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Developing a Model to Explain the Process of Aging with Adult-Onset Physical Disability

Kristen Alicia Bishop

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Developing a Model to Explain the Process of Aging with Adult-Onset Physical Disability

(Spine Title: Conceptual Model of Aging with Disability (MAWD))

(Thesis format: Integrated-Article)

By

Kristen Alicia Bishop

Graduate Program in
Health & Rehabilitation Sciences – Health & Aging

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

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The thesis by

Kristen Alicia Bishop

entitled:

DEVELOPING A MODEL TO EXPLAIN THE PROCESS OF AGING WITH ADULT-ONSET PHYSICAL DISABILITY

is accepted in partial fulfilment of the requirements for the degree of Master of Science

Date ___________________________ ________________________________

Chair of the Thesis Examination Board
Abstract

People aging with adult-onset physical disabilities are a group who have been overlooked in the recent aging boom. Their needs differ greatly from the able-bodied population and understanding their perceptions may help to better inform policy and practice agendas. This constructivist grounded theory study used focus groups and interviews with participants. Concepts identified were said to be factors influencing the perceptions of people aging with disability. These factors included the entanglement of aging and disability, the multiplicity of experiences, financial resources, attitude and self-efficacy, and family and social support. These factors were used to create the Model of Aging with Disability (MAWD), a model that explains the process of both aging and disability together. Unlike the mainstream hypotheses and one set of models that look at aging with disability, this model is balanced in that it captures a range of experiences including positive, negative, and neutral ones.

Keywords: aging with disability, MAWD, adult-onset physical disability, grounded theory, model development
Co-Authorship Statement

This thesis is the original work of Kristen Bishop, who is the primary author for all publications stemming from this material and lead researcher for all aspects of this project from idea conception and formulation, literature review, data collection, and analysis to manuscript writing and preparation for publication. Creation of this study was shared by K. Bishop and Professor Hobson. Any time the first person plural is used (e.g. we, our) I am referring to the research team.

As thesis supervisor, Professor Sandra Hobson is a co-author of all ensuing material and publications of this thesis. In the role of committee members, Dr. Vandervoot and Dr. Shuey have been offered co-authorship for Chapters 3 and 4. We intend to submit a manuscript based on Chapter 2, the scoping review, to the Canadian Journal on Aging. We plan to submit a manuscript based on Chapter 3, participants’ perceptions of aging with disability, to Qualitative Health Research. We also intend to submit a manuscript based on Chapter 4, the Model of Aging with Disability (MAWD), to The Gerontologist.
**Acknowledgements**

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To my supervisor Sandra, thank-you for always being available, willing and excited to move forward with me on this project. Even in times when I became frustrated, mildly discouraged, and uncertain, you have always been a source of encouragement helping me to see the excitement in this passage. The candy filled bowls on your desk never hurt either. You have inspired me, and made me feel so fortunate to have you on my team. I appreciate everything you have done.

My committee members Dr. Vandervoort and Dr. Shuey, thank-you for graciously volunteering your time to help guide this project and for your unique insight to help give it that something extra.

To my participants, thank-you for your honesty, bravery and willingness to share. It is only through sharing your experiences that together, we can try to increase understanding and raise awareness. Thank you for inviting me into your lives, sharing your struggles and allowing me to learn. Each of you have touched my life in a way I will not forget and I hope you can see the little pieces of yourself throughout this project.

To my friends, some of you have been on this journey with me longer than others, but your advice, caring nature and support is limitless. Our dinners, coffee dates and hallway conversations make me feel blessed to have a life enriched by all your friendships. Thank-you for your support.
My family, where to start? My family has served as the inspiration for this project. Growing up with both a mother and grandmother who are physically disabled has given me a unique perspective on life and a strong appreciation for family. I have seen my family members endure hard times financially, physically, and emotionally. I have watched them not be able to get out of bed, cry in pain and feel saddened by their limitations, but I have also witnessed a closeness I've never encountered before, a love for one another which is unrivalled, and a sense of resilience in the face of obstacles that is admirable. They have taught me to be strong, never give up, to see the beauty in the bumpy roads of life, and have been by far my greatest supporters along the way. I admire their strength, their courage and their honesty with me, which has helped me to understand better, love deeper and see the beauty in every step of life's journey.

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## List of Abbreviations

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<tr>
<td>CPP</td>
<td>Canadian Pension Plan</td>
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<tr>
<td>FICCDAT</td>
<td>Festival of International Conferences on Caregiving, Disability, Aging and Technology</td>
</tr>
<tr>
<td>FTO</td>
<td>Future Time Orientation</td>
</tr>
<tr>
<td>GOWD</td>
<td>Growing Older with a Disability Conference</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disability and Handicaps</td>
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<tr>
<td>KB</td>
<td>Primary Author Kristen Bishop</td>
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<td>MAWD</td>
<td>The Model of Aging with Disability</td>
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<tr>
<td>MS</td>
<td>Multiple Sclerosis</td>
</tr>
<tr>
<td>ODSP</td>
<td>Ontario Disability Support Program</td>
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<td>RA</td>
<td>Rheumatoid Arthritis</td>
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<td>SH</td>
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1 INTRODUCTION

“Regardless of their impairments, people with disabilities were no longer to be left in back wards and attics, watching the days pass without risk, significance, or achievement” (Crewe, 1991, p. 159)

In 2007 Canadian seniors aged 65+ made up 13.4% of the population, and looking ahead to 2056, half a century from now, the numbers for this population will more than double to 27.1% (Lee, 2007). Although the most educated and productive cohort to date, the baby boomers are experiencing a high prevalence of chronic and age related diseases, causing utilization rates of health services to skyrocket (Romanow, 2002). For the disabled population, life expectancy has also increased, but it still is not equivalent to the general population. In terms of survival, the general population can expect to live approximately 56 years past the age of 20, whereas someone living with a spinal cord injury incurred before age 20 can expect to live between 32-49 years, depending on level of injury and severity: these trends are seeing people living with long-term impairment acquired early in life, living into old age (DeVivo & Stover, 1995; Seelma, 1999; Wiley, 2003).

Financially, “the average annual per capita spending on health care for people 65 and over is roughly three times the amount spent on all age groups” (Romanow, 2002, p. 20). In 2006, Canada spent an average of about $2,630 per person, but over the age of 60 “expenditures increase sharply, to just under $20,000 per person for those over age 90” (Lee, 2007, p. 11), and although this group now makes up only 13.4% of the
population, seniors account for a whopping 44% of the total public health care spending budget. Looking even further ahead to 2026, it is expected that seniors will be responsible for approximately 60% of total health care spending (Ruggeri, 2002).

In 2006, there were approximately 1.8 million seniors with disabilities in Canada. With another approximately 825,000 age 55-64 and 741,000 aged 45-54 (also as of 2006), the number of Canadian seniors with disabilities is expected to rise dramatically (Statistics Canada, 2006a). However, it is important to keep in mind that these numbers may be deceiving. Poor classification of what constitutes a disability and reliance on self-report disability measures allow for a subjective interpretation of disability. Efforts to locate health care cost estimates for older adults with disabilities were unsuccessful, but it can be presumed that their healthcare costs will be greater per capita than those of older adults without long-term disabilities. Even with conservative estimates, cost alone makes this rapidly growing population one worthy of further study.

Those aging with physical disability have been largely ignored within the broader population aging rhetoric. Some reasons for this may include recent increases in longevity for this disability population, the successful aging movement, and a strong focus in the literature on those aging with developmental, intellectual, and congenital disabilities.

The creation of the Medical Care act in 1966 was a significant driver in increasing health status for all Canadians. The removal of user fees for medically necessary services and the creation of the Canada Health Act in 1984 gave rise to a free universal
health care system (Romanow, 2002). Since then, Canadians have enjoyed considerable
gain in life expectancy, as demonstrated in an approximately 10 year increase in life
expectancy for both men and women since the 1960s and a 20 year increase since 1920
(Statistics Canada, 2006b). Gains in life expectancy are even greater for those with
disabilities, possibly attributable to better access to health care. As never before,
people with severe physical impairments are living into old age, due to advances in a
number of sectors, including public health, emergency medicine, rehabilitation
programs, and technology (Campbell, 1996; Putnam, 2002). Previously, people aging
with a long-term physical disability did not reach old age, due to complications from
their injury/disability. For the first time ever, estimates are predicting that 1 out of
every 100 older Americans is aging with some kind of long-term physical impairment,
which is surprising, because just 50 years ago the life expectancy for someone with a
spinal cord injury was less than three years after onset (Ansello, 2004; Wirtz, Favour, &
Ang, 1996). The functional decline associated with old age imposed on a person with
disability used to be a rarity, but with such significant gains in life expectancy, it is not
uncommon to see people who have acquired physical disability in midlife reaching old

The successful aging movement has raised consciousness about staying healthy
and aging optimally. At one time, gerontology focused mostly on aging as a series of
losses and declines requiring adaptation from the aging individual, but the last two
decades have brought a number of new perspectives that are in strong contrast to the
original negative view (Minkler & Fadem, 2002). Much emphasis has been put on maintaining a youthful appearance, exercising regularly, and avoiding functional declines at all cost. Many people even appear to believe that “with hard work and perseverance, we can and should achieve a near perfect state of health” (Hayden, 1993, p. 264), and it seems that with this obsession of aging successfully, “maintaining a healthy lifestyle has become close to a moral imperative” (Hayden, 1993, p. 264).

Looking back to the beginning of the successful aging movement and the emergence of Rowe and Kahn’s (1998) Successful Aging theory, problems were evident. The three components of Rowe and Kahn’s Successful Aging concept are the avoidance of disease and disability, maintenance of high physical and cognitive function, and active engagement with life. Together these concepts posit that the absence of disease and disability makes it easier to maintain mental and physical function. And maintenance of mental and physical function in turn enables (but does not guarantee) active engagement with life. It is the combination of all three – avoidance of disease and disability, maintenance of cognitive and physical function and sustained engagement with life – that represents the concept of successful aging most fully (Rowe & Kahn, 1998, p. 39).

For the group aging with adult-onset physical disabilities, the avoidance of disease and disability creates an issue. Although successful aging has done a wonderful job of making people more conscious about their health, the components of this model and the terminology itself may be causing further stigmatization and marginalization of people who are aging with severe physical impairment (Minkler & Fadem, 2002). It is evident that control over the acquisition of disability or impairment is not fully within our control and that someone can fall outside the “normal aging” trajectory through no
fault of their own. Further criticism of successful aging relates to its failure to recognize
the significance of losses as well as gains during old age, the process of aging across the
life course, the lack of an operationalized definition, and the failure to include the
disability population (Minkler & Fadem, 2002). Rudman (2005) also suggested that its
emphasis on self-responsibility for health could lead to blaming older adults with a
disability for failing to look after themselves adequately. The dominance of successful
aging as a model raises the question of what will happen for the people aging with
disability who, by definition, fail to age successfully and have been excluded from the
mainstream rhetoric of successful aging? As Wiley (2003) stated, “until the stories of
survivors aging with a disability are heard, answers to the “Why?” and “How?” of
successful aging with a disability may be unattainable” (p. 44).

Lastly, of the research that has been conducted on aging with long-term
disabilities, much of it has been focused towards congenital, developmental,
intellectual, or psychological impairment. In terms of numbers, approximately 526,000
American seniors are growing older with some form of intellectual impairment (Sheets,
2005). With a real focus on mental retardation, developmental disabilities have seemed
to dominate the aging with disability literature, and even though they are a significant
group in both numbers and importance and provide a framework from which to extend
disability related research, it is imperative to consider people aging with disabilities
other than cognitive ones (Gilson & Netting, 1997).
The research objectives of this thesis are:

1) To explain the mutual interaction of aging and disability in the lives of individuals aging with adult-onset physical disability,

2) To identify gaps in the existing knowledge base in order to provide future directions for research in this area,

3) To understand the factors influencing the perceptions and personal process of individuals aging with adult-onset physical disability, and

4) To create a balanced model to explain aging with adult-onset physical disability.

1.0 Location of the Researcher

Before moving forward in this thesis, it is important for the reader to understand how this study came to be and why I selected this topic. As a researcher, my interest for this project and my views toward the topic were generated from my experience living with two family members, my mother and my grandmother, who are aging with adult-onset physical disabilities. Both sustained spinal nerve trauma in mid-life after errors in surgery, leaving them with chronic pain that affected their work and daily life, as well as their process of aging. Although at very different life stages, I have seen my mother face the challenges associated with premature disability onset, and I have been able to watch my grandmother transition from the disability system to the aging system. Gone were the days of picking up and going to the beach, going shopping, or just spending time together; the pain became a monster that overtook every aspect of our lives.
Everything changed so suddenly, and even at 8 years old, I knew it would never be the same again. It pained my mother so terribly that she was not able to keep doing everything she used to do. She was so active, involved, and was present at every event in which my brother and I took part. Her absence now is not for lack of desire, but due to painful debilitation. I have seen them struggle, go without, and feel burdened by the limitations of their disability. Living with chronic pain is enough, but the secondary complications associated with reduced mobility, bed rest, and high doses of medications have also taken their toll. Yet despite some extremely burdensome limitations, they have found happiness and have some of the deepest, most meaningful relationships I have ever witnessed. I see in them an appreciation for life and thankfulness for what they do have. We have created a family life together that is understanding and adaptive. Living this experience has given me a strong appreciation for family, developed in me deeper understanding and compassion, and taught me to embrace the bumpy roads of life’s journey. I admire their strength and their courage, which helps them to keep fighting each day. I have seen instances of great adaptability and acceptance when negative outcomes occur, and it is because of this that I believe living with a long-term disability is not all negative, as much of the literature portrays.

Due to my experience, I do recognize that people living with physical disabilities are marginalized and disadvantaged in many ways, but at the same time, I feel that not everything about their disability status is negative, and perhaps the future is not as pessimistic as the literature portrays.
I feel it is important to be transparent about the way I view this study and the fact that I approached it with both critical and appreciative inquiry lenses. Using a critical lens allowed me to recognize the marginalization of those aging with a disability, as supported by my experience and portrayed in the literature, then problematize the phenomenon and understand the way larger social systems have influenced the lives of this group (Carpenter & Suto, 2008). An appreciative inquiry lens allowed me to take the problem identified, and together with the participants, share information and a dedication to foster positive change through positive questioning, which was based on concerns, issues, and topics the population felt were necessary for success (Whitney, Trosten-Bloom, & Cooperrider, 2010).

In order to maintain trustworthiness and authenticity in the study, I used reflexive journaling and a continuous process of reflexivity with my supervisor and advisory committee. In the data collection stage, I used reflexivity through field notes and reflexive journaling after focus groups and interviews with participants. This allowed for reflection on how the relationship between researcher and participant evolved, how power imbalances were managed, and recorded thoughts about the co-construction experience (Finlay, 2002). In the data analysis stage, I had weekly meetings with my supervisor to debrief, communicate, and discuss ongoing analysis. Reflexivity requires engagement with others. The team approach was effective, because it was a way to keep interpretation on track and also cautioned the team from allowing a single researcher's feelings or emotions to skew the interpretation (Finlay, 2002). Reflexivity
helped me grow as a researcher and realize my own position and relationship to the material, participants, and topic. This helped me to maintain transparency and prevented my own attitudes from driving data interpretation.

I chose to approach this thesis from a constructivist standpoint because I believe that different people have very different perceptions and understandings of what it is like to age with a disability. Any number of factors or circumstances can greatly alter someone's experience of aging with a disability, and constructivism embraces the multiple realities of people. Constructivism finds value in multiple, equally valid realities that have the potential to change as they become more or less informed (Guba & Lincoln, 1994). Further, given my belief that there are multiple accounts of growing older with a disability, it seems impossible for a single truth to exist. Constructivism also rejects the idea of a single reality and accepts the multiplicity of people's experiences (Guba & Lincoln, 1994). Throughout this thesis I spoke to participants, heard their stories, and understood their perceptions in the hopes of increasing understanding about this rapidly growing population, and through their words, shed light on a number of issues they face. Constructivism is transactional and subjectivist, which assumes that meaning is co-constructed between the researcher and participants (Guba & Lincoln, 1994). It is through this co-construction and deep reflection that meaning and understanding is brought to light (Guba & Lincoln, 1994; Ponterotto, 2005).
1.1 Thesis Outline

This thesis begins with an overview of the problem in Chapter 1. People aging with adult-onset physical disabilities have received little attention despite the aging boom we are experiencing. Throughout this thesis I have selected to use the term adult-onset physical disability unless otherwise noted in the literature. Based on the four filter questions from the Participation and Activity Limitation Survey (PALS) (Statistics Canada, 2006a), we have defined disability in our study population as a physical impairment that was acquired before age 62, and one that affected the amount or kind of activities you could do in your paid work and daily life. This is a group that has been overlooked in the literature for a number of reasons including recent increases in longevity, the successful aging phenomenon, and a focus on intellectual, developmental, and psychiatric disabilities in the literature. Chapter 2 is a scoping review that seeks to explore the existing knowledge about aging with adult-onset physical disabilities and identify gaps in the literature. Chapter 3 explores people’s perceptions of the process of aging with adult-onset physical disabilities. Chapter 4 details the creation of the Model of Aging with Disability (MAWD), a conceptual model that explains the process of aging with disability. Finally, Chapter 5 discusses overall strengths and limitations of this thesis, addresses how quality criteria were implemented, and suggests future research directions based on the findings of the thesis.
1.2 Conclusion

It is evident that late life disability rates are expected to skyrocket with the large number of people approaching the 65+ age bracket, including those aging with a disability. Much of the literature has focused on the need for successful aging and the need to avoid disease and disability in order to maintain long term functional health. Most of the literature about aging with a disability has focused on individuals with developmental and intellectual disabilities. This focus on successful aging, advances in life expectancy, and a focus on developmental or intellectual disability have allowed the group aging with adult-onset physical disability to fall under the radar. Although the group is not overly large now, in coming years it will grow to have a significant impact on our health care, home care, and political sectors. This impact will be felt the world over.

"People aging with physical impairments are a group of individuals who will likely have had different life experiences with disability than those older adults who have not lived long term with physical impairment or who did not have physical impairments earlier in life" (Putnam, 2002, p. 800). As Hayden (1993) put it "the chronically ill will never get well" (p. 265), and there are hundreds of thousands of people who live with illness as part of their everyday life. Their disability is not a deviation from normal, and as gerontologists we should be concerned with understanding the progression of adult-onset physical disability into old age and the outcomes associated with such (Hayden, 1993). This study will explain the process of aging with adult-onset physical disability and the mutual interaction of aging and disability factors on the experience.
1.3 References


EXPLORING AGING WITH ADULT-ONSET PHYSICAL DISABILITY: A SCOPING REVIEW

"Aging with physical impairment is likely a permanent trend and one that needs attention" (Putnam, 2002, p. 799)

2.0 Abstract

The sheer number of aging adults has received considerable attention, but one sector of the aging cohort that has fallen under the radar is those aging with a long-term physical disability. The purpose of this scoping review was to explore the mutual interaction of aging and disability in individuals aging with adult-onset physical disabilities and to highlight gaps in existing literature. A number of themes emerged from the literature. These included a lack of definitional clarity, challenges to cooperation between aging and disability sectors, and a significant lack of models that explore both aging and disability factors together. Literature to date has presented predominantly negative themes. This scoping review demonstrated the lack of understanding of both positive and negative aspects to aging with a disability. It has also highlighted the need for further research and the development of a more balanced model to explain the inter-relationship of disability and aging factors.

