Factors Associated with Rehabilitative Service Use by Adults with Cerebral Palsy in Ontario
Home Care

by

Rachel Cooper

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Author's Declaration:

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

Cerebral Palsy (CP) is a childhood-onset neurological disorder caused by a non-progressive lesion in the developing brain. It causes permanent motor and movement disorders, and can sometimes cause secondary cognitive, sensory, and communication conditions. The majority of children with CP will survive into adulthood; however, a relatively small amount of research has been done about adulthood and aging with CP. Using data collected in Ontario with the Resident Assessment Instrument for Home Care (RAI-HC), a retrospective, cross-sectional analysis was performed to create a clinical profile of adults with CP receiving long term home care services in Ontario. Of the 519,443 people in the sample, 2,000 had CP. Persons with CP tended to be younger than comparison groups, had higher scores on functional assessment scales, and were more likely to use assistive devices. They tended to have lower scores on scales meant to predict decline in health or function than the comparison groups, suggesting increased health and functionality stability compared to other Home Care recipients. A second analysis assessed the association between functional assessment scales, demographic variables and clinical indicators and use of physical therapy (PT), occupational therapy (PT) and either PT or OT for persons with CP in this population. Using three logistic regression models, indicators that were found to have positive, significant associations with use of rehabilitative services were: receipt of initial assessment, likelihood of decline in functionality, use of a wheelchair, being married, and CCAC of assessment origin. Living in a private residence compared to living in an assisted living situation had a significant, negative effect on rehabilitative service use. These findings suggest that PT and OT are referred to persons with CP in reaction to risk of health declines, and not in an attempt to improve baseline functionality. Future research on the factors that would indicate likelihood of improvement with PT or OT could identify whether these associations are appropriate for optimum care for persons with CP who receive home care services.

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In recent years, there has been a move towards deinstitutionalization of persons with disabilities, with the last three institutions in Ontario for persons with developmental disabilities closing as recently as 2009 (Pedlar and Hutchinson 2000, Lemay 2009). The benefit of home care services as a long-term care option for many people, not just those with disabilities, has also recently become clear (Romanow 2002). These two factors alone suggest that there will be increased demand for home care. This suggests that understanding the populations that access home care for long-term care will become increasingly important. Adults with Cerebral Palsy are an emerging population that often relies on long-term care services. Understanding the driving forces behind the resource utilization of this population will benefit the home care system.

Review of Literature

Cerebral Palsy: An Introduction

Cerebral Palsy (CP), with a prevalence of about 2.5 cases per 1000 children (Clark and Hankins 2003, Oskoui 2012), is the most common cause of childhood physical disability (Rosenbaum 2003). It is a neurological disorder caused by a non-progressive lesion in the developing brain (Rosenbaum et al. 2007). This lesion leads to permanent motor, movement and posture disorders, and, in some cases, cognitive, communication, sensation, and perception disorders, secondary muscoskeletal disorders, and epilepsy (Bax et al. 2005). Movement disorders in CP are classified predominantly by the movement irregularity: spastic, dyskinetic (including dystonia, athetosis and chorea [Albright 1996]) or ataxic (Rosenbaum et al. 2007, Brunstrom 2001), and by the areas affected in the person: monoplegia through quadriplegia (Albright 1996). Although as many as 75- 85% of persons with CP are categorized as spastic, the diagnosis is made inconsistently (Krach 2001, Brusntrom 2001). Spasticity in the strictest terms

is meant to describe resistance in joints and/or passive stretching that is dependent on force

(Rethlefsen et al. 2010, Brunstrom 2001), but is often attributed to persons with any stiffness

(Brunstrom 2001). This may reduce the usefulness of the diagnosis. It is clear that neurological

subtype cannot be used on its own when creating plans for care or determining severity.

It is important to consider severity of CP for understanding complexity and identifying

specific treatment needs. Venkateswaran and Shevell (2008) found that children with the

neurological subtype spastic quadriplegia were at an increased risk for vision and hearing

problems, and epilepsy. Beckung and colleagues (2008) found a correlation between motor

function and physical well-being, and Wake and colleagues (2003) found that although all

children with CP had notably lower health quotients then the general population, severity of the

CP diagnosis had a negative effect on the score, even when controlling for epilepsy. Adults with

developmental disabilities, including CP, are at an increased risk of having 4-5 chronic

conditions (Thorpe 2012). Severity is often classified with the Gross Motor Function Class

System (GMFCS), a standardized measure of abilities of persons with CP (Palisano et al. 1997,

Palisano et al. 2000). It was initially meant for children under 12, but has been shown to be

reliable with adults (Jahnsen et al. 2006).

The GMFCS is a clinician's tool that classifies severity on the basis of movement;

however, its use as a severity indicator seems to have broader implications. Clinical complexity

and comorbid diagnoses seem to increase with severity, which has important implications for

care needs and service use. Using the GMFCS, Shevell and colleagues (2009) found that there

were higher levels of comorbid diagnoses in children with CP who were non-ambulatory (who

were in Gross Motor Function Classification System levels IV-V) than children who were

ambulatory (who were in Gross Motor Function Classification System levels I-III).

Concurrent health conditions among adults with CP may increase demand on health services. Adults living with CP have been shown to have an increased risk of death from cardiovascular disease and cancer (Strauss et al. 1999). The authors of the study suggest that the increased risk of cancer mortality might be related to inadequate cancer screening, increasing the risk of discovering cancer after it has progressed to late stages (Strauss et al. 1999). Based on the high number of self-reported unmet needs by persons with disabilities (McColl et al. 2010), this is unlikely to be the only gap in care for adults with CP.

Treatment and Continuity of Care to Adulthood

A range of interventions and treatments have been established for CP, including surgical, pharmacotherapy, and physical rehabilitation. Surgeries for CP might include inserting feeding tubes or shunts, or interventions in the gastrointestinal system or respiratory system (McLellan et al. 2012). Gastroenterology and other feeding tube nutritional solutions are implemented in cases where chewing and swallowing problems create a risk of malnutrition, or choking complications. Gastroenterology accounts for 90% of feeding tubes used with persons with CP (Brooks, Shavelle and Strauss 2012). Orthopedic surgeries may be used to prevent or fix hip dislocation, stretch tendons, or to surgically insert rods to guide growth (McElroy et al. 2012).

Pharmacological interventions often take the form of pain relief and antispasmodic agents. Antispasmodic pharmaceuticals can be delivered orally, and through injection (e.g., Botulinum neurotoxin; Benini and Shevell 2012). In some cases, a source of baclofen, a GAMA inhibitor, is implanted to focus distribution of the drug within the spinal fluid (Krach 2001).Williams and colleagues (2012) found better outcomes for persons that received both physiotherapy and antispastic pharmacotherapy than persons that received only one or the other,

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suggesting that a multidisciplinary approach to treatment may yield better results. This is not

surprising considering the multisystem effect of CP.

Physical therapy is a common component of treatment for persons with CP, particularly

during childhood. Both Palisano and colleagues (2012) and Bailes and Succop (2012) found a

positive relationship between functioning as assessed by the GMFCS and the amount of

physiotherapy received by children. Positive associations were also found between the age of the

child being treated, the child's level of insurance coverage and the number of units of

physiotherapy received in the second study (Bailes and Succop 2012). Palisano and colleagues

(2012) found that younger children received more PT and OT than older children, but focused

solely on very young children. These studies continue to draw samples from children with CP, so

it is unclear whether age has a ceiling affect. While there may be an association between age and

use of physiotherapy in childhood, this association may be reduced or even in the inverse

direction in adults. Literature on transitioning into adult care suggests that access to these

services may be reduced (Oskoui 2012). While not specified in the cited study, this could be

related to the association between insurance coverage and units of physiotherapy. While

insurance coverage is likely to have a greater effect for children in a private health care system

like those in the United States, such as the children in Bailes and Succop's sample, the transition

from pediatric eligibility to adult eligibility by provincial health plans and private health

insurance for physiotherapy in Canada may show reduced access to some services.

Adults with CP reportedly feel they have less access to the health services that they need

as they grow older. Adults reported that, upon transitioning from pediatric care, they no longer

had access to many of the rehabilitation services that they received previously, even though a

need still exists (Oskoui 2012). Adults with CP are found to report many unmet care needs when

asked to report their experiences (McColl et al. 2010, Nieuwenhuijsen et al. 2008), including

ongoing information from their physician or medical provider about CP and what to expect as an

adult (Roebroeck et al. 2009, Balandin and Morgan 1997). Literature on the subject also suggests

that weak transition procedures have led to adults with CP being dissatisfied with the disability

specific care they receive in adulthood. The level of need and receipt of treatment among adults

with CP is a complex issue. There is also a need to consider the use of service plans tailored to

the person's age. For example, Strax et al. (2010) cautioned against overusing physical therapy

(PT) as persons age as many of the age-related muscoskeletal conditions in CP are related to

overuse of joints, such as degenerative arthritis (Horstman et al. 2009; Murphy et al. 2007). The

authors recognized the importance of tailored PT for adults on a case-by-case basis as it may still

be a beneficial treatment for preventing osteoporosis or other muscoskeletal deterioration (Strax

et al. 2010).

CP and Aging

Research on aging with CP is beginning to emerge but is limited compared to younger

populations. The lack of research may be due to a number of factors. First, the fact that much of

the research about CP focuses on children may be attributable to the fact that many people with

CP have had shorter life spans (Strauss et al. 1999), with an especially high childhood mortality

rate for persons with severe CP (Westbom et al. 2011; Hutton and Pharoah 2006). Hutton and

Pharoah (2006) found independent associations between severity of cognition, severity of motor

disabilities, and severity of visual disabilities for a person with CP, and their chances of

mortality. Respiratory diseases are a traditional explanation for these deaths, explaining up to

52% of the excess mortality rate for people with CP (Strauss et al. 1999). A later study by

Strauss and colleagues (2007) found that gastronomies were one of the stronger predictors of

mortality. It is worth noting that the gastronomies themselves are unlikely to be causal factors for

earlier mortality, and instead are indicators of severity of the diagnosis. Despite these increased

odds of mortality, however, more than 90% of persons with CP survive into adulthood (Oskoui,

2012; Gorter, 2012).

Strauss and Shavelle (1998) found that children who were able to walk at least 10 feet

without aid had more than a 90% probability of surviving at least 15 years, no matter whether

they were self-feeding, or relied on others to eat. A later study, also by Strauss and colleagues

(2007) found a significant reduction in mortality for children with severe disabilities, and for

adults who rely on gastroenterology (tube feeding) compared to prior findings. This could be

because of medical advancements in childhood that reduce the risk of mortality from

malnutrition or infection. More recently, persons with mild symptoms can be expected to survive

to adulthood at rates similar to unaffected children (Hutton & Pharaoh 2006). Even the children

with the greatest motor deficits (GFMCS level V) have a 60% survival rate to age 19 (Westbom

et al. 2011). This has not always been the case. Strauss and colleagues (2007) found a decrease

of mortality in persons with severe CP by about 3.4% each year from 1983 to 2002—a five-year

increase in life expectancy. While the prevalence of CP in children has not changed, there is a

possibility that there has been a shift in the severity of the condition among children with CP.

One argument for the stability of the prevalence of CP despite medical advancements is that

more children at risk for CP survive at birth than did before. Surman and colleagues (2009)

found that low-birth weight babies—babies who are often preterm, and whose survival has been

augmented by new medical technology—are more likely to develop CP than average weight

babies; however, low birth weight babies who develop CP are less likely to develop severe CP

than average weight babies who develop CP (Surman et al. 2009). This potential increase in the proportion of children with milder CP may increase the number of children transitioning into adulthood and older adulthood with CP.

Understanding the trends in CP, both in terms of age and clinical severity, are important to consider for treatment planning. To date, these trends have not been well studied. A long-term study in Sweden found that there was a temporary reduction in overall CP prevalence. After prevalence returned to its previous level, the study found an increase in the prevalence of a neurological subtype generally considered severe (Himmelman, Hagberg & Uvebrant 2010). This would not necessarily change the proportion of mild to severe cases. Himmelmann (2011) has pointed out that studying trends of CP is largely reliant on having a consistent definition of the disorder, and a consistent measurement technique. As reported earlier, standardization of the measurement of severity is relatively recent and relies solely on physical indicators. It may not be possible to judge the proportion of children with severe CP to children with mild CP. Similarly, the prevalence of CP in adults is not easily calculated, and thus the same trends in the adult population do not seem to be available for comparison.

As the population of aging persons with these disorders grows, understanding how to best provide care to these adults becomes increasingly important. There is evidence, as reviewed by Svien et al. (2008), that persons with CP might experience some symptoms commonly associated with aging while younger than the general population may experience them. Persons with CP report increased pain and decreased ambulation earlier in their lives than people without CP (Svien et al. 2008). As Strax et al. (2010) and Haak et al. (2009) found, persons with childhood onset disabilities tend to age faster than their counterparts in the population, and have greater clinical needs for aging related issues earlier. In a longitudinal study, Maaskant et al. (1996)

found that, after adjusting for severity, there was a decrease in ADL function over time for older

adults with intellectual disabilities, while the same decrease was not seen in adults under sixty

years old. While not all persons with Cerebral Palsy have intellectual or cognitive disabilities,

cognitive and other related disabilities are included as possible manifestations in the definition

developed at the 2007 International Workshop on the Definition and Classification of CP

(Rethlefsen et al. 2010).

Physical fitness is another important consideration for persons with CP, particularly

adults with CP. CP has been reported to have a negative impact on physical fitness (Hombergen

et al. 2012). Muscle strength has been shown to have an increasingly strong negative relationship

to CP as GMFCS levels increase (Thompson et al. 2010). Addressing access to physical activity

could be important to ensure that persons with CP are able to continue being mobile later in life.

Strauss et al. (2004) found that there is a decrease in independent walking from younger

adulthood to older adulthood, with independent walking falling from 37% for 40-year-olds to

25% for 60-year-olds. Osteoporosis is also a concern for adults with disabilities, as about half of

this population has low mineral bone density (Sheridan 2009). This is of great concern for adults

with CP as osteoporosis is related to low physical activity and poor nutritional intake—two

common issues for people with CP (Strax 2010, Svien 2008). Best practices for service provision

for adults with CP is an area that could use further development.

Berry and colleagues (2012) concluded that children with neurological impairments have

a significant impact on resource use, measured by the proportion of bed days used by children

with neurological disorders, and the amount of money billed by the hospitals for the care of these

children. It is not clear whether this increase in resource use is magnified by age, or even

increases in step with aging related resource use, as it is already understood. Goodman and

colleagues (2002) found that one of the most common diagnoses for adults using pediatric

hospitals was CP. A later study by Goodman and colleagues (2011) found that there is an

increasingly large number of persons accessing care in pediatric hospitals who transition from

pediatric to adult care and have greater resource intensity than other inpatient care recipients.

McColl and colleagues' 2011 study confirmed that disability and aging both increase use of

clinical resources; however, the difference between resource use of people with and without

disabilities tends "level out" with age (McColl et al. 2011). This study included persons with any

type of long-term disability, with no distinction for age of onset. Some of the explanations for the

"leveling out" effect might not be applicable to persons who have lived with their disability for

their entire lives. For instance, some people might not access more resources to address their

disability if they believe that their symptoms are just part of "slowing down" with age (McColl et

al. 2011). It is possible that someone who did not have mobility issues before they began to age

may be likely to assume this about their aches and pains than someone who has recognized these

issues as part of their disability throughout their lifetime.

