis treatment and does Internet searches to learn more about what the doctors and nurses tell him. Although the Internet can be useful for learning about the side effects of medications, Dorothy does not have a computer and is skeptical about the type of information provided on websites. She thinks people are too trusting with the information supplied on the Internet. Jake uses his past experiences to remind himself to continue to speak up for himself. His theory is, if the medical staff stops paying attention to you then you “holler louder.”

## ***Conclusion***

The experiences of my participants show that coping with a physical impairment is an ongoing process that requires constant change and adaptation. My participants had to learn coping mechanisms, mostly on their own, to adjust to physical changes and limitations, reduced income and extra expenses and the social changes that are associated with aging with long-term physical impairments.

To cope physically and continue living in their own home with minimal assistance, most of my participants purchased assistive devices and completed home modifications. Finances play an important role in the life of my participants as many have reduced incomes and more expenses. Many of them felt forced to retire early because of their physical limitations.

My participants spoke in great detail about emotional coping mechanisms. Only a few of my participants spoke about religious faith making it easier for them to accept limitations and find strength to continue living. In contrast, all of the participants use humour as a coping mechanisms. They were able to make jokes about their experiences and laugh about themselves. My participants had strong family and friend support networks that helped them cope. Although

they may recognize the importance of support groups, very few of my participants belonged to support groups. Most of my participants take control of their health care by speaking back to health care professionals and talking to pharmacists.

The following chapter compares my research findings with the existing literature in the field. While aging with a long-term physical impairment is a relatively new research topic, the research that is available, overall, is consistent with my findings. Areas of similarity and difference will be highlighted.

## Chapter 5 – Discussion

This study used in-depth, semi-structured interviews to learn in detail the perspectives of my eight participants on aging with a long-term impairment and changes experienced through the life course. Participants were encouraged to discuss their experiences, expand on them, and highlight the ones most important to them. This process allowed me to learn about the changes they have experienced as a result of their original impairment and as a result of the aging process, and how they have developed coping mechanisms to adapt to changes.

In this chapter I compare and contrast the findings from my own research with the existing literature on the experiences of people aging with long-term physical impairments. In general, my own study found that while people aging with long-term physical impairments experience obstacles in mainstream society, they learn coping mechanisms, mostly on their own, to help them navigate everyday life and feel more integrated into mainstream society. Most, but not all of the participants in my research are aging with chronic, progressive diseases that cause impairments. However, all of my participants and the participants in other research share a common experience of aging with long-term physical impairments in a society that is designed to meet the needs of people who are young and able-bodied. This thesis organizes their experiences into neat and tidy compartments, but this is an artificial organization which belies the fact that they do not compartmentalize their experiences in this manner.

### ***Physical Impact***

My participants discussed in great detail the problems they experience on a regular basis due to physical limitations. Their physical limitations have changed and progressed throughout their life course, and every participant has had to quit at least one activity that they used to be

able to complete. However, unless they had no physical ability in their lower extremities, as was the case for two of my participants, they continued to push themselves to complete some physical tasks. Even though some of the activities would leave them in pain, weak and tired, being able to complete physical tasks was considered an accomplishment.

Similar to the participants in Pentland et al.'s (1999) research who discussed the need to participate in activities to prove they are still capable, most of my participants also push themselves to prove they are still capable despite their impairments. Being able to stay active, even at a reduced rate, was important to them. Their activities show that despite their impairment, they are still full members of society.

Being active and continuing to participate in valued activities was important to my participants. Those who were unable to continue such activity spoke about missing this aspect of their life and wishing they could still do the activities they used to enjoy, such as dancing, biking, hiking and bowling. There is a lack of literature focusing on the inability to complete activities and the impact this has on people aging with long-term physical impairments. More research is needed to explore the impact of loss of activities and how people determine which activities to continue participating in, regardless of pain and limitations.

Most of my participants, to the extent that they still had mobility and felt healthy, believed that being active prior to their impairment has had a positive impact on their mobility as they age. Mark and Victoria explicitly made this point in their interviews. Their belief is supported in the literature. Bowling et al. (2005), for example, promote physical activity throughout the aging process because it will lead to better physical functioning in old age.

### Accelerated Aging

Based on the literature review, there appears to be widespread agreement that people with long-term physical impairments will age faster than those without impairments, and their aging process has been characterized as similar to a second impairment. This was not, however, an expectation shared by my participants. Although they spoke about a reduction in activities, which would be considered part of accelerated aging by researchers such as Thompson (2004), Zarb (1993a), and Zarb and Oliver (1993), none of my participants viewed their experiences in terms of accelerated aging.

For example, my two participants who are aging with MS appeared to have more limitations than the other participants, especially since neither one was able to walk, but they did not discuss feeling older or feeling as though their aging process was accelerated. Victoria, the only participant who acknowledged feeling older than her chronological age, nevertheless did not believe that she was aging faster. Rather, she felt limited based on the pain she experienced on a daily basis. The others reported feeling younger than their chronological age and some, especially Karli, spoke about looking younger than their actual age. For my participants, determining whether changes in physical strength and mobility were related to the original impairment or the aging process (or both combined) was not an issue.

Possibly, my participants denied feeling older than their chronological age and experiencing accelerated aging because of the negative stigma associated with old age. For those who are unable to hide the signs of physical impairment, old age may be something that they can hide. Based on their visual appearance, some of my participants can successfully pass as younger than their chronological age. This ability to pass allows them to avoid the stigmatization associated with old age. At the same time, my participants were not reluctant to recognize that

they were aging, and they were derisive about the concept of successful aging. They pointed out that although people can hide signs of aging, they are still going to age.

### Making Changes to Accommodate Impairment

#### **Home Modifications**

Approximately half of my participants made some modifications to their home to accommodate their impairment. The most common modifications were outside ramps and wheelchair accessible bathrooms. Other modifications that were not as expensive were grab bars in the bathroom and removing doors to allow more room for a wheelchair.