Keywords: aging with disability, physical disability, adult-onset disability, elderly, scoping review.
2.1 Introduction

Large numbers of seniors, both with and without physical disability, are benefitting from increases in life expectancy, and with such large numbers of seniors, some of whom are sure to experience some form of functional decline, the number of seniors with disability is predicted to skyrocket over the next half a century (Robert Wood Johnson Foundation, 1996). For the first time in history, people with polio, spinal cord injuries, multiple sclerosis, and other severe physical impairments are reaching life expectancies of 30, 40 or more years after disability onset (Crewe, 1991). Typically a group which has been allowed to fall under the radar due to a number of factors, including these recent increases in longevity, this makes people aging with adult-onset physical disability “pioneers in essentially uncharted territory, without previous generations of role models and facing medical questions that sometimes can be answered only with educated guesses” (Crewe, 1991).

The research objectives of this study were:

1) To explain the mutual interaction of aging and disability in the lives of individuals aging with adult-onset physical disability, and

2) To identify gaps in the existing knowledge base in order to provide future directions for research in this area.

2.2 Methods

A scoping review was completed to identify gaps in the existing knowledge base. Selected for its ability to discover these gaps, a scoping review does not seek to evaluate
the quality of included articles, but it does present an effective tool for exploring emerging fields.

This type of review was selected because the process of aging with adult-onset physical disability is an emerging topic and a scoping review provides a "technique to 'map' relevant literature in the field of interest" (Arksey & O'Malley, 2005, p. 20). It also allows an author to give a holistic conceptualization of research completed to date and permits them to synthesize findings to offer a new perspective on the topic of interest (Torraco, 2005). By identifying gaps in the existing knowledge base, a scoping review "takes the process of dissemination one step further by drawing conclusions from existing literature regarding the overall state of research activity" (Arksey & O'Malley, 2005, p. 21). This allows researchers to identify future directions and implications for research.

Searches were conducted using PubMed, CINAHL, and SCOPUS to generate relevant articles on this topic. PubMed was selected for its range of medical, nursing, and health system research; CINAHL for its comprehensive inclusion of nursing and other allied health field literature; and finally, SCOPUS for its multi-disciplinary scope covering the science, social science, and psychology fields. Search terms were categorized by topic. To cover the aging aspect of this project terms used included *aged, elderly, aging, geriatric, and aging with disability*. To reach the disability literature, terms included *disabilities, disability, disabled, impairment, and persons with disabilities*. To narrow the large body of evidence search terms including *physical,*
physically, physically disabled, and physically challenged were added to bring out our focus on physical disabilities. To further specify the search, adult-onset, pre-existing, and late-onset were added. Searches were limited to English-language articles published after 1975. The year 1975 was selected as a cut-off point for sources, because on a preliminary scan, relevant material started to emerge around the 1980s. With the surge of the disability rights movement in the 1970s, 1975 seemed like an appropriate starting point in order to try to be inclusive. A fourth method of searching, called citation tracking, was also used across the bibliographies of all the articles retrieved.

A data-driven thematic analysis as described by Dixon-Woods, Agarwal, Jones, Young, and Sutton, (2005) was conducted on the literature. This allowed recurrent and prominent themes to be addressed from multiple articles using similar thematic headings.

2.2.1 Inclusion and Exclusion Criteria

In order to be eligible for inclusion in the scoping review, articles had to (a) focus on individuals aging with adult onset-physical disability; (b) provide insight on terminology used in describing someone aging with an adult-onset disability; and/or (c) describe models of disability and aging. Exclusion criteria for this review were articles (a) published before 1975; or (b) about congenital, intellectual, developmental, or psychiatric disabilities.
2.2.2 Selection Process

Both electronic searching and citation tracking were used as two methods to retrieve relevant articles. Database searching was completed through three separate searches in PubMed, CINAHL, and SCOPUS. Database search results can be seen in Figure 2-1 and are summarized below.

**Figure 2-1. Flow diagram of literature search and selection process**

The total search yielded 285 articles. After excluding two articles published before 1975, 283 were included. Of these, 13 were excluded because they were not
written in English. Each of the remaining 270 articles was retrieved and reviewed by title and abstract, and duplicates (n=3) were removed. Articles were excluded if they did not provide adequate information on the process of aging with adult-onset physical disability. The screening and selection of articles was performed by the primary author (KB). If uncertainty arose, the relevance of the study was decided through discussion and consensus with the second author (SH). In total, three articles met the eligibility criteria. Citation tracking was also used to gather 30 additional sources not found through database searching.

2.3 Results

All sources reviewed are summarized in Table 2-1. After analysis of the 33 articles, 3 overarching themes and 2 prevalent hypotheses emerged. Themes included terminology used in the articles when describing aging with a disability, linkages or the lack of them between aging and disability sectors, and the paucity of models that explore both aging and disability together, the prominent Double Jeopardy hypothesis and the Age as a Leveler hypothesis. This table shows where each article fits under the major themes that emerged during this review.
<table>
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<th>Reference</th>
<th>PRE-EXISTING DISABILITY</th>
<th>PROLONGED DISABILITY</th>
<th>LONG-TERM DISABILITY</th>
<th>LATE-ONSET DISABILITY</th>
<th>LIFELONG DISABILITY</th>
<th>AGING WITH DISABILITY</th>
<th>LATER-IN-LIFE DISABILITY</th>
<th>Linking Aging and Disability</th>
<th>Talks about Models, Theories, or Hypotheses</th>
<th>Double Jeopardy</th>
<th>Alternative Hypotheses</th>
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<td>Finch &amp; Robinson (2003)</td>
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2.3.1 Defining Aging with Adult-Onset Physical Disability

This section highlights the disparity found in the literature when speaking about or defining aging with adult-onset physical disability. There were significant inconsistencies in the use of terminology across articles, which immediately became evident when only three articles were retrieved through a formalized search. Many articles did not even use a specific term for this population and merely spoke of a population that is aging with a disability. Finally, many articles failed to effectively distinguish among those aging with long-term physical impairment and few provided definitions for what constitutes membership in this group.

In the literature, the most common terms used were aging with disability \( (n = 6) \) and long-term disability \( (n = 4) \), but there was no one term consistently used across...
articles. This lack of consistent terminology not only made accessing research difficult, but it impedes researchers' ability to build a body of knowledge about the topic.

Most commonly, articles merely spoke of a disabled population that is aging. For this scoping review, aging with disability was selected as the term of choice over other terms, including lifelong disability, long-term disability, or pre-existing disability. Aging with disability was selected because it effectively captured the process of getting older with a disability and allowed room for the descriptors adult-onset and physical disability to be added.

Few articles defined the population of which they spoke. Although some articles used terms listed above, few provided readers with a distinction between the process of aging with a disability and “normal” aging. One of the few articles that provided a definition for people aging with a pre-existing disability was by Gilson and Netting (1997). They separated people aging with pre-existing physical disabilities into two groups and provided two definitions based on different experiences of living with a disability. They put forward that, one group will reach the threshold of chronological old age having already experienced a prolonged period of accommodation because of the pre-existing disabilities they have had for years. The manner in which they approach their disabilities may reflect different philosophies between the disability community and the aging community – before joining the community of older people they were part of the community of people with disabilities. The second group comprises adults with pre-existing disabilities who are aging in place in what might be called an accelerated aging process. Physically, they are experiencing what others may not experience until reaching the point where they are viewed as “old-old” or “frail.” This group may not reach a chronological age of 85 or 90 years, but they
will undergo that process, although at a younger age (Gilson & Netting, 1997, p. 290).

A second definition that could be used to better define this group and help clarify membership in it are individuals who acquire an impairment earlier in life and live with this impairment and its complications into old age (Campbell, 1996; Trieschmann, 1987). This differs from those individuals who experience functional decline and limitation in old age and only for their elderly years do they feel this burden (Putnam, 2002). This differentiation might be most easily understood as the difference between those who age with disability as opposed to those who age into disability. It is important to recognize that, in a lot of the literature, “distinctions among people who are engaged in prolonged or accelerated aging are not made” (Gilson & Netting, 1997, p. 291), although these paths may render very different outcomes and may have significantly different effects on healthcare, service delivery and policy.

2.3.2 Merging of Aging and Disability Sectors

A second major theme was the lack of connection between the aging and disability sectors. The aging and disability systems have remained separate, despite multiple attempts to merge agendas. Historically, both systems have progressed and developed independently with success, but they have failed to successfully partner, despite multiple overlapping concerns, including accessible public housing, access to healthcare, long-term-care needs, and financial stability (Sheets, 2005). To create a bit of a timeline, the 1980s saw an attempt to affiliate the aging and disability portfolios when talks surfaced over the need to create a unified policy agenda for common needs between
the two groups; the 1990s followed with numerous attempts, but failed over differing perspectives and a lack of clearly defined problems and solutions (Kane, 2004; Sheets, 2005; Zola, 1988). Putnam (2002) believes that the two sectors are “ideologically at odds” (p. 799) and built upon differing philosophies, which makes amalgamation difficult. Campbell (1996) speaks about the need to bridge the gap between the aging and disability sectors and offers reasons why both have failed to come together effectively. She suggests that

the “aging network” is made up primarily of providers, who are professionally trained to deliver services to, and to advocate for, older Americans, who because of functional limitations and/or socio-economic disadvantage are assumed to need help in maintaining their health and well-being. The “Disability community” in contrast, is composed primarily of young and middle aged self-advocates – both professional and non-professional, who are engaged in systems change on behalf of themselves and other like them; their primary commitment traditionally has been to empowering consumers to manage their own lives and not to providing services (Campbell, 1996, p. 2).

Fortunately in recent years, care for the aging population in Canada has shifted to a more client-centered approach with a strong focus on self-management. Putnam (2002) spoke of failed linkages and suggested that the aging service sector tends to focus towards the medical model of care and a care-centered approach to service delivery, whereas the disability sector is more likely to base service delivery on the needs and philosophies important to the people within the system. Bigby (2002) also recognized issues of merger between the two sectors and suggested that differences were due to varying conceptualizations of what constitutes an aged person. The aging sector generally defines an aged person over 65 years of age and aims to create policies for
those over 70, whereas the disability group deems a person as aged somewhat younger generally around 55, often due to the premature aging caused by complications arising from disability (Bigby, 2002).

Although philosophies and plans for both sectors do not fit precisely, aging and disability have continued to naturally overlap through the life course (Verbrugge & Yang, 2002), and with increasing numbers of seniors, including those with disabilities, the need for updated policies will force a closer linkage between the two divisions (Kennedy, 2002). According to Ansello (2004) "there is an absence of articulated national public policy directed to the well-being of aging adults with lifelong disabilities" (p. 1). Expert predictions hold that "disability rights issues will surface within an aging policy context as larger numbers of people aging with physical impairment begin to use old age programs and services" (Putnam, 2002, p. 799). Although the group of individuals aging with adult-onset disabilities is not large, it is projected to have a significant impact. As large numbers of people with long-term impairments age, there will be an expansion of the range of diagnostic conditions associated with physical impairment present in the older adult population, and this large group will also become consumers of the old-age services instead of the disability services (Putnam, 2002).

2.3.3 Aging with Disability Models

A number of models and theories have been put forward to explain issues associated with both aging and disability (see Table 2-2), but few have been put forward that link these two processes. Table 2-2 summarizes various models and theories regarding
aging and disability. Putnam (2002) also does an excellent job summarizing a number of key models that attempt to tackle, or could be applied to, aging with long-term physical impairment but fall short in either the aging or disability aspect.

One model and another group of models that particularly stood out in the literature were the Affirmation Model of Disability and the Accelerated Degradation Models. The Affirmation Model of Disability has a unique perspective. This model rejects the traditional negative or ‘tragedy view’ associated with disability and attempts to shed light on the positive aspects of living with impairment (Swain & French, 2000). Although exploration of living with physical impairment is pertinent to this study, this model unfortunately falls short in addressing the process of aging with impairment over the long term. The Accelerated Degradation Models are the only group of models to incorporate aging with disability. These models showcase the interplay of disability with the functional decline of aging, but they have been criticized as highly mathematical, in languages other than English, and fairly generic (Hayes, Wolfe, Trujillo, & Burkell, 2010). This is of concern, because many people are not able to understand the information. To conceptualize such dynamic and fluid processes as aging and disability with rigid mathematical equations seems inappropriate. Also, the focus on functional decline in old age take away any opportunity to consider positive experiences.

Campbell (1996) talks about the gaps in current models and explains that “to fill these gaps in our knowledge, we need to develop and test new models that incorporate concepts from both gerontology and disability studies, and broaden our base of
colleagues to include representatives of both communities” (p. 2). She also argues that conducting more “theoretically integrated and collaborative research on key issues [...] can help strengthen these ties by equipping members of both communities with the data needed to improve the quality of life for persons of all ages with disability” (Campbell, 1996, p. 3). Creating new and collaborative models will not only provide frameworks with which to address the needs of those aging with adult-onset disabilities, but will help to link these sectors more adequately to improve service delivery and guide policy development.

<table>
<thead>
<tr>
<th>Theory</th>
<th>Original Author</th>
<th>Basic Premise</th>
<th>Strengths</th>
<th>Limitations</th>
<th>Recognizes Aging with Disability or Severe Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disengagement Theory</td>
<td>Cumming &amp; Henry (1961)</td>
<td>Mutual and gradual withdraw or disengagement of elders from society and societal roles as they age.</td>
<td>Tries to separate a normal experience from a pathological one.</td>
<td>Based on Kansas City Study of Adult Life.</td>
<td>Recognizes Aging with Disability or Severe Impairment</td>
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<tr>
<td></td>
<td></td>
<td>Done in order to gain life satisfaction.</td>
<td></td>
<td>Excluded chronically ill elders in original sampling.</td>
<td>Recognizes Aging with Disability or Severe Impairment</td>
</tr>
<tr>
<td></td>
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<td>Did so in order to study &quot;normal aging&quot; process.</td>
<td>Recognizes Aging with Disability or Severe Impairment</td>
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<td>Not everyone disengages.</td>
<td>Recognizes Aging with Disability or Severe Impairment</td>
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<td>No</td>
<td>Recognizes Aging with Disability or Severe Impairment</td>
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<tr>
<td>Activity Theory</td>
<td>Lemon, Bengston, &amp; Peterson (1972)</td>
<td>Maintenance of activities important to the individual is crucial for increased life satisfaction in later years.</td>
<td>Tries to separate a normal experience from a pathological one.</td>
<td>Based on Kansas City Study of Adult Life.</td>
<td>Excluded chronically ill elders in original sampling.</td>
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<tr>
<td>Continuity theory</td>
<td>Atchley (1989)</td>
<td>Older adults make adaptive changes to sustain continuity between past and present to help maintain and evolve as the years pass.</td>
<td>Tries to separate a normal experience from a pathological one.</td>
<td>Initially excluded people aging with severe physical impairment.</td>
<td>Although mentions how it could apply to impairment in old age, fails to address persons aging with severe physical impairment.</td>
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<tr>
<td>Model of Aging</td>
<td>Balance point between individual abilities and environmental demands - a change in the equation and the tipping of optimal functioning, requires re-balancing and modification in either the person or environment.</td>
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<td>Ecological Model of Aging</td>
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<td>Gives insight into how disability occurs and how to modify environment to help.</td>
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<td>Lawton &amp; Nahemow (1973)</td>
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<td>States disability can be eliminated by modification.</td>
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<td>Person-environment Model</td>
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<td>Believes it is possible to eliminate disability by putting an environment into balance and by recognizing how disability occurs.</td>
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<tr>
<td>Person-environment Model</td>
<td>The better matched personal abilities are with the demands of an environment, the better the interaction will be.</td>
<td>Recognizes the adaptability and modification necessary for navigating in environment with a disability.</td>
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<tr>
<td>Medical Model of Disability</td>
<td>Focuses only on physical self - fails to recognize social and psychological factors affecting illness and disability.</td>
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<tr>
<td>Medical Model of Disability</td>
<td>Unable to locate original source.</td>
<td>Sees disability as something to avoid.</td>
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<td>Medical Model of Disability</td>
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<td>Social Model of Disability</td>
<td>According to Shakespeare &amp; Watson (2001), developed by the Union of the Physically Impaired Against Segregation (UPIAS) and given credibility by Barnes (1991); Finkelstein (1980, 1981); Oliver (1990, 1996)</td>
<td>Removes disability from the body</td>
<td>Believes it is society that marginalizes people with disability because disability is something put on top of physical impairment.</td>
<td>Takes into consideration other factors than the individual.</td>
<td>Shifts blame from the individual to society - blame should not be an issue.</td>
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<td>ICIDH</td>
<td>World Health Organization (1980)</td>
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<td>An international classification of disablement.</td>
<td>Impairments are changes in body structure or function. An impairment becomes a disability when it limits activities of daily living. This disability is a limitation of someone’s ability to perform normal functions. It becomes a handicap when impairment or disability limits someone’s fulfillment of a role that is normal.</td>
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<td>Proposes that society imposes the handicap on the person through attitudinal barriers.</td>
<td>Recognizes the social environmental factors of disablement.</td>
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<td>Thought to over medicalize disability.</td>
<td>Attempts to provide a non-medical model of disablement.</td>
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<td>Thought to focus on the impairment and not on changing activity or restrictions external to the person.</td>
<td>Does not specifically address the process of aging with disability.</td>
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<td>ICF</td>
<td>World Health Organization (2001)</td>
<td>Recognizes that functioning and disability are multi-dimensional phenomena experienced at the level of the body, the person, and society. Recognizes disability as a universal human experience and mainstreams the experience of it. Acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Helps reduce discrimination and offensive language.</td>
<td>Looking at impairments alone does not give a complete portrait of lived experience of disability. Does not specifically address the process of aging with disability. Does not make a distinction between physical and mental health conditions. No</td>
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<tr>
<td>Affirmation Model of Disability</td>
<td>Swain &amp; French (2000) attributes this to the Disability Arts Movement but does not cite source.</td>
<td>A non-tragic view of disability. Not about oppression or disadvantage, it is about having a positive disability identity and living full happy lives. Takes the focus away from a tragic view of disability. Provides a positive view of disability.</td>
<td>Do not specifically address aging. No</td>
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Highly mathematical and complicated for anyone without an advanced statistics or calculus background.

Much of the literature on these models is published in Russian or other European languages, making them inaccessible for many readers.

Yes, but does so in a negative way only - speaks of declines associated with aging.

<table>
<thead>
<tr>
<th>Accelerated Degradation Models</th>
<th>Mathematical models.</th>
<th>Recognizes the relationship between disability and the aging process</th>
<th>Table 2-2. Summary Table of Aging and Disability Models</th>
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</table>
2.3.4 Hypotheses

Two prevalent hypotheses in the literature try to explain the process of getting older with a disability. These include the Double Jeopardy hypothesis and the Age as a Leveler hypothesis. These hypotheses offer competing notions about what it is like to age with a disability. These hypotheses differ from models, because the models have been empirically tested a number of times and the hypotheses have not been fully developed or tested. Both hypotheses deal with aging and disability together and seek to explain the process of both factors occurring simultaneously.