Health Services for Adults with CP

Adults with Cerebral Palsy live in a variety of settings, and access health care in a variety

of ways. Janicki's 1989 study of New York adults with CP and intellectual found an increase in

institutional care with age; More than half of the sample lived in institutional settings by age 55,

and 70% lived in these settings after age 75 (Janicki 1989). Maaskant et al. (1995) found a

relationship between ADL needs and care dependence for adults with intellectual disabilities. It

is possible that this has changed over time, or is variable depending on the location. Lifshitz et al.

(2007) observed persons with intellectual disability in community and residential care settings

and found persons with CP were most at risk for ADL decline with age, across care settings.

Andersson and Mattsson (2001) found that 84% of the adults in their sample lived

independently; however, this sample was much younger and excluded persons with learning

disabilities, which perhaps focused the study on a population with CP that was more likely to be

able to live independently. This is an important distinction to make—intellectual disability is not

an inherent part of cerebral palsy. It is not clear whether intellectual disability is predictive of

residential care for people with CP. Evenhuis et al. (2012) found a relationship between severe

intellectual disability, motor impairment, and frailty. This is not necessarily evidence that

intellectual disability is predictive of residential care, but it does provide overlap between

established indicators of CP severity and complexity with indicators for frailty. Increased frailty

or complexity could put persons in greater need of constant care.

Persons with CP may access residential care at greater rates with age due to loss of

formal or informal home care supports. Persons with CP who rely on their parents as their

informal caregivers must deal with the eventuality that their parents will also age. Prosser (1996)

found that few aging parents of people with intellectual disabilities had planned for their adult

children's continuation of care. Dillenburger and McKerr (2010) point out that there is a lack of

resources for carers to do so. It is unclear what happens for people with CP who need, but lack, a

continuation of care plan, but a move to a state-funded residential care setting is not outside the

scope of imagination. What is clear, however, is that helping people to remain in their home with

home care services tends to be more cost efficient and result in greater satisfaction for care

recipients. The 2002 Romanow report featured home care as an important piece of the future of

the Canadian Health Care System. In order to successfully promote the use of home care for the

entire population of people with CP, it is essential that the needs of adults with CP be

understood.

Comprehensive assessment procedures in care settings have been shown to be an

effective method of identifying the needs and addressing the issues of care recipients.

Assessment instruments, such as the Resident Assessment Instrument Minimum Data Set for

Home Care, can improve care in home care, resulting in improved outcomes, measured by

indicators such as a reduction in admissions to hospitals, including when compared to other

assessment procedures (as opposed to compared to having no assessment procedure in place)

(Landi et al. 2001, Landi et al. 2001). One study also found that, controlling for health service

use; the cost for home care for recipients assessed with the RAI-HC was 21% less than recipients

assessed with the standard tool for the system (Landi et al. 2001a). A smaller study in Germany

found reduced ADL and IADL decline in persons assessed with the RAI-HC (Stolle et al. 2012).

Landi and coworkers (2001) found evidence that use of the instrument for Home Care could

decrease institutionalization of older persons living in community. The information gathered by

these comprehensive assessments has shown that it has the power to improve services in general.

It is likely that the information can be useful in describing the needs of specific populations and

can be used to increase the efficacy of care planning for these populations.

Physical and Occupational Therapy, and PT and OT based care plans for persons with CP

should evolve with the person as they go from childhood to adulthood. While PT and OT in

younger age groups might focus on basic skills and reaching the person's maximum potential for

movement, PT and OT in adulthood might be more useful in preventing decline, and in adapting

to best work within the home and work environments experienced by persons with CP (Levitt

2004). Levitt, in her 2004 manual <u>Treatment of Cerebral Palsy and Motor Delay</u> outlined six

specific aims for PT and OT with adults with CP:

"1) To maintain motor abilities and reactivate abilities decreased by disuse.

2) To prevent and decrease deformities wherever possible.

3) To learn a healthy lifestyle including physical fitness.

4) To develop appropriate community mobility.

5) To continue the training of self-care skills.

6) To teach the individual all he or she needs to know about the condition."

Study Purpose and Rationale

The increasing trend of persons with CP who survive into adulthood underscores the importance that health services are able to recognize the needs of this growing population. The number of studies investigating the medical and psychosocial care of adults with Cerebral Palsy is increasing; however the majority of these studies are focused on improving transitions for adults from pediatric care. While the importance of effective transition from pediatric to adult care has been demonstrated, it is also essential that the care received by adults be examined to ensure its efficacy, quality and ability to address the needs of adults with Cerebral Palsy. With an increasing emphasis on long-term home care services, this is a service setting worthy of special focus.

The goal of this thesis is to explore three questions:

1. What are the patterns of characteristics, needs, and patterns of rehabilitative service use among adults with CP that are receiving long-term Home Care?

2. How are different types of commonly used functional assessment scales derived from the RAI-HC related to variation in receipt of rehabilitative services among adults with CP?

3. What factors are associated with the variations in receipt of rehabilitative services among adults with CP?

In Canada, a unique opportunity to explore these questions arises based on the availability of standard assessment information about adults with CP. The interRAI suite of assessment instruments provide detailed information about the needs and resource usage of persons in a variety of health care settings. The data collected by these instruments allows for analysis that can inform clinical practice and decision-making. Since data are available on a

consistent basis across sectors and health regions, research can also be carried out examining

differences between health sectors. Research about CP using data from these instruments has the

potential to provide important insight. It provides information about most, if not all, persons with

CP accessing long term care services; however, to our knowledge, studies about adults with CP

using data obtained with interRAI instruments have not been previously published. Using the

RAI-HC to determine factors that are associated with rehabilitative service use will allow health

care providers in these settings to be able to quickly recognize if the reported issues apply to

their organization, and can monitor if any suggested changes improve outcomes.

Using data collected in Ontario by the Resident Assessment Instrument for Home Care

(RAI-HC), a profile of persons with CP can be created at different ages in adulthood, and

different severity levels in Home Care in Canada. The intent of these profiles is to illustrate the

current state of adults with CP in the health care system, and to point out differences and

discrepancies between age groups, people of similar levels of mobility, and comparison groups.

These discrepancies may be in terms of the need indicators of the population themselves, the

accessing of different resources, or the relationship between need indicators and the resources

accessed.

Methodology

A retrospective, cross-sectional analysis of the service utilization of adults with CP receiving long-stay home care services in Ontario was performed.

Sample and Data

The study sample was based on long-stay Home Care (HC) clients living in the community who were assessed with the RAI-HC in Ontario between January 21, 2002 and December 31, 2010. The sample had 519, 443 unique cases across the three diagnosis groups considered. Long stay clients are defined as those expected to be on service for more than sixty days. Under the *Health Insurance Act*, home care services are defined as:

"(a)   the services that are provided, on a visitation basis, by a nurse or a nursing assistant,

(b)   the services provided, on a visiting basis, by a physiotherapist, occupational therapist, speech therapist, social worker or nutritionist [4],

(c)   the provision of dressings and medical supplies,

(d)   the provision of diagnostic and laboratory services,

(e)   the provision of hospital and sickroom equipment,

(f)   the provision of transportation services to and from the home to a hospital, health facility or the attending physician's office, as the case may be." (CCAC 2006)

Individuals in Ontario have access to Home Care if they are covered by the Ontario Health Insurance Plan, need one of the professional services available through home care (nursing, physiotherapy, occupational therapy or speech therapy, etc.), need services to stay in or return to their home, cannot receive these services through community based settings, live in a safe and effective place to receive services, and the services prescribed are reasonably expected to lead to rehabilitation (CCAC 2006). An assigned case manager from the person's local

Continuing Care Access Centre (CCAC) determines the eligibility and range of home care services provided. There are 14 CCACs in Ontario.

The data used in this study consist of assessments compiled in the Home Care Data Base and the Ontario Association of Community Care Access Centers. Assessments are conducted electronically by CCAC case managers, using automated entry software that automatically checks for inconsistencies and illogical answers (Poss 2006). People in home care are assessed at intake, and then reassessed every six months. Case managers can decide to reassess earlier than six months if they feel that there have been substantial changes in the home care recipient's condition, living situation, or other pertinent personal factors. Persons assessed with the RAI-HC are assigned a meaningless, but unique number (MBUN) to identify their specific case through multiple assessments. The most recent available assessment was used for subjects, and each subject is only included in this data set once.

Instrument – The RAI –HC

The RAI-HC has been mandated in Ontario since 2002 for all HC users expected to be on service for longer than sixty days. The RAI-HC describes each home care recipient using many variable indicators, including physical and cognitive function, service utilization, and behaviors (Morris et al. 1997). The reliability and validity of the RAI-HC has been established in Home Care populations (Morris et al. 1997, Landi et al. 2000). This reliability and validity, and the breadth of information made readily available through assessments collected with this instrument lead to its selection for this study.

Independent Variables
Neurological Condition

Neurological conditions were operationalized using a variable with three groups: persons with CP (referred to as "CP"), person with a neurological disorder other than CP (Non-CP), and person with none of the 11 priority neurological disorders, as listed below (Other). Cases with CP were identified from text fields included in the RAI-HC. Please see Appendix A for specific coding. Persons with neurological conditions other than CP include persons with Epilepsy/seizure disorder, Spinal Cord Injury, Amyotrophic Lateral Sclerosis, Muscular Dystrophy, Cerebral Palsy, Brain Tumor, Dystonia, Hydrocephalus, Spina Bifida, and Tourette's Syndrome. Other diagnoses included were Multiple Sclerosis, Parkinson's Disease, Alzheimer's Disease and related dementias, Traumatic Brain Injury, and Stroke. Please see Appendix A for population tables and coding information.

Age

An age group variable was created to include four categories: 18-24, 25-44, 45-64, and 65 plus. The first age group consists of persons between 18-24 to adjust for persons who may be in transition from pediatric care, or have recently transitioned or been transferred without transition from this care. The second age group of 25-44 may account for adults that have completed their transitioned to adult care. An age group of 45- 64 represents middle age for people with mild CP, and likely the end of life years for people who are more severely affected by their diagnosis. The final group includes adults over the age of 65. This age group is unlikely to encompass persons with moderate to severe CP.

Severity

Activities of Daily Living

The Activities of Daily Living Hierarchy (ADLH) was used as an indicator of functional condition severity. This functional assessment scale was identified for use in this thesis because of its ability to identify functional capacity beyond simply measuring physical functioning. The ADLH has been found to be a reliable and valid indicator of functional capacity (Snowden et al. 1999). This scale measures each person's ability to independently perform tasks necessary for self-care. The ADLH scale encompasses physical and cognitive reasons for need without distinction. Four main tasks are used to judge placement on the hierarchy: personal hygiene, toilet transfer, locomotion and eating. Each of the four tasks are scored from 0 (total independence) to 6 (total dependence), and then an overall score is determined from these scores (Morris et al. 1999). Please see appendix b for the criteria for this ranking. A categorical variable for the ADLH was created to identify persons with a score of 3 or more (1) in comparison to persons who score 0-2 (0).

Another variable used to examine ADLH needs is the ADL Clinical Assessment Protocol (ADL-CAP). The ADL CAP is based on RAI-HC variables assessing the risk of preventable ADL decline. It has three distinct levels: a CAP score of 0 represents a person whose ADLH score is unlikely to change; a CAP score of 1 represents a person whose ADLH score is likely to improve, and a score 2 represents a person whose ADLH score is likely to decline. One of the indicators used within the CAP is receipt of physiotherapy. The CAP was modified by removing the code for physiotherapy, as the receipt of physiotherapy was an outcome of interest in the study.

The Gross Motor Function Classification Scale (GMFCS)

The other independent variable for severity, the GFMCS scale, does not exist within the interRAI family of instruments. Instead, a data cross-walk was created between items on the

RAI-HC that represented clinical domains assessed by the GMFCS; this crosswalk included

RAI-HC items on physical functioning, use of assistive devices, and use of stairs. Please see

appendix b for the GFMCS scale crosswalk, and an explanation of the translation using RAI-HC

variables. Crosswalks between the interRAI family of instruments and other severity scales have

been completed in the past. One such crosswalk was completed by Berg and colleagues (2009),

who found variable matches between the RAI-HC assessment and variables within the

International Classification of Functioning, Disability, and Health (ICF). This crosswalk found

variable matches for 43% of Body Function codes (Berg et al. 2009). The ICF is often used by

clinicians and researchers to describe function of people with CP, and as such, a successful

crosswalk between the ICF and the RAI-HC increases confidence that the instrument will have

sufficient explanatory variables to crosswalk a CP-specific severity scale.

Clinical Complexity

Other measures of clinical complexity and severity that will be assessed in the

relationship between CP and service utilization include the Cognitive Performance Scale (CPS),

the number and type of comorbidities reported for the person, the person's score on the Changes

in Health, End Stage Disease, Signs and Symptoms (CHESS) scale, and the person's score on the

depression rating scale (DRS).

The CPS measures the home care recipient's ability to make "daily decisions" on his or

her own (Morris et al. 1997). It is calculated by assessing how easily and often the person being

assessed is able to make safe and healthy choices in their daily life, and how much supervision is

required because of their level of ability. Like the ADL scale, it is also measured from 0-6, with

0 being no impairment, and 6 being very severe impairment. Please see appendix b for full scale

information. The CPS has been shown to be a reliable measure of cognitive performance (Landi

et al. 2000).

Comorbidities will be measured additively. The comorbidities that will be considered will

be Chronic Obstructive Pulmonary Disorder (COPD), diabetes, coronary artery disease,

congestive heart failure, other cardiovascular disease, and cancer. These diseases are more

prevalent in older populations in general, and may distinguish the health status of persons with

CP.

The CHESS scale is a measure of the instability of the health of the home care recipient.

It reports, on a scale of 0-5, the risk of the home care recipient's health declining seriously. Each

home care recipient's CHESS score is determined by health indicators such as ADL and CPS

decline, vomiting and dehydration, end-stage disease, unintentional weight loss, respiratory

problems, loss of appetite, and water retention (Hirdes et al. 2003). Please see appendix b for

complete score determination information. The CHESS scale was also found to be similarly

associated to negative outcomes associated with frailty as traditional frailty measures (Armstrong

et al. 2010). As both a measure of health instability and a corollary for frailty, the CHESS scale

should be an indicator of increased clinical need.

The Depression Rating Scale (DRS) is a scored from 0-14 with 14 indicating the greatest

frequency and diversity of depressive indicators. The DRS is based on the observed frequency

seven mood indicators (Burrows et al. 2000). Please see appendix b for full determination

information.

Demographic Variables

Demographic measures that were assessed include the person's use of an interpreter,

marital status, whether the assessment was a new intake or a routine assessment [initial

assessment], whether the person lived in a private residence or an assisted living situation [lives

in community], and the origin of the assessment [CCAC]. These first three variables will

measure the home care recipient's likelihood of being able to be a strong self-advocate, or have

an advocate for his or her care needs. Advocacy by or on behalf of the home care recipient could

result in improved access to needed services (Palisano et al., 2012). The type of assessment—

new intake or routine—was included to screen for PT or OT that is provided in response to acute

events, or for on-going rehabilitation.