Many homes, as explained by Dunn (1990) and Nishita et al. (2007), are not suitable for people with impairments because of barriers such as stairs and narrow hallways. Fortunately, several of my participants live in one storey homes so they did not need to confront stairs, and this lessened the need for home modifications. Nevertheless, even their one storey homes required some modifications.

While some of my participants hope that they will not require additional home modifications as they age, others, such as Dorothy and Victoria, are already anticipating what else needs to be completed so they can continue living in their own home. As Trieschmann (1987) discusses, home modifications are a continual process as people with long-term physical impairments age. At the same time, my participants needed to be mindful of the expense. Renovations can be very costly, and not all could afford to renovate their homes to make them more accessible.

#### **Assistive Devices**

Most of my participants have purchased assistive devices, such as wheelchairs, grabbing and dressing sticks, and canes. These devices have greatly improved their ability to function

independently. Similar to Pentland et al.'s (2002) participants who are aging with SCI, assistive devices give them more independence by reducing the need to rely on personal support workers. With their assistive devices, my participants did not need to ask for help as often and could be mobile.

Only two of my participants require the use of a wheelchair on a regular basis. Most of the other participants were hoping to avoid needing a wheelchair, although Victoria and Dorothy realize that this may not be something they can control. As discussed by Ripat and Booth (2005), the need for assistive devices changes as a person ages with a long-term physical impairment. Dorothy and Victoria spoke about requiring a wheelchair in the future because they have been told that most people with RA, which is what they have, will eventually need to use a wheelchair. Similarly, Carol, who has MS, realizes that she needs a power wheelchair to allow her more independence, especially now that she is no longer able to walk.

There is a stigma associated with using a wheelchair as it has become a visual marker for disability (Tighe, 2001). Tighe's participants reported that people view them based on the visual marker of a wheelchair and do not look past the wheelchair to see the person using it. Her participants also believed that others assume wheelchair users are older people or people who are sick. Although these experiences were not discussed by Karli, my only participant who was using a wheelchair at the time of the interview, it could explain why some of my participants want to avoid using a wheelchair.

Some of my participants, similar to those included in Tighe's (2001) research, explain the stigma associated with wheelchairs in terms of a lack of exposure to people in wheelchairs. A common way to remove the stigma, as discussed by Tighe's participants and my participants, is to educate people about wheelchairs. Some of my participants believe that children need to be

taught about disability, and more specifically by people who have an impairment. They argued that it is important to encourage children who are curious about disability to ask questions of people who appear visually different and learn about disability. They bemoaned the fact that parents, and especially mothers, seem embarrassed by their children's curiosity and do not let their children talk to the person who looks different to learn about their experiences.

Most of my participants who use assistive devices on a regular basis were continually looking for devices that will meet their needs. This is a common experience as described by the participants in Pentland et al.'s (2002) research who also searched for assistive devices that effectively meet their needs. What is not discussed in the literature is how people actually go about finding assistive devices, yet this was an issue discussed by several of my participants, who generally find what they need through trial and error. That is, as their needs changed, they were required to find assistive devices without guidance from a professional. As a result, a few of them, and especially Dorothy, have purchased assistive devices that proved not to be useful. Guidance from someone, such as an occupational therapist who would have a good understanding of what might be needed, would likely help Dorothy and others in a similar situation to make wiser purchases, so that money would not need to be spent on products that were not helpful. Indeed, there is ample evidence in the literature to show that as people with impairments age, their needs change (e.g.: Charmaz, 1995; Harrison, 2006; Kemp & Krause, 1999; Pentland, et al., 1999; Plach, Stevens & Moss, 2004). As it is, however, people do not have affordable access to professional guidance regarding how to best address their needs.

When my participants were unable to find assistive devices that met their needs or perhaps did not want to buy assistive devices, they often designed their own device. Many have become resourceful in this way. Unfortunately, not all of the self-designed devices were easy to

use, but they did complete the specific task. My participants received satisfaction in knowing they could create something to solve their problems, especially when many of the devices they purchased were deemed useless.

Despite the benefits of assistive devices, the cost of purchasing them may be prohibitive. Verbrugge, Rennert & Madans (1997) found that many people with physical impairments had a challenging time affording products that would assist them in completing everyday tasks. My participants did not speak about what they could not afford and appeared to be able to purchase the products that they believed would benefit their lives, but it is unclear how long they will be able to maintain this ability. The cost of assistive devices could also explain why some of my participants design their own devices rather than purchasing them. It may be cheaper to modify products that they already own rather than purchasing new products that may not be effective.

### **Workplace Modifications or Early Retirement**

As people age with long-term physical impairments there may be a time when they have to make a decision about whether to continue working, ask for modifications or retire earlier than originally anticipated. Because of their physical limitations, all but two of my participants made the decision to retire from the paid workforce prematurely.

As discussed by Mitchell, Adkins and Kemp (2006), people aging with impairment are likely to retire from the workforce when in their forties. It is interesting, therefore, that this was also the age when most of my participants decided to quit working.

For my participants who retired early, the decision was precipitated by their declining physical abilities and the desire to limit the possibility of further damaging their bodies by working too much. They did not discuss the larger societal context of stereotypical ideas about when it is or is not appropriate to retire (McMullin and Shuey, 2006), but it is likely that this also

influenced their decisions. That is, people do not usually retire in their forties, but it is easier to retire at that age than it is to retire at an even younger age. John, for example, my participant who lost an arm at age 28, did not seriously consider retiring, possibly because he saw himself as too young to quit working. In contrast, Carol, Dorothy, Mark, and Jake were all in their forties and were worried about not being able to meet the expectations of their jobs, and they did not want to be labeled as ‘disabled’ in the workforce.

Instead of leaving the workforce, another option would be to ask for modifications to the work environment. My participants, however, did not choose this option. In fact, there was little discussion about accommodations to the work environment during my interviews, and no one asked for modifications. McMullin and Shuey (2006) reported that people may not ask for modifications because they are embarrassed to admit their weaknesses or they do not believe their employers would listen. Applying the findings from McMullin and Shuey, it may be that my participants believed that their employers would not listen or they did not want to draw attention to their limitations.