2.3.4.1 Double jeopardy.

Much of the literature suggests that gains in life expectancy for individuals aging with adult-onset physical disability may be bittersweet. The idea of “Double Jeopardy” or being “doubly disadvantaged,” due to being disabled and old, is the predominant discourse for those reaching old age with physical impairment. Pentland and colleagues (2002) used these terms to describe the premature aging experienced by those with pre-existing disabilities. In her study Sheets (2005) discusses discrimination faced by those aging with pre-existing disabilities and describes some of the pathology behind the process. Both Sheets (2005) and Campbell, Sheets, and Strong (1999) recognize that, in midlife, those aging with long-term impairments often experience secondary health complications, unanticipated health issues, and declines in the form of weakness, frailty, mobility restrictions, pain, and fatigue. These complications are separate and in addition to any declines associated with aging. Kemp and Mosqueda (2004) describe
these declines as "premature aging", because these changes typically take place about 15-20 years before "normal" aging occurs. It is the overlay of the aging process on the disability process that creates this Double Jeopardy situation. Finch and Robinson (2003) discuss a similar double disadvantage when discussing accommodation to disability. They explain "persons with late-onset disabilities face the dual challenge of adjusting to both their disability and aspects of growing older with the accompanying physical and role changes" (p. 38). Trieschmann (1987) hypothesized that, due to daily stress and adaptation, coping skills of persons with disabilities may already be stretched to the limit when added changes due to aging are incurred. In these instances, Pentland et al. (2002) concurred that "the increased demands of aging (adapting physically, psychologically, economically, etc.) could be the 'straw that breaks the camel's back'" (p. 375).

The consequences associated with being old and disabled are hypothesized to be extensive. Because of limitations, those aging with disability may not be able to continue working and may be forced to retire without adequate time to save and prepare for typical retirement issues such as housing, insurance, caregiving, and income (Torres-Gill & Putnam, 2004). At the same time, they are still too young to receive a senior supplement, resulting in financial and quality of life issues that can threaten independence of this group (Sheets, 2005). With significant amounts of negative literature forecasting such a grim future, the additive effect of holding membership in
more than one disadvantaged category has become something to fear and avoid (Pentland et al., 2002).

2.3.4.2 Age as a leveler.

Over the past 20 years, new perspectives have been put forward that counter the original negative view associated with aging with long-term impairment (Minkler & Fadem, 2002). The Age as a Leveler hypothesis contrasts the negative views of the Double Jeopardy literature. Although plenty of literature exists on the Double Jeopardy hypothesis, much less exists to counter it. Living with impairment forces an individual to live with and adjust to limitations on a constant basis (Hayden, 1993). For people with disabilities,

age has been called a "leveler" in the sense that persons with disabilities have learned how to adapt to major physical changes, whereas people without disabilities have not and therefore may struggle more when confronting the physical decline and functional changes associated with aging (Reyes, 2009, p. 2). The strategies employed to adapt to disability could be a beneficial learned resource when adaptation is needed for age-associated impairments. Because individuals living with disability undergo a constant process of adaptation, many individuals employ strategies to adapt to situations without even being conscious of this act. As Pentland et al. (2002) pointed out, these individuals may be more adequately prepared for age-related changes and declines due to special experience in coping with disability related changes. Charmaz (1995) talks about the stages that individuals go through when adapting to disability, which could also be applied as strategies for adapting to aging.

For successful adaptation three things are necessary: a realization of having the
impairment, the awareness that, due to this occurrence, life and the future will change, and finally the acceptance of this impairment while trying to rebalance one’s life (Charmaz, 1995). People aging with a disability who have already experienced these stages of adaptation have extra experience and skill in valuable coping strategies. Ferraro and Farmer (1996) suggest that age may be a leveler because “minority persons adopt coping strategies throughout their life” (p. 319). As individuals “reassess their lives from a new and changing perspective,” (Gordon, Feldman & Crose, 1998, p. 5) it is this constant restructuring of life through self-reinforcement, active participation, and integration of learning that leads to successful adaptation (Wiley, 2003).

Although not overly positive, the Age as a Leveler hypothesis assumes that disability is not entirely a negative experience. It suggests not that someone aging with a disability has an advantage over the able-bodied population, but rather that when an able-bodied person acquires an impairment they are brought down to the level of the person with the disability. Although this hypothesis rejects the traditional negative view of aging with a disability it does little to offer any advantage to the experience.

2.4 Discussion

It is evident that disability rates are expected to rise dramatically with the large numbers of seniors crossing the threshold into old age. The literature has focused on the need for successful aging and the need to avoid disease and disability in order to maintain health. Most of the literature about aging with a disability has focused on individuals with developmental and cognitive disabilities. This focus on successful aging, increased
longevity for this group, and a focus on developmental or intellectual disability have allowed those aging with adult-onset physical disability to be overlooked. Although the group is not overly large now, in coming years it will grow to have a large impact on policy, healthcare, and service delivery sectors.

There exists a real lack of consistency in terminology when speaking about those aging with adult-onset physical disabilities. This became evident very early when only three relevant articles were found using a formalized search. Not many articles used the same terms to describe the population, and some articles did not use a label at all. Of the sources that did provide terminology, very few defined the group they were discussing. The impact of this is that it makes it difficult for researchers, the public, clinicians, and policy makers to access important information. This also impedes building a body of knowledge about those aging with adult-onset physical disability because research is ineffectively linked. If research cannot be accessed, then the information cannot be disseminated and effective policies and strategies cannot be enacted. The lack of definitional clarity in the literature is consistent with the nature of disability itself. Sheets (2005) describes the dynamic nature of disability well when saying that “disability is fluid and changing; it can vary depending, for example, on the gap between the capability of the individual and the environmental context” (p. 38). With disability being such a heterogeneous experience, combined with the dynamic process of aging, definitional uncertainty for aging with adult-onset disability is almost expected. The lack of a definitive term to capture this phenomenon may arise out of
individuals' difficulty with being labelled as disabled, this may hinder their acceptance of
the disability and also create conflict over what actually constitutes a disability (Gordon et al., 1998). Another potential reason for lack of an operational definition could be the
fact that people with disabilities do not fit well on the continuum between sickness and
health. Marks (1997) suggests that people with disabilities seem to defy the boundary
between illness and wellness by violating the terms of the sick role with never fully
recovering, but at the same time never being capable of full participation, making them
a difficult group to categorize. Defining something that society has been conditioned to
fear through the successful aging movement may also have something to do with it. "To
some, those with physical and mental disabilities become objects, the permanent
reminders of lost or losing struggle, the symbols of a past and continuing failure.
America likes winners. It forgets, denies, rejects and neglects losers" (Zola, 1988, p.
373).

A number of attempts to merge the disability and aging sectors have been
unsuccessful. This is a major issue because "many people aging with physical
impairment will become consumers of old-age services after having been consumers of
this is important for us to consider, as researchers, because "the service models of
disability and aging are typically distinct" (p. 799). This matters because people aging
with a disability are experiencing unprecedented increases in longevity, and for the first
time in history, people are living into old age with disability. More people in coming
years will be making the transition from disability service to old age services and in order to accommodate the increased need for services and updated policies, people need to begin working together. It is through this service transition that the need to establish successful partnerships will become evident, in order to make sure that services are not only accessible during and after the transition, but are appropriate and responsive to the requirements of this aging and physically disabled population.

Few models and hypotheses exist that attempt to explain the process of aging with adult-onset physical disability. There is a real need for collaboration between the aging and disability sectors to create models that can explain the experiences of people who are aging with a disability. There are a number of models that address disability on its own as well as a number of models that address aging on its own. The division of the fields has divided the literature and is perhaps partly to blame for so few models linking these two concepts together. Campbell (1996) suggested that models need to be created that incorporate concepts from both gerontology and disability studies and built by a collaborative team of providers from both sectors.

In a topic that has traditionally been portrayed negatively in the literature, the Double Jeopardy hypothesis and the Age as a Leveler hypothesis completely reject the possibility of aging with a disability being in any way an advantageous experience. The Affirmation Model of Disability described by Swain and French (2000) contradicts the traditional negative view and offers the possibility for some advantage arising out of disability, but it does not specifically address aging with disability. The idea of a
balanced model of aging and disability is a novel idea, and one that deserves further attention.

2.4.1 Strengths and Limitations

The main strength of this scoping review is the contribution it will make to the literature about the intersection of aging and disability. Aging with adult-onset physical disability is an emerging area of study, and this review has brought to light a number of issues and gaps that exist in the literature and need to be addressed in the future. Further, this study probes alternative hypotheses which look at the influence of aging and disability, moving away from the traditional negative view prevalent in published literature. One limitation to this study is the significant variation in terminology, making a formalized search strategy difficult. Because of this difficulty, it is conceivable that relevant articles were missed. Secondly, by nature, scoping reviews do not seek to assess quality of included articles. However, given the paucity of literature on the topic this was the most appropriate method for the literature review. There would have been insufficient material for an integrative or systematic review (Arksey & O'Malley, 2005; Torraco, 2005).

2.5 Conclusion

Issues of inconsistency in terminology and poor definitional clarity are evident, making the population of those aging with disability difficult to conceptualize and even harder to measure. Many models exist that tackle challenges associated with either aging or disability, but few bridge/explore the relationship of these factors adequately, which is
necessary to understand aging with long-term physical impairment. Evidence points towards a doubly disadvantaged situation for this population and highlights their status as a marginalized and oppressed group. On the other hand some, but significantly less, literature contrasts the all negative view and describes that age may actually be a leveler, due to extra experience in coping and adaptation. What is clearly lacking in the literature is a model that explores both the positive and negative impacts of concurrent aging and disability on the lives of those aging with adult-onset physical disability.

2.5.1 Future Research Directions

This scoping review explores an important but overlooked section of the aging cohort. By researching this area further, we may be able to help inform practice and policy agendas for this fast growing population. This review highlights the need for a balanced model to explain the mutual influence of aging and disability factors on individuals’ life experiences. Further research should address the creation of a more balanced model that takes into consideration the multiplicity of experiences of aging with a long-term physical disability and that recognizes both positive and negative aspects to the experience.

2.6 References


3 PERCEPTIONS OF THE PROCESS OF AGING WITH ADULT-ONSET PHYSICAL DISABILITY

"I don’t know how long I’ll be able to keep doing the things I am, but I’m a fighter so I just keep pushing." (Andrea)

3.0 Abstract

People aging with adult-onset physical disabilities are living longer than ever before. Many will soon make the difficult transition from the disability service system to the old age system and a need for updated research and service and policy initiatives is evident in order to best serve this population. A constructivist grounded theory approach was used to understand the factors influencing people’s perceptions of aging with adult-onset physical disability. Two focus groups and four follow-up interviews were used to gather data. Five major concepts emerged that influenced people’s perceptions of the process of aging with adult-onset disability. These included the entanglement of aging and disability, the multiplicity of experiences, financial resources, attitude and self-efficacy, and family and social support. Understanding these factors and perceptions has the potential to better inform practice and policy agendas while increasing participation between the fields of aging and disability.

Keywords: aging with disability, perceptions of aging with disability, grounded theory approach
3.1 Introduction

The aging population has received considerable attention with the sheer number of baby boomers who will soon reach 65 and cross over the threshold into old age. One facet of the aging population that has managed to remain under the radar is individuals aging with adult-onset physical disabilities. There has been little focus on capturing the perceptions of people aging with adult-onset physical disabilities and understanding the mutual influence of aging and disability on these perceptions. Reduced attention to aging with adult-onset physical disabilities may be attributed to the heavy focus on congenital, developmental, intellectual, and cognitive disabilities in the literature, the successful aging phenomenon, and recent increases in longevity for this group.

Although the group of those aging with adult-onset physical disabilities is not large now, in coming years it will grow to have a large impact on our health care, home care, and political sectors. In order to continue effectively serving this population, research into the factors influencing their perceptions of growing older with a disability is necessary. Understanding what influences their transition through the life course with a disability has the potential to inform a number of service and policy debates.

The research objectives of this study were:

1) To explore the mutual interaction of aging and disability in individuals aging with adult-onset physical disability, and

2) To understand the factors influencing the perceptions and personal process of individuals aging with adult-onset physical disability.
3.2 Literature/Background

In 2006, there were approximately 1.8 million seniors with disabilities in Canada. Given that approximately another 825,000 Canadians with disabilities are age 55-64 and 741,000 aged 45-54 (also as of 2006), Canada can expect a dramatic rise in the number of seniors with disabilities in the next two decades (Statistics Canada, 2006). Poor definitions of what constitutes a disability and reliance on self-report measures may mean that these figures are over or under estimated (Gordon, Feldman, & Crose, 1995). Although not a large population now, those aging with disabilities are projected to majorly impact healthcare, service delivery, and policy development around the world in coming years.

Defining disability has long been a problem. In the literature, there is a further lack of definitional clarity when speaking about growing older with a disability. In the sources reviewed in Chapter 2, “aging with disability” was the most commonly used term, but there was no clear consistency in terminology across articles. In the literature, “distinctions among people who are engaged in prolonged or accelerated aging are not made” (Gilson & Netting, 1997, p. 291), although these paths will produce different outcomes and have varying effects on healthcare service delivery and policy. Distinctions must be made between those aging with disability and those aging into disability.

Outcomes for people aging with disabilities have been portrayed as predominantly negative. The prominent Double Jeopardy hypothesis suggests that
someone aging with a disability is doubly disadvantaged, by having aging placed on top of the disability process and by the “premature aging” that occurs years before “normal aging” is supposed to begin (Campbell, Sheets, & Strong, 1999; Kemp & Mosqueda, 2004; Pentland et al., 2002; Sheets, 2005). Another hypothesis attempts to counter the traditional negative view; the Age as a Leveler hypothesis posits that people aging with a disability may be no worse off than any other older adult, because they can use strategies they acquired from adjusting to their disability and apply them to aging (Reyes, 2009). Only one set of models exist that attempts to explain the interaction of aging and disability together, the Accelerated Degradation models. Unfortunately, these involve complex mathematics and are often published in languages other than English, making them inaccessible to many (Hayes, Wolfe, Trujillo, & Burkell, 2010). Campbell (1996) talks about the lack of models and states that, in order “to fill these gaps in our knowledge, we need to develop and test new models that incorporate concepts from both gerontology and disability studies, and broaden our base of colleagues to include representatives of both communities” (p. 2). Conducting “theoretically integrated and collaborative research on key issues […] can help strengthen these ties by equipping members of both communities with the data needed to improve the quality of life for persons of all ages with disability” (Campbell, 1996, p. 3).

The disability and the aging networks have failed to effectively partner on multiple occasions, despite a number of overlapping concerns, including accessible
housing, appropriate healthcare, access to services, and financial support (Sheets, 2005). In order to understand the perceptions of people aging with adult-onset disabilities, there needs to be a greater attempt at bridging the gaps between these two sectors. With increasing numbers of seniors, including those with disabilities, the need for modernized policies will highlight the need for closer linkages between the two sectors (Kennedy, 2002; Verbrugge & Yang, 2002). It has been predicted that “disability rights issues will surface within an aging policy context as larger numbers of people aging with physical impairment begin to use old age programs and services” (Putnam, 2002, p. 799). Only through understanding the factors that influence people’s perceptions of what it is like to grow older with a disability can we seek to effectively partner these two sectors, understand the true needs of this population, and deliver services effectively.

3.3 Methods

This study used a constructivist grounded theory approach. Constructivism allowed us to gather and find value in multiple, equally valid perceptions, while a grounded theory approach offered a definitive set of tools to gather, organize, and understand the interactions between researcher and participant.

Constructivism rejects the idea of a single definitive reality and embraces multiple constructions held by different people, which are no more or less true than one another, and which may be more or less informed (Guba & Lincoln, 1994). These realities, known as constructions, have the ability to change or become influenced
socially or experientially, and often elements of these constructions can be shared across many individuals (Guba & Lincoln, 1994). Constructions are created as the interaction of researcher and participant evolves, and the two individuals are said to be linked in the process. Through this interaction, constructions may be elicited and refined, with the ultimate goal being to develop a construction that is more sophisticated than any previous constructions (Guba & Lincoln, 1994).

A grounded theory approach allows qualitative researchers to “construct a picture that draws from, resembles, and renders subjects’ lives. The product is more like a painting than a photograph” (Charmaz, 2003, p. 270). This approach lends itself to capturing the variation in human lives and fits well with constructivism and the idea of finding value in understanding multiple perceptions. “The rigor of grounded theory approaches offers qualitative researchers a set of clear guidelines from which to build explanatory frameworks that specify relationships among concepts” (Charmaz, 2003, p. 251). Strategies used in grounded theory include the simultaneous collection and analysis of data, a two-step coding process, constant comparison, analysis through memo writing, and theoretical sampling to refine ideas, which all aid in concept development (Charmaz, 2003).

“Qualitative research has a role to play in identifying the concepts that help us understand people’s lives” (Carpenter & Suto, 2008, p. 21). A constructivist grounded theory approach gave us the tools to understand the perceptions of multiple people
aging with an adult-onset physical disability and provided an approach to appreciate the meaning of those personal realities.

In grounded theory, using focus groups as the primary data collection tool and follow up in-depth interviews as a secondary technique allows researchers to gather an overall picture from the focus groups and then return to participants a second time through in-depth interviews to clarify, refine, and probe further (Morgan, 2004). Having small groups allows everyone a chance to share their experience and insight while still attaining diversity in their perceptions (Krueger & Casey, 2009). Although Morgan (1988) recommends three to five focus groups in the data collection stage, returning for follow up in-depth interviews, in addition to the focus groups, allows for information refinement as opposed to population representation (Charmaz, 2006). In this study, two focus groups were completed in the primary phase of data collection, and follow-up in-depth interviews were conducted as the second phase of data collection.

3.3.1 Inclusion and Exclusion Criteria

The inclusion criteria for this study were both men and women over 65 years of age living with an adult-onset physical disability for more than three years duration before the age of 65. The three year disability time frame was selected in order to distinguish a chronic disability from an adverse health event and to provide an adjustment period to the acquisition of disability. The disability must have been one that affected paid work and daily life. The participants needed to be English speaking and able to participate in an interview process. The age limit of over 65 years was selected to ensure that all
participants had already experienced the transition from the disability service system into the aging system.

Exclusion criteria for this study were participants with any congenital, intellectual, developmental, or psychiatric disabilities. Although people with these disabilities are very important and worthy of study, a significant portion of the existing literature on aging with disability has focused on these groups. Those with physical disabilities have been less prominent in the literature, so the researchers chose to focus on this group.

3.3.2 Sampling

This study used purposeful sampling to recruit individuals who experienced the phenomenon under study. What mattered was that participants were all aging with an adult-onset physical disability. The exact nature of the disability (i.e., diagnosis) was of less significance. In fact, individuals with different diagnoses were actively sought to allow for a more variable sample.

3.3.3 Participant Recruitment

The recruitment process began after ethical approval was received from the University of Western Ontario's Research Ethics Board (Appendix A). A number of disability organizations across Southwestern Ontario, including, the MS Society, the Parkinson's Society, Stroke Recovery, Kidney Foundation, the Diabetes Society, the Heart and Lung Society, the Canadian Paraplegic Association, the Arthritis Society, a Chronic Pain support group, a Fibromyalgia support group, Cheshire Homes, and Hutton House, were
contacted and informed about the study. A telephone or in-person conference was held with those organizations interested in helping with the study. A gatekeeper was identified at each participating organization to inform eligible participants about the study. Once a potential participant was identified, the gatekeeper transferred contact and study information (Appendix F) to the potential participant, who was free to contact one of the researchers.

When a potential participant contacted the research team, we provided more information about the study by telephone, and the consent procedure was fully explained. Any questions the potential participants had were answered, and their option to terminate participation at any time during the study was re-iterated. If the individuals were willing to participate, they were informed that they would be contacted a second time once enough participants had been recruited to schedule a group. Focus group times were scheduled at the convenience of participants.