The CCAC variable was coded by a categorical variable in the OACCAC database that

listed the CCAC of assessment origin. To include this information in the analysis, dummy

variables were created to represent each CCAC. As seen in figure 1, the majority of persons in

the entire population, and of the specific population of persons with CP lived in the Hamilton

Niagara Haldimand Brant (HNHB) CCAC. This CCAC represented 14.7% of the total

population and 17.0% of persons with CP. This CCAC had the second largest relative

concentration of persons with CP, with a discrepancy of 2.3% between the concentration of the

total population and the concentration of the population of persons with CP; the Chatham CCAC,

representing 8.4% of the population, was the origin of assessment for 11.0% of persons with CP

in the population, creating a discrepancy of about 2.6%. Please see Table 7 in Appendix B for a

full comparison of populations in CCACs. Because of the magnitude of the size of the CP

population and its disproportionate representation in the HNHB CCAC, this CCAC was selected

as the reference level for the CCAC dummy variables.
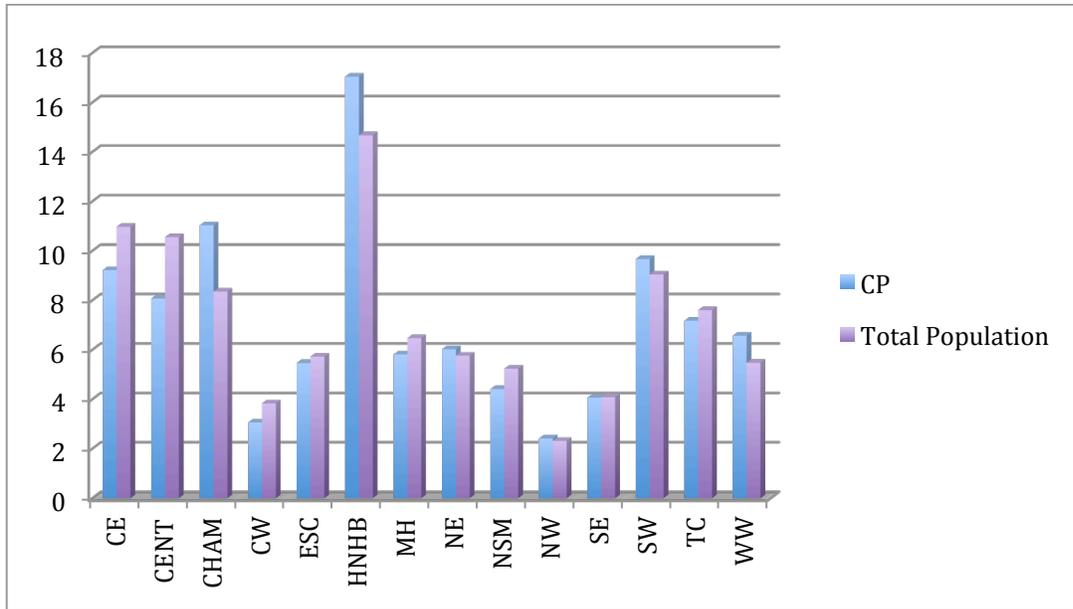
Figure 1: Percent of sample population with CP residing in each CCAC compared to percent of total sample residing in each CCAC

Dependent Variables

There will be three dependent variables examined: use of physical therapy in the past 7 days (P1f), use of occupational therapy in the past 7 days (P1g), and use of at least one or both of the two therapies in the past 7 days (P1f and/or P1g). Although the RAI-HC records the amount of time spent with each of these therapists, this analysis will focus solely on whether or not the therapy has been prescribed to and received by the home care recipient. This analysis will focus on the bivariate response of therapy or no therapy to begin to identify the patterns of usage by this population; however, the number of minutes of therapy will be used to screen out cases of visits by therapists solely to check on equipment. PT or OT sessions will be considered a therapy session if the person is said to have received at least 20 minutes of the specified therapy. The variable combining persons who have received at least one of the therapies will not include persons who have a combined total of 20 minutes between the two therapies: i.e., a person who received 10 minutes of PT and 10 minutes of OT will continue to be excluded. Further studies may choose to identify what predictors affect the amount of therapy received once PT or OT has been prescribed to the home care recipient.

Data Analysis:

Data analysis was divided into three distinct sections. The first section describes the characteristics and therapy utilization of people with Cerebral Palsy in Home Care as compared to other home care recipients, including demographics and mobility levels. The second section compares the association of the Gross Motor Function Class System and the Activities of Daily Living Hierarchy Scale individually for the utilization of occupational (OT) and physical (PT) therapy in Home Care for people with Cerebral Palsy. The final section builds a new model using indicators that show promise of strong association.

Descriptive Statistics

Statistical analysis was performed using Statistical Analysis Software version 9.2 (SAS). Analyses were performed to describe the general profile of care recipients within the home care system using the independent variables that will be tested for association with service utilization. These profiles will be stratified first by diagnosis (person with CP, person without CP, but with another neurological condition, or person without a neurological condition). Chi-square tables were used to determine what significant differences exist between persons with CP and the comparison groups in terms of both service utilization, and distribution of the variables to be tested for association. Age stratification was used to test for effects caused by differences in age distributions.

Variables Associated with Therapy Usage

Further analysis was carried out solely among persons with Cerebral Palsy. Preliminary data analysis was again performed using chi-square tables to test for associations between the independent variables and use of therapy. Scale variables were tested, twice with each dependent variable: once as coded, and once coded into a bivariate variable at a cut-off point (severe vs. not-severe). In all cases, the optimal coding for analysis purposes was a collapsed, 3 level variable.

Variables significantly associated with therapy usage, either in general or for use of a specific therapy (either OT or PT, but not both), in the bivariate analyses were then used in logistic regression models. There were three models tested. The first two assessed, independently, the effect of the GMFCS and ADL hierarchy on service use. The third model

assessed all potential variables associated with service use, including the GMFCS, ADLH, and

other variables found to be significant in bivariate analyses.

Specifically, the first logistic regression model tested evaluated the strength of

association with the translated GMFCS. The second model will evaluate the ADLH, as well as

the ADL CAP (first separately, and then together). Finally, the third model will evaluate the

ADLH, GMFCS, and other variables found to be significant in bivariate analyses. The model

was built finally by testing variables that have shown significance in the aforementioned

bivariate analysis in order to avoid entry and deletion effects. Odds ratios within the models will

be analyzed using confidence intervals. Confidence intervals will be calculated for each

regression coefficient. Once these intervals have been translated from the natural log, the

significance of the corresponding variable within the model will be determined by whether or not

the interval includes 1.0, or a neutral odds ratio. The significance of association will be

determined using the c-statistic. The c statistic measures how well the model differentiates those

that experience an event (in this case, receive PT, OT or PT and/or OT) from those who do not

(Cook, 2007). Finally, the Hosmer-Lemeshow test will be used to determine model fit.

Results

I.   Clinical Profile

In table one, descriptive statistics are presented showing the distribution of demographic

variables, clinical indicators, and use of PT and OT across the diagnosis groups. All associations

were significant to $p<0.0001$ unless otherwise specified.

Table 1: Descriptive statistics for demographic and clinical variables by diagnosis group

	Total Population (n=519,433)	Comparison Group (n=319,930)	Other Neurological Condition (n=199,480)	Cerebral Palsy (n=2,000)
DEMOGRAPHICS				
Female (%)*	63.1	64.7	60.6	51.9
Married (%)*	39.3	38.9	42.0	9.0
Lives Alone (%)*	32.7	36.9	26.0	22.8
Use of an Interpreter (%)*	9.2	8.2	10.7	10.5
Age Group (%)*				
18-24	0.5	0.5	0.2	16.9
25-44	3.3	4.2	1.5	38.7
45-64	14.3	17.7	8.8	31.9
65+	81.9	77.6	89.5	12.5
Initial Assessment (%)*	53.3	67.8	44.8	36.3
Lives in Community (%)*	90.3	93.1	85.8	82.2
CLINICAL INDICATORS				
Activities of Daily Living Hierarchy (%)*				
0	62.2	73.1	45.0	28.3
1-2	23.4	18.1	32.0	17.8
3+	14.4	8.8	18.1	53.9
Gross Motor Function Classification System Crosswalk (%)*	10.6	10.5	10.8	5.1
2	59.3	63.6	52.4	49.3
3	28.8	25.1	34.8	42.9
4	1.3	0.8	2.0	2.7
5				
Modified ADL CAP (%)*				
0- Decline or improvement unlikely	64.6	75.1	47.7	42.9
1- Improvement likely	11.6	7.8	17.4	44.7
2- Decline likely	23.8	17.1	34.9	12.4
CHESS Scale (%)*				
0	30.3	31.2	28.5	64.8
1-2	55.3	54.4	57.0	32.5
3+	14.4	14.4	14.5	2.7
Use a Feeding Tube (%)*	1.0	1.0	1.0	8.6
Use of a Wheel Chair (%)*	9.3	6.8	12.7	57.2
Cognitive Performance Scale (%)*				

0	46.7	63.5	19.5	32.8
1-2	39.7	33.1	50.5	33.1
3-4	8.6	2.4	18.6	11.2
5-6	5.0	1.0	11.4	23.0
Depression Rating Scale 3+ (%)*	15.8	14.5	18.1	9.9
Difficulty with Expression (%)*	10.9	3.0	23.5	36.4
Difficulty with Comprehension (%)*	11.8	3.7	24.8	26.8
Fell within the past 30 Days (%)*	31.9	28.8	36.8	23.8
Number of Comorbidities (%)*				
0	18.8	16.0	22.9	70.8
1	25.3	23.3	28.7	19.4
2	28.3	30.1	25.6	6.4
3+	27.9	30.6	22.2	3.4
Receipt of Rehabilitative Services (%)				
At least 20 minutes of PT*	9.5	10.1	8.5	7.5
At least 20 minutes of OT	9.2	9.2	9.2	9.6
At least 20 minutes of either PT or OT*	16.2	16.8	15.2	14.7

*=p<0.05

Demographic Variables

Among the 519,443 cases the study sample, 2000 had a diagnosis of Cerebral Palsy (CP), 197,513 had a neurological disorder diagnosis other than CP, and 319,930 had no neurological disorder diagnosis. The sample was concentrated in the older age groups, with 81.9% (n=425,384) age 65 years or older, and 14.3% (n=74,509) of cases reporting an age of 45-64 years; the two younger age groups of ages 18-24 and 25-44 represented 0.47% (n=2,452) and 3.3% (n=17,098) of cases, respectively.

Persons with a CP diagnosis had a significantly different age distribution than either of the comparison groups. As shown in table 1, 55.7% (n=1109) of cases with a CP diagnosis were under the age of 45 and 12.5% (n=250) were over the age of 65. The majority of cases from both comparison groups were over the age of 65, with 89.5% (n=176,745) of cases with a neurological disorder other than CP were in this age group, as were 77.6% (n=248,339) of cases

without a neurological disorder (98.3% and 95.3% of cases were above the age of 45, respectively).

Although just over half of persons with CP were female (51.9%, n=1036), the proportion of women was higher among the other comparison groups. A smaller proportion of persons with CP were married (9.0% compared with 42.0% of persons with a different neurological disorder, and 38.9% of persons with no neurological disorder). Marriage was associated with whether or not someone receiving home care lives alone in the general population and within the population of persons with CP. Despite this association, a significantly smaller proportion of persons with CP lived alone than persons in both comparison groups; however, the most sizeable difference was from the comparison of persons in one of the neurological disorder diagnosis groups (CP or other) and the comparison group: 22.8% of persons with CP and 26.0% of persons with a different neurological disorder lived alone, compared to 36.9% of the comparison group of persons with no neurological disorder.

When stratified by age, a larger proportion of persons were male than were female in the youngest age group, across all three diagnosis groups. This was of interest as all three groups had a higher proportion of persons who were female over all. The proportion of persons with CP who were female grew larger slowly, but steadily, across the first three age groups, and was slightly smaller in the oldest age group than in age group 3. All proportions were close to the overall proportion of 51% female. With the exception of the youngest age group in the comparison group with no neurological disorders, there was a larger proportion of persons with CP who were male than in the other two diagnosis groups, across age groups. In both comparison groups, there was a sharp contrast between age groups 1 and 2, and age groups 3 and 4. The demographics of the first age group had a male majority, while the second age group had a large female majority.

The third age group had a slightly smaller female majority than age group 2, while the oldest age

group had a much greater female majority.

The proportion of persons who were married steadily increased in the first three age

groups across all diagnosis groups. This proportion decreased slightly in the oldest age group for

the two comparison groups, while it continued to increase to 18% for persons with CP. The

proportion of persons with CP who were married continued to be much lower than the proportion

of persons who were married in either comparison group, never reaching even half of the rate of

marriage in either group. All three diagnosis groups had a very low proportion of their

population living alone in the two younger age groups, and a larger proportion of the population

living alone in the older age groups. Persons with CP had a lower proportion of persons who

lived alone over all, and in the younger two age groups, but a larger proportion of persons who

lived alone in the two older age groups. Please see tables 9-11 in appendix a for full results.

Use of an interpreter was significantly associated with diagnosis; however, this difference

was mainly between the two groups of persons with a neurological disorder (10.5% of persons

with CP and 10.7% of persons with a different neurological disorder used an interpreter) and the

comparison group (8.6%).

Location of residence was also of interest. Diagnosis was significantly associated with

the CCAC of assessment origin, and receipt of services while living in community, and not while

living in an assisted living situation of some kind.

A smaller portion of persons with CP resided in private residences within the community

compared with the comparison groups; 17.8% of persons with CP lived in group homes, nursing

homes, or other, supported living situation, compared to 14.2% of persons with a different

neurological disorder, or 6.9% of persons with no neurological disorder. Finally, there was a

significant association between diagnoses and whether the assessment included within the data

set was the person's initial assessment. A substantially larger proportion of persons with CP were

receiving a follow up assessment at time of included assessment than either of the two

comparison groups: only 36.3% of assessments completed for persons with CP were initial

assessments, compared with 44.8% of persons with a different neurological disorder, and 58.7%

of persons with no neurological disorder.

Clinical Indicators

There was a significant association between indicators of health status stability and

diagnosis. A substantially smaller proportion of persons with CP scored in the severe categories

for either the CHESS scale or the modified ADL CAP. Only 2.7% of persons with CP had a

CHESS score of 3 or above, compared to 14.5% for both of the other comparison groups. About

12% of persons with CP had an ADL CAP score of 2 (indicating a risk of ADL decline),

compared to 35% of persons with a different neurological disorder and 17% of persons with no

neurological disorder. The majority (64.8%) of persons with CP had a CHESS score of 0, a

substantially higher proportion than persons with a different neurological condition (28.5%) and

persons with no neurological condition (31.2%); however, a substantially smaller proportion of

this population had an ADL CAP score 0 (42.9%), indicating that there is no likelihood of

increase nor decline in ADLH score, than the two other groups (47.7% and 75.1% respectively).