Dyck’s (1999) participants who are aging with MS were less likely to report limitations when they had an invisible impairment. They were concerned about the reaction they would receive when disclosing their impairment. My participants, who had invisible impairments, may have avoided asking for accommodations for the same reason. As well, the participants in Dyck’s research who were more educated and/or worked in jobs with more control were more likely to ask for accommodations than those who did not have much control over their job (*ibid*). A similar dynamic seems likely in the case of my participants, as few of them worked at jobs where they had control over their working conditions. Those who did have control in their jobs were able to organize their work so that their limitations would be accommodated. Victoria, for

example, was able to take breaks between her cleaning jobs, and she believes she would have had to quit working if she did not have this flexibility. As well, John was able to continue working because he started his own company. As his own boss, he had the ability to set his own working conditions.

### ***Barriers and Stereotypes in Mainstream Society***

People who are aging with long-term physical impairments face obstacles in mainstream society because youthfulness, independence and physical ability are favoured characteristics. Our society is structured to meet the needs of a young, able-bodied population, and my participants discussed the ways in which they were affected by societal structure and expectations.

#### Physical Barriers

The barriers in mainstream society are both physical and interpersonal. Physical barriers make it challenging for people to leave their homes and access services, leaving them isolated from the outside world. Interpersonal barriers are stereotypes in society that make people with impairments feel like second class citizens. Similar to previous research (Fong, Finlayson & Peacock, 2006, Pentland, Tremblay, Spring & Rosenthal, 1999; Tighe, 2001), my participants experienced many physical and interpersonal barriers in their lives.

The most common physical barriers encountered by my participants were a lack of curb cutouts, lack of automatic doors, and lack of accessible transportation. These were also common barriers encountered by the participants included in Fong, Finlayson and Peacock (2006), Pentland, Tremblay, Spring and Rosenthal (1999) and Tighe's (2001) research. As well, two of my participants spoke in great detail about the inaccessibility of public washrooms that are supposed to be designed for people who use wheelchairs. All of these physical barriers limited their ability to go out and interact in mainstream society.

There is recognition in the literature of the need for accessible public transportation (e.g., D'Aubin, 2006; Grenier, 2005), but there is no discussion of the transportation needs of those who live in small towns or rural areas that are not served by public transportation. All of my participants were in this situation, and so they all needed to have access to private means of transportation.

Four of my participants did not own an accessible vehicle, which meant that they had to rely on family, friends and volunteers to meet their transportation needs. They did not like needing to rely on others for transportation, especially because they did not want to be a burden on their families and they liked to have control over their actions, which was not always possible when someone else has to provide a ride. This was a significant issue for my participants, as their ability to make decisions about where and when to go someplace was undermined. It would be useful to have more attention paid to the transportation options for people with impairments who live outside of urban centres.

Another noteworthy issue about transportation to emerge from my interviews was about the need to change their personal vehicles to accommodate impairment. That is, several participants used to own vehicles that served them well when they did not have significant impairments to limit their mobility, but as their impairments increased, they found that they needed a different vehicle. One participant found that she could no longer get in and out of her small car, while another found that he needed to change from driving with manual transmission to using automatic transmission.

### Interpersonal Barriers

Interpersonal barriers were encountered by my participants on a regular basis. While they spoke about a variety of negative experiences, the most common ones included: being treated as

though there was something wrong with them mentally when they have a visible physical impairment, being ignored while the person talks to the companion rather than the person with a physical impairment, and being judged for using a wheelchair accessible parking spot. Altogether, these experiences often made them feel excluded and different. Similar to the participants in van de Ven et al.'s research (2005), they often felt judged based on their impairment and not who they perceived themselves to be. They found this discouraging and upsetting.

My participants with visible physical impairments, such as Dorothy and John, experienced being treated differently based on their visible differences. This was a common experience discussed by the participants in DeSanto-Medeya (2006) and Tighe's (2001) research. Their participants felt judged by others when they had visible impairments and/or used assistive devices, such as a wheelchair. This was not always the case for my participants, mostly because only one participant used a wheelchair on a regular basis. But, being treated different based on visible difference was common for Dorothy and John, neither of whom used a wheelchair. Dorothy appeared visibly different because of the RA, and often felt as though others treated her as though there was something wrong with her mind. John noticed that people, including people he knew, would not make eye contact with him after he lost his arm. He also noticed people staring at him, especially when he was wearing his prosthetic arm.

On the other hand, my participants with invisible impairments, such as Victoria and Jake, felt judged and frustrated because they were expected to behave as though they were able-bodied. Victoria and Jake used parking spots reserved for disabled people because it was challenging for them to walk long distances. They both felt that others judged them as not having a right to the spots because they did not look 'disabled'. Their experiences are similar to those of

the participants in Gordon, Feldman and Crose's (1998) research. It is not uncommon for people with physical impairments to feel they have to justify the use of a disabled parking spot. This detracts from their ability to feel comfortable in mainstream society.

### Gendered Stereotypes

The literature notes that women with impairments often struggle to appear feminine despite their limitations and pain (e.g., Harrison, 2006). Some of my female participants mentioned a few things in passing, such as not wanting to dress up because they have to wear special shoes that do not look good with a dress, but in general my participants did not seem concerned about whether they appeared feminine. On the other hand, my male participants were all concerned about their ability to undertake stereotypically masculine activities. Similar to the men studied by Charmaz (1994), they were generally interested in pushing themselves to hide their impairments, rather than letting others see their limitations.

All but one of my male participants had invisible impairments. What was difficult for them was that they appeared physically able to complete physical tasks, but in reality, their limitations prevented them from completing expected tasks. The experiences were severe enough to promote lengthy discussions during interviews about the way they felt when they were not able to do a task that others expected them to complete.

### ***Financial Consequences***

There can be a significant financial impact for people who are aging with long-term physical impairments. They often have a reduced income, based on prematurely leaving the workforce as described earlier, and extra expenses to accommodate their impairment. Nevertheless, finances were not discussed in great detail during my interviews. Participants

appeared to be managing their current financial situation but many expressed some concern about the future.