Eight participants were identified who fit the inclusion criteria for this study. Recruitment attempts were successful from the MS Society, the Parkinson’s Society, Hutton House, and Stroke Recovery, which resulted in five participants. Unable to locate participants from any other organizations we contacted, snowball sampling was used to recruit three other participants. After a last-minute drop-out due to medical reasons, we completed the study with seven participants.
3.3.4 Description of Participants

Of the seven participants included in the study, five were females and two were males. Table 3-1 summarizes the demographic information for all seven participants. Participants experienced a number of different disabilities, and their ages of onset ranged from 33 years to 62 years of age. All reported using some kind of assistive devices, either a mobility aid or in the form of home modifications. Only one participant still drove. Immigration status was not applicable for all but two participants who had emigrated from the United Kingdom a number of years ago. Three participants reported living on their own, two lived with their spouses, one in a congregate living facility, and one with an adult child in her home. Three participants were forced to stop working immediately after disability onset, whereas four were able to continue working. All but one participant had to reduce work hours in order to accommodate their disability and all reported being forced to stop working before they desired. This thesis will refer to all participants by pseudonym.
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<th></th>
<th>Harold</th>
<th>Genevieve</th>
<th>Gwen</th>
<th>Andrea</th>
<th>Judy</th>
<th>Wilhelmina</th>
<th>Daniel</th>
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*Table 3-1. Summary table of participant demographic information*
3.3.5 Data Collection

3.3.5.1 Phase 1.

Participants were asked to take part in focus groups and, in addition, were asked if they would be willing to be contacted for an in-depth follow up interview. Two focus groups took place (Appendix C) with four participants in the first focus group and three participants in the second. Before starting the focus groups, the research team discussed the need to maintain confidentiality and the importance of respecting the privacy of other members in the group. The informed consent process was also explained and discussed in detail before the signing of consent forms. Demographic data questionnaires (Appendix E) were completed before the focus groups began.

Both focus groups lasted 1 hour. Only one participant required a short break to use the washroom facilities during the second focus group. Focus groups were audio taped. Participants were compensated for transportation costs in the form of parking reimbursement, fare costs for public transit, or Para-transit fees.

3.3.5.2 Phase 2.

Interviews were conducted as a second phase of data collection to augment the data. These follow up interviews were conducted to help fill in the gaps in our analysis. Due to the emergent design of this qualitative research study, the data collection process evolved as the project continued. The number of follow-up interviews was not determined until both focus groups had been completed. Follow-up participants and interview questions (Appendix D) were selected after hearing data from the focus
groups, in order to see what topics required further exploration and decide who could best speak to where the data were directing us. Participants were selected based on their contributions during the focus group and their perceptions of what it had been like growing older with a disability. Before starting the follow-up interviews, ethical approval for phase two was obtained from the University of Western Ontario Research Ethics Board (Appendix B).

Four in-depth follow-up interviews were completed with participants from both focus groups. Three participants were selected from the first focus group and one was selected from the second group. At the start of each interview, participants were again reminded of their choice to terminate participation at any time. Interviews lasted between 30 and 40 minutes and were audio-taped.

3.3.6 Data Analysis

In a grounded theory approach, data collection and analysis occur at the same time. Once the focus groups were completed, the audio files were transcribed verbatim. Demographic data were analyzed using simple descriptive statistics. Narrative data were analyzed using the constant comparative method described by Charmaz (2003). Themes arising from the focus groups were identified. There were areas where clarification was needed and/or more information was necessary to saturate the emerging concepts. Theoretical sampling was used to return to the participants for further clarification and refinement of ideas during phase 2 of the data collection.
3.3.6.1 Coding and memo writing.

Data were organized and analyzed using the coding software program NVivo9®. Coding makes it easier for a researcher to categorize and understand the data. Charmaz (2003) explains that the coding process “helps us to gain a new perspective on our material and to focus further data collection” (p. 258). Transcripts were coded using line-by-line coding, followed by more focused coding as ideas and concepts emerged. Starting with line-by-line coding “sharpens our use of sensitizing concepts – that is, those background ideas that inform the overall research problem” (Charmaz, 2003, p. 259). Line by line coding allowed the researchers to identify gaps and understand directions for further, more focused data collection. Once more data had been collected from the follow-up in-depth interviews, more focused coding took place. At that point, data were organized into larger concepts and relationships among concepts were explored.

Through constant comparison within and between participants, focus groups, interviews, and questions, differences, similarities, and new concepts became evident. Memo writing is a technique to bring thoughts together, to explain what is coming out of the data, to spark new ways of thinking, and to record of the interaction between researcher and data. Memo writing was used in this study to help maintain reflexivity and to openly explore the data.

3.4 Results

From the focus group and interview data, five major themes emerged that were identified as factors influencing the process of aging with adult-onset physical
disabilities for our participants. These factors included the entanglement of aging and
disability, the multiplicity of experiences, financial resources, attitude and self-efficacy,
and family and social support. The data demonstrated one of Andrea’s comments,
“there are a lot of different variables in the experience.”

3.4.1 Entanglement of Aging and Disability

Many participants reported significant difficulty in separating the process of aging from
their disability. Although many recognized their disability as one separate entity and the
process of getting older as another, it was their experience of the two processes
occurring together that they found difficult to untangle. As Daniel described, “I don’t
know how to separate [my disability] with the aging process because I’m experiencing
both together, and I ask myself how much of this problem is aging and how much of this
is disability.” Harold agreed,

I have Parkinson’s and there are so many things associated with Parkinson’s that
are associated with getting older and you don’t know it [LAUGHS] I guess I don’t
really worry about it too much. I’ve got the problem and whether its old age or
Parkinson’s and I have to put up with it.

Recognizing this entanglement, his Doctor also cautioned him

be careful about, as you get old, blaming everything on Parkinson’s. He says it
will cause a lot of problems but it doesn’t cause everything. So he says, some
people will blame anything from sore muscles to a headache on Parkinson’s and
he says there are lots of things that are going to happen to you in the future that
have nothing to do with Parkinson’s. (Harold)

Andrea shared Harold’s uncertainty when saying “I’ve always associated some of these
problems with my disability, with Multiple Sclerosis (MS), so I don’t really think about it
as being aging. Although when you bring it up, I do stop and think, well, maybe that is part of it.”

Age of disability onset was raised as a contributing factor to this entanglement.

Many felt that the younger someone acquires a disability, the more difficult it is to tease out the two concepts. Genevieve offered that the two concepts are somewhat entangled. I think it depends on when you start your disability as well. If Parkinson’s started very much later on in life, I could see that he might wonder whether it was due to the Parkinson’s or aging, but I think when you have a disability much earlier on, it all becomes intermingled.

It is important to emphasize that, although the two phenomena, aging and disability, remain distinct in the eyes of the participants, their daily lives, understandings, and personal experiences remain entangled. It became almost impossible for participants to distinguish what aspects of their lives were attributed to their having a disability and what was recognized as being part of the natural aging process. Understanding this entanglement may have implications for bridging the gap between the aging and disability service sectors as well as policy agendas.

3.4.2 The Multiplicity of Experiences

During the focus groups, the Double Jeopardy hypothesis and the Age as a Leveler hypothesis were discussed with participants. Many could relate to feeling disadvantaged at some point during their process of aging with a disability, and many also stated that at other times they felt no worse off than any other older adult without a disability. What was even more interesting was the number of participants who spoke of it being almost advantageous to acquire a disability earlier in their life. Participants
spoke of having a multitude of experiences that did not fit exclusively into either of the mainstream hypotheses presented in the literature.

3.4.2.1 Double jeopardy.

The Double Jeopardy hypothesis says that someone aging with a long-term impairment is doubly disadvantaged due to the aging process being overlaid on the disability process, causing the “premature aging” that takes place about 15-20 years before natural aging occurs (Campbell et al., 1999; Kemp & Mosqueda, 2004; Pentland et al., 2002; Sheets, 2005). Participants confirmed that there were some disadvantages to having a disability earlier in life, which have had repercussions for them as they have aged. Some of the disadvantages mentioned included mobility limitations/loss of independence, maintenance of family and social relationships, and inability to reach normal milestones, such as employment, promotion, and retirement.

Mobility limitations and loss of independence were of primary concern to participants. Many felt that not being able to drive a car anymore and having to rely on alternative transportation were limiting factors in their life. Gwen said it is difficult “not being able to get around on my own. I have to go on Paratransit. To not be able to visit family; there are so many disadvantages of it.” Wilhelmina also had feelings of restriction about the loss of independent transportation. She felt that when you have a disability you give up a lot of things that you could normally do, and my biggest thing is driving my car. I really miss that, jumping in the car and just going to the mall, and now you have to wait, and again family supports you and takes you where you want to go but just that independence...well I’m going out for a couple hours I’ll be back...that’s what I miss the most.
Andrea missed even being able to be a passenger in a car. "It was a lot easier for me to arrange transportation when I could get in and out of people's cars." Judy, a regular Paratransit user, felt that life had become somewhat constricted due to the need for constant advance planning because of her deteriorating physical state and her reliance on external transportation. "If I have a hard time handling my wheelchair, I can walk but it's not pretty and I tire really fast, so if we're going to do something, I try to make it somewhere I can take Paratransit."

Another disadvantage identified by all participants was the difficulty in accessing family and sustaining family relationships, which was attributed to a number of factors including physical limitations, inaccessible locations, lack of understanding from others, and geographic distance between family members. Andrea shared that her extensive physical limitations make building and maintaining family relationships difficult. A particularly poignant comment was

I now have five grandchildren and one was just born last Wednesday, and they brought the baby over on the way home, but I don't dare hold the baby. Because my arms and my hands are weak and I don't want to hurt him. Everybody else was passing the baby around and I just try to ignore it, but you do feel it.

Gwen found it difficult to visit family;

I'm not able to go to family functions, except for at my sister's who has MS as well and her house is accessible, whereas the other four family members don't have homes like that. So I'm sorry about that, and they'll come to me, but it's not that often that that happens anymore.

Genevieve spoke of a relationship ending:

I think it's true that some people do think you're different. I had a couple of boyfriends, or one particularly who I was quite fond of when I was younger, and
he suddenly said to me one day "We can’t go out" he said “because you’re different. I don’t think I could deal with somebody with a disability” and it’s very true even today.

Lack of understanding from others was a recurring point in the discussion.

Wilhelmina shared,

I have some people I always thought were my great friends, and after a while you get sick they’re busy all the time, cause they’re tired of hearing it or they haven’t got time. They say they’re going to visit you and they don’t, and you have to be patient with them because their lives are going on. They’re not just sitting there waiting for a visitor, and people can tend to be neglected, a lot of them.

Andrea, fortunate to have a supportive family, has also faced lack of understanding from others.

I find even when I go to things like church, I mean people are very good about making sure everything is fine for me but I never see them afterwards. They don’t call me up and say ‘let’s go to the movies’ or ‘let’s go for a ride around town’ or something, cause they know I’m restricted and they don’t want that restriction. And I have often just turned a blind eye to that, but I am aware of it.

Harold used humour to disguise some of the pain of rejection.

I have found a few people, especially when I was first diagnosed with Parkinson’s, people who knew absolutely nothing, which was just the same or slightly less than what I knew. But they didn’t know anything about it, so they thought the best thing was to stay away. Do we catch it? Or can I drink out of the same cup as you? It was quite a battle, it kind of surprised us. It bothered my wife, I think, more than me, because we had some very good friends that just stopped coming around. Or they would come around once and a while and they’d say they’d be back in a month or two, well a month or two would turn into a year, but it’s improved now. They realize now that I’m harmless most of the time.

Daniel and Genevieve had a different family situation than most. Both came from the UK, and most of their immediate family still reside there. Genevieve shared that after acquiring a disability “it was very interesting to see how my friends, I’d made
many friends, how they saw me. And actually in some ways I had to carry on and pretend I was just quote 'normal' because I didn’t have family support.” Daniel wonders about his future with his family living all over the world. At the moment

my family situation is a little anxiety really. My wife is still going strong, she’s the only family member nearby. Two daughters, one in Washington and one in the UK, so as I look towards the future, I do wonder what’s going to happen, because we are coping now but both the daughters are a long, long way away. It’s not impacting right now, but it’s something I think about.

The impact of aging with a disability also had a significant effect on the ability to reach certain life milestones. Genevieve, spoke of the challenges she faced from acquiring her disability in her thirties. When acquiring a disability so young, she shared “your milestones may not be reached. Your developmental stages are all put out of whack.” Not being able to advance in a career or the inability to attain regular advancements or promotions made planning for retirement very difficult if not impossible. Being forced to stop working would not only impact financial status at the time of disability onset, but would have latent consequences for financial status after the age of 65. The effects of being “off-time” in these milestones resonated through the years into old age. Andrea also felt that aging with a disability “does make it extra hard, because you have to sort of be realistic, which we’re not always realistic but maybe not being realistic helps us. It’s that double jeopardy in a way.”

All participants shared that, at certain times during the process of aging with a disability, they could identify with feeling doubly disadvantaged. Having a disability earlier in life had created a number of situations in which they felt disadvantaged,
however it was the repercussions of acquiring the disability earlier in life that affected their perceptions of what it was like to grow older with a disability.

3.4.2.2 Age as a leveler.

The Age as a Leveler hypothesis suggests that people aging with a disability may, in fact, be no worse off than any other older adult, because they can use the strategies acquired from adjusting to disability and apply them to the challenges associated with aging (Pentland et al., 2002; Reyes, 2009). Participants could also relate to this hypothesis. Genevieve felt that, because of her experience, she is now able to help others.

*I think you've learned a few things if you have a disability earlier on, and you can use different strategies or you can help other people in dealing with things and coping, so I think it is probably a leveler.*

Andrea also commented that age has made her more similar to her peers.

*I have been on disability for so long, I'm now celebrating 25 years that I have learned to cope with it, and I have often socialized with more of an older group of people because of my disability, because people my age were always working and too busy with other things, so that sort of integrates the two, so now I just sort of fit in now, because I've reached that point.*

3.4.2.3 Advantageous experience.

Most interestingly, participants suggested that having a disability earlier in life was actually advantageous. Many felt that if they were going to acquire a disability, they would prefer to do so in their adult years as opposed to after age 65. Wilhelmina offered,

*I already know what it was like, so it wasn't such a shock to me. Some people just wake up and have a stroke or something and their whole life changes within*
minutes, and there’s nothing they can do about it, and they’ve had no adjustment to it. Not that you want to be sick before you get there, but if it happens it’s a bit of an advantage, because you already know, well, I couldn’t do that before, I can learn to do something else.

Judy spoke of the benefit of having time to adjust. “I can relate definitely to it being advantageous to acquire a disability earlier in life and slowly adjusting to it. It doesn’t become a traumatic ordeal.” Genevieve related to the struggle of acquiring a disability in old age through a friend’s experience.

I think having a disability after 65 is sometimes harder then starting off with a disability and you gradually are seeing the deterioration. The things you can’t do, you start to accommodate to. A friend of mine was diagnosed with rheumatoid in his 70s he’s really had it badly, and he is finding it so hard to deal with. He’s a doctor and he just can’t believe that, you know, he won’t experiment sometimes and he just is very depressed about it, because he could do so many things before and go out on his own and now he just can’t.

All participants spoke of the shock felt by people who suddenly acquire a disability in older age and felt thankful for an adjustment period. They recognized the traumatic nature of a dramatic change in later years and felt uneasy at the thought of having to start adjusting after age 65.

Amusingly, one of the greatest advantages of having a disability was said to be their accessible parking permit, which allowed them to park closer to where they were going. This was put forward by the one participant still able to drive and agreed upon by all members still able to be a passenger in a family member’s or friend’s car.

Another advantage the participants identified was related to their families.

Wilhelmina explained,
I think the advantage we said before was that you’re not getting a shock all of a sudden I can’t do this and we have time to adjust to it so I think it’s an advantage and also for your family, it’s not like they’re being hit with something new that they don’t understand, they slowly get accustomed to your life changing as their lives change. Sounds like you want to have that disability, but you don’t. I’m saying if you have to have it, I’d rather have it this way.

Ultimately, what came out of this experience being advantageous was that people were thankful for the time to cope. “You know how to cope already” Judy told the group, and it was that constant, subliminal process of adaptation they so valued.

3.4.2.4 Multiplicity of experience.

It is evident that the participants’ personal experiences and perceptions about getting older with an adult-onset physical disability do not fit into either one or other of the two main hypotheses presented in the literature but instead support both and even suggest that aging with a disability can be advantageous. In her own words, Genevieve supported the inadequacy of either model alone;

I think we all have different coping mechanisms of dealing with something, and each day is even different. Some days we can feel pretty good and pretty good about ourselves and things go right, and another day and the weather changes and it’s a struggle to do everything.

Harold agreed, “with something like this I think you’re going to find something in everything. I don’t think you can be just one thing or one group.” His early experience with Parkinson’s illustrates the multiplicity of experiences of aging with disability.

When I first got Parkinson’s, I got a day when I was really good. I would forget I had Parkinson’s and push myself a little too far. On bad days I would cut the front lawn one day and the back lawn another day, but if you get a good day you go out and you cut both and then when you’re eating your dinner at night you can barely stay awake long enough to eat it and you don’t know what’s wrong with you. Eventually I learned what the problem was, it was me.
Genevieve, stimulated at the exploration of this topic, assured us that we would find a lot of variables that make up people's perceptions and personal experiences.

3.4.3 Financial Resources

Financial resources were identified as a significant factor influencing participants' perceptions of the process of growing older with a disability. Each participant's financial situation after the age of 65 was impacted by his or her age of disability onset, marital status at any point during the disability, employment status at the age of onset, and access to benefits or pensions.

Age of disability onset had a significant influence on financial status after the age of 65. All participants believed that the younger someone acquires a disability, the greater the impact getting older with a disability would have on their financial resources after age 65. Having to stop working at an earlier age meant fewer years contributing to a pension plan, if any, and living on a limited income left less money to put away and save for the future.

Harold, after working close to retirement age, left work around age 55 and was unable to contribute those last few years before retirement.

"I was getting more money on disability than a lot of people I know working 40 hours a week. But it was still nowhere near what I was getting when I was working; that makes quite a bit of difference when you're building up a nest egg for retirement. That's taken quite an effect on me and my wife."

He also offered that "the most I could have worked was 12 years [longer]. Someone who is 35 would have 30 years left. It would be horrific. I can't imagine what an impact."
Daniel became disabled around 62, very close to the time he was scheduled to retire. "I was able to work out my full, work all the way to 65 and retire on the sort of maximum possible pension level" and with all his extended health benefits, he explained. His financial situation differed greatly from that of the other participants. Daniel had those extra work years to make provisions, invest and plan, but he recognized that if I had been cut off earlier I might not have taken all the forethought. I went to various retirement planning things and looked at my investments but I'm really bad at thinking financially, so I got advice from people who knew where to put money and balance things out and so on. But if I had been caught mid career it could have been quite devastating. I'm sure it can be a real problem.

Genevieve spoke of a more difficult financial situation with a younger onset of disability.

I think the person who is 33 who has problems and children, perhaps a young husband who is eager, it might impact them a lot more actually. Especially if they had been working. They would have the loss of that income. Over age 65 you still need enough to live on, and it can be very hard if you are on disability or $12,000 the lowest form of it, because all the little extra things that are needed.

Judy was in her early thirties when she became disabled.

When I had my stroke I was 33 and two children and of course no income after I had my stroke except CPP [Canadian Pension Plan] eventually. Money was tough. There was no extra money ever but you learn how to make it stretch that sort of stuff. It was hard, very hard.