General clinical indicators of severity and/or increased needs had mixed results for

persons with CP, both for physical, cognitive, and mental health indicators. A much greater

proportion of persons with CP used assistive devices such as a wheel chair (57.2% compared

with 12.7% of persons with a different neurological disorder, or 6.8% of persons with no

neurological disorder) or a feeding tube (8.6%, compared with 1.0% of either comparison

group), than either of the two comparison groups. As shown in table 1, a smaller percentage had recently fallen and fewer had one or more specified comorbidities. A larger proportion of this population had difficulty expressing themselves, comprehending communicated information, and to score a 3 or higher on the CPS. Difficulty of expression could be indicative of two distinct clinical indicators. A person with CP could have difficulty expressing him or herself because of a cognitive issue. The issue could also lie in the physical manifestation of CP creating a barrier to control or use of muscles that are necessary to form words. A smaller proportion of persons with CP scored above a 3 on the DRS than the two comparison groups.

When these results were stratified by age, there was a general trend across all three diagnosis groups of larger proportions of persons with ADLH scores of 3 or above in the youngest groups. The proportion of persons with ADLH scores of 3 or above was lower in each subsequent age group. One exception was the oldest age group in the comparison group with no neurological disorders, which had a slightly larger proportion of persons with severe ADLH impairment in age group 4 compared to age group 3. Persons with CP continued to have a higher proportion of persons with severe ADLH scores than the two comparison groups across all age groups. The proportion of persons with a CHESS score of 3 or higher increased with increasing age groups across all three diagnoses. Persons with CP maintained a substantially lower proportion of persons with a CHESS score of 3 or above compared to the other groups.

The trend for CPS scores differed greatly between diagnosis groups across age groups. The proportion of persons with CP with a CPS score of 5 or 6 decreased dramatically as age groups increased, from 37.7% of persons aged 18-24 and 31.6% of persons 25-44 to 12.3% of persons 45-64 and 3.6% of persons age 65 +. Persons without a neurological disorder shared this trend, but had a much lower proportion of persons with these severe CPS scores, and so the trend

was less dramatic, starting at 10.8% in the youngest age group, and falling to 0.8% in age group 4. The comparison group of persons with a neurological disorder that was not CP had a substantial decrease in the proportion of persons with a CPS score of 5 or 6 from age group 1 to age group 2, from 25.1% to 8.7% and a smaller decrease from age group 2 to age group 3, but had a moderate increase from age group 3 to age group 4, from 6.6% to 11.8%. Please see appendix a for full results.

Receipt of Rehabilitative Care

When comparing the three dependent variables: receiving at least 20 minutes of physical therapy (PT) in the last week, receiving at least 20 minutes of occupational therapy (OT) in the past week, and receiving at least 20 minutes of either or both PT or OT, the three diagnosis groups were not substantially different. This is illustrated in figure 2. There were statistically significant associations between diagnosis and access of PT (χ^2=378.98, p<0.0001), and access of at least one of the therapies (χ^2=242.80, p<0.0001), but the association between diagnosis and OT was not significant (χ^2=0.51, p=0.7747). A smaller proportion of persons with CP received PT, or received at least one of the two therapies than the other two diagnosis groups, but, as stated earlier, not substantially.

Stratification by age produced a few noticeable, but small trends. The proportion of persons with CP who received PT, or at least one of the services, was slightly higher across all four age groups. The proportion of persons with no neurological disorder who received at least one of the two therapies decreased as the age groups increased. There were no clear patterns for OT. These results can be found in tables 9-11 in appendix a.
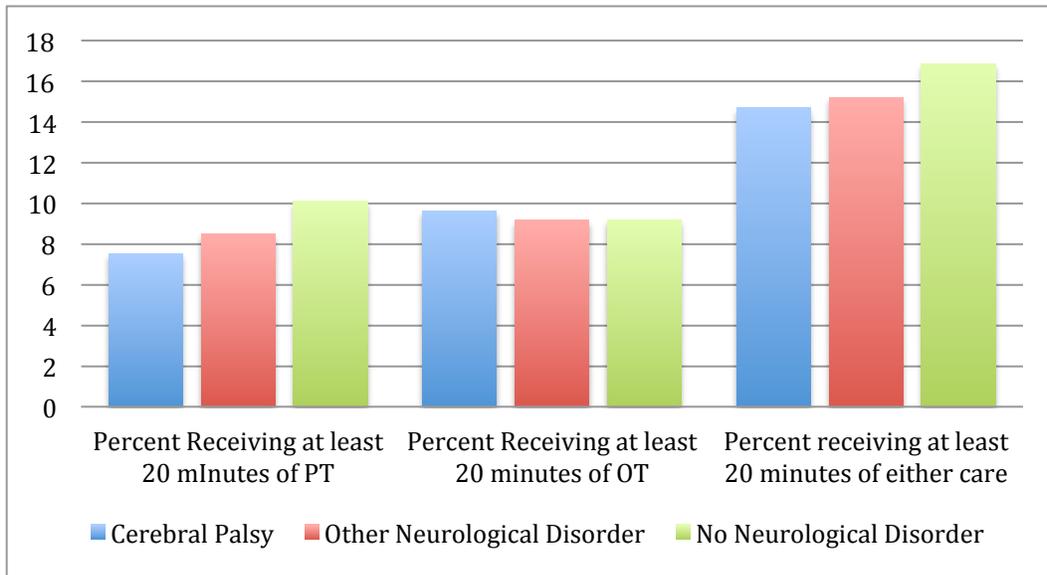
Figure 2: Comparison of the percent of each diagnosis group that received PT, OT, or either PT or OT, or both.

II.   Comparison of the Activities of Daily Living Hierarchy and the Crosswalk of the Gross Motor Function Classification System

As was presented in table 1, The Gross Motor Function Classification System (GMFCS) Crosswalk and Activities of Daily Living Hierarchy (ADLH) were also found to have a significant association with diagnosis. Persons with CP had substantially higher rates of increased ADL needs, and increased rates of being categorized as having little to no independent mobility on the GMFCS, as summarized in figures 3 and 4. More than half of persons with CP had ADLH scores of 3 or above, whereas only 23% of persons with a different neurological disorder and 8.8% of persons in the general comparison group shared this level of need. While no group had a substantial number of persons with a GMFCS score of 5, a greater proportion of persons with CP (45.5%) had a score of 4 or 5 compared to persons with a different neurological disorder (38.8%) and the comparison group (25.9%). Persons with CP showed lower levels of independence in movement and daily activities than the two other comparison groups. Within the

population of persons with CP, there was not a strong association between ADL needs and

GMFCS score. The moderate correlation between GMFCS and the ADLH was significant,

($r_{spearman} = 0.61$, p<0.0001), and chi-square analysis was also significant. The relationships

between ADL needs and GMFCS level with the dependent variables are illustrated in charts 5

and 6.
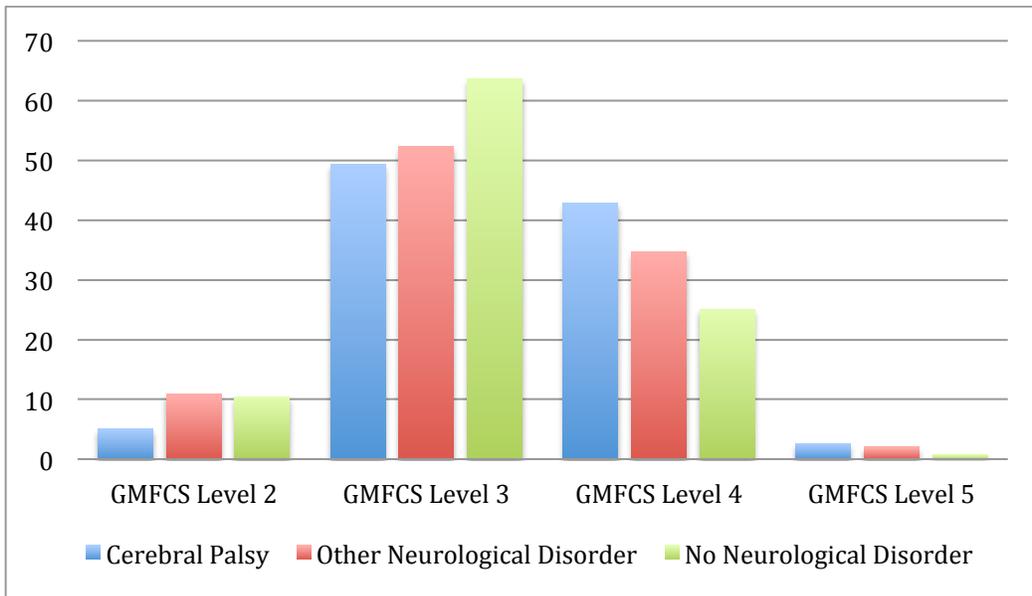
Figure 3: Percentage of each diagnosis group by level of the GMFCS
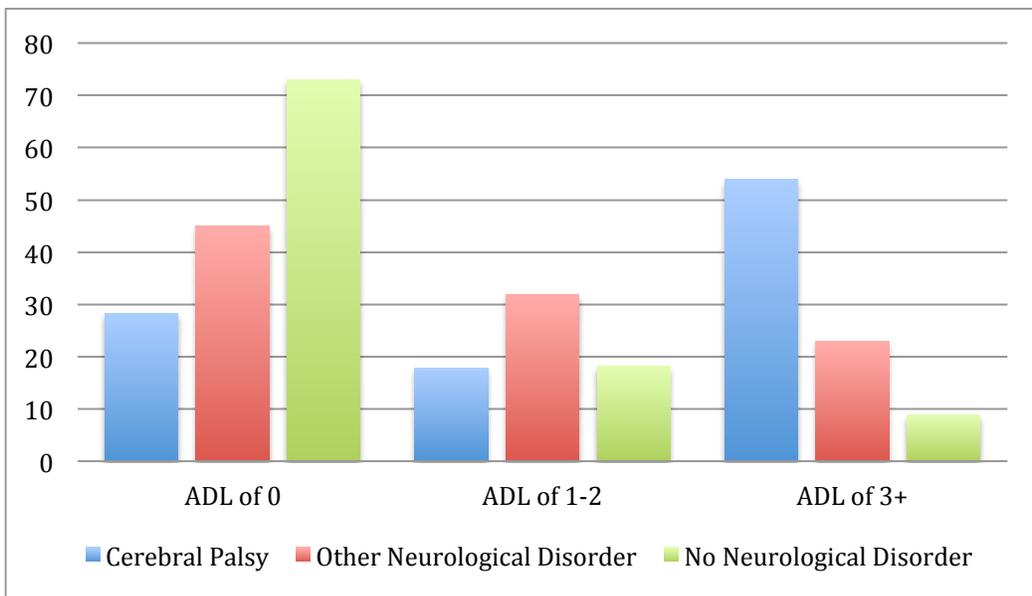
Figure 4: Percentage of persons in each diagnosis group by ADLH score.
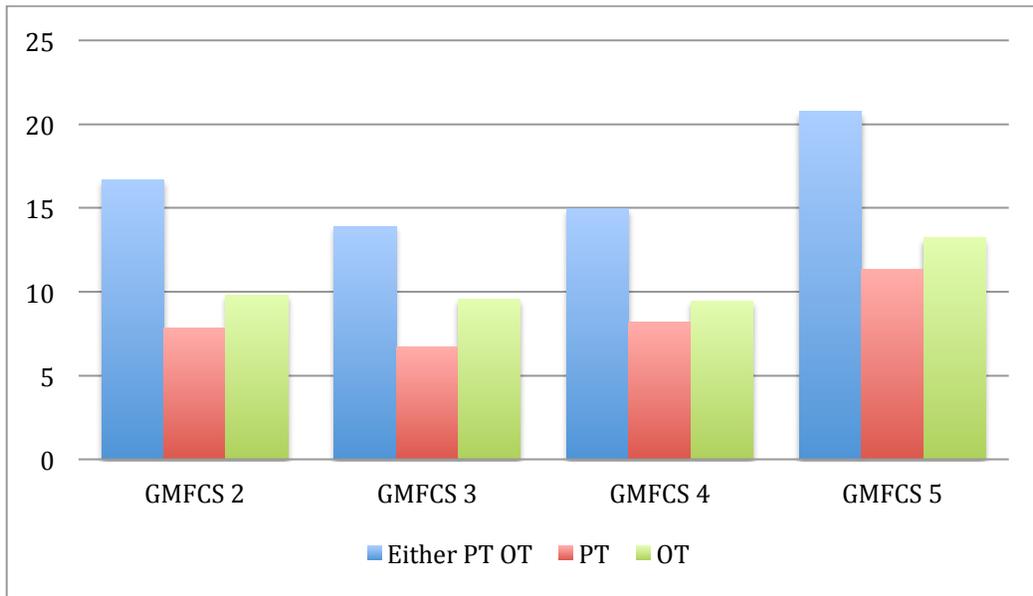
Figure 5: Percentage of persons with CP receiving rehabilitative care by GMFCS level
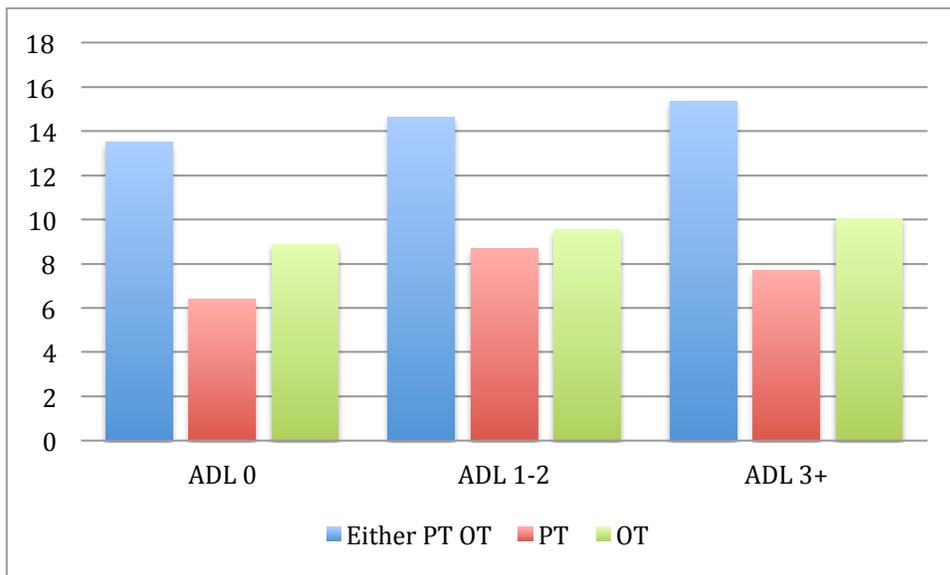
Figure 6: Percentage of persons with CP receiving rehabilitative care by ADLH score

The associations between access to rehabilitative services and these two measures of severity were assessed using chi-square analyses. The preliminary chi- square tables, reported in table 2, showed no significant association between the severity measure (either ADL or GMFCS)

and the dependent variables within the sample of persons with Cerebral Palsy. Bivariate logistic

regression examining the relationship between receipt of rehabilitative services and functional

measures showed similarly insignificant results, with c-statistics of just over 0.5. Given this lack

of association, no multivariate models were specified. Several other indicators of mobility and

independence, such as needs within the Instrumental Activities of Daily Living and the ADL

Long Form, were tested as well, with no significant associations found.