Timmons (2006) discusses a link between impairment and poverty that was not apparent in my research. My participants, although they could use more money, were not impoverished. Part of the reason for their economic situation was that most of them were in relationships with another earner, they had access to a private health insurance plan offered by an employer, and/or they received adequate income from the Canadian Pension Plan Disability Support or a long-term disability plan through their employer. The financial situation of my participants does not appear to be typical for those who are aging with physical impairments.

### ***Coping with Bodily Change***

Although my participants faced obstacles in their lives as they age with long-term physical impairments, they were able to develop coping mechanisms to adapt to their limitations and overcome barriers. Generally, they appeared proud of their ability to develop coping mechanisms on their own.

#### Coping Physically

Research (e.g.: Charmaz, 1995; Fong, Finlayson & Peacock, 2006; Harrison, 2006; Pentland et al., 2003; Plach, Stevens & Moss, 2004) shows that people with long-term physical impairment typically learn to adapt to their limitations by making decisions about what they will do on a day to day basis, depending on the amount of pain and limitations they experience. This was a strategy adopted by my participants as well. They were interested in limiting potential wear and tear on their bodies, and wanted to avoid pain, discomfort and fatigue. They would determine which activities to participate in by deciding which activities meant the most to them and which ones were not worth the pain and discomfort.

As well, my participants tried to find alternative ways to complete activities without having to give up being active. For example, John, who enjoys fishing, bought a flat bottom boat to replace a canoe so he could continue fishing. Mark, who enjoyed participating in sports, coached and umpired sports rather than playing. They took pride in their ability to figure out how to continue to participate in favoured activities.

### Coping Emotionally

#### **Religious Faith**

Although religious faith was not discussed by most of my participants, having a sense of religious faith was seen as a coping mechanism by a few of them. Religious faith gave them a sense of purpose and helped them to find strength in their lives. In this regard, they were similar to the participants in DeSanto-Madeya's (2006) research who found comfort in realizing that there was a purpose to their life with an impairment.

#### **Sense of Humour**

Another common coping mechanism for my participants was having a sense of humour. They were able to use humour as a way to deal with difficult situations, and they joked about past experiences. Although the interviews included emotional and serious topics, every interview included laughter and jokes. The usefulness of having a sense of humour is also discussed by Pentland et al. (1999), Pentland et al. (2002) and Stone (2007).

#### **Social Support**

The importance of social support for maintaining or even enhancing a sense of health and well-being is well established in the literature (e.g., Cohen, Underwood, and Gottlieb, 2000; King, Willoughby, Specht, and Brown, 2006). Support can come from family members, friends,

and/or support groups. My research provides further evidence of the importance of social support, as all of my participants discussed the ways in which others in their lives assisted them with completing tasks, and all but one talked about others they could turn to for help on an emotional level.

Victoria, the one participant who said that she had no one to talk to about how she was feeling, was also the only one to say that she sometimes felt lonely. Although Victoria was married she did not want to talk to her husband about her experiences, but preferred to say that everything was fine even when she felt that she was not doing well. Victoria's case can teach us that we should not assume that people who are married necessarily feel able to reach out to their spouse for emotional support. Moreover, other participants discussed their concerns about causing stress for family members by asking for too much help. They did not want to be a burden, and so they tried to avoid relying on family members. They preferred to do things independently as much as possible, or get help from paid support workers.

Regarding the use of support groups for information and emotional support, few of my participants were interested in this. At the time of the interview, only one participant, John, was involved with a support group of similarly-situated others, and he has been very involved with this group for many years. Perhaps my other participants were not enthusiastic about the idea of a support group because they already feel supported by their friends and family, or because they simply do not want to talk about their problems. Thus, even though there is evidence in the literature on the benefits of peer support for people with impairments, it is clear that not everyone feels that peer support is necessary for their well-being.

### Coping with the Health Care System

As was the case for participants in others' research (DeSanto-Madeya, 2006; Krahn, Putnam, Drum & Powers, 2006; Kroll et al., 2006; Pentland et al., 2002; Shapiro, Mosqueda & Botros, 2003), my participants found that health care professionals often viewed them solely based on their impairment and not the entire person. Consequently, they did not always feel that their needs were always adequately addressed.

My participants coped with the lack of attention by health care professionals by speaking up to health care professionals. As other research has shown, this is a common way for people with long-term physical impairments to take control of their health care experiences (Pentland et al. 1999; Shapiro Mosqueda & Botros, 2003). When my participants spoke about talking back to health care professionals, there was a sense of pride in their voice. They appeared to enjoy the sense of control they had over their health. While there are few things they have control over when aging with a long-term physical impairment, having control over health care might be something that can be achieved.

### **Conclusion**

There are many similarities between my own findings and previous research. Similar to previous studies, my participants experience personal limitations as a result of their physical impairment and aging and having to learn coping mechanisms to adapt to the changes. My own research findings, however, diverge from the literature in important ways. That is, much of the literature focuses on negative aspects of aging with long-term physical impairments such as accelerated aging, problems with health care professionals, poverty, and social isolation, but my participants either did not have these problems or did not dwell on discussing them. Instead, they focused on ways they have overcome obstacles to continue having control over their lives. My

participants are constantly changing and adapting to their bodies and the world around them.

Aging with a long-term impairment is a continuous process of learning how to adapt and cope with change. It is unfortunate that my participants had to do this largely without help or guidance from health care professionals. The concluding chapter discusses the policy implications of my findings.

## Chapter 6 – Policy Implications and Conclusion

Disability policies in Canada have changed drastically over the past twenty years, both positively and negatively. As more people advocate for changes, policies that impact people with impairments should continue to increase. Unfortunately, there are still many changes that need to occur as discussed by the authors in McColl and Jongbloed's (2006) edited book about disability and social policy in Canada.