Marital status at any point during disability could reduce some of the financial hardship associated with aging with physical disability. Harold explained,

I figured we would have a hard time immediately. Of course you have to worry about it, being a male you know, but I thought it would have an effect...really it didn’t have an effect on us. I mean sure we weren’t making as much, but it wasn’t that much of an effect as what I thought it would be. My wife was moving up in her job and she gets well paid, ... she moved up pretty good about
the same time I had to stop working, so I guess overall there wasn’t that much of a difference.

Andrea experienced the loss of a spouse and discussed the impact financially it had on her family. She spoke about a life insurance policy she received after his death.

*It was $100,000. I could put that in the bank and supplement my income from that. So that made a difference, I guess if he had been around it would have made a difference. He had his own business ... so I didn’t have that supplementary, but I did have the $100,000, and I still have that and I get a supplementary income off that, but if I had been working up until 65, yes I would of had a much better lifestyle.*

Employment status at the age of disability onset was another major factor influencing financial status after age 65, as well as access to benefits and pensions. The type of financial assistance received after becoming disabled was directly affected by the type of employment held at the time of onset. The participants varied significantly in the types of employment held when onset occurred. Daniel, having worked until retirement age, was able to retire with a full pension plan and all its extended benefits from the University. Wilhelmina, a stay at home mom caring for her young children at the time of onset, did not have formal employment or a disability pension and lived on minimal income from ODSP until reaching 65. She explained;

*It’s harder as you’re aging because you have expenses with being disabled that you didn’t have before and it’s a challenge you really have to budget your money to make it go as far as it should but again there’s ways around it. If you look at the positive side you can stretch a dollar, make it go a little further.*

Thankful for the extended health benefits that are available with ODSP until age 65, she found it difficult to manage the extra costs after transitioning to the old age system and has often gone without necessary medical equipment (hearing aids, power scooter,
routine dental work etc.) due to lack of funds. Judy, also a stay at home mom without support from a husband or outside employment, had no income until eventually qualifying for CPP after her stroke. She told the group of the struggle to make money stretch and about never having anything extra. Interestingly, Judy’s life improved significantly after she turned 65 and started receiving old age pension.

Once I turned 65 it’s another world. You live, you don’t exist. I had to pay $280.00 for my scooter, I had to get new batteries, and before I would have had to borrow from my sister and pay her back dribs and drabs, but now when you become a senior, you have money and I’m enjoying it too.

After being home for seven years with her children, Andrea took on a part-time teacher’s aid position.

I went on disability in January of 1987. I was diagnosed June of 1986 and I had gone downhill so fast that I just couldn’t cope with things. CPP ... you used to have to work 5 of the last 10 years, but the day I went on disability you had to work 2 of the last 3 years. I had just worked 2 of the last 3 years, so I got my disability ... the advantage was that they paid for all of my healthcare up till I turned 65.

However she explained that when I turned 65 [I] lost all those health care benefits. I had to rush out and get my wheelchair a little earlier than I needed it, the new wheelchair, because they [CPP benefits] would pay for it and that made a big difference.

For Andrea, this loss of benefits and coverage was devastating, and forced her to think ahead about what her needs might be and to acquire things before actually needing them, in order to be able to afford them.

Talk about the financial impact of aging with disabilities further highlighted the multiple different experiences of the participants. For some, financial resources were a
non-issue, and disability onset had very little effect on resources. For those with a younger onset, without a spouse for support, or without formal employment at the time of onset, financial hardships were more evident.

3.4.4 Attitude and Self-Efficacy

It became abundantly clear from the data that the participants had a strong sense of self-efficacy. Their positive attitudes and sense of self-efficacy mitigated their perceptions of what it had been like to age with a disability. Despite the obstacles they had faced, their outlook for the future was generally optimistic. Everyone shared their pleasure in the challenge of coming up with their own solutions. “You learn to cope, you find solutions to things and I like to find my own solutions” Daniel told the group.

Andrea felt that

> although I have a disability ... I’ve had a lot of advantages that many people don’t have like my family and my church and my kids, and I’ve had a lot of good things happen to me so I like to focus on that. I don’t like to focus on the disability. I’ll live with it and fight it and do what I have to and I don’t worry about the rest of the stuff. I can get myself really depressed if I do and there’s no advantage to that. I just work with it.

Judy does not let having a disability stop her from doing the things she loves. “I do anything I want to do but I find my own way of doing it.” Andrea shared that

> I still feel very positive about my future. I’ve been able to fight this thing along for 25 years; I think I can keep going. I think I can adjust, face facts. My kids don’t think I’m facing up...but I think it’s because they’re looking at me and they don’t realize what I’ve had to do.

Despite their positive attitudes, some had mixed feelings about the future. Andrea, self-described as significantly physically disabled explained;
my disability is continuous and progressive so it's always been on a long term basis. I do worry a bit about getting really old cause I'm getting weaker. I don't know how long I'll be able to keep doing the things I am, but I'm a fighter so I just keep pushing.

Many felt that they were coping and coping well, but worried what might happen further down the road, especially if a spouse who is currently caring for them took ill. Harold had a positive outlook when asked if he thought he would be able to continue coping in the future.

I think we'll be able to. I have a very good wife. She's terrific! [STARTING TO GET EMOTIONAL] She looks after me a lot more than what she needs to actually. She says she has a hard time knowing when to stand back and let me struggle through something.

However, Daniel described his uncertainty about the future. He explained, “you're no longer one person, you're two people and it's not like having your own particular health, its health for two people.” He also added that “in my case, we are two people. These are pieces of combined health that I need to think about, and right now my wife is doing very well, but she's only one year younger.” This duality of concern for self and spouse was evident in both married participants. For those who were divorced, single, or widowed, this concern was transferred to family members. Wilhelmina believed that “our family suffer more than we do, because they feel helpless to what they can do to make it better, but they can't, but they have to realize that just by them being there they're doing something.”

An unusual finding emerged when discussing the future. When asked whether they were confident or concerned about the future, the majority replied that they had
not thought about it. They all seemed to employ a “shortened planning horizon” when looking into the future. Genevieve described this well:

I haven’t really thought about it. I realize I just wait for something to happen and deal with it as I best can. If I worried about it too much, I think I’d be in a worse state. I prefer to look at it that way, and I do get things happening, and then I have to sort it out. I’m fortunate, I think, being a nurse to have some knowledge of things and you can sort of say ok well I’m not going to die tomorrow I hope; well, down the road I might get this. So I’m positive health wise in a way, but I can realize it can get worse with my mobility and things and I just take it as it comes.

She also shared that

I’ve always lived about 3 months ahead. I really don’t think a lot about the future. I realize that the aging does make a difference with the disability added. I try and cope with things just as they come up. I’m not looking for them and I try to make the most of it with the challenges.

Andrea shared a similar concern about looking too far forward.

As I get older I guess I’m going to have to think about when I can’t cope here or can’t take care of it I will have to go to a nursing home. I don’t want to think about it, but it’s there and I have to plan ahead.

Some refusal to look very far into the future was also evident from Gwen. “Definitely things change, because of aging, but I think that again I’m not thinking that I’m aging yet, so I haven’t totally come to grips with it; maybe it’s just a device on my part.”

3.4.5 Family and Social Support

Family was identified as a major factor influencing perceptions on what it is like to grow older with a disability. Although family was previously mentioned under the Double Jeopardy section, it became evident very quickly that a supportive family, as an independent factor, had the possibility to greatly affect perceptions about what it is like
to grow older with a disability. Family was a very important to most of our participants, but some were also careful to clarify that it would depend on the family and whether they were, in fact, a source of support. Wilhelmina probably shared the most about her family life, and from her comments it became evident that she had a willing and supportive family to help her.

At first I was very embarrassed about having to ask for help, because I’m a very independent person and I can do it, and I had to get to the point where I thought it’s ok if you can’t do it, let somebody help you and that was one of my challenges. I must say my family have just been amazing in supporting me through that and saying don’t be embarrassed it’s just one of those things you learn to live with, so I contribute [sic] a lot of my healing through my relationship with my family.

Harold became very emotional when speaking about his family and the great source of support they were for him. “They’re very important. They’re always important! They’re there to help you. They’re there to help me in whatever problem I have. I’ve deteriorated a bit lately but we’re working through it.” Andrea’s family is her inspiration to keep fighting.

I want to remain independent and I have been able to manage that way, but family support is absolutely important. I know people that don’t have it, and they don’t have the life I do, and that gives me courage to keep fighting.

Although having a supportive family, the distance between them was troubling for Daniel. He explained,

it’s something you think about yes. Particularly for the way families move around the world these days, it’s a big question. For us in this family it’s mainly just the two of us with the knowledge that our daughters are very reliable, caring, and responsible and they will do everything the possibly can, as I said, but they are a long way away. It is a bit of a worry!
Genevieve was in a similar position:

I don't have any family support over here, so I had to rely on friends, and I had to become very independent with my disability, and even into the aging process I've probably advised some of my younger friends and they ask me and have shocked me by saying they're scared stiff of getting old, and they don't have a disability. But my family, from a long way away, are very supportive or when I've been to visit them or that sort of thing. We've all in the family, because it's genetic, most of the autoimmune disease in the family, they're so busy dealing with their own issues that we understand each other. So we don’t try and demand a lot.

She also offered her opinion on the advantages and disadvantages of family support.

If you’re lucky to have family, I think it can be positive and negative. I think aging with a disability is a double whammy, and I think some families can overprotect and possibly it’s not the best thing for someone who is coping with a disability and trying to be independent. But knowing also it will probably get more difficult as they age. The negative thing is, well another negative thing is, sometimes family don’t want anything to do with you if you have a disability. They can sort if abandon you, some marriages break up, high rate of marriage break up, but if you have a supportive family who understand then I think you yourself if they live with or visit and see you coping with a disability and try to keep your independence it’s probably, it’s very good to have a family support. (Genevieve)

Judy, spoke mostly of assistance from her son and how, at a very young age, families can still understand our needs.

My boy was nine when I had my stroke and when I was coming home from wherever, it would be, he’d be at the front door at the bottom of the stairs with his arm out waiting for me to hook on to go up the stairs. He just did it. I never had to ask him.

She also mentioned “I’m lucky I have a lot of wonderful friends and my family that are, you know, I’m always on the phone or they’re coming over or I’m going there.” Both having MS, Gwen and her sister have been able to build a supportive relationship from mutual understanding and common needs. Her sister is her primary means for support, because often she is unable to access gatherings with the family.
Andrea had a very different account of family. Although speaking of the supportive family network she had, it became apparent that she was cautioning us about another reality she had encountered.

I came here [to London] mostly because my husband couldn’t cope with my disability. He didn’t want to. He basically sent me away, like basically, where do you want to go? It just wasn’t his personality; he just couldn’t cope with it. He said, well I’ve dealt with it for 4 years, wow I’m a big hero. I knew I had to leave and that was very, very difficult because my kids were just finishing high school, and I knew that if I could just have stayed a couple years until they finished high school and went off on their own, then we could have done our own thing, but he wouldn’t. I was still walking then. Like I wasn’t in a wheelchair, I was still walking, he just couldn’t cope.

After basically being shown the door, she built a life for herself in London, Ontario with the help of her brothers and sisters, who co-owned a townhouse unit downtown and allowed her to live in it once their father passed away.

The reason I can afford to live here is because of my brothers and sisters. This unit belongs to all five of us, and my dad, when he died he left everything to all five of us. Well, we have split up the money that was there, but this unit is still under the name of five of us, and I live here, because it is paid for, and pay the expenses; that’s how I can afford to live on my own, because it costs me about $800 a month, but to have the same advantages would cost me more on my own, and I wouldn’t have it, I don’t know where I would be.

Although most of Andrea’s family lives at a distance, her church groups and friends have filled some of the support needs, but she cautioned that

if you put too much pressure on people, you know I know there are some people that have turned away, they don’t call me, they don’t show up you know they’re just afraid they’re going to be asked to do something.

Fortunately having some family support close by helps, but she feels for others.

Because I have my sisters who are very close, they have made it possible for me to participate in things we all share interest in. I’m busy enough that I don’t think
about the other things. But I'm sure there are other people with disabilities that
don’t go out, never have visitors, never do anything.

Many participants expressed worry about asking too much from their family or
becoming a burden. Daniel spoke about his daughters:

If you said one of us has collapsed, either would take a leave of absence and
come to sort things out just like that, so we know we've got two very good
daughters who will do everything in their power to help us out, but you know we
can’t ask too much of them, because they have their own life, they have their
own careers and stuff so we can’t expect them to drop everything for us.

Andrea felt similarly when talking about her living situation.

At the time my children were too young, now they have families they haven’t got
money to support me, and I wouldn’t want them to. I want to remain
independent, and I have been able to manage that way, but family support is
absolutely important.

Threaded through the talk of family was a genuine sensitivity towards the needs of
others.

3.5 Discussion

Five major concepts emerged from this study as factors influencing people’s perceptions
about aging with a disability. These factors were the entanglement of aging and
disability, the multiplicity of experiences, financial resources, attitude and self-efficacy,
and family and social support.

The entanglement between aging and disability described by participants was
very interesting. For them, there was a cognitive separation between the two concepts,
but their lived experience of the two processes occurring together was said to be almost
impossible to tease apart. A potential explanation for this entanglement may be the
fact that all but one participant in this study had progressive disabilities. Perhaps if more participants with non-progressive conditions (e.g., spinal cord injury) were studied this entanglement would not fit their reality. However in the literature, Sheets (2011) states that disability is not a static condition, it is a continuous process of change throughout the life course. This leads us to believe that even non-progressive disabilities, for instance, spinal cord injuries, are subject to the progression of disability regardless of whether the progression is caused by the primary disability or secondary health complications. These secondary health complications are additional impairments resulting from the acquisition of disability, and may include pressure sores, chronic pain, urinary tract infections, or increased damage to joints from the use of assistive devices (Sheets, 2011). Regardless, their progression is a direct result of the primary disability. Even more interesting, the secondary complications arising from a non-progressive disability make up a main pillar of the Double Jeopardy hypothesis. It is said to be the superimposition of the aging process on the disability process and the associated “premature aging” occurring 15-20 years before “normal aging” sets in that creates a doubly disadvantaged situation (Campbell et al., 1999; Kemp & Mosqueda, 2004; Pentland et al., 2002; Sheets, 2005). It would appear from the literature that even non-progressive conditions change over time and that progression is independent of disability type, making it quite possible that the entanglement of aging and disability may be true for multiple disability populations.
When listening to the participants' experiences, it became clear that both mainstream hypotheses about aging with disability were supported, but neither exclusively. What was surprising was the participants' claim of an actual benefit from acquiring a disability earlier in life that was not captured in any of the aging with disability literature we found. One model present only in the disability literature, the Affirmation Model of Disability, rejects the traditional negative or 'tragedy view' associated with disability and attempts to shed light on the positive aspects of living with impairment (Swain & French, 2000). Although this model fails to address aging with impairment over the long-term, it does take a step forward in probing the possibility of other than negative realities for people aging with disabilities. This study has taken that understanding even further by clearly demonstrating the non-exclusive and multiple realities of people aging with disabilities.

Mobility limitations, transportation, and maintenance of relationships seem to be inextricably linked in the double jeopardy process. Limited mobility made it difficult for a number of participants to access and maintain relationships with both family and friends. Years of this limited access to people and participation had reduced their social support network as they aged. Once they began losing contact due to their disability, they had a smaller support network as they got older. This shrinking network included loss of not only family but friends too. As mobility became more limited, participants even lost the ability to travel freely as passengers in personal vehicles. With an increased need for more complex assistive devices (e.g., power scooter over walker),
transportation became an issue for many, even further limiting their ability to access and maintain social relationships. Reduced ability to drive a car or access public transportation has been shown to negatively affect social support networks (Newsom & Schulz, 1996). The entanglement of growing older with a disability made it impossible for them to distinguish whether these changes were associated with disability progression or aging on top of the disability process, creating a doubly disadvantaged situation.

Inability to reach milestones was an interesting discussion point, and one that was closely associated with financial resources. The participants spoke of being “off-time” in reaching normal life milestones after acquiring their disability, and this had repercussions as they aged. Sheets (2005) noted “a related problem is that people aging with disabilities may face early and forced retirement as they become physically unable to continue working. In such cases, they often have not had time to plan for how they will address typical retirement issues such as housing, health insurance, transportation, income, and caregiving” (p. 38). Inability to continue working, to advance in employment, and to contribute regularly to a pension or retirement plan had a significant effect on their financial status after age 65. It was the consequences of not reaching these normal career milestones that affected them financially later in life, creating a doubly disadvantaged situation.

All participants had a strong sense of self-efficacy and a positive attitude when talking about the future. However the notion of a “shortened planning horizon” was
unexpected in the face of the strong sense of self-efficacy and positive attitude they generally employed. This phenomenon has been associated with disability, “an alteration in future time orientation (FTO), such as a foreshortening or truncation of an individual’s time perspective after the occurrence of a disability, may be an unrecognized psychological limitation related to disability” (Martz, 2004, p. 86).

Individuals with disability have traditionally had shortened life expectancy, so they may not have planned for old age. Further, all but one of the participants had progressive disabilities, and the prospect of further deterioration may have discouraged them from looking ahead to an un-promising future. As Martz (2004) described, “a foreshortened sense of the future, which has been observed to follow trauma, may be manifested in an individual’s inability to imagine him- or herself having a career, family, marriage, or normal lifespan or in an individual’s belief that he or she will die young or experience another disaster” (p. 86).

Participants believed that family and social support were essential in the process of growing older with a disability. Most participants had supportive families who were willing to provide support. Beach (1997) found that caregiving within a family actually had positive effects on family relationships, including more time spent together as a family and younger individuals becoming more empathetic to the needs of others (Beach, 1997). It has been observed that even when a spouse or adult-child is caring for someone, younger generations often become part of the caregiving circle. This may be one way to combat a shrinking social network for someone aging with a disability.
However, the participants were quite resourceful in creating their own opportunities for networking. They even used the opportunity the focus groups provided as a way to network, share information, and build contacts.

Bridging the gap between the aging and disability sectors has not proven to be an easy task. There exists a real intellectual divide between disability studies and gerontology. "Growing older and having a disability are different experiences. Or at least that's how individuals, institutions, and public policies have historically posited them" (Putnam, 2007, p. 5). This divide seems to be mirrored in the service delivery field. For participants, the transition between the two service sectors was not smooth. Some lost benefits and services, whereas others gained. This has been a major issue for people aging with a disability and will continue to be because "many people aging with physical impairment will become consumers of old-age services after having been consumers of disability-related services" (Putnam, 2002, p. 799). Understanding this transition may have quality of life implications for this population, and this new consciousness may encourage researchers, service providers, clinicians, and policymakers to work harder at creating and maintaining effective partnerships.

3.5.1 Strengths and Limitations

A strength of this study was that it brought both critical and appreciate inquiry lenses to a topic that has traditionally been portrayed negatively in the literature. We were critical of approaching this topic from only the predominant negative viewpoint...
and deliberately added an appreciate inquiry lens to probe both the positive and negative aspects to aging with a disability.

One limitations of this study is that all but one participant had progressive disabilities, although, as shown in the literature, even non-progressive conditions are subject to change and progression. A second limitation was the small sample size (n=7). However, in qualitative research we do not aim for generalizability. Instead, we hope to have described our population in sufficient detail for the reader to assess transferability of these findings to other populations of interest.