III.   Multivariate Model

Table 2: Results of bivariate analysis of the relationship between demographic and clinical
indicators, and use of rehabilitative services for persons with CP

	Received Physical Therapy		Received Occupational Therapy		Received either Physical or Occupational Therapy	
	%	P-Value	%	P-Value	%	P-Value
Sex (%)		0.18		0.69		0.44
Female	6.7		9.3		14.1	
Male	8.3		9.9		15.3	
Marital Status (%)		0.66		0.021*		0.09 Ŧ
Married	8.3		14.4		18.9	
Unmarried	7.4		9.1		14.23	
Living Situation (%)		0.86		0.49		0.67
Lives Alone	7.7		10.4		15.2	
Does not Live Alone	7.5		9.3		14.4	
Use of an Interpreter (%)		0.29		0.76		0.31
Uses an Interpreter	5.7		9.0		12.3	
Does not use an Interpreter	7.7		9.7		14.9	
Age Group (%)		0.46		0.45		0.72
0-24	8.2		8.2		13.4	
25-44	6.7		9.4		14.3	

	Received Physical Therapy		Received Occupational Therapy		Received either Physical or Occupational Therapy	
	%	P-Value	%	P-Value	%	P-Value
45-64	7.2		11.0		15.4	
65+	9.6		8.4		16.0	
Initial Assessment (%)		0.0003*		<0.0001*		<0.0001*
Initial Assessment	10.3		14.0		20.1	
Follow Up Assessment	5.9		7.1		11.6	
Residence (%)		0.0002*		0.018*		0.002*
Lives in Community	6.5*		8.8*		13.2*	
Lives in Supported Living Situation	12.3*		12.9*		20.9*	
CLINICAL CHARACTERISTICS						
Activities of Daily Living Hierarchy (%)		0.40		0.76		0.62
1	6.4		8.9		13.5	
2	8.7		9.6		14.6	
3+	7.7		10.0		15.3	
Gross Motor Function Classification System Crosswalk (%)		0.56		0.85		0.52
2	7.8		9.8		16.7	
3	6.7		9.6		13.9	
4	8.2		9.5		15.0	
5	11.3		13.2		20.8	
Modified ADL CAP (%)		<0.0001*		<0.0001*		<0.0001*
0- Decline or improvement unlikely	7.7		9.6		15.0	
1- Improvement likely	5.0		7.5		11.2	
2- Decline likely	15.7		17.3		26.2	
CHESS Scale (%)		0.002*		0.004*		0.001*
0	6.0		8.1		12.3	
1-2	10.0		12.0		18.6	
3+	13.0		16.7		24.1	
Use a Feeding Tube (%)		0.029*		0.33		0.025*
Uses a feeding tube	11.*		11.7		20.5	
	7.1		9.4		14.1	

	Received Physical Therapy		Received Occupational Therapy		Received either Physical or Occupational Therapy	
	%	P-Value	%	P-Value	%	P-Value
Does not use a feeding tube						
Use of a Wheel Chair (%)		0.48		0.12		0.09 ᵀ
Uses a wheel chair	7.9		10.5		15.8	
Does not use a wheel chair	7.0		8.4		13.1	
Cognitive Performance Scale (%)		0.17		.17		0.14
0	8.5		11.4		16.5	
1-2	6.8		9.1		13.9	
3-4	4.5		6.7		10.3	
5-6	8.5		9.1		15.2	
Depression Rating Scale (%)		0.81		1.00		0.83
0-2	7.6		9.6		14.7	
3+						
	7.1		9.6		14.1	
Expression (%)		0.67		0.28		0.26
No Difficulty with Expression	7.8		10.1		15.3	
Difficulty with Expression	7.0		8.7		13.5	
Comprehension (%)		0.53		0.27		0.28
No Difficulty with Comprehension	7.7		8.4		15.2	
Difficulty with Comprehension	7.1		10.0		13.3	
Falls (%)		0.20		0.67		0.72
Did not fall within the past 30 days	7.1		9.4		14.5	
Fell within the past 30 days	8.8		10.1		15.2	
Number of Comorbidities (%)		0.008*		0.80		0.24
0	7.6*		9.3		14.7	
1	8.0*		10.9		15.3	
	3.9*		8.7		11.8	

	Received Physical Therapy		Received Occupational Therapy		Received either Physical or Occupational Therapy	
	%	P-Value	%	P-Value	%	P-Value
2 3+	11.5 *		10.3		19.3	

Ŧ= P<0.1 *=P<0.05

Bivariate Analysis

In preparation for building the full model, bivariate analysis using chi square tables was performed comparing the independent variables individually with each of the three dependent variables. Analysis was performed using only the population of persons with CP. Results for this analysis are reported in table 2, except for results from the CCAC dummy variables. Please see Appendix A for full results of comparison with each CCAC.

There were five variables that had significant associations with all three dependent variables: the indicator that the included assessment was the person's initial home care assessment, living in an assistive environment (not the community), living in the Waterloo Wellington CCAC, increased CHESS scores, and an ADL CAP of 1 or 2. Closer analysis of the initial assessment variable revealed significant positive associations between the person with CP having been discharged from the hospital sometime in the last 30 days and accessing PT, OT or either. For all three dependent variables, having an ADL CAP of 2 increased the likelihood of receiving a rehabilitative service compared to those who triggered the ADL CAP of 1.

The proportion of persons with CP receiving PT increased significantly among persons using a feeding tube for primary food intake. Having comorbidities was significantly association with PT. Among persons having 1 comorbidity, 8.1% received PT while 6.6% of persons with 2

or more comorbidities received PT. Being married significantly and substantially increased the

likelihood of receiving OT; the effect was similarly substantial, but not statistically significant

(P=0.09) for persons receiving either PT or OT. Similar results were found for persons using a

wheel chair.

Logistic Regression

To create three multivariate models—one for each dependent variable—logistic

regression was performed using the variables significant in bivariate. All three models were

created by first running a model that included all associated variables. CCAC was tested using

dummy variables for each CCAC, with the Hamilton Niagara Haldimand Brant (HNHB) CCAC

serving as a reference level. The ADL CAP was analyzed using the class statement to

examingthat the contribution of each level as related to receipt of OT, PT, or Both. A score of 0,

or the indicator that the person being evaluated is likely to maintain (neither improve or have a

decline in) their ADLH score was used as a reference level. Spearman correlation was used to

identify variables that could be collinear; however, no strong correlations were observed between

any independent variables tested. Finally, although it was not significant in bivariate analysis,

each model included CPS. Since a CPS score of 6 would preclude a person from receiving PT or

OT, it was deemed necessary to control for persons with a CPS of 6 within the analysis. This was

done in three ways: the first was to include the collapsed scale coding in the model. This did not

increase the explanatory value of the model, and so was rejected. The second was to include a

bivariate indicator for a CPS score of 6 or not. This also did not improve the model. Finally, the

models were run with persons with a CPS score of 6 excluded. This caused a minor improvement

on the c-statistics of the models, but had no substantial effect on any of the explanatory values. It

was decided that all persons in the population with a diagnosis of CP and a defined age of 18 or over would be considered in analysis.

Receiving Either PT or OT

When the first model was run examining factors associated with receiving either PT or OT (or both), the independent variables included were: initial assessment, community living, the CHESS scale, use of a feeding tube, marital status, use of a wheel chair and CCAC of assessment origin. This model had a c-statistic of 0.67, showing some, but not strong explanatory value. The variables for initial assessment, living in the community, the CHESS scale, and living in the Waterloo Wellington CCAC were significant within a 95% confidence limit. Use of a wheelchair was significant within a 90% confidence limit.

Removing the variable for marital status, which had no significant association in the first model, only lowered the c-statistic to 0.66, suggesting that it did not increase the explanatory value of the model substantially, and should not be included. In this second model, living in community joined use of a wheel chair to be only significant at a 90% confidence limit, leaving just the indicator for initial assessment, the CHESS scale, and the indicator for living in the Waterloo Wellington CCAC significant at a 95% confidence limit.

When the indicator for use of a feeding tube was removed, the c statistic once again only decreased a small amount, to 0.66. Living in community and use of a wheelchair were both significant at a 95% confidence level in this model, suggesting that the severity indicated by use of a feeding tube may have been already accounted for by these variables. Initial assessment, the CHESS scale, and living in the Waterloo Wellington CCAC remained significant at the 95% confidence level.

Table 3: Logistic regression results examining factors associated with receipt of at least 20 minutes of PT, OT or Both.

Variable	Parameter Estimate	Standard Error	P- Value	Odds Ratio	Confidence Interval (95%)	
Initial Assessment	0.59	0.14	<0.0001	1.81	1.39	2.35
Community Living	-0.35	0.16	0.028	0.71	0.52	0.96
CHESS Scale	0.47	0.12	<0.0001	1.60	1.28	2.00
Use of a Wheelchair	0.33	0.14	0.018	1.39	1.06	1.82
CCAC						
Central East	-0.018	0.28	0.949	0.98	0.57	1.71
Central CCAC	0.20	0.28	0.478	1.22	0.71	2.10
Chatham	0.26	0.25	0.285	1.30	0.80	2.12
Central West	0.090	0.42	0.832	1.09	0.48	2.48
Escarpment	-0.61	0.40	0.134	0.55	0.25	2.22
Mississauga-Haldon	0.19	0.31	0.531	1.21	0.66	1.60
North East	-0.20	0.34	0.559	0.82	0.42	1.60
NSM	-0.043	0.36	0.904	0.96	0.48	1.92
North West	0.41	0.41	0.313	1.52	0.68	3.41
South East	-0.55	0.46	0.228	0.58	0.24	1.41
South West	0.24	0.26	0.361	1.27	0.76	2.11
Toronto Central	0.32	0.28	0.253	1.38	0.79	2.40
Waterloo Wellington	0.89	0.27	0.0008	2.44	1.45	4.10

Note: C-Statistic= 0.66; Hosmer-Lemeshow Goodness of Fit: p=0.74

The estimates of this final model suggest that a person with CP in Ontario Home Care is

more likely to receive either PT or OT at the time of their initial assessment, if they have a higher

CHESS score, use a wheelchair, live in a supportive care environment and/or live in the Waterloo Wellington CCAC (as compared to the HNHB CCAC). The Waterloo Wellington (WW) CCAC indicator had the largest effect of these variables increasing the odds of receiving PT or OT by 2.44, or 144% as compared to persons living in the CCAC with the largest population of persons with CP. Holding all other variables constant, persons receiving their initial assessment were 1.81 times more likely to receive PT or OT. On a 3 point collapsed CHESS scale (as described in the methods section), each increase of 1 point increased odds of receiving PT or OT by 1.6, which would suggest that persons who scored a 2 on this scale (3 or greater on the full CHESS scale), would have odds increased by 3.2 compared to persons who scored a 0. Use of a wheelchair increases the odds of receiving PT or OT by 1.39. Living in the community, as opposed to in a supported living environment, reduces the odds of receiving PT or OT by 30%.

Physical Therapy

The preliminary full model for access to physical therapy took the indicators for initial assessment, living in community, the modified ADL CAP, the CHESS scale, use of a feeding tube, number of comorbidities, and CCAC of assessment origin into consideration. As the CHESS scale takes into account ADL decline (or potential for decline), it was determined that the model could not contain both of these variables at once and so the model was run twice, substituting one for the other. In both cases, the c-statistic for this model was 0.69. In this model the indicators for initial assessment, living in the community, the CHESS scale, use of a feeding tube, the ADL CAP levels 1 and 2, and CCAC region indicators (the Central CCAC, the Chatham CCAC, and the Waterloo Wellington CCAC) were all significant at the 95% confidence level.

Removing the insignificant indicator for number of comorbidities increased the

explanatory value of the model slightly to a c-statistic of 0.69. The significance level of all other

variables remained unchanged. Removing the insignificant indicator for feeding tube left the c-

statistic at 0.69 for the model with the dummy variable indicators for the ADL CAP levels, and

at 0.68 for the model using the CHESS scale. The model with the ADL CAP levels was selected

to be the final model.

Table 4: Logistic regression results examining factors associated with receipt of at least 20 minutes of PT.

Variable	Parameter Estimate	Standard Error	P- Value	Odds Ratio	Confidence Interval (95%)	
Initial Assessment	0.37	0.18	0.038	1.45	1.02	2.07
Community Living	-0.55	0.20	0.007	0.58	0.39	0.86
ADL CAP Level 1	-0.40	0.21	0.053	0.67	0.45	1.00
ADL CAP Level 2	0.75	0.22	0.0008	2.12	1.36	3.29
CCAC						
Central East	-0.58	0.52	0.26	0.56	0.20	1.54
Central CCAC	0.75	0.36	0.038	2.11	1.04	4.29
Chatham	0.73	0.33	0.027	2.08	1.09	3.99
Central West	-0.021	0.65	0.97	0.98	0.28	3.47
Escarpment	-0.091	0.52	0.86	0.91	0.33	2.53
Mississauga-Haldon	-0.056	0.49	0.91	1.06	0.41	2.74
North East	0.28	0.44	0.53	1.32	0.56	3.14
NSM	0.58	0.45	0.19	1.80	0.75	4.30
North West	0.77	0.54	0.15	2.17	0.75	6.24
South East	0.13	0.57	0.82	1.14	0.37	3.49
South West	0.38	0.37	0.30	1.47	0.71	3.03

Toronto Central	0.64	0.38	0.094	1.89	0.90	3.99
Waterloo Wellington	1.25	0.35	0.0003	3.49	1.77	6.88

Note: C-Statistic= 0.693 Hosmer-Lemeshow Goodness of Fit: p=0.569

Once again, in this model the indicator with the largest significant effect was the

indicator for assessments originating in the Waterloo Wellington CCAC. Persons assessed in the

WW CCAC had increased odds of receiving physical therapy of 3.49 than persons living in the

HNHB CCAC, all other measured factors held constant. Living in the Chatham CCAC or the

Central CCAC also increased the odds of receiving physical therapy, by 2.03 and 2.11 compared

to the reference level respectively. Persons with CP who were at risk of ADLH decline (a two on

the ADL CAP) had increased odds of receiving PT by 2.12 compared with persons who were not

at risk of ADLH decline, nor likely to have improvement on the hierarchy. Persons who were

receiving their initial assessment had increased odds of receiving physical therapy by 1.45.

Finally, living in the community, instead of in a supported living environment, decreased the

chances of receiving physical therapy by 58%.

Occupational Therapy

The preliminary explanatory model for use of occupational therapy included the

indicators for initial assessment, living in community, marital status, the modified ADL CAP or

CHESS scale (once again, tested individually), wheelchair usage, and CCAC of origin, which

produced a c-statistic of 0.67. In this model, the indicators for initial assessment, marital status,

CHESS scale, wheelchair use, and assessment origin in the Waterloo Wellington CCAC were all

significant at the 95% confidence level. Removing the indicator for living in the community

reduced the c-statistic to 0.67 and did not change the significance of any of the variables;

however it left a model with only significant indicators (considering the indicator for CCAC of

origin as one indicator despite the many parts played within the model). Although the models

including ADL CAP and the CHESS scale were nearly identical in c-statistic, it was determined

that the model with the ADL CAP indicators was the stronger model considering the strength of

individual indicators.