Currently, policies related to disability do not take into consideration the fact that people with impairments will age, and their needs will change during the aging process (Zarb, 1993a). Prince (2006) is among the few to recognize that the population of people with impairments is aging, and draws attention to the policy implications of this. There need to be more supports and services available to people with impairments, especially since available supports and services are fragmented, unavailable and unaffordable (Prince, 2006). In this concluding chapter, I outline the policy implications that arise from a consideration of what my participants had to say about aging with a long-term impairment.

### Home Modifications

My participants would benefit from receiving assistance to modify their homes to accommodate their changing needs. Most of my participants who modified their home managed both the expense and the design on their own, without assistance. Discussions with people who have experience with home modifications would be beneficial so that my participants could learn how to complete the modifications to meet their needs. There are many different options available for modifying a home to make it more accessible, and it can be difficult to determine which options would be most suitable in each particular case. Having access to someone

knowledgeable about available options may eliminate the need for people to require additional modifications, which becomes costly.

While organizations such as the Ontario March of Dimes offer financial assistance to people requiring home modifications, only one participant used this assistance. Others were not aware that such assistance was potentially available. More financial assistance needs to be available for people who require home modifications. There also needs to be more awareness about programs available that offer financial assistance.

### Personal Support Workers

There were different opinions expressed during my interviews about personal support workers and the adequacy of the number of hours they were entitled to 'free of charge'. Some of my participants felt they were receiving enough hours of assistance, such as Victoria and Carol, while others, such as David and Karli, could use more hours.

Furrie (2006) examined data from the 2001 PALS to profile Canadians with impairments. She found that 31.4% of adults between the ages of 25 to 64 who have an impairment are not receiving enough support, mostly because they could not afford to pay for themselves. My findings and Furrie's research show that government programs to pay for personal support workers are inadequate to meet the needs of everyone who needs assistance. Many people require additional services and cannot afford them.

Personal support workers, who contact people with long-term physical impairments on a regular basis throughout their life could also be helpful for assisting with decisions regarding home modifications or assistive devices. My participants, as discussed in this thesis, were on their own when it came to deciding what they should purchase. Especially regarding assistive devices, some of them purchased devices that later proved to be useless. Being able to consult

with someone who had expertise about available options would have been helpful. A personal support worker could be an advocate and use the knowledge gained from clients to educate others. A system such as this could provide people with continuous support as their needs change throughout the aging process.

### Finances

Most of my participants were not working in the paid labour force, but received income from the Canada Pension Plan (CPP) Disability Benefits program, based on their previous employment earnings. Only one participant, Mark, talked about the problems he experienced with trying to be determined eligible for the program. Another participant, Victoria, said that she had thought about applying for CPP Disability Benefits but she had heard that it would take over six months before she could be eligible to receive funding and she did not think she could wait that long, so she has continued working. These experiences show that there are problems with the CPP Disability Benefits program. It would be useful for program policy to be changed so that it is more responsive to the income needs of people aging with long-term impairments.

### Health Care

In a discussion of access to health care for people with disabilities, McColl (2006) recommends that policies need to be changed so that health care professionals would be adequately compensated for making house visits and telephone consultations. My research findings also show that such a policy change would be beneficial, as some of my participants discussed having family physicians who made house visits. They appreciated this, because they often experience difficulty leaving their home.

McColl (2006) recommends revamping the funding scheme so that physicians are more willing to take on patients with more health problems, and she argues that physicians need more

training in providing care for people with impairments because many do not have enough experience. People with physical impairments often require extra time during appointments and extra services that are typically not available to every patient (*ibid*). Current policy systematically detracts from the ability of people with impairments to access the health care that they need. As my participants discussed, if they did not themselves take responsibility for speaking up to their doctors or doing their own research, they would not have their needs met. Policy changes could lead to physicians becoming more proactive and responsive to the needs of their patients with impairments. Although my participants enjoyed taking an active role in their health care, they needed to have a physician who was willing to listen to them.

#### Rehabilitation/Alternative Health Care Services

Currently in Ontario, physiotherapy services are only covered by the governmental health insurance plan for people who are over sixty-five years of age, people under nineteen years of age, residents of long-term care homes at any age, people who require services in their home after surgery or hospitalization (any age), and recipients of the Ontario Disability Support Program, Family Benefits and Ontario Works (Ministry of Health and Long-Term Care, 2006). Unfortunately, many of my participants did not meet these criteria. They were therefore unable to access physiotherapy services that may have proven beneficial, because they could not afford to pay for it themselves.

The government, moreover, will not cover the cost of other services such as acupuncture or massage. John, my own participant who paid for therapy sessions himself, talked in detail about the benefits he receives from his therapy sessions. He said that all people with a physical impairment should have access to continuous therapy sessions, and there should be financial assistance to help them receive the treatments they need throughout the aging process. Certainly,

my participants aging with RA would likely benefit from physiotherapy or alternative health care services which could help to improve their mobility or help to alleviate some of the pain and discomfort caused by RA.

### Transportation

Access to transportation is a problem for many people who are aging with long-term physical impairments (D'Aubin, 2006). My participants, however, faced the additional problem of living in communities that are not served by public transportation. Consequently, they needed to have access to private means of transportation, but for at least some of them, this was either not affordable or easily available. There is a need for policy to address the transportation needs of people such as these participants.

### ***Directions for Future Research***

A key finding from this research is that health care professionals played an important role in the lives of my participants. With more support from health care professionals it may be easier for them to develop coping mechanisms to adapt to the changes that occur based on aging with a physical impairment. More research is needed to explore how health care professionals, including physicians, nurses, rehabilitation professionals, and others physiotherapists, can have a positive impact on the aging experience of people with long-term physical impairments.

Another area that requires further exploration relates to employment accommodations. This was not a topic that was discussed at length in my interviews with participants, but it would be useful to have a detailed understanding of the decision-making process behind retiring from the workforce, why people do or do not ask for workplace modifications, and what happens when they do ask for modifications.