3.5.2 Quality Criteria

To enhance the rigor of this study, the two main quality criteria used in constructivism, trustworthiness and authenticity, (Guba & Lincoln, 1994) were addressed. To ensure trustworthiness, an audit trail was kept to chronicle the collection and analysis processes. Trustworthiness was also maintained through reflexive journaling that allowed for us to interact with our thoughts about the data and be transparent about how we approached it. Authenticity was maintained through the use of quotes and thick descriptions from participants. As shown by the number of participant quotations, using their words allowed their voice to show through, creating an authentic representation of their experiences.

3.5.3 Future Research Directions

One implication for future research is the entangled nature of aging and disability. These concepts emerged from a study looking only at people aging with
physical disabilities. Future research should investigate whether these themes resonate with people living with congenital, intellectual, developmental, or psychiatric disabilities. As well, participants in this study had predominantly progressive disabilities. Another area for future inquiry would be doing a similar study in a population with non-progressive disabilities. The notion of a “shortened planning horizon” for people aging with a disability was a novel discussion point and is also an area that would benefit from further research. Understanding the perceptions of people aging with a disability may help to inform a model for understanding the process of aging and disability occurring together.

3.6 Conclusion

The research objectives of this study were:

1) To explain the mutual interaction of aging and disability in the lives of individuals aging with adult-onset physical disability, and

2) To understand the factors influencing the perceptions and personal process of individuals aging with adult-onset physical disability.

This study employed a grounded theory approach using both focus groups and in-depth follow-up interviews with seniors aging with adult-onset physical disabilities. Five concepts emerged as factors influencing their perceptions of the process of growing older with a disability. These factors included the entanglement of aging and disability, the multiplicity of experiences, financial resources, attitude and self-efficacy, and family and social support.
In conclusion, there have been a number of calls for cooperation between the aging and disability sectors. If our goal is to do research and create policies to better serve this population, then our concern is really about the people, and it is our social responsibility to understand the factors influencing their reality of growing older with a disability. This study has demonstrated that participants can cognitively separate aging and disability, which reduces the threat to independence for both fields. The power to foster necessary partnerships and collaboration may lie in better understanding the complex entanglement of both processes occurring together for this population, which was the goal of this study. “The more we understand the experience, the more adept we will be at addressing service needs for this population and creating public policy that reflect their interests” (Putnam, 2002, p. 805).

3.7 References


4 AGING WITH ADULT-ONSET PHYSICAL DISABILITY: MODEL CREATION

"To fill these gaps in our knowledge, we need to develop and test new models that incorporate concepts from both gerontology and disability studies, and broaden our base of colleagues to include representatives of both communities" (Campbell, 1996, p. 2).

4.0 Abstract

Few models exist that seek to explain the process of aging and disability together. Two mainstream hypotheses exist but neither is sufficient. The purpose of this study was to create a balanced model to explain the process of aging with adult-onset physical disability. This constructivist grounded theory study used focus groups as a primary means of data collection and follow-up in-depth interviews as a secondary method. A balanced conceptual model, the Model of Aging with Disability (MAWD), was created to explore multiple factors and explain how these factors influence the perceptions of people aging with adult-onset physical disability. This model is the first of its kind to address aging and disability together while allowing for the possibility of multiple, varying experiences.

Keywords: aging with disability, model creation, MAWD, grounded theory

4.1 Introduction

Two thousand and eleven marks entry of the world's largest birth cohort into the 65+ age category. Over the next half century, Canada's aging population is expected to
double as the remaining Baby Boomers cross the threshold into old age (Lee, 2007). The sheer number of aging adults has received considerable attention, but one sector of the aging cohort that has fallen under the radar is those aging with a long-term adult-onset physical disability. In 2006, there were approximately 1.8 million seniors with disabilities in Canada, and with another 825,000 age 55-64 and 741,000 aged 45-54 (also as of 2006), the number of seniors with disabilities is undeniably rising (Statistics Canada, 2006). This population will grow to have a significant impact on our health care, long term care, social service, and policy sectors. Increased collaboration between the disability and aging fields is imperative to bring knowledge from disability studies and gerontology together.

4.2 Literature/Background

The aging and disability fields have for many years developed separately and pursued their own objectives and agendas. This progression of both fields separately, although fostering many positive outcomes, has failed to address the challenges to collaboration between the two sectors. Putnam (2002) ascribes these challenges to differing philosophies and ideologies. Despite a number of overlapping concerns and often similar aspirations, the two fields have been unable to effectively partner, creating a number of service delivery and policy issues. Some of these issues include accessible and affordable public housing, appropriate healthcare, and access to services and supports, long-term care, transportation, and financial stability (Sheets, 2005). The aging sector has misconceptions about the disability population, and the disability
population has misconceptions about the aging sector. The disability population ignores aging because they are focused on full participation and involvement, and the aging sector ignores disability because they have additional age-related issues with which to be concerned (Bickenbach, 2011). “Bridges across the fields of disabilities and ageing have been limited, and they coexist with significant barriers to communication and information sharing” (Salvador-Carulla et al., 2010, p. 2).

Two international declarations have been put forward in an attempt to raise awareness about the need for successful partnerships between the aging and disability networks. The Graz Declaration on Disability and Aging of 2006 (Weber & Wolfmayr, 2006) and the Barcelona Declaration of 2009 (Salvador-Carulla et al., 2010) were initiatives under the European Union, and the Toronto Declaration, which is currently being developed as an outcome of the 2011 FICCDAT Growing Older with a Disability conference, will aim to “expand the international reach” (Toronto Declaration Planning Meeting, personal communication, June 7, 2011) of the previous two.

Aging and disability are concepts that naturally overlap throughout the life course, and due to increasing numbers of people aging with disability, the need for better service delivery and modernized policy objectives may compel the two sectors to work more closely together (Kennedy, 2002; Putnam, 2002; Verbrugge & Yang, 2002). It is essential to remember that, with increased life expectancy and better healthcare, many people who are aging with long-term physical impairment, who have been consumers of disability-related services, will transition and become consumers of age-
related services (Gilson & Netting, 1997; Putnam, 2002). It is through understanding this transition, and the new sets of care needs, that we will be able to better understand the experience of aging and disability together.

Two main hypotheses were found in the literature to help explain the process of aging with long-term disability. The Double Jeopardy hypothesis postulates that someone aging with a disability is doubly disadvantaged, both due to the aging process being superimposed on the disability process and as a result of "premature aging", which occurs from secondary complications arising before "normal aging" would typically occur (Campbell, Sheets, & Strong, 1999; Kemp & Mosqueda, 2004; Pentland et al., 2002; Sheets, 2005). This strongly negative view discounts any chance of benefit or positive experience as a result of having a disability. Much literature exists to support the Double Jeopardy hypothesis, but significantly less literature exists to counter it.

The Age as a Leveler hypothesis is the other main hypothesis in the literature that seeks to explain growing older with a disability. It hypothesizes that people aging with a disability are no worse off than any other older adult, because they can use the skills they have acquired from adapting to their disability and apply them to aging (Gordon, Feldman & Crose, 1998; Hayden, 1993; Reyes, 2009). For people with disabilities, age has been called a "leveler" in the sense that persons with disabilities have learned how to adapt to major physical changes, whereas people without disabilities have not and therefore may struggle more when confronting the physical decline and functional changes associated with aging (Reyes, 2009, p. 2).
Although somewhat more positive than the overtly negative Double Jeopardy hypothesis, the Age as a Leveler hypothesis attempts to even the playing field by bringing able-bodied persons down to the level of the person with a disability.

The difficulty in amalgamating the two fields is reflected in the literature through the scarce number of models that address the concepts of both aging and disability together. Many theories seek to address issues of aging, including the activity theory, disengagement theory, and continuity theory. Multiple disability models also exist that exclusively examine disability, including the Medical model, the Social model and the Affirmation model of disability. But few models exist that look at both processes of aging and disability occurring together.

Only one group of models, called the Accelerated Degradation Models, have showcased the interaction of aging and disability together. They explore the relationship of disability with the functional declines associated with aging, but unfortunately they are quite mathematical and often published in languages other than English, making them inaccessible to most of the population (Hayes, Wolfe, Trujillo, & Burkell, 2010).

Clearly lacking are models that explain the mutual interaction of aging and disability factors together and that address both the positive and negative aspects to aging with a disability. Campbell (1996) emphasized the lack of existing models and stressed the need to forge relationships between the aging and disability service sectors in order to transfer knowledge and increase understanding. She suggested that "to fill
these gaps in our knowledge, we need to develop and test new models that incorporate concepts from both gerontology and disability studies, and broaden our base of colleagues to include representatives of both communities” (Campbell, 1996, p. 2). It is through this kind of model creation that we may have "the possibility to examine positive feelings some people with physical impairments have about themselves while still holding negative views about experiencing disabilities” (Putnam, 2002). Understanding this multiplicity of experiences and the entanglement of aging and disability in people’s lives may help to bridge the gap between these two sectors and increase partnerships to more effectively serve this population, as Bishop and Hobson described in chapter two of this thesis. Models need to account for the fluid and dynamic nature of both disability and aging and recognize the entanglement of the two processes when they occur simultaneously in the life of someone aging with a disability, while still acknowledging the autonomy of the two fields. “The more we understand the experience, the more adept we will be at addressing service needs for this population and creating public policy that reflects their interests” (Putnam, 2002, p. 805).

The research objectives of this study were:

1) To explain the mutual interaction of aging and disability in the lives of individuals aging with adult-onset physical disability,

2) To understand the factors influencing the perceptions and personal process of individuals aging with adult-onset physical disability, and

3) To create a balanced model to explain aging with adult-onset physical disability.
4.3 Methods

This study used a constructivist grounded theory approach. Constructivism allows us to recognize the value in multiple realities that have the opportunity to change as people become more or less informed (Guba & Lincoln, 1994). Epistemologically, constructivism is transactional and subjectivist, which means that knowledge is co-created between the researcher and participants who make up the interaction, and truth cannot exist outside their relationship (Guba & Lincoln, 1994). This co-construction of meaning and the value placed on people's multiple realities is appealing for grounded theory, because it allows creation of a model that can address a wide range of experiences and perceptions. Methodologically, constructivism is dialectical and hermeneutical, meaning that the interaction between researcher and participant is shaped and modified through the interaction process.

Grounded theory allows actual problems to be explained logically, and a clear set of methods gives researchers the tools to understand the observed world (Charmaz, 2003). Known for being a rigorous form of qualitative research, it also provides a defined set of strategies by which to identify relationships between concepts and build theory.

Constructivism and grounded theory work well together because they allow a researcher to elicit meaning and co-create understanding with each participant and then use multiple stories to generate a new framework to be applied to a larger population (Charmaz, 2003). Understanding the process of aging with adult-onset
disability from different individuals allowed us to appreciate multiple perspectives and, in turn, create a model that will explain both positive and negative influences of both aging and disability factors on the lives of people aging with a disability.

Two focus groups and four follow up in-depth interviews were used to collect data from seven participants. Focus groups were used as the primary means of data collection, with follow-up in-depth interviews as a secondary method to fill in gaps in our analysis and clarify concepts. Using smaller groups allowed all participants a chance to share their perceptions of growing older with a disability, while still achieving diversity in the experiences recounted (Krueger & Casey, 2009). The goal of qualitative research is not to represent the population, and although three to five focus groups for data collection was recommended by Morgan (1988), the fact that we were returning for follow-up in-depth interviews in addition to focus groups allowed us to gather an overall group picture and then return for further clarification of the concepts needed to build the model (Morgan, 2004).

Grounded theory offered a rigorous set of guidelines for model creation that helped to identify emerging concepts and highlight relationships between them. The techniques used included the simultaneous collection and analysis of data, a two-step coding process, constant comparison, analysis through memo writing and reflexivity, and theoretical sampling to elaborate and saturate key concepts (Charmaz, 2003). These processes allowed salient concepts to emerge and assisted with building a model that explained the process of aging with adult-onset physical disability.
Throughout the data collection and analysis phases, coding and memo writing were used to reflect upon, immerse ourselves in, and foster new ways of thinking about the data. Recording the interaction between researcher and the data helped to maintain reflexivity and explore the data from new angles.

4.3.1 Inclusion and Exclusion Criteria

The inclusion criteria for this study were men and women over 65 years of age living with an adult-onset physical disability of more than three years duration before the age of 65. A duration of three years was selected in order to distinguish chronic disability from an isolated adverse health event. Also, this ensured that the disability was long-standing and allowed an adequate amount of time to adjust to the acquisition of disability. The disability must have been a one that affected paid work and daily life. The participants had to be English speaking and able to participate in an interview process. Participants needed to be over 65 years of age so that they had experienced the transition from disability services to aging services.

Exclusion criteria for this study were participants with any congenital, intellectual, developmental, or psychiatric disabilities. Although that population is significant, for this study, it was only feasible to focus on one set of issues. Also, a large portion of literature has focused on aging with congenital, developmental, intellectual, and psychiatric disabilities, whereas physical disabilities have received less attention to date.
4.3.2 Sampling

This study employed purposeful sampling. Participants with varying physical disabilities were actively recruited to create a sample with maximum variation, which enhances transferability. The specific nature of the disability itself was of less importance; what really mattered was that all participants were aging with some form of adult-onset physical disability.

4.3.3 Participant Recruitment

The recruitment process began after ethical approval was received from the University of Western Ontario’s Research Ethics Board (Appendix A). Disability organizations across Southwestern Ontario were contacted and informed about the study. Individual conferences were held with those that expressed an interest in helping with the study. A gatekeeper approach was used in each participating organization. The gatekeeper was responsible for identifying participants and transferring contact and study information (Appendix F) to them.

Eight participants were recruited in total. Five participants were recruited from the Parkinson’s Society, Hutton House, the Multiple Sclerosis Society, and Stoke Recovery. Snowball sampling was used to find the remaining three participants. After a last minute drop-out due to medical reasons, seven participants took part in the focus groups. Four participants took part in follow-up interviews. The research team encountered significant difficulty in locating and accessing suitable participants who met the inclusion criteria. A number of other organizations, including the Kidney
Foundation, the Diabetes Society, the Heart and Lung Society, the Canadian Paraplegic Association, the Arthritis Society, a Chronic Pain support group, a Fibromyalgia support group, and Cheshire Homes, were contacted but unfortunately did not yield any participants.

4.3.4 Description of Participants

Participants included five females and two males. Demographic information for all participants is summarized below in Table 4-1. All participants lived within Southwestern Ontario in the London area. Two female participants had Multiple Sclerosis, one woman experienced chronic pain due to spinal nerve trauma, one man had Parkinson’s, one woman had an early-onset stroke, one man had an undiagnosed neurological condition significantly affecting his mobility and use of his legs, and the final female participant had long-standing rheumatoid arthritis. Participants ranged in age from 65-75. Only one male participant was still able to drive. All participants used some kind of assistive device for mobility and for activities of daily living and had modified their home in some way to accommodate their disability. Pseudonyms were used for participants throughout the thesis to preserve confidentiality.
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*Table 4-1. Summary table of participant demographic information*
4.3.5 Data Collection

4.3.5.1 Phase 1 – focus groups.

Two focus groups were completed with participants. The first focus group had four participants and the second had three. All participants were asked if they would agree to the possibility of a follow-up in-depth interview. The research team discussed the importance of respecting the privacy of other members in the group before the focus groups began. At this time, the informed consent process was also explained and discussed in detail. Consent forms were then signed and demographic data (Appendix E) collected before the focus groups began.

Both focus groups were 1 hour in length (Appendix C). Breaks were offered, but only one participant required a short restroom break during the second focus group. This was the only time the primary investigator (KB) was out of the room during data collection, and another member of researcher team kept the discussion going. Audio recorders were used to ensure accurate transcription. Participants received compensation in the form of transportation or parking re-imbursement.

4.3.5.2 Phase 2 – follow-up in-depth interviews.

Follow-up in-depth interviews were a secondary method of data collection. These interviews were conducted after the initial focus groups in order to saturate the concepts. The interview questions (Appendix D) and number of follow-up interviews were not decided until both focus groups had been completed and the research team had had a chance to immerse themselves in the transcripts. Participants were selected
based on their contributions during the focus group and their ability to speak to and provide clarification of emerging concepts. Before follow-up interviews were completed, ethical approval from the University of Western Ontario Research Ethics Board was obtained for phase two of the study (Appendix B). Follow-up interviews each lasted between 30 and 40 minutes, and all four interviews were audio taped.

4.3.6 Data Analysis

Simple descriptive statistics were used to analyze demographic data. Focus Groups and follow-up interviews were both transcribed verbatim and entered into NVivo9®. In grounded theory the collection and analysis processes occur simultaneously. Data were analyzed using the constant comparative method outlined by Charmaz (2003). Emerging themes were identified from the focus groups, and when more information was necessary to fully understand the concepts, theoretical sampling was employed to revisit participants and refine and clarify the data. This two-stage collection and analysis gave rise to the main components of our model.

Coding made the management and organization of data easier. Coding allows a researcher to gain perspective on what is being presented in the data and helps decide directions for further, more focus coding (Charmaz, 2003). Coding began with line-by-line coding. Line-by-line coding is a technique to sharpen our minds to the underlying, background ideas that enlighten us to the overall research problem (Charmaz, 2003). It was at this time, after primary data collection, that gaps were identified and plans for more focused coding were made. Once further data had been collected (i.e., follow-up
interviews), focused coding was used to organize data into larger concepts, which would eventually become the components of our model. Throughout this process of constant comparison, memo writing was used as a technique to foster reflexivity, create new ideas, keep a record of comparisons within, between, and amongst data, and document emerging understandings.

4.4 Results

4.4.1 Model Components

From the focus groups and follow up in-depth interviews, a number of concepts emerged. This conceptual model was built on the perceptions of what shaped participants’ personal process of aging with disability. Major concepts included the entanglement of aging and disability, the multiplicity of experiences, age of disability onset, type of disability, attitude/self-efficacy, financial status, employment status at onset, marital status, and family and social support.

4.4.1.1 Entanglement of aging and disability.

Participants recognized aging and disability as separate processes, but they found that the experience of the two things occurring in their own lives difficult to untangle. Daniel described “I don’t know how to separate [my disability] with the aging process, because I’m experiencing both together, and I ask myself how much of this problem is aging and how much of this is disability.” Andrea agreed,

I know I’m slowing down, I can’t do as much, but it’s hard for me sometimes to decide if it’s the MS progressing or it’s just the aging process you know. It's six of one, half a dozen of the other when it's happening.
There was a clear cognitive divide between aging and disability in the minds of participants. They recognized both as separate processes, but it was the experience of the two occurring simultaneously that became difficult to tease apart. It became almost impossible for participants to distinguish which perceptions to attribute to aging and which to attribute to disability.

4.4.1.2 Multiplicity of experiences.

The participants spoke of having a multiplicity of experiences. When discussing the prevalent hypotheses in the literature, they all revealed that varying parts of their experience of aging with a disability could fit under each hypothesis, but their experience could not fit exclusively under either of the hypotheses. Many could relate to feeling doubly disadvantaged at times; at other times they felt they were no worse off than any other able-bodied older adult; and at others they expressed it as being advantageous to acquire a disability earlier in life. Genevieve felt that “each day is [...] different. Some days we can feel pretty good, and pretty good about ourselves, and things go right, and another day and the weather changes and it’s a struggle to do everything.” Harold agreed, “with something like this I think you’re going to find something in everything. I don’t think you can be just one thing or one group.”