Table 5: Logistic regression results examining factors associated with receipt of at least 20
minutes of OT.

Variable	Parameter Estimate	Standard Error	P- Value	Odds Ratio	Confidence Interval (95%)	
Initial Assessment	0.71	0.16	<0.0001	2.029	1.49	2.77
Marital Status	0.53	0.24	0.025	1.70	1.07	2.69
ADL CAP Level 1	-0.25	0.18	0.16	0.78	0.55	1.10
ADL CAP Level 2	0.59	0.21	0.0049	1.81	1.20	2.72
Use of a Wheelchair	0.44	0.17	0.0083	1.55	1.12	2.14
CCAC						
Central East	0.18	0.31	0.56	1.20	0.65	2.20
Central CCAC	-0.17	0.35	0.63	0.85	0.43	1.68
Chatham	0.061	0.30	0.84	1.06	0.59	1.91
Central West	0.14	0.47	0.77	1.15	0.46	2.91
Escarpment	-0.96	0.55	0.080	0.38	0.13	1.12
Mississauga-Haldon	0.59	0.32	0.066	1.81	0.96	3.39
North East	-0.46	0.43	0.28	0.63	0.27	1.47
NSM	-0.18	0.44	0.68	0.84	0.35	1.98
North West	0.14	0.51	0.79	1.15	0.42	3.15
South East	-0.84	0.62	0.17	0.43	0.13	1.45
South West	0.21	0.30	0.47	1.24	0.69	2.22

Toronto Central	-0.019	0.35	0.96	0.98	0.50	1.95
Waterloo Wellington	0.68	0.31	0.027	1.97	1.08	3.59

Note: C-Statistic= 0.67; Hosmer-Lemeshow Goodness of Fit: p=0.36

The indicator that had the largest significant effect in this model was the indicator for initial assessment. At initial assessment, persons with CP had 2.12 increased odds of accessing occupational therapy. All other indicators being held constant, persons with CP who had an ADL CAP score of 2 had increased odds of 1.81 compared to persons with a stable ADLH score. Living in the Waterloo Wellington CCAC increased the odds of access OT by 1.98. Being married increased the odds of accessing OT by 1.63. Use of a wheelchair increased the odds of accessing OT by 1.53.

Discussion

The purpose of this project was to examine the characteristics of persons with CP in

Ontario Home Care, and specifically to illuminate those characteristics associated with

rehabilitative service use in this population. The project explored the receipt of two services,

physical and occupation therapy, which are considered to be rehabilitation-focused services. This

study examined associations between receipt of services and demographic, clinical, and service

related characteristics assessed on the Resident Assessment Instrument for Home Care. Overall,

the project illustrated a potential gap between rehabilitative service need and provision. Despite

the nature of the rehabilitation goals for the services studied, there were no multivariate

associations between receipt of rehabilitative services and the scales of functionality. There were

strong associations between other systemic and clinical indicators.

Clinical Profile

Persons with CP constitute a small, but distinct, high-needs proportion of all Home Care

clients in Ontario. Demographically, this population was substantially younger, relatively evenly

split between the sexes, and a smaller proportion were married than the two comparison groups.

Age stratification suggested that some of the variation could be due to the concentration of

younger persons. In the case of persons with CP having a larger proportion of persons identified

as male within the sample than the two groups, it is possibly related to the much larger

concentration of persons in the sample who are not in an older stage of life. It has been well

established that women tend to live to older ages than men, but if these older age groups were

not represented in the sample, as they are in the two comparison groups, this effect would not be

accounted for. In the two comparison groups, age stratification showed a large increase in the proportion of women in the population of persons over 65 compared to the younger age groups.

In the case of marriage rates, there may be some effect from the larger concentration in the sample of persons with CP who are younger than Canada's median age of first marriage, however the substantially lower proportion of persons who are married across all age groups suggests that this is not the only factor involved. It is possible that CP, as a childhood onset disability, may reduce the likelihood of marriage, because of issues such as societal bias towards individuals with CP, or physical, intellectual or cognitive barriers to finding a partner. This might affect the ability of the person with CP to rely on informal supports, especially in later adulthood, when parental involvement is unlikely.

Clinically, a smaller proportion of this population had age-associated comorbidities. Age stratification suggested that there was some relation to the concentration of younger persons within the sample; however, a smaller proportion of persons with CP had these comorbidities even in the older age groups. This may speak to the reasons why persons with CP access home care, and why they may need to access more intensive care setting later. Reducing the number of comorbidities could reduce the complexity of treatment needed for each person. Conversely, while other groups may maintain a complexity that is manageable within home care even with these comorbidities, adding comorbidities with the aging process of CP may necessitate more needs than can be addressed in the home.

Cognitively, a larger proportion of persons with CP had a score of 5 or 6 on the CPS. There was also a larger proportion that had difficulty expressing themselves or comprehending information than the other two groups. This could have an impact on the complexity of treatment and care because it could hinder communication between the person with CP and their providers.

All diagnosis groups had substantially higher proportions of persons with severe CPS scores in the youngest age groups. This may suggest that increased CPS needs could be a factor in deciding whether a young persons with clinical needs can access services in the community, or whether they need to receive them at home. A CPS score this high could have implications for rehabilitative service use. Especially in the case of a person with a CPS score of 6, the CPS needs may be too great to receive PT or OT. Indeed, in the case of the ADL CAP, a person with a CPS score of 6 is automatically considered unlikely to have a change of ADLH score because this level of cognitive impairment will preclude independent activity. As PT or OT would not be provided to persons with a score this high, the increased proportion of persons with CP with severe CPS scores might have lowered the proportion of persons with CP receiving rehabilitative services.

A smaller proportion of persons with CP had fallen in the past 90 days. Fewer falls could also indirectly lead to increased health stability as it reduces the risk of an acute event that often causes physical damage. This rate could have been supported by the more than quadruple rate of wheelchair use by persons with CP compared with the two other diagnosis groups. In fact, further analysis found that persons with CP who did not use a wheel chair actually had increased rates of having recently fallen compared to the group of persons with no neurological disorder. Mobility needs that were addressed in childhood might lead to earlier use of an assistive device that could protect against an adverse event such as a fall. Indeed, use of such a mobility device as a wheelchair reduces or eliminates the opportunity for the user to fall. Other groups in the population may only receive their assistive device in response to an acute or adverse event, such as a fall. Further research could address this.

The health status of persons with CP appeared to be more stable than the comparison groups. A smaller proportion of this population scored a 2 (out of 2) on the modified ADL CAP or a 3 or above on the CHESS scale. The score on the CHESS scale could also mean that persons with CP are less likely to be clinically frail than persons in the other two groups (Armstrong et al. 2010). Persons with CP did show some increased risk of ADL needs compared to the other two groups. This suggests that although the general health of persons with CP is more stable than the other two populations, the population were likely to experience progression in the characteristic physical manifestation of the disorder.

The mobility and functionality needs of this population, as measured by the ADLH, were also substantially higher, suggesting that the amount of services needed may be increased compared to the rest of the population. Persons with CP also had lower levels of mobility, measured by the GMFCS crosswalk and the rate of use of a wheelchair. A greater proportion of persons with CP were receiving services while living in a supported or assisted living environment than the two other groups. A smaller proportion of persons with CP were receiving their initial assessment than the comparison groups, which suggests that persons with CP in this sample had sustained their services for longer. Literature suggests that, taking into account these findings, persons with CP would use more resources in their care, and specifically increased use of PT or OT (Palisano et al. 2012). While this could be true for other types of services that were not tested, there was actually a smaller proportion of persons with CP who received PT or either PT, or OT, or both, than the two comparison groups, and there was no significant difference in the percent receiving OT across diagnosis groups.

Along with other adults with childhood onset chronic illnesses, adults with CP have been noted to access care from pediatric facilities as adults, especially during transitional years

(Goodman et al. 2011). The transition between pediatric care, for which PT and OT seem to be more standard, and adult care may also affect service receipt, The relationship between need indicators and resources accessed within a few years of ending pediatric services might be informed by the person's relationship with their pediatric care team, and the expectations they have developed for the type of care they need. Therefore the first age group, that consists of persons between 18-24 to adjust for persons, may be in transition from pediatric care, or have recently transitioned or been transferred without transition from this care.

It must be acknowledged that persons with mild CP are likely to have different service needs than people with moderate to severe CP. The older age groups are likely to be represented mostly by persons with mild CP, and so these differences could be magnified. The age stratification showed increased ADLH and CPS scores in younger age groups, and increased prevalence of the other measured comorbidities in older age groups. This may suggest that persons with CP who access home care at older ages may be accessing this care for a primary diagnosis other than CP. While having CP might complicate the diagnosis for which they are receiving care, it may not be the driving factor behind receiving services for this group. This would suggest that services provided to the person might not be CP related.

Receipt of Rehabilitative Services

This project examined the association between receipt of rehabilitative services and clinical and demographic factors using two approaches. The first approach used bivariate analysis through chi-square tables and logistic regression to compare the association between receipt of the aforementioned services and two difference clinical scales measuring functionality: one, the ADLH, which measures independence, regardless of assistive device use, and one, The

GMFCS, which measures functionality taking assistive device use into account. The second

approach drew on a wide variety of clinical and demographic variables, first testing for their

association with the dependent variables through chi-square analysis, and then through

multivariate logistic regression analysis.

Activities of Daily Living and the Gross Motor Function Classification System

It was feasible to develop a crosswalk from interRAI HC items to create an adapted

GMFCS because of the breadth of measures included in the RAI-HC assessment. The GMFCS is

a scale totally based on independent mobility, with many distinctions drawn by where the

assessed is in need of assistive devices for mobility. Using the RAI-HC's indicators for mobility

devices indoors and outdoors as a basis for scale placement, the placement upon the scale could

then be by testing for ability to use stairs, and level of independence indoors and outdoors once

any assistive device has been implemented. This last measure of independence used ADL

indicators. Although the ADLH does not distinguish between use of an assistive device or not,

the persons assessed had already been distinguished for this characteristic. The independence

indicator allows for distinguishing people who are unable to transport themselves independently

even with assistive device, which increases their placement on the GMFCS.

The moderate correlation found between the GMFCS and the ADLH may indicate that

they are measures of different functional needs of persons with CP. The GMFCS, while

demonstrated to be useful in predicting the overall severity of CP in children, is a scale that is

based solely on mobility indicators. The starkest contrast between the levels comes from the use

of mobility devices where little emphasis is put on whether the use of the mobility device allows

for the person being scored to be independent. Conversely, the ADLH excludes the use of a

mobility device, and instead considers the person's ability to independently complete tasks,

testing for independence using any assistive devices that the person would use in completing these tasks in their everyday life. In this way, the two scales are differentiated between measuring levels of mobility and measuring independent functionality needs. The lack of association between either of the functional assessment scales and the dependent variables did not clarify the utility of either for assessing adults with CP. In home care, at least, providers may find the ADLH more useful than the GMFCS for care planning, as the ADLH encompasses more of the factors necessary to assess what services are needed for independent living. The GMFCS may be more useful in assessing the need for physical rehabilitative services specifically, or for quantifying baseline measurements of physical needs. Further research could assess whether the association between increased GMFCS scores and clinical complexity in children with CP is sustained in adults with CP. This relationship would increase the utility of the scale for home care providers, especially at intake.

Neither functionality scale was associated with rehabilitative service use. It is possible that this finding is related to the regulation for home care services that mandates that PT or OT must be used exclusively in cases where their use is expected to lead to rehabilitation. While complete rehabilitation of persons with CP is not realistic, it is important to note that despite the high levels of health stability in this population, persons with CP are at risk of increased physical symptoms as they age, and that these outcomes tend to take affect earlier in the life span than in the in the general population (Strax 2010). Services such as PT or OT may increase the person's ability to remain in their private residence instead of accessing residential care. As both scales do not take into account many other daily activities for which persons with CP may need assistance, living environment adaptations, or skills training to perform, such as food preparation, getting

dressed, or making and keep appointments, there may be other functionality factors driving

rehabilitative service use.

Rates of access of PT and OT were fairly stable across the ADLH and the GMFCS

among persons with CP. This may be related to the non-progressive nature of CP. Although the

physical symptoms do progress over time, this is not as abrupt as the experience of someone who

has received a traumatic brain injury, broken a hip, or is beginning to manifest symptoms of an

adult-onset disorder with a fast progression. Indeed, there was some evidence of increased use of

these services and recent hospital admission, suggesting again that an adverse event was more

likely to lead to rehabilitative service than natural, gradual deterioration. The person with CP is

likely to have roughly the same mobility needs as they had in childhood (Jahnsen et al. 2006), or

be able to blame their increased needs on regular aging characteristics (McColl et al. 2011). This

might lead to a person with CP not asking or strongly self-advocating for rehabilitative services.

There was an association with increased receipt of these services and health status or ADL level

instability, which suggests that negative physical progression is indeed a trigger for referral to

these resources, while baseline need is not.

It is worth noting that the GMFCS crosswalk may be less accurate for those in high-

independence, low mobility-assistance needs categories. The crosswalk failed to categorize any

persons within the sample as scoring a 1 on the scale while there was a high concentration of

persons scoring a 3 on the scale. This might be because of the subtleties between a person who

would score a 1 on the scale, and one who would score a 2. Neither person would use an

assistive mobility device. The distinction would be made a practitioner. Using the practitioner's

tool, a person who scored 3 would be a person who used some sort of mobility device (usually

powered manually), but retained independence with this device both inside and outside. This

level of mobility seems likely for persons who are at once in need of supports but unable to

receive these supports by accessing them in their community, while clinically stable and

independent enough to continue living in a private residence, instead of a long term care setting.

The low percentages of persons in all groups scoring a 5 is also promising; it would be difficult

to rely solely on home care supports with zero movement independence, and those that are able

to do so are likely to rely on informal supports heavily. This would be an unlikely option for

someone without strong in-home informal support systems. While it is unlikely that no home

care recipients had the full range of movement required to score a 1 on this scale, literature, as

reviewed earlier, suggests that severity, in terms of clinical complexity, is most affected by levels

IV and V (Shevell et al. 2009). Mobility is also most greatly differentiated between levels I and

II, and levels III-V, as level III is at which level mobility assistive devices are introduced. This

crosswalk was able to make the distinction between those who use a mobility device and don't,

and then was further able to distinguish those who were able to maintain independence through

use of a mobility device (level III), and those who had restricted independence (level IV) or

virtually no independence (level V) of mobility.

Other Variables

While clinical and functional variables had limited explanatory power in multivariate

models examining service use, a number of process and structure variables were identified. The

strongest association to receipt of rehabilitative services was the indicator a new admission to

Home Care services (identified by "initial assessment"). An initial assessment suggests that the

person has been newly referred to Home Care services (or has been re-referred after

discontinuing services in the past). While this is not, in and of itself, a clinical indicator, it does

suggest that an event other than being born with Cerebral Palsy precipitated the access of

rehabilitative services. This analysis ruled out falls as an event that might be associated with these services; however, this does not rule out adverse events leading to the referral. Falls may have failed to show a significant association with receipt of rehabilitative services not because there is no association between adverse physical events and receipt of these services, but because it is unlikely that a person that uses a wheelchair for most or all of their mobility needs will fall. The finding that there was an association between accessing these services and recent hospital admissions further supported this assumption that some adverse event is likely to have led to a referral.