Finally, there is a growing gerontological literature on the importance of ‘aging in place’ (e.g. Andrews and Phillips, 2005), but it focuses on people who have already attained the status of ‘senior citizen’. Based on the in-depth discussions by my participants, it seems that people who are aging with long-term physical impairments have three options when they reach a point when they cannot live in their home due to physical barriers. The first option is to modify the home to include a main floor bedroom and wheelchair accessible bathroom. If this is not feasible, either because of the structure of the house or because of the cost, then the person will have to stop using inaccessible rooms, or find another place to live that is more accessible. Significantly, my participants were interested in modifying their homes. While a few spoke about the possibility of eventually needing to move to a long-term care facility, they hoped it would not be necessary until far into the future. There needs to be attention to the ability of those who are still approaching old age to stay in their own homes.

## ***Conclusion***

As the baby boom generation ages and people live longer, it will become more common for people to age with long-term physical impairments. This is an area that requires more research attention to ensure the needs of this population are met. More policies and services are needed to address the health and well-being of this population, and so that they are not forced to cope with their experiences in isolation. It would also be helpful to have more awareness about disability and impairment in mainstream society, so that physical barriers, interpersonal barriers, stigmas and stereotypes about disability can be removed. My participants were resourceful people who were enjoying life, despite the obstacles and barriers erected by others. More needs to be done to remove those obstacles and barriers, so that anyone aging with a long-term impairment can expect to participate in mainstream society on the same basis as everyone else.

## **Appendix A – Interview Guide**

### **Interview Themes and Possible Thematic Questions**

#### **Demographics:**

1. What is your date of birth?
2. What would you describe as your impairments or disabilities?
3. How old were you when you acquired each impairment/ disability?
4. What is your marital status? Has this status changed?
5. What is your employment history? Has this status changed over time?
6. What is the highest level of education that you have achieved? (Prompting questions to determine if the person was disabled at a very young age and to identify if the impairment had an impact on education achievement levels) Are you satisfied with the highest level of education that you have achieved? Is there anything you wish you could have done differently?
7. What income bracket best describes your situation? (Include about 4 different levels)
8. Are you satisfied with this level of income? (Prompt if the level is less adequate or more adequate in old age compared to when younger)
9. What are your current living arrangements? Have these arrangements changed as you aged?

#### **Questions regarding age and impairment-related experiences:**

10. Do you know people who experience limitations in their life as a result of an impairment/disability? What types of limitations did this person experience? Can you provide examples?
11. And yourself, has your impairment impacted your lifestyle? If so, in what ways? Are you able to participate in activities that you enjoy? Have you had to make sacrifices because of your impairment? Have you ever felt left out because of your impairment? Have you had to make modifications to your life because of your impairment? If you have, what types of modifications were required and how did you achieve them? (If the participant mentions walking is difficult, then I can ask probing questions about assistive devices.)

12. What are some strategies that people could use to help cope with their impairment/disability? Would you say that you have been able to cope with your impairment/disability? Do you remember incidents when it was more difficult to cope?
13. How would you describe your life as someone who has a physical impairment/disability? (what are some key words that come to your mind?)
14. Have you experienced any difficulties in your life as a result of your impairment/disability? Can you expand on these experiences.
15. Do you feel that it is easier or harder to age with an impairment/disability? Please explain.
16. How would you describe your current level of satisfaction with life? Has this changed during your life? Please explain why or why not. (Probe to learn the role played by impairment vis-à-vis dissatisfaction.)
17. How would you define someone who has a high quality of life? Have you noticed a difference in your quality of life as you age? Please expand.
18. What changes would need to occur in your life to improve your level of satisfaction? Would you say that personal or social changes would make a bigger difference?
19. Have you noticed a difference in the way people perceive you as you age? Do you think society is accepting of people with physical impairments?
20. Have you ever heard the term “successful aging” before?
  - a. If yes: what do you understand it to mean? Do you think it is a useful term? Can you provide an example of someone you know who has aged successfully? What is it about their experiences that make it successful? What do you think of the term “successful aging”?
  - b. If no, explain successful aging. Based on this definition - do you think it is a useful term? Can you provide an example of someone you know who has aged successfully? What is it about their experiences that make it successful? What do you think of the term “successful aging”?
21. Who would you classify as your peers? Why do you consider these people to be your peers? How do you compare yourself to this group? Do you ever compare your aging experience to theirs? How does this make you feel?

**Health Status:**

22. Have you noticed a difference in your health status as you have aged? If yes, what?
23. Have you acquired additional health problems as you age? If yes, what? Are these a result of your original impairment/disability or a result of the aging process?
24. Have you noticed a change in your physical abilities? Please expand.
  - a. If the person has noticed changes, ask: were you prepared for these changes?  
What could have been done to make you more prepared for these changes?
25. Do you receive adequate medical care?
26. How would you describe your experiences with the medical system? Can you suggest any improvements that would improve your experiences?
27. Please describe some positive and negative experiences that you have had over the years regarding the medical system. Do you think your age at the time had anything to do with your experience? Do you think your impairment at the time had anything to do with your experience? What impact does age and impairment/disability have with a person's experience in the medical system?
28. What do you think could be done to improve your experiences regarding the medical system?
29. Have you noticed that as you age, medical professionals treat you differently? Do you ever feel that medical problems are overlooked based on the fact that you are aging or because you have an impairment/disability?
30. Do you think health policies adequately meet your needs? How so? Could you suggest any changes that would make aging with a long-term physical impairment easier?

**Social Support and Assistance:**

31. Can you discuss your support network during the aging process? Who have you relied on for support and care? (parents, siblings, friends, spouse/partner, children)
32. Has your support network changed over the course of your life? How so?
33. What types of assistance do you require? With what activities do you require assistance in completing? Has this changed during your aging process? Are you receiving enough assistance?
34. Do you require more or less assistance as you age?
35. Is it easier or more challenging to receive assistance in old age? With what tasks are people more willing to assist you? With what tasks is it more difficult to receive

assistance? Why do you think you are more readily offered assistance with some tasks and it is more challenging to get assistance with other tasks?