4.4.1.3 Age of disability onset.

Age of disability onset was said to be a key factor in influencing one’s perception of aging with adult-onset physical disability. The age at which someone acquires a disability had an impact on a number of factors, including financial status after age 65,
employment, benefits and services available, marital status, and retirement planning.

The younger someone acquired a disability the more significant the impact of the disability on the aging process. Harold explained,

_I was getting more money on disability than a lot of people I know working 40 hours a week. But it was still nowhere near what I was getting when I was working; that makes quite a bit of difference when you’re building up a nest egg for retirement. That’s taken quite an effect on me and my wife._

He also offered that “the most I could have worked was 12 [more] years. Someone who is 35 would have 30 years left. It would be horrific. I can’t imagine what an impact.”

With a much younger onset in her thirties, Judy explained;

_When I had my stroke I was 33 and two children and of course no income after I had my stroke except CPP [Canada Pension Plan] eventually. Money was tough. There was no extra money ever but you learn how to make it stretch that sort of stuff. It was hard, very hard._

Although acquiring a disability in their adult life had a significant impact on both, the effects were more strongly felt by the one with a younger onset.

### 4.4.1.4 Type of disability.

All but one participant in this study had progressive disabilities. Even the participant with a stroke, which initially was a non-progressive health condition, had developed secondary health complications and had continued to notice the progression of her disability. Andrea spoke of various disabilities and the impact the type of disability may have.

_You have to realize there are different types of disabilities. Mine puts me in a wheelchair, but I’m not in pain. I know people that have arthritis and they are in terrible pain, and that’s disabling in itself, but it is quite different._
The type of disability has the potential to greatly influence people’s perceptions of what it is like to age with an adult-onset physical disability.

4.4.1.5 Attitude/self-efficacy.

All participants had a real sense of self-efficacy and, for the most part, a positive attitude. It was really the participant’s attitudes that mitigated their experience of aging with a disability. Andrea shared that

> although I have a disability [...] I’ve had a lot of advantages that many people don’t have, like my family and my church and my kids, and I’ve had a lot of good things happen to me so I like to focus on that. I don’t like to focus on the disability. I’ll live with it and fight it and do what I have to, and I don’t worry about the rest of the stuff.

Despite their self-efficacy, many participants employed a “shortened planning horizon”, which was counterintuitive given their positive attitudes. Genevieve explained:

> I’ve always lived about 3 months ahead. I really don’t think a lot about the future. I realize that the aging does make a difference with the disability added. I try and cope with things just as they come up. I’m not looking for them, and I try to make the most of it with the challenges.

4.4.1.6 Financial status.

Financial status was said to be affected by a number of things, including the age of disability onset, employment status at disability onset, and marital status at any point during disability. All participants believed that the younger someone acquired a disability, the more significant the impact financially as they age. Employment status at the age of onset determined the type of benefits for which participants were eligible, whether they qualified for or had any kind of disability pension, and whether they were
able to continue making a comparable income after onset. Marital status and having the supplement of a second person’s income was believed to be a major factor in financial status after the age of 65. Harold could relate to this and explained,

I figured we would have a hard time immediately. Of course you have to worry about it, being a male you know, but I thought it would have an effect...really it didn’t have an effect on us. I mean sure we weren’t making as much, but it wasn’t that much of an effect as what I thought it would be. My wife was moving up in her job and she gets well paid [...] she moved up pretty good about the same time I had to stop working so I guess overall there wasn’t that much of a difference.

Having another salary to count on made the experience less of a struggle than it was for a single-income person.

4.4.1.7 Employment status at onset.

Employment status at onset of disability onset had a direct effect on the financial situation of someone aging with a disability after age 65. Employment status at onset determined assistance eligibility, whether or not they had a disability pension, and access to benefits. Andrea described her experience of becoming disabled recently after returning to work after raising children.

I went on disability in January of 1987. I was diagnosed June of 1986 and I had gone downhill so fast that I just couldn’t cope with things. CPP ... you used to have to work 5 of the last 10 years, but the day I went on disability you had to work 2 of the last 3 years. I had just worked 2 of the last 3 years, so I got my disability ... the advantage was that they paid for all of my healthcare up till I turned 65.

However she explained that

when I turned 65 [I] lost all those health care benefits. I had to rush out and get my wheelchair a little earlier than I needed it, the new wheelchair, because they [CPP benefits] would pay for it and that made a big difference.
For Andrea, this loss of benefits and coverage was a significant ordeal. Being forced to think ahead and judge her potential needs was difficult. This transition from disability system to the old age system has the potential to create different situations for people aging with a disability.

4.4.1.8 Marital status.

Marital status at any point influenced the experience of getting older with a disability, both financially and in terms of support. A second income made financial resources less of an issue, and having a partner created a supportive network of care for the person with a disability. However, having a spouse also caused a new area of concern. When discussing health in the future, Donald explained, "you’re no longer one person you’re two people, and it’s not like having your own particular health, its health for two people." Participants worried for their own health, but also the health of their caregivers, and they were very conscious of not wanting to become a burden to others. In participants without a spouse, this duality of concern transferred to their family or support circle.

4.4.1.9 Family and social support.

Family was identified as a very important concept in the process of aging with a disability. Having a supportive family strongly influenced the process. Most participants had very supportive families and relied on them as a major source of support. However, they also cautioned us that the impact of family would depend on the family and whether or not that family was actually a source of support for the person. Gwen was
able to remain connected because her sister, who also had MS, had an accessible house but that is not always the case, she explained.

"I'm not able to go to family functions, except for at my sister's who has MS as well and her house is accessible, whereas the other four family members don't have homes like that. So I'm sorry about that, and they'll come to me, but it's not that often that that happens anymore.

Andrea explains how family helps her reach her goals.

"I want to remain independent and I have been able to manage that way, but family support is absolutely important. I know people that don't have it, and they don't have the life I do, and that gives me courage to keep fighting."

On another note, she also cautioned us that whether or not the family was a source of support or not could also have implications for the way someone views aging with a disability. She explained;

"I came here [to London] mostly because my husband couldn't cope with my disability. He didn't want to. He basically sent me away, like basically, where do you want to go? It just wasn't his personality; he just couldn't cope with it. He said, well I've dealt with it for 4 years, wow I'm a big hero. I knew I had to leave."

4.4.2 Model Structure

The Model of Aging with Disability (MAWD) (Figure 4-1) is a conceptual model and was created based on the concepts identified by people aging with adult-onset physical disability from Chapter 3. The diamond in the centre of the model emphasizes the autonomy of the aging and disability concepts as two distinct entities, with the spiral between the two pillars showing the entanglement of the two occurring simultaneously in the life of the person aging with disability. Placing the model on point demonstrates the precarious nature of aging with a disability. Despite their self-efficacy and positive
attitudes, participants expressed uncertainty about the future. They have been positive and have coped thus far, but they recognized that aging with a disability is not linear, that things could change and leave them unable to cope. Further, placing the model on point emphasizes the dynamic, as opposed to static, nature of both aging and disability, and thus of aging with disability. Aging with a disability is represented as inherently unstable, with multiple factors influencing the process in ways perceived as advantageous or disadvantageous.

The words advantage and disadvantage were selected because they mirrored the language used in the Double Jeopardy Hypothesis - the double disadvantage of aging with disability, and the voices of the participants themselves in their description of an advantageous disability experience earlier in life. Advantage and disadvantage are relative concepts in that they indicate one position relative to another. The factors, including the entanglement of aging and disability, the multiplicity of experiences, age of disability onset, type of disability, attitude/self-efficacy, financial status, employment status at age of onset, marital status, and family and social support may at any point push perceptions of the process of aging with disability towards advantage or disadvantage in different directions, at different times, for different people. This movement between advantage and disadvantage is having an advantage or disadvantage over some other circumstance. This showcases the uniqueness of the experience of aging with disability for each person in their own particular circumstances.
Some factors may tend to push more towards advantage or disadvantage, but this also could vary depending on individual or circumstance. For example, strong family and social support network may lead to the perception of a more advantaged process of aging with disability, but for someone who lives alone and does not have a supportive family or social support network, lack of support may tend to create a more disadvantaged experience. Similarly, financial resources may be an advantage while someone is living on ODSP and receiving additional drug and dental benefits, but the transition from the disability system to the old age system may decrease income and benefits may be lost, pushing towards disadvantage. The model also accounts for the possibility in change of circumstances over time, as depicted by the arrow on which the diamond sits. For example, having a strong sense of self-efficacy may push towards advantage, but a change in circumstances, such as loss of a caregiving spouse or a change in disability status, may cause concern and/or uncertainty about the future, resulting in loss of confidence, which may push towards disadvantage. Some individual factors also may influence others; change in one factor may directly or indirectly affect others and thus push a person’s perceptions of aging with disability toward advantage or disadvantage. For example, marriage may be an advantage and may also positively influence financial resources and family support, but if marriage breakdown occurs, marriage no longer pushes towards advantage, and other associated factors (i.e., family support and financial resources) may change as well. The model is situated in time and these interactions take place as one ages and progresses through the life course.
Figure 4-1. The Model of Aging with Disability (MAWD)
4.5 Discussion

According to the literature "disability and aging are dynamic processes" (Verbrugge & Yang, 2002, p. 254), which suggests the need for a model that can account for variation and represent this fluidity and dynamism in order to explain the process aging with adult-onset physical disability. A model was needed that was fluid and non-static, that could account for change not only within the individual but within the larger context of the environment. This creates layers of instability, which are illustrated with multiple arrows pushing toward advantage or disadvantage, and allows the model to demonstrate the different realities of different people and allows for change over time.

The Accelerated Degradation Models are the only group of models currently found in the literature that address the process of aging with a disability. These models attempt to “characterize the interaction between disability and the functional decline of aging and to provide insights about the processes of aging with disability” (Hayes et al., 2010). However, there are a number of criticisms leveled at this set of models. These include the fact that they only address the functional decline associated with aging and they fail to address the possibility of a positive experience of aging with a disability. Further, the Accelerated Degradation models are often highly mathematical, making them inaccessible to people without significant training in advanced mathematics or statistics, and often published in languages other than English. More interestingly, “the accelerated degradation models that do exist are limited to certain functional domains such as the age-related decline in intellectual performance in individuals with dementia.
They do not exist for many domains of physical disability” (Hayes et al., 2010). The Model of Aging with Disability (MAWD) is presented with accessible language and a simple illustration, and it addresses the process of aging with physical disability. In addition, the MAWD allows for multiple experiences and does not restrict explanations of the process of aging with disability to decline, neutrality, or advantage. It promotes consideration of all three.

The Double Jeopardy Hypothesis and the Age as a Leveler hypothesis are the two mainstream hypotheses in the literature for looking at outcomes associated with aging with disability. The Double Jeopardy hypothesis postulates that aging with a disability is doubly disadvantageous because of “premature aging” (Campbell et al., 1999; Kemp & Mosqueda, 2004; Pentland et al., 2002; Sheets, 2005). The Age as a Leveler hypothesis suggests that someone aging with a disability is no worse off than other older adults because they have acquired strategies from adjusting to disability that can be applied to the aging process (Gordon et al., 1998; Hayden, 1993; Reyes, 2009). Both address aging with a disability but fail to consider the possibility of multiple experiences. The Double Jeopardy hypothesis assumes outcomes to be predominantly negative, whereas the Age and a Leveler hypothesis contrasts this negative view to some degree but still falls short of realizing the potentially positive aspects of aging with a disability. The MAWD accounts for positive, negative, and neutral perceptions and acknowledges that perceptions of the process of aging with disability may change over time and based on circumstances. This allows the model to capture the multiplicity of
an individual's experience and provides a way to explain variations in perception both within and between individuals.

The Affirmation Model of Disability employs a non-tragic view of disability and instead creates an affirmative model that focuses on positive social identities and recognizes the benefits of lifestyle and life experiences that may occur while being disabled (Swain & French, 2000). Unfortunately, this model fails to account for the process of aging over the long-term. It does recognize the potential of an advantageous experience of having a disability, but the process of aging with the disability is not addressed. The MAWD incorporated the possibility of an advantageous experience of having a disability postulated by the Affirmation model as well as addressing the process of aging with the disability. The time arrow at the bottom indicates the progression of time as a person ages.

The MAWD identifies with a number of mainstream hypotheses and models in the literature. It recognizes the possibility of disadvantage postulated in the Double Jeopardy hypothesis; it allows for equality, as described in the Age as a Leveler hypothesis; and it recognizes the potential advantage of the acquisition of disability suggested in the Affirmation Model of Disability. It is unique in accommodating the multiplicity of people's experiences and specifically addressing change over time. The MAWD shows aging with disability on point to acknowledge that perceptions change, change back, and change again. This model also dynamically adjusts to accommodate as
factors in an individual's process of aging with disability are influenced by life circumstances.

4.5.1 Quality Criteria

As described by Glaser (1978), quality criteria for model construction include fit, work, modifiability, and relevance. To ensure fit of the data, an audit trail was kept to affirm that the data fit the theoretical categories that were developed. To ensure work, the model was tested against the experiences of the participants. To assure modifiability, the model was constructed to allow for re-configuration as new data or circumstances emerge. Modifiability was demonstrated through the unstable nature. However, further empirical testing of the model may lead to further modification of the model. Relevance was attained through theoretical sampling. Theoretical sampling drove the follow-up interviews, and through these we confirmed that the concepts that went into the model were relevant to the experiences of the participants.

4.5.2 Strengths and Limitations

A strength of this study was that we have created a conceptual model that demonstrates the fluid and dynamic nature of the process of aging with disability and can represent the differing experiences of people aging with adult-onset physical disabilities. Another strength is that this is the only balanced model that addresses aging and disability together and incorporates perceptions of both advantage and disadvantage. This model is also empirically derived, unlike the two predominant hypotheses.
A limitation to this study is that this model only seeks to address the experience of people aging with adult-onset physical disabilities. In qualitative research we do not aim for generalizability, but instead aim for transferability. By describing our participants in detail, we have endeavoured to support transferability by giving readers sufficient information to make an informed decision on whether the results may be applicable for their population of interest. Another limitation may be the fact that all but one participant had progressive disabilities. This may have highlighted the fluid nature of aging with disability; however aging is a dynamic process in and of itself, so some degree of dynamism was necessary; a static model would have been inappropriate. Lastly, the small sample size (n=7) may be a limitation. However, we did obtain theoretical saturation.

4.5.3 Future Research Directions

This model is the first of its kind to address the process of aging with disability in a non-tragic way. We invite scholarly critique of the model by those in the fields of both aging and disability. A next step would be empirical testing of the model on those aging with adult-onset physical disability. As well, it would be interesting to test the model on other populations including those with non-progressive disabilities and those with congenital, intellectual, psychological and developmental disabilities to see if this model explains their realities.
4.6 Conclusion

The research objectives of this study were:

1) To explain the mutual interaction of aging and disability in the lives of individuals aging with adult-onset physical disability,
2) To understand the factors influencing the perceptions and personal process of individuals aging with adult-onset physical disability, and
3) To create a balanced model to explain aging with adult-onset physical disability.

A number of concepts emerged that were built into the Model of Aging with Disability (MAWD), including the entanglement of aging and disability, the multiplicity of experiences, age of disability onset, type of disability, attitude/self-efficacy, financial status, employment status at age of onset, marital status, and family and social support. These concepts were described as factors influencing the process of aging with adult-onset physical disability.

The MAWD addresses a number of concerns present in the aging and disability models and hypotheses found in the literature, including the need for a model that addresses a range of experiences, that explains both positive and negative impacts of aging with disability, and that accounts for variation. This model allows for a variety of experiences, influenced by a number of circumstances. The dynamic nature of the model is quite fitting with the nature of disability and aging themselves. Together the model components explain influences on perceptions of the process of aging with adult-onset physical disability. The model works to explain the phenomena under study, the
data fit well into the theoretical categories, it modifies itself as new circumstances or situations are encountered, and it is relevant to the experiences of the participants.

4.7 References


5  CONCLUSION AND FUTURE RESEARCH DIRECTIONS

"In the case of individuals ageing into, and with, a disability, there is a strangely absent
alliance between disability organizations and those representing the elderly. This is
strange because they have so much in common and there is a clear strategic value in
their joining forces" (Bickenbach, 2011).

5.0 Introduction

This chapter will re-cap the study and focus on the implications for future research
arising from the thesis presented in the previous four chapters. As stated in Chapter 1,
those aging with adult-onset physical disabilities are a group that has been largely
ignored, but their growing numbers and potential health and social service impact make
them a significant population worthy of study. The purpose of this study was to explain
the mutual interaction of aging and disability on the lives of people aging with adult-
onset physical disability. Specific research objectives of this thesis were:

1) To explain the mutual interaction of aging and disability in the lives of
   individuals aging with adult-onset physical disability,

2) To identify gaps in the existing knowledge base in order to provide future
directions for research in this area,

3) To understand the factors influencing the perceptions and personal process
   of individuals aging with adult-onset physical disability, and

4) To create a balanced model to explain aging with adult-onset physical
disability.
5.1 Thesis Overview

Chapter 1 outlined the background to the research problem; those aging with adult-onset physical disabilities have somehow slipped under the radar amongst the aging boom the world is currently experiencing. In 2007 Canadian seniors aged 65+ made up 13.4% of the population, and looking ahead to 2056 the population of this age group will more than double to 27.1% (Lee, 2007). The numbers of seniors is rapidly increasing for a number of reasons including increased longevity and better healthcare. Life expectancy for the disabled population is increasing as well, although it still does not match that of the general population. These recent increases in longevity, a heavy focus on successful aging, and a strong presence of literature addressing those with intellectual, developmental, and psychiatric disabilities are some reasons why those aging with adult-onset physical disabilities have received little attention to date. It seemed obvious that this was a group worthy of study; as Putnam (2002) explained, “aging with physical impairment is likely a permanent trend and one that needs attentions” (p. 799).

With validation to continue investigation of this group, a scoping review (Chapter 2) was completed to explore the current state of research on this topic and see where gaps existed. Gaps became evident very quickly when a formalized search using three major databases returned only three articles talking about aging with adult-onset physical disability. At that point, theme 1 became clear. There exists a real lack of definitional clarity in the literature when speaking about this population. What struck
us the most, however, was the significant lack of models that attempted to explain aging with disability. Only one group of models looked at aging and disability together. Unfortunately they are mathematically advanced and often published in languages other than English, making them inaccessible to most. The two mainstream hypotheses were either predominantly negative or rejected the possibility of any kind of advantageous experiences. This framed the research goal of the thesis, building a model to address both positive and negative aspects and to explain the process aging with adult-onset physical disability.

To address the research goal, we first investigated the perceptions of people aging with adult-onset disability (Chapter 3) to ultimately inform a model that would explain the process. Factors influencing their personal process of growing older with a disability were both positive and negative. These factors were the entanglement of aging and disability, the multiplicity of experiences, financial resources, attitude and self-efficacy, and family and social support. Their perceptions did not fit into either of the mainstream hypotheses, and certainly did not look only at the interplay of disability and the functional decline of aging like the Accelerated Degradation models. These findings further validated the need for a more balanced model to explain aging with a disability.

Chapter 4 presented the process of model creation, based on those perceptions of the participants identified in Chapter 3. Campbell (1996) offered that “to fill these gaps in our knowledge, we need to develop and test new models that incorporate
concepts from both gerontology and disability studies, and broaden our base of
colleagues to include representatives of both communities” (p. 2). She also argued that
collaborative models may equip “members of both communities with the data needed
to improve the quality of life for persons of all ages with disability” (Campbell, 1996, p. 3).
Data from the participants suggested that such a model needed to account for
variation, be sensitive to change, and capture the realities of a number of people aging
with adult-onset disability.

The Model of Aging with Disability (MAWD) captures the fluidity and dynamic
nature of both aging and disability and allows for instability and change over time. In
the center of the model, aging and disability are identified as distinct, autonomous
concepts, but the swirling arrows between them showcase the entanglement of
participants' experiences when both occur simultaneously. The arrows surrounding the
diamond shape are factors said to influence people’s perceptions of the process of
growing older with a disability. These factors may, at any time, push the experience
more toward advantage or disadvantage. The beauty of this model is that the influence
these factors have can vary to capture the differing experiences of multiple people. This
model is situated in time as aging takes place.

5.2 Strengths and Limitations

The main strength of this thesis lies in the creation of a conceptual model, the first of its
kind, that explains the process of aging with adult-onset disabilities. A second strength
of this thesis is that it approached the topic of aging with adult-onset disability with
both a critical perspective and an appreciative inquiry lens. Aging with a disability is a topic typically portrayed negatively in the literature, but we problematized this unbalanced perspective and actively sought to probe both the positive and negative aspects of the process in order to create a balanced model. A third strength to this thesis is the contribution the scoping review will make to the literature about the intersection of aging and disability. Aging with adult-onset physical disability is an emerging field, and one that has received little attention thus far. The scoping review brought to light a number of issues and highlighted several research gaps that need to be addressed in the future.

Limitations of this study include that the model created only seeks to address the process of aging with adult-onset physical disability and that the model was developed with data from individuals with predominantly progressive disabilities. However, even non-progressive conditions have been shown to change and progress due to secondary health complications, so it seems possible that even non-progressive conditions are subject to change. Further, a static model would have been inappropriate given the dynamic nature of both aging and disability. Another limitation is the small sample size (n=7) employed in this study. Although only seven participants took part, in qualitative research we do not aim for generalizability. We aim for transferability, and by describing our sample in sufficient detail, we hope to have given readers enough information to assess transferability for themselves. A third limitation to this thesis was the significant variation in terminology when speaking about this phenomenon, making
a formalized literature search strategy very difficult. Because of this difficulty, it is conceivable that articles were missed. Also, given the nature of a scoping review, we did not assess the quality of the literature. However, given the paucity of the literature on this topic, a scoping review seemed the most appropriate choice. Finally, a fourth limitation was the significant recruitment troubles we experienced throughout this study, despite contacting a large number of disability organizations.

5.3 Quality Criteria

In constructivism, trustworthiness and authenticity are the two main quality criteria (Guba & Lincoln, 1994). In order to ensure trustworthiness, an audit trail detailing data collection and analysis processes was kept. In addition, reflexive journaling was used to keep a record of the co-construction process, be aware of our own biases, and reflect on the emerging data. Authenticity was maintained through the use of participants’ quotations and thick descriptions of their perceptions. Using their words allowed their voices to be heard, creating an authentic representation of their experiences.

In terms of model development, Glaser (1978) described fit, work, modifiability, and relevance as the four main quality criteria of model construction. To ensure fit, an audit trail was kept to be certain that all the data could be subsumed into the theoretical categories that were developed. To address work, the model was tested against the experiences of each participant to make sure it was useful in explaining all of their experiences. Modifiability was demonstrated through the unstable nature of the
model and the possibility to re-configure or change it when new circumstances or factors present themselves. Finally, to ensure the model was relevant to the participants, theoretical sampling was used to return to participants for follow-up interviews; these confirmed that the concepts on which the model was built were relevant to their perceptions.

5.4 Future Research Directions

Future research should include critique of this model by scholars from both gerontology and disability studies as well as people working in the field of aging with disability. In addition to this critique, the MAWD should be empirically tested. A further step would be to test the model with people aging with non-progressive, congenital; intellectual, developmental, and psychiatric disabilities to see if it is valid for multiple populations of those aging with disabilities. The entangled nature of aging and disability became apparent in this thesis. Perhaps this might warrant further investigation in a study where the sample is not dominated by progressive disabilities. In addition the discovery of a “shortened planning horizon”, evident in our study population, despite the sense of self-efficacy and positive attitude, merits further research.

I anticipate three manuscripts will be submitted for publication from this thesis and I personally plan to pursue further study on aging and disability as a PhD student. I hope to explore existing policies affecting people aging with disability and to understand the transition from the disability system to the old age system better. I believe that
through understanding this transition, we will be able to better serve this population in both practice and policy arenas.

5.5 Conclusion

There remains one significant issue surrounding the aging of the disability group. A number of articles have been put forward to try to solve the amalgamation difficulties between the two fields. Some articles talk about the need to merge these two fields, some discuss the importance of merging in order to understand needs better and deliver services more effectively, and some articles outline key elements to successful partnerships; but the question remains, why are these sectors not working together to best serve people aging with a disability? If our concern is how to best serve and care for these people, then it is time we are accountable; it is time to stop talking and take action. Scholars, interest groups, governments, clinicians, and policy makers have not adequately dealt with this merger. There have been two European declarations, the Graz Declaration of 2006 (Weber & Wolfmayr, 2006) and the Barcelona Declaration of 2009 (Salvador-Carulla et al., 2010), about bridging the gap between aging and disability, and work has begun on a third international declaration about how to successfully partner these two sectors, based on discussions at the recent FICCDAT GOWD international Conference in Toronto, Ontario. If nothing is done to move them forward, these declarations are simply words. On an international scale, the United Nations has addressed the two populations with their Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the United Nations Principles for
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Older Persons (United Nations, 1991) but neither of these addresses people aging with disabilities. We need an international forum that addresses the unique concerns of those who are aging with disability. At the 2011 FICCDAT GOWD conference, Michelle Putnam spoke about the need to build policy objectives into research because this might facilitate the uptake of research and transform knowledge into action (Toronto Declaration Planning Meeting, personal communication, June 7, 2011). Perhaps that is part of the solution.

We need to understand the experiences of people aging with disabilities in order to design appropriate services for them. This group is growing rapidly and has, until this point, been overlooked. Their needs are not being fully met in either the disability or senior sector, and the transition from disability to older adult services is not seamless. We are seeing people barely making it financially. They are going without necessary devices, such as hearing aids, power scooters, and compression stockings, because they simply cannot afford them. They are living pension cheque to pension cheque without funds to plan for the future. They are limited in so many ways, yet they are showing us they are strong, they are resilient, and they can keep fighting. When do we start to fight for them? We are doing this group a great injustice if we let things continue the way they have been. The number of people aging with disabilities is increasing, and soon even more people will face this transition from the disability system to the old age system. In this study, they have shared their experiences with us. We have a golden opportunity to hear them and to tailor initiatives to meet their self-described needs.
Now is the time to make the scholarship, policy, and practice pieces fit. It is our social responsibility to take care of our aging citizens, regardless of disability.

5.6 References


Appendices
Appendix A. Ethical Approval

Office of Research Ethics
The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 660-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Western

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Prof. S.J.G. Hobson
Review Number: 17398E
Review Date: August 25, 2010

Protocol Title: Exploring the Mutual Interaction of Aging and Disability in Individuals Aging with Adult-Onset Disabilities: A Grounded Theory Study
Department and Institution: Occupational Therapy, University of Western Ontario

Sponsor: Not Funded

Ethics Approval Date: September 21, 2010
Expiry Date: August 31, 2011

Documents Reviewed and Approved: UWO Protocol, Letter of Information and Consent

Documents Received for Information:
This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REBs as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time, you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the changes involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:
- changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- all adverse and unexpected experiences or events that are both serious and unexpected;
- any new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert
FDA Ref. #: IRB 00000940
Appendix B. Ethics Revision Approval

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Prof. Sandra Hobson

Review Number: 17398-1

Review Level: Delegated

Approved Local Adult Participants: 12
Approved Local Minor Participants: 0

Protocol Title: Exploring the Mutual Interaction of Aging and Disability in Individuals Aging with Adult-Onset Disabilities: A Grounded Theory Study

Department & Institution: Occupational Therapy, University of Western Ontario

Sponsor:

Ethics Approval Date: May 12, 2011
Expiry Date: August 31, 2011

Documents Reviewed & Approved:

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB), which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/tCl l Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REBs as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB’s periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSREB who are named as Investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB0000046.

This is an official document. Please return the original in your files.

The University of Western Ontario
Office of Research Ethics
Support Services Building Room 5150 • London, Ontario • CANADA - N6A 3K7
PH: 519-661-3036 • F: 519-850-2466 • ethics@uwo.ca • www.uwo.ca/research/ethics
Appendix C. Focus Group Guide

1. Tell me about your experience of aging with a disability
   a. In what ways do you feel your experience of aging is similar to others who do not have a disability?
   b. In what ways do you feel your experience of aging is different from others who are not aging with a disability?

2. Can you tell me about any factors or circumstances that influence your experience of aging that are related to the fact that you have a disability?
   a. Family situation?
   b. Services?
   c. Symptoms?
   d. Functional limitations?
   e. Economic factors?

3. Do you think you might have some advantages in the aging process based on your experience of having a disability?
   a. In what ways?
   b. Tell me more.

4. Do you think you may experience any disadvantages in the aging process because of your disability?

5. Some of the literature suggests that people with disabilities experience double jeopardy as they age. This refers to the fact that you are getting older and that you have a disability, and that this makes it extra hard for you.
   a. Do you think this is true?
      i. In what ways does it fit with your experience?
      ii. In what ways does this not fit with your experience?
   b. In what way does this reflect your reality?

6. Some different literature suggests that age can be a leveler – that in fact you will be no worse off than any other older person because you can use some of the strategies you’ve acquired from adjusting to your disability and apply them to some of the challenges of getting older.
   a. How do you feel about this idea?
   b. Does this resonate for you? Does this explain your experience?
Appendix D. Interview Guide

1) During the focus group a lot of people talked about it being difficult to separate aging and disability.
   
   a) Is that your experience?
   b) Can you explain or elaborate a little more?

2) In the focus group people gave examples that would support different theories about aging with a disability. Some gave examples of double jeopardy (having extra disadvantages when aging because of having a disability) and some gave examples of age as a leveler (you are no worse off than any other older adult because you can use some of the strategies you’ve acquired from adjusting to your disability and apply them to some of the challenges of getting older). Some people even talked about it being advantageous to acquire a disability earlier in life and were glad they were able to accept their disability before facing old age.
   
   a) Which of these is true for you or can you relate to more than one of these?
   b) Can you elaborate please?

3) In the focus group we heard conflicting reports about the effect of aging with a disability on financial status.
   
   a) What role do you think that the age of disability onset plays on financial status after age 65 for those who have aged with a long-term physical disability?
   b) Did you anticipate that aging with a disability would have an impact on your financial status after the age of 65?
      a. If so, what impact did you anticipate it would have?
      b. Is what you expected what actually happened?

4) In the focus group some people told us that they had concerns about the future and yet some people were confident that they could cope with the challenges that may come as they age further.
   
   a) As a person with a disability, how do you feel about your future?

5) In the focus group a lot of people talked about the importance of their family in helping them to adapt and to cope.
   
   a) How important do you think family is to aging with a disability and why?
Appendix E. Demographic Questionnaire

Participant Demographic Questionnaire

Alphanumeric Code: ________

1. In what year were you born? ________

2. Relationship Status (please check one)
   □ Single
   □ Married
   □ Common-law
   □ Divorced
   □ Widowed

3. Immigration Status (please check one)
   □ 1st Generation immigrant
   □ 2nd Generation immigrant
   □ N/A

4. Living Arrangements (please check one)
   □ Live alone
   □ Live with family members (e.g., adult child etc.)
   □ Live with spouse/partner/friend?
   □ Live in Congregate Living setting (e.g., Seniors complex, a retirement community, etc.)

5. Friends and Relatives: (How many close friends or relatives do you have contact with on a regular basis – at least once a week)
   ________

6. Home (Please check all that apply)
   □ Own
   □ Rent
   □ One-floor residence
   □ Multi-Story residence
   □ Congregate Living

7. Financial Resources: (please check one)
   I have:
   □ More than enough money for what I want and need to do
   □ Enough money for what I want and need to do
□ Just barely enough money for what I want and need to do
□ Not enough money for what I want and need to do

8. Level of Education (please check highest level attained)
   □ Elementary School
   □ High school
   □ College/Trade School
   □ University Degree (Undergraduate)
   □ University Degree (Graduate)

9. Employment
   a. Were you able to work after your onset of disability? (please check one)
      □ Yes
      □ No
   b. How many years after disability onset did you work? _____
      a. Did your disability cause you to reduce your work hours? (please check one)
         □ Yes
         □ No
      b. Did your disability force you to stop working before you wanted to? (please check one)
         □ Yes
         □ No

10. Disability Onset
    i. Age or year of onset _______________________
    ii. Type of diagnosis ________________________

11. Please list the top 3 limitations you experience as a result of your disability.
    i. __________________________________________
    ii. __________________________________________
    iii. __________________________________________

12. Do you use any assistive devices regularly? (please check one)
    □ Yes
    □ No
13. Have you modified your home (e.g., installed grab bars, moved to a one story home, etc.)
   to accommodate your disability (please check one)
   □ Yes
   □ No

14. Are you willing to be contacted for a follow up interview? (please check one).
   □ Yes
   □ No
Appendix F. Letter of Information and Consent Form

Exploring the Mutual Interaction of Aging and Disability in Individuals Aging with Adult-Onset Disabilities: A Grounded Theory Study

Investigators
Prof. Sandra Hobson, Health of Rehabilitation Sciences Program, University of Western Ontario
Kristen Bishop, Graduate Student, Health of Rehabilitation Sciences Program, University of Western Ontario

Dear potential participant,

My name is Kristen Bishop and I am a master’s student at the University of Western Ontario in the Health and Rehabilitation Science Program. I am collecting information for my thesis in the Health and Aging program.

You are being invited to participate in a research study looking at the process of aging with adult-onset disability. The purpose of this letter is to provide you with the information required to make an informed decision about participating in this research study and to help answer any questions you may have. It is important for you to understand why the study is being conducted and what it will involve. Please take the time to read this carefully and feel free to ask questions if anything is unclear or there are words or phrases you do not understand.

We are asking you to take part because you have personal knowledge into the experiences that people aging with disabilities encounter and will be able to provide individual insight about the factors affecting the interaction of aging and disability.

Purpose of this study
The purpose of this research is to explore the process of aging with an adult-onset physical disability. Objectives of this study are
a. To explore the positive and negative aspects to aging with a disability, and
b. Develop a balanced model to explain the inter-relationship/mutual influence of disability and aging factors on individuals’ life experiences and outcomes.
By exploring aging with a pre-existing disability, we hope to become better able to serve this population because of better informed policy and practice agendas. The number of individuals growing older with physical disability is increasing significantly and the group is understudied.

**Inclusion/Exclusion Criteria**

To be included in this study, you must

- be a man or woman over age 65,
- speak English and be able to participate in a group discussion and perhaps an individual interview,
- have a physical disability that started at age 62 or before, and
- this disability must have affected the amount or kind of activities you could do in your paid work and in your daily life.

You are not eligible to participate in this study if you have a congenital (from birth), intellectual (learning or thinking), developmental (delay in maturation), or psychiatric (mental health) disability.

**Research activities for this study**

If you decide to take part of this study you will be asked to take part in a focus group with other participants who are also aging with disabilities. Focus groups will take place at the University of Western Ontario. At the start of the focus group, you will be asked to complete a demographic questionnaire. It will ask some basic questions about your life circumstances and disability. You will also be asked whether you would be willing to be contacted to participate in a follow-up in-depth interview after the initial focus group. Individual interviews would take place at a location mutually agreed upon between the researcher and participant (e.g., participant's home or office at the university). You will be reimbursed for transportation costs in the form of parking reimbursement, fare costs for public transit, or Para-transit fees for transportation to the University for focus groups. Refreshments and snacks will also be provided for focus groups. If you are asked for an individual follow up interview and chose to have it at the University, you would be reimbursed for transportation costs in the form of parking reimbursement, fare costs for public transit, or Para-transit fees for transportation to the University. Focus groups will be audio and video taped to allow for transcription and speaker identification.

**Enrollment**

Approximately 8 to 12 participants will be recruited for this study.
How much time you must commit to participate in this study
The focus group will last approximately 1.5-2 hours in length. If you participate in a follow up interview, it will last approximately 1-1.5 hours but this will take place on a different occasion.

An initial meeting will occur over the telephone before the study begins to answer any questions about the study and go over this letter of information and consent form. If you agree to participate, I will arrange a time to hold the focus group, based on your availability and availability of other participants, once we have enough participants.

Risks and discomforts to you if you participate in this study
There are no known risks to participation. You may be asked to reflect on situations in your life that you may have found difficult, which may trigger a variety of emotions. You are free to refuse to answer any question or to withdraw from the focus group or interview at any time. Contact information for local counselling services will also be made available in case you wish to seek assistance.

The benefits to you if you take part in this study
There is no immediate benefit to you as a result of participation. However, reflecting on your prior adjustment to disability may highlight resources and coping skills you can bring to any new challenges you may face in the aging process. In addition, this study may help inform future policy and practice for those aging with physical disabilities.

Voluntary participation
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no consequences.

Privacy & Confidentiality
Every possible measure to maintain confidentiality will be taken. Each participant will each be assigned an alphanumeric code that will be used for all study materials (for example, demographic questionnaire, focus group audio recordings and transcripts and individual interview audio recordings and transcripts). Only the research team will have access to the master list of codes. Your research records will be kept in a locked file cabinet in a locked office at the University or on a pass-word protected computer and only shared among the research team.
During the writing process, the alphanumeric codes will be exchanged for pseudonyms to give a more human feel to your experiences. You will have the option to choose your own pseudonym. If the results of the study are published, your real name will not be used and no identifying information will be given out. No information that discloses your identity will be released or published without your explicit consent to the disclosure. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. If we find information we are required by law to disclose, we cannot guarantee confidentiality in order to protect your safety or the safety of another member of the study.

Your rights as a participant
You do not waive any legal rights by signing the consent form.

If you have any questions about your rights as a research participant or the conduct of the study you may contact the Office of Research Ethics at (519) 661-3036 or by email at ethics@uwo.ca.

Study Results
If you would like to receive a summary of results after the study is complete, please write your name and address on a separate piece of paper and give to one of the members of the research team.

This letter is for you to keep. You will be given a copy of this letter of information and consent form once it has been signed.

If you have any other questions, please feel free to contact myself or my supervisor, Sandra. We will be happy to answer any questions you may have.

Study investigator
Kristen Bishop, BHSc (Hons.)
Health & Rehabilitation Sciences, Health and Aging Field
Elborn College, 1201 Western Rd.
London, ON N6G 1H1
519-671-2947
kbishop5@uwo.ca
Signature ____________________

Study supervisor
Sandra Hobson, MAEd, LLD, OT Reg. (Ont.)
Associate Professor, School of Occupational Therapy
Elborn College, 1201 Western Rd.
London, ON N6G 1H1
519-661-2111 ext. 88957
shobson@uwo.ca
Signature ____________________
Informed Consent Form

Exploring the Mutual Interaction of Aging and Disability in Individuals Aging with Adult-Onset Disabilities: A Grounded Theory Study

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Research participant:

Name _____________________________________________________ (please print)

Date __________________________

Signature __________________________________________________

Person Obtaining Informed Consent:

Name _____________________________________________________ (please print)

Date __________________________

Signature __________________________________________________