36. Who provides you with assistance?
37. Do you experience any problems with your assistance (ie. spousal tension, role reversal for children)
38. What could be done to ensure that you receive the level of assistance required?
39. Has your financial situation changed during your aging process?
40. What role do you think finances plays in your ability to get the assistance you need?
41. Do you worry about your financial situation as you age? Why or why not?

**Modifications:**

42. Have you ever required modifications to the workplace? What type of process was required before these modifications occurred? Have these modifications been implemented into the workplace?
43. Have you ever required modifications to your home? Please describe? How often do you require modifications? Are these modifications always implemented? How are the modifications made? Are there any modifications that you expect will need to be made in the future? If so, what? As you grow older, do you want to continue living in your current home? Is this possible?
44. What are your feelings about the future? Is there anything about the aging process that you are concerned about?
45. Do you think society, as a whole, is structured to meet the needs of people who are aging with a long-term physical impairment? What changes would you suggest?
46. Can you imagine a photograph or image that would summarize your experiences of aging with a long-term physical impairment? Can you describe this image to me?

## **Appendix B – Cover Letter**

COVER LETTER FOR PARTICIPANT TO BE WRITTEN ON LAKEHEAD UNIVERISTY  
LETTERHEAD

AGING WITH A LONG-TERM PHYSICAL IMPAIRMENT: AN EXPLORATION OF  
INEQUALITIES DURING THE AGING PROCESS AND AN EXAMINATION OF HEALTH  
POLICES

Dear Potential Participant:

As a graduate student in the Department of Sociology with Specialization in Gerontology at Lakehead University, I am conducting research on the aging experiences of people who have aged with long-term physical impairments/disabilities. This research is being conducted in partial fulfillment of the requirements for the MA degree in Sociology. I am focusing attention on men and women aged fifty to sixty-five who have lived with a long-term physical impairment/disability for at least twenty years. If you meet these criteria, I would like to invite you to participate in an interview regarding your aging experience and your impairment-related experiences. This study is being supervised by Dr. Sharon Dale Stone in the Department of Sociology.

As the Canadian population ages, an increasing number of people who were physically impaired when they were younger will be reaching old age. Improvements in quality of life have positively impacted people who are aging with a long-term physical impairment. Life expectancy for those who became physically impaired at a young age is greatly improving. However, there is inadequate information on the actual aging process for people with a long-term physical impairment. If you agree to participate in this research, you may benefit psychologically from the opportunity to share your story. The experiences of individuals aging with an impairment are often ignored in society. This research study will give you an opportunity to express your feelings and thoughts about your aging experience.

Depending on how long you wish to spend talking to me, the interview will take from one to two hours of your time. With your permission, the interview will be tape-recorded and transcribed for later analysis. I will be asking questions about your impairment-related life experiences, health status, support networks, and need for environmental modifications. Many of the questions will be of a personal nature and there is a slight chance that the questions might temporarily cause minor psychological distress, but no more likely than if you were to talk about your aging and impairment-related experiences with anyone else. I do not anticipate this being a problem; however, please keep in mind that you are not required to answer any questions that you are not comfortable with, and that you are a volunteer and may withdraw from the research at any time. Following the interview, should you want to talk about your concerns and feelings, I will provide a contact number of a counsellor who can help you.

Your identity will be kept completely confidential and you will be granted anonymity with the use of a pseudonym. No one, other than me, will have access to any information that would

allow you to be identified. The interview tape-recordings and all potentially identifying information will be securely stored at Lakehead University for seven years upon completion.

If you wish to receive a summary of the project, following its completion, you may e-mail me at [rcasey1@lakeheadu.ca](mailto:rcasey1@lakeheadu.ca) or write to me at Lakehead University. If you have any further questions concerning this research project, please contact me or my supervisor Dr. Sharon Dale Stone at (807) 346-8530 or [sharondale.stone@lakeheadu.ca](mailto:sharondale.stone@lakeheadu.ca).

Sincerely,

Rebecca Casey  
Graduate Student at Lakehead University  
Collaborative Masters Program in Sociology/Gerontology  
[rcasey1@lakeheadu.ca](mailto:rcasey1@lakeheadu.ca)

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## Appendix C – Consent Form

CONSENT FORM (TO BE WRITTEN ON LAKEHEAD UNIVERISTY LETTERHEAD)

AGING WITH A LONG-TERM PHYSICAL IMPAIRMENT: AN EXPLORATION OF  
INEQUALITIES DURING THE AGING PROCESS AND AN EXAMINATION OF HEALTH  
POLICES

I, \_\_\_\_\_ have read and understood the cover letter explaining the nature of the above-named study, its purpose, and procedures, and I agree to participate in the study by Rebecca Casey on the aging experiences of someone who has aged with a long-term physical impairment/disability. I also understand the following:

1. I am a volunteer and may withdraw at any time from the study.
2. There is minimal risk of temporary psychological distress, and there is the potential to benefit psychologically by talking about my experiences.
3. I will be asked questions of a personal nature that may arouse feelings of discomfort. I am under no obligation to answer questions that I am uncomfortable with answering.
4. I understand that my identity will be kept confidential, I will remain anonymous in any presentation of research findings, and I will not be named, or identified in any way.
5. I understand that the interview will be tape-recorded and that no one except Rebecca Casey will have access to the tape-recordings, and that they will be securely stored for 7 years at Lakehead University.
6. I will receive a summary of the project, upon request, following the completion of the project.

---

Signature of Participant

Date

Rebecca Casey  
Graduate Student at Lakehead University  
Collaborative Masters Program in Sociology/Gerontology  
rcasey1@lakeheadu.ca

## **Appendix D – Participant Characteristics**

### **Karli Fox**

Karli was 59 years old at the time of the interview. She was hospitalized when she was 27 years old with symptoms relating to Multiple Sclerosis (MS) but it was not until a few years later that she received a formal diagnosis of MS. Karli has been aging with MS for over thirty-two years.

Karli currently lives in her own home with her husband. The house is a bungalow with main floor bedrooms and bathroom. There is a ramp outside the house as Karli uses a wheelchair on a regular basis. The doors have been removed from most of the rooms to allow Karli access with her wheelchair.

Karli's work experience includes selling products for Avon and Regal. She assisted her husband's company with book keeping until the company grew too large and required a full-time employed employee. When she and her husband lived on a farm she helped him feed the chickens. She no longer sells products or assists her husband with his work.

### **Carol Smith**

Carol Smith was 51 years old at the time of the interview. Carol's symptoms appeared in 1976 and seemed similar to MS, but she was not diagnosed until 1980. She has been living with MS for over 30 years.

Carol is a widow who lives in her own home with her two adult children. One son lives with her and the other son has an apartment in the same house. Both sons assist Carol when needed. Carol recently modified her bathroom and installed a wheelchair ramp outside.

Carol is currently unemployed and receives income from the Canadian Pension Plan Disability program. She quit working when she felt she could not overcome her limitations and felt they were getting in the way of her job. She also had difficulty seeing which made it impossible to drive to work.

### **Victoria Franklin**

Victoria Franklin was 54 years old when I interviewed her. She has been diagnosed as having Rheumatoid Arthritis (RA) and Fibromyalgia. She did not receive a formal diagnosis until several years after presenting symptoms related to RA. Victoria cannot remember when she first noticed symptoms but at the beginning of the interview she approximated that she has had RA for at least ten years. Towards the end of the interview she realized that she has had symptoms relating to RA for almost twenty years. She benchmarked her symptoms with the birth of a nephew.

Victoria currently lives in a one-story home with her husband. There have been few modifications completed in her home but she wishes the washing machine and dryer could be relocated to the main floor of the house. Victoria expects to install a wheelchair ramp outside of the house at some point.

Victoria is employed by a cleaning company. Although she experiences pain and stiffness from the RA she continues to work. She is encouraged by health care professionals to quit working but she heard that the processing time for CPP disability is over six months and she does not want to wait six months without receiving an income. Victoria is also concerned about sitting still because she thinks working has helped her keep mobile without her joints stiffening.

### **Dorothy Gilmore**

Dorothy Gilmore was 63 years old when she was interviewed. She presented symptoms that were later diagnosed as RA when she was 48 years old. Her symptoms were sudden after a traumatic event in her life. Dorothy has been living with RA and osteoporosis for 15 years.

Dorothy has never married and lives in her own home that is attached to her nephew's home. She has lived in this home for most of her life. She recently modified the bathroom to make it more accessible. Other than the bathroom and the laundry room, everything Dorothy needs is located on one level. She expects that a lift will need to be installed on the stairs leading to the bathroom.

Dorothy is currently unemployed. She decided to quit looking for a job when her previous employer went bankrupt. She was already experiencing stiffness as a result of the RA. Based on her physical appearance, Dorothy did not believe anyone would hire her. She now receives CPP disability and cashes in some of her shares to supplement her income.

### **Mark Brown**

Mark Brown was 59 years old when I interviewed him. Physicians diagnosed him as having Legg-Calvé Perthes Syndrome in his right hip when he was eleven years old. This syndrome is often referred to as Legg Perthes, which is what Mark called it during the interview. Legg Perthes is a degenerative disease of the hip joint. He has had multiple surgeries on his right hip, including several hip replacement surgeries.

Mark and his wife live in a one-storey home. They purchased the home knowing that Mark would experience physical limitations and knew that a one-storey home would reduce barriers for Mark. Mark's wife works part-time to supplement the family income.

Mark quit working when he thought he might require a wheelchair unless he reduced the wear and tear on his artificial hip. He decided that he was further jeopardizing his health and wellbeing by pushing himself to continue working. Standing on his feet all day was a painful experience for him. When Mark made the decision to quit working he experienced many problems accessing CPP disability. His appeal was recently accepted and he now receives financial assistance. The appeal process was emotionally draining for Mark and his family.

### **David Red**

David Red was 68 years old when he was interviewed. David was diagnosed with Muscular Dystrophy (MD) when he was 40 years old. He has been living with MD for over 28 years. There is a genetic link in his family to MD as several family members also have MD.

David is currently living in his own home with his wife. The family has lived in the same home for forty years. Unfortunately the home is a two-story house with the bedrooms located on the second floor. When David fell down the stairs a decision was made to make a bedroom for David on the main floor. A single bed was moved to the living room and a wheelchair accessible bathroom was being built on the main floor. The family was also talking about building a wheelchair ramp outside.

David changed occupations throughout his aging process to accommodate his impairment. When he was no longer able to work as a veterinarian, he worked at several different jobs within the government.

### **John Green**

John Green was 56 years old when he was interviewed. John had his left arm amputated over 28 years ago. He talked about how he has spent half his life with two arms and the other

half with one arm. He is now experiencing some pain and numbness that are linked to wearing a prosthetic arm for so many years.

John lives in his own home with his wife and they are both employed. After John's arm was amputated, he started his own construction company because as the boss he had more control and power over his working conditions. He continued working in construction until he was concerned about overextending his existing arm and the additional wear and tear on his body. He wants to continue being active throughout his life and felt that pushing himself to work would further limit his physical abilities. John is currently employed as a researcher and an advocate for injured workers.

### **Jake Black**

Jake Black was 56 years old when I interviewed him. He was born with polycystic kidney disease. Jake has received two kidney transplants, which were both rejected, and has been on kidney dialysis for over 14 years. He has been noticing a decline in his body weight and muscle strength which he notes is a result of so many years on dialysis.

Jake currently lives in his own one-story home, with his wife. His wife is employed full-time and her income helps support the family. He has not made any modifications to the home. However, he has completed several renovation projects to the home since being on dialysis treatment.

Jake is currently unemployed because he requires dialysis treatment three times a week. He is unable to work due to this schedule. He is currently on long-term disability through his previous employer and is eligible for economic support for the cost of transportation to the hospital for dialysis treatment. This support barely covers the cost of transportation for dialysis.

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