The argument that the initial assessment indicator may be a proxy for clinical needs could also be applied to the indicator for living in community. Of the 376 persons with CP in the population who did not live in a private home at time of assessment, 300 of these lived in a group home or other assisted living situation that was not a residential care facility. It is possible that these persons were referred to receive home care because of an event that necessitated a move from independent living to an assisted living environment, and the rehabilitative goal is to allow them to return to independent living.

The last non-clinical indicator that was significant across all three models was the indicator for living in the Waterloo Wellington CCAC, compared with the Hamilton Niagara Haldimand Brant CCAC. Further research may take a medical geography approach to identifying the effects of demographic shifts on the access to these services. Other factors that should be considered are the number of therapists registered to work in these CCACs, and if there are different policies in different CCACs. Tests using other CCACs as a reference variable maintained the significance of the Waterloo Wellington CCAC's effect, but weakened it. This suggests that the contrast between these two areas is especially strong.

The sole clinical indicators that maintained a significant effect across all three models were the indicators for patient decline: the CHESS scale and the modified ADL CAP. Although the collapsed CHESS scale was not included in two of the final models, it maintained significance when tested, if with less explanatory variable than the ADL CAP. There was a clear positive association between a score of 2 on the ADL CAP (increased risk of decline in ADL status) and increased access to PT or OT compared to those having a score of 0 (likely to have a stable ADLH score). Bivariate analysis showed a significant positive association with a score of 2, and a negative association with a score of 1, for all three dependent variables. This could be interpreted in a number of ways. First, it could be determined that rehabilitative services are being implemented to prevent further decline in health status—or in the case of the ADL CAP, decline in independent mobility. Evidence that this is a real approach to treating this issue is included in the original CAP protocol: before modification, use of PT is considered an indicator that there is risk of ADL decline (or, if it is the only indicator that is positive for the individual, evidence that the individual is likely to improve). Although this seems to be a reasonable intervention, the strength of this association and the lack of association between either functional assessment scale highlights the possibility that rehabilitative services are being used as a "band aid" approach. Further research could determine whether use of these rehabilitative services for people who have stable health and mobility statuses are effective in improving independence or maintaining health stability.

Another interpretation of the sustained significance of the ADL CAP (or the CHESS scale) is that risk of health decline in persons with CP who live independently can be a driving force for receiving a referral for home care services. This would suggest an interaction between the initial assessment indicator and the CHESS scale. Although there was a significant

association between these two variables, an interaction variable had no affect in the models.

Even so, further research on the ability of PT and OT to stabilize health status for persons with

CP may be illuminating.

Occupational Therapy had 2 additional significant indicators in its model (one of which

maintained significance in the model for receiving either therapy): use of a wheelchair and

marital status. OT's association with wheelchair use suggests that occupational therapy may be

used to assist persons with CP with learning to remain independent with their assistive device.

Future research that has the capability of controlling for whether the person is new to wheelchair

use or not may find explanatory value in doing so. The positive association between receiving

OT and being married suggests that receipt of OT is positively associated with having a strong

advocate. It may be worthwhile to see if having a parent as a primary caregiver has a similar

effect.

While the Andersen-Newman Model for health service utilization was not used as a basis

for this analysis, post-hoc analysis allows for classification of the findings within the framework

of the model. Although the traditional or most common factors measured within each of the

categories were, in general, either not considered or not included in the final model, each of the

included variables can be classified within this framework. The Andersen-Newman Model

suggests that health service utilization is driven by three categories of indicators: predisposing

characteristics, enabling resources, and need. More recent updates to the model have placed these

characteristics within the framework of "population characteristics", and sandwiched them

between environmental characteristics (such as the health care system), and health behaviors and

outcomes (Andersen 1995). While there was clear variation in receipt of services between

CCACs of assessment origin, all members of the population lived within one larger health

system: the Ontario health system. Use of health services was in part controlled for—all persons

included were receiving home care services—and, in a larger part, the dependent variable for this

analysis. Outcomes related to the use of PT and OT were not easily measured in this analysis, as

it was not a longitudinal analysis. Thus the "population characteristics" portion of the Andersen-

Newman model is of most interest and applicability.

There were several predisposing characteristics included in the model. While not quite a

variable within the model, CP diagnosis may be the most important predisposing characteristic.

It is a permanent motor and movement disorder, suggesting that the person has needs that could,

theoretically, be addressed with PT or OT. This is in comparison to other diagnoses that could

lead to use of home care services, directly or indirectly, but for which PT or OT is less naturally

linked, such as renal failure. Other demographic variables that may be considered predisposing

variables were found only in the models that included OT use in the dependent variable:

wheelchair use and marital status. Wheelchair use once again spoke to the needs of the person

being evaluated: use of a wheelchair shows mobility impairment. While some wheelchair users

might have mobility impairments beyond what could be addressed physically, occupational

therapy could improve independence of movement with the wheelchair. Marital status is a

predisposing characteristic in the way it was analyzed in the model: being married may increase

the likelihood that the person being evaluated has a strong advocate to help them access the

services that they and their partner perceive that they need.

Enabling resources were defined in the model by CCAC of origin, and the indicator for

living in a private residence versus an assisted living environment. CCAC of assessment origin

could be considered an enabling resource in this context because of the variation between

CCACs in the models. It was clear in the models that some CCACs, namely the WW CCAC,

provided these services more readily than other CCACs. The indicator for living in a private residence versus an assisted living environment was also an enabling resource. Living in an assisted living environment could make accessing rehabilitative services easier, in some cases by having a PT or OT on staff at the center.

Finally, need was represented in the model by the indicators for risk of decline (the ADL CAP or CHESS scale), and the initial assessment indicator. The initial assessment indicator was not necessarily a need indicator in and of itself, but, as discussed previously, it did indicate that something had occurred in the life of the person being assessed that necessitated a home care referral. All in all, it can be argued that the final models do fit within the Andersen-Newman framework; however, this framework was not the driving force for hypothesis formation, variable selection, or analysis.

Future Research

This thesis found evidence of association between receipt of rehabilitative services and factors that suggested that the recipient had a change in health status resulting in an acute need. Future research could take two approaches to these findings. The first approach could be to determine the efficacy of PT or OT in addressing these needs. Improving the understanding of how well PT or OT rehabilitates persons with CP after an acute event, and which acute events are best suited to these interventions in this specific population could improve outcomes. Conversely, if it were found that there are health status or acute events for which PT or OT is used in the general population, but for which these interventions are not useful for persons with CP, resources could be better distributed and care could be improved with this new understanding. A recent study by Cook, Berg, Lee, Poss, Hirdes and Stolee (2013) found that use of PT or OT in home care improved outcomes for recipients across baseline functionality scores.

Narrowing this research to focus solely on persons with CP could strengthen arguments in this thesis.

Another avenue for further research could explore the efficacy of these interventions for maintaining health status for persons with CP. Persons with CP and other persons with permanent physical disabilities may benefit from receipt of these services in a preventative capacity. Although the disorder itself is non-progressive, its physical symptoms are not, and the close monitoring that consistent work with a physiotherapist or occupational therapist would provide could allow for these professionals to address issues before they begin to limit activities or independence, or before they lead to an acute event. Future research might also benefit by focusing on other therapies, and on care provided by workers other than specific therapists that may be considered rehabilitative. This may be in the form of personal support workers and nurses assisting care recipients with following a care plan that may have been developed by a rehabilitative therapist. A longitudinal study, following a cohort of children with CP into adulthood might be an especially useful approach.

Limitations and Generalizability

This study has several limitations. Most importantly, it should be recognized that secondary analysis has the inherent limitation of not allowing researchers to craft their own data collection techniques, or data collection instruments. It may have been useful to have more information about the reason for referral specifically for PT or OT services, the purpose of the PT or OT visit (which would have eliminated the need to create a time threshold to screen for equipment checks), the goals of the rehabilitative care (which could differ from the goals of the home care services as a whole), and, in the case of the majority of persons in the sample with CP

who use an assistive device, whether they were new to the assistive device, or whether they had used a device since childhood.

The Canadian health care system is provincially based, which creates another limitation. As we will be using Ontario specific data for our analysis, the power of the associations described in each of the three models may differ in other provinces that have other health care policies, different demographics, different cultural norms or expectations, or different geographical challenges than Ontario. The descriptive nature of this thesis mitigates much of this limitation.

Finally, it is worth noting that this population does exclude persons entering home care that are not expected to need long term services. It may, therefore, exclude a segment of the population of persons with CP that access therapies in home care in response to acute events. The chronic nature of CP suggests that those that access services do so consistently and for long periods of time, and so this limitation is unlikely to change the conclusions of this study substantially. Even if there is a substantial population of people with CP who access home care services only as a response to acute events, it is useful to address the service patterns of long-stay clients of the HC system on their own; the sustained needs of this group is important to address, no matter how easily generalized conclusions about this population are to the wider population of people with CP.

Conclusion

As expected, persons with CP were shown to be a higher-needs population. This
population seems to access services at younger ages, and sustain their services for longer periods
of time than the general population. They were less likely to receive rehabilitative services than
the rest of the home care population, and there does not seem to be a clear clinical predictor of
receipt of rehabilitative services except for risk of decline. In the future, care for persons with CP
may be improved by study of the efficacy of these rehabilitative services for persons with CP
whose health status is stable, and provider education about the benefits of rehabilitative services
for these groups. By improving the care of persons in this population, it may be possible to
increase the amount of time for which they are able to rely on home and community based
services instead of needing residential care. The overwhelming evidence that home and
community based service receipt is better for the recipient and for the health care service should
be enough motivation to perform this research; however, the high-needs nature of CP and the
earlier onset of aging symptoms makes this research more compelling. This is truly an
opportunity to affect the quality of the later-life years of a clinically complex population.

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APPENDIX A:

Data Set Specifications

Table 6: Percent of Population by Neurological Status and CCAC

Diagnosis Group	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW
CP	9.2	8.1	11.0	3.1	5.5	17.0	5.8	6.0	4.4	2.4	4.1	9.7	7.2	6.6
Other Neurological Disorder	11.1	9.9	9.9	3.5	5.7	14.5	6.2	5.6	4.9	2.3	4.6	8.6	7.2	6.2
Comparison	10.9	11.0	7.4	4.0	5.7	14.7	6.7	5.9	5.5	2.3	3.8	9.3	7.9	5.0
Total Population	11.0	10.6	8.4	3.8	5.7	14.7	6.5	5.8	5.2	2.3	4.1	9.0	7.6	5.5

Table 7: Neurological Status by Age Group (N)

Care Setting	Home Care		
Group	CP	Neuro Comp	Comp
Age 18- 24	340	394	1718
Age 25- 44	774	3036	13288
Age 45-64	636	17318	56555
Age 65+	250	176765	248369
Total	2000	197513	319930

Table 8: Selected age stratified results persons with CP

	18-24 Years Old	25-44 Years Old	45-64 Years Old	65+ Years Old
Female	46.3	51.9	54.3	53.6
Married*	0.3	4.7	15.4	18.0
Lives Alone*	3.3	14.6	35.0	43.4
ADLH Score of 3+*	78.3	62.7	37.9	34.4
CPS score of 5-6*	37.7	31.6	12.3	3.6
CHESS score of 3+*	0.9	1.2	4.6	5.2
At least one comorbidity	11.6	7.1	40.2	62.0
Access Rehabilitative Services At least 20 minutes of PT	8.3	6.7	7.2	9.6
At least 20 minutes of OT	8.3	9.5	11.0	8.4
At least 20 minutes of either PT or OT	13.4	14.3	15.4	16.0

*=p<0.05

Table 9: Selected age stratified results for persons with a different priority neurological disorder

	18-24 Years Old	25-44 Years Old	45-64 Years Old	65+ Years Old
Female*	39.1	55.2	53.2	61.5
Married*	2.8	32.2	48.1	41.6
Lives Alone*	6.4	17.1	23.7	26.4
ADLH Score of 3+*	53.1	29.2	23.5	22.8
CPS score of 5-6*	25.1	8.7	6.6	11.9
CHESS score of 3+*	3.8	7.6	10.2	15.1
At least one comorbidity*	18.0	31.5	61.6	79.5
Access Rehabilitative Services At least 20 minutes of PT*	13.2	14.3	11.4	8.1
At least 20 minutes of OT*	14.7	19.6	16.0	8.3
At least 20 minutes of either PT or OT*	23.1	27.6	22.8	14.2

*=p<0.05

Table 10: Selected age stratified results for persons with no priority neurological disorder

	18-24 Years Old	25-44 Years Old	45-64 Years Old	65+ Years Old
Female*	47.7	62.2	58.6	66.4
Married*	6.2	42.2	51.7	36.0
Lives Alone*	6.6	16.1	25.2	40.9
ADLH Score of 3+*	23.2	11.0	7.2	9.0
CPS score of 5-6*	10.8	3.2	1.0	0.8
CHESS score of 3+*	4.1	7.4	13.1	15.2
At least one comorbidity*	29.5	50.9	78.9	87.4
Access Rehabilitative Services At least 20 minutes of PT*	11.1	9.9	9.6	10.2
At least 20 minutes of OT*	10.7	11.5	10.1	8.8
At least 20 minutes of either PT or OT*	18.5	18.2	17.1	16.7

*=p<0.05

Table 11:Diagnostic Coding (Created by IDEAS-PNC team)

Items Used	CCRS
Multiple Sclerosis (MS)	i1y
Epilepsy/seizure disorder	i1cc
Parkinson's Disease (PD)	i1aa
Alzheimer's disease and related dementias (ADRD)	i1r, i1v
Traumatic Brain Injury (TBI)	i1ee
Huntington's Disease (HD)	i1x
Spinal Cord Injury (SCI)	ICD 10/ i1z / i1bb
Amyotrophic Lateral Sclerosis (ALS)	i1q
Muscular Dystrophy (MD)	ICD-10-CA
Cerebral Palsy (CP)	i1t
Brain Tumour	ICD-10-CA
Dystonia	ICD-10-CA
Hydrocephalus	ICD-10-CA
Spina Bifida	ICD-10-CA
Tourette's Syndrome	ICD-10-CA
Stroke	i1u

APPENDIX B:

GMFCS Translation to interRAI variables:
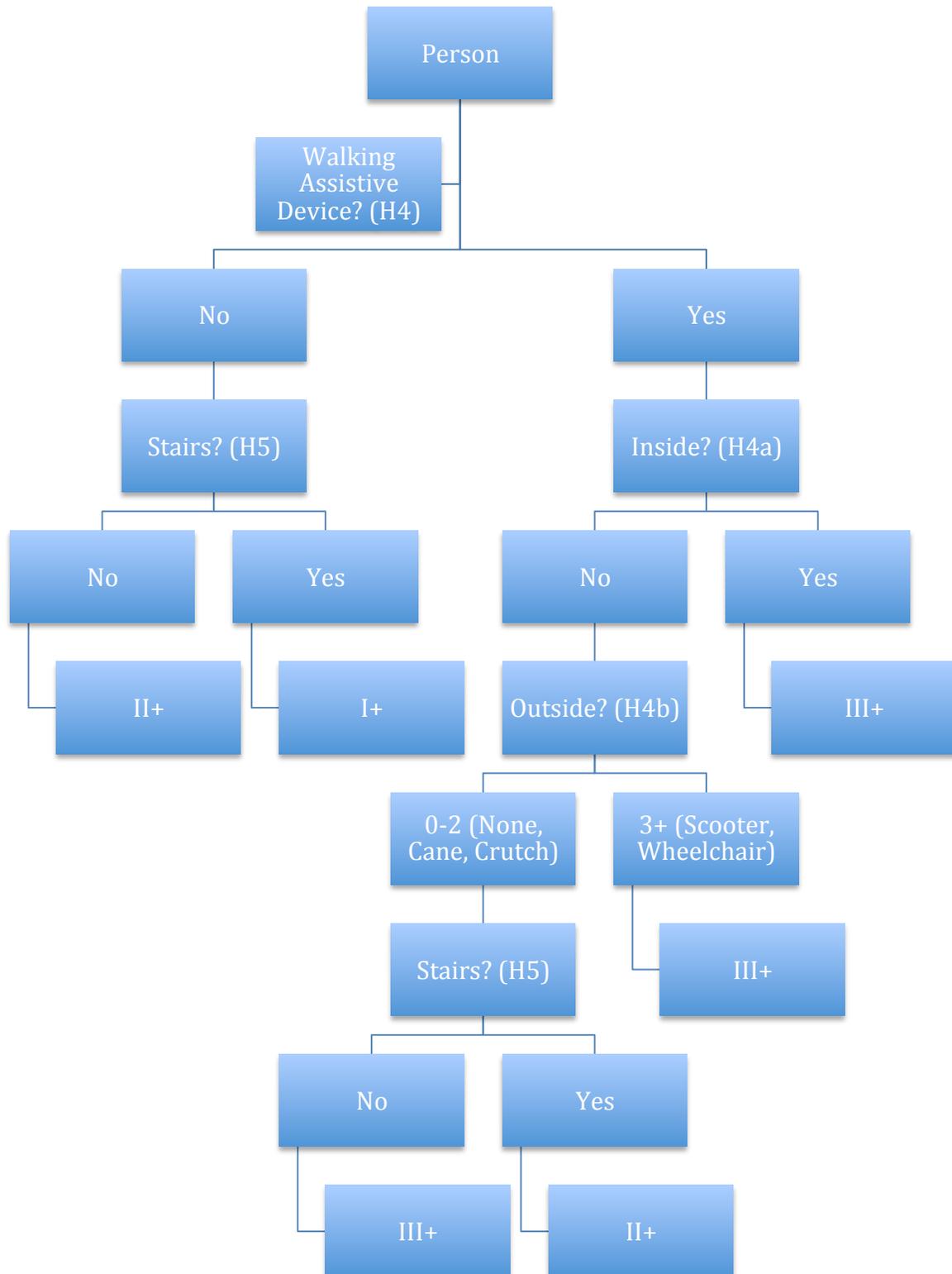
```
                          Person
                             |
               Walking Assistive Device? (H4)
                   |                    |
                  No                   Yes
                   |                    |
              Stairs? (H5)         Inside? (H4a)
              |        |            |         |
             No       Yes          No        Yes
              |        |            |          |
             II+      I+      Outside? (H4b)  III+
                          |              |
                   0-2 (None,      3+ (Scooter,
                   Cane, Crutch)   Wheelchair)
                        |               |
                   Stairs? (H5)        III+
                   |        |
                  No       Yes
                   |        |
                  III+     II+
```

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GMFCS Tier II

```
                          ┌──────────────┐
                          │    Person    │
                          │ assessed with│
                          │    Tier I    │
                          └──────┬───────┘
                        ┌────────┴────────┐
                        │  III+ From 1st  │
                        │     Tier?       │
                        └────────┬────────┘
            ┌────────────────────┴──────────────────────┐
        ┌───┴───┐                                    ┌───┴───┐
        │  No   │                                    │  Yes  │
        └───┬───┘                                    └───┬───┘
        ┌───┴───┐                                ┌───────┴────────┐
        │  II+? │                                │   Locomotion   │
        └───┬───┘                                │  Inside Home   │
            │                                    │   ADL (H2c)    │
     ┌──────┴──────┐                      ┌──────┴────────┐
 ┌───┴───┐     ┌───┴───┐              ┌───┴───┐       ┌───┴───┐
 │  No   │     │  Yes  │              │  <3   │       │  3+   │
 └───┬───┘     └───┬───┘              └───┬───┘       └───┬───┘
 ┌───┴───┐  ┌──────┴──────┐    ┌──────────┴────┐   ┌──────┴──────┐
 │   I   │  │  Locomotion │    │   Locomotion  │ ┌─┴───┐     ┌───┴──┐
 └───────┘  │ outside home│    │  outside home │ │ 3-4 │     │  5   │
            │  ADL (H2d)  │    │   ADL (H2d)   │ └──┬──┘     └───┬──┘
            └──────┬──────┘    └───────┬───────┘ ┌──┴──┐     ┌───┴──┐
            ┌──────┴──────┐    ┌───────┴───────┐ │ IV  │     │  V   │
        ┌───┴──┐    ┌─────┴─┐  ┌───┴──┐  ┌─────┴─┐└─────┘    └──────┘
        │  <3  │    │  3+   │  │  <3  │  │  3+   │
        └───┬──┘    └───┬───┘  └───┬──┘  └───┬───┘
        ┌───┴──┐    ┌───┴───┐  ┌───┴──┐  ┌───┴───┐
        │  II  │    │  III  │  │ III  │  │  IV   │
        └──────┘    └───────┘  └──────┘  └───────┘
```
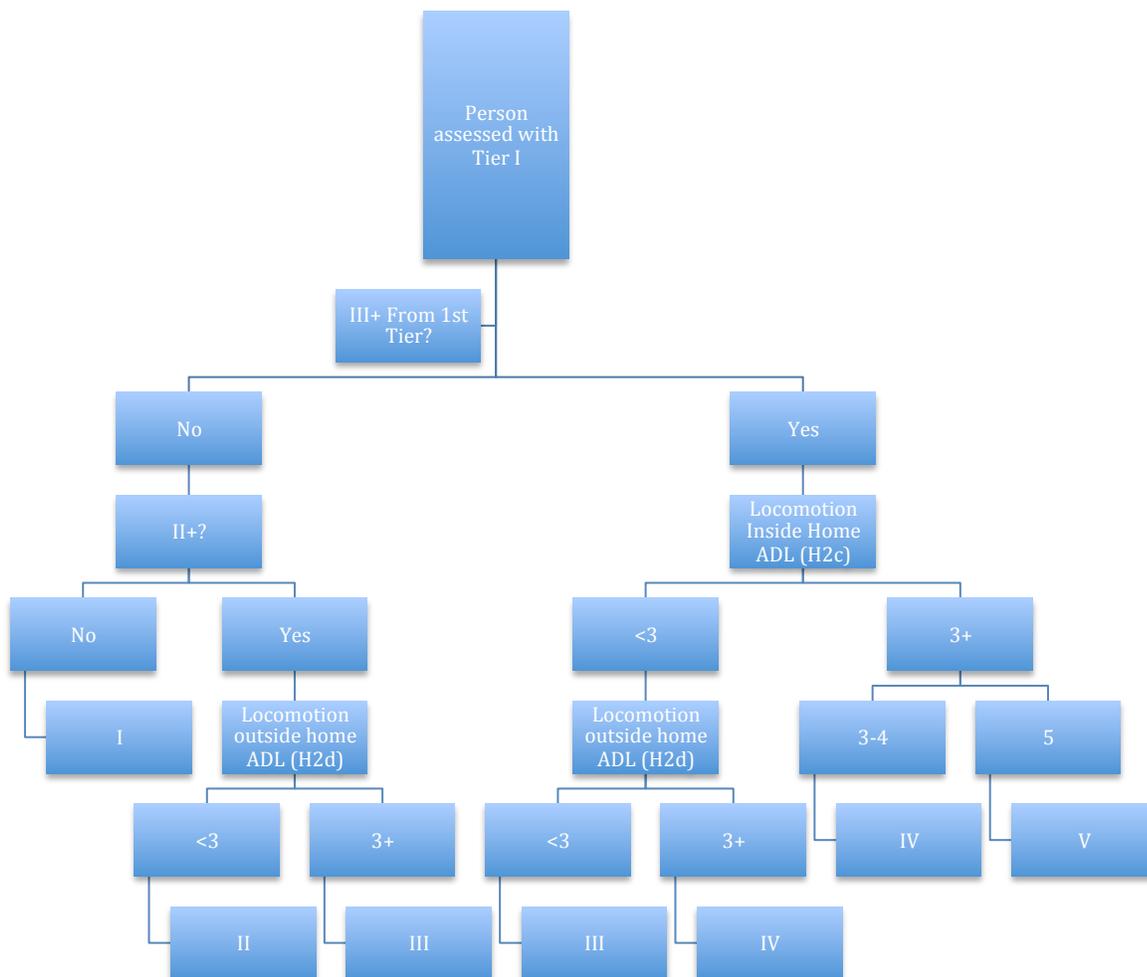
GMFCS Flow Chart explanation:

Tier 1:

- Walking assistive device? (H4>0 for either a or b)
  - NO: must be in tiers I or II by definition; proceed to measure of gross motor function ability.
    - Use of stairs (H5)
      - Yes
        - Shows evidence of general gross motor function. Tier I.
      - No
        - Shows deficit in gross motor function. Tier II or higher.
  - YES: Most likely in tiers III+. Low use of walking assistive device could allow for a clinician to make a judgement call placing person in tier II.
    - Are walking assistive devices used inside? (H4a>0)
      - NO:
        - What walking assistive devices are used outside? (H4b)
          - 1-2 (Cane, Crutch)
            - Light assistance. Check for gross motor function status. Stairs? (H5)
              - Yes
                - Light assistance with evidence of higher GMF. II+
              - No
                - Assistance with evidence of lower GMF. III+
          - 3-4 (Scooters, wheelchairs)
            - Increased assistance. III+
      - YES:
        - Assistance used in less rigorous situations. III+

- Tier 2:

- III+ from Tier 1?
  - Yes
    - Locomotion inside home ADL (H2c)
      - Less than 3
        - Locomotion outside home ADL (H2d)
          - less than 3
            - III
          - 3 or greater
            - IV
      - 3 or greater

- 3-4
  - IV
- 5+
  - V
- No
  - II+ from Tier 1?
    - Yes
      - Locomotion outside home ADL (H2d)?
        - Less than 3
          - No or little use of assistive devices for walking, evidence of lower GMF (from tier 1), independent outside of home: II
        - 3 or greater
          - III
    - No
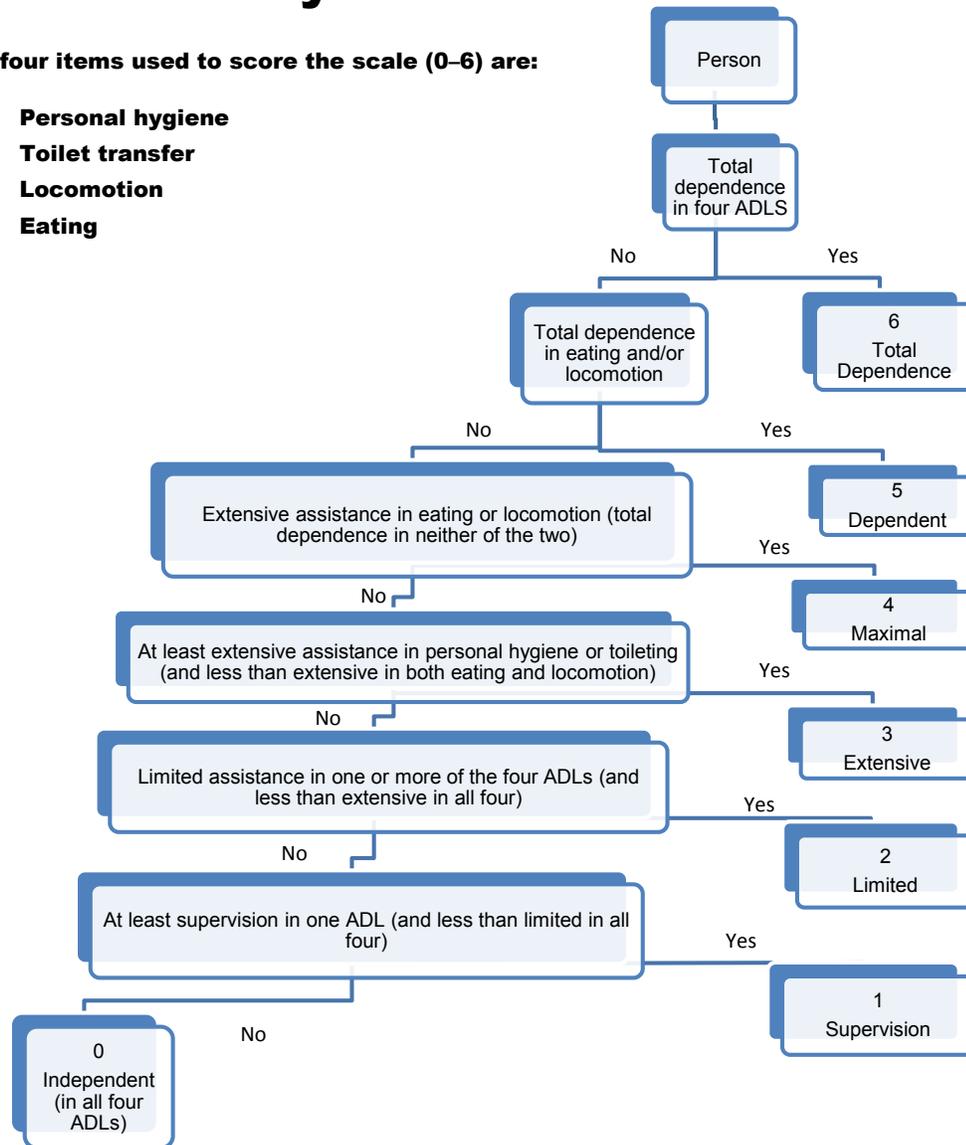   - Level I: No assistive devices, evidence of greater gross motor function: I

Activities of Daily Living Hierarchy: Retrieved from www.interrai.org

ADL Hierarchy Scale

The four items used to score the scale (0–6) are:

- **Personal hygiene**
- **Toilet transfer**
- **Locomotion**
- **Eating**

Person

Total dependence in four ADLS

No / Yes

Total dependence in eating and/or locomotion

6 Total Dependence

No / Yes

Extensive assistance in eating or locomotion (total dependence in neither of the two)

5 Dependent

No / Yes

At least extensive assistance in personal hygiene or toileting (and less than extensive in both eating and locomotion)

4 Maximal

No / Yes

Limited assistance in one or more of the four ADLs (and less than extensive in all four)

3 Extensive

No / Yes

At least supervision in one ADL (and less than limited in all four)

2 Limited

No / Yes

0 Independent (in all four ADLs)

1 Supervision

Source: **Morris JN, Fries BE, Morris SA**. 1999. Scaling ADLs within the MDS. *Journal of Gerontology: Medical Sciences* 54(11): M546–M553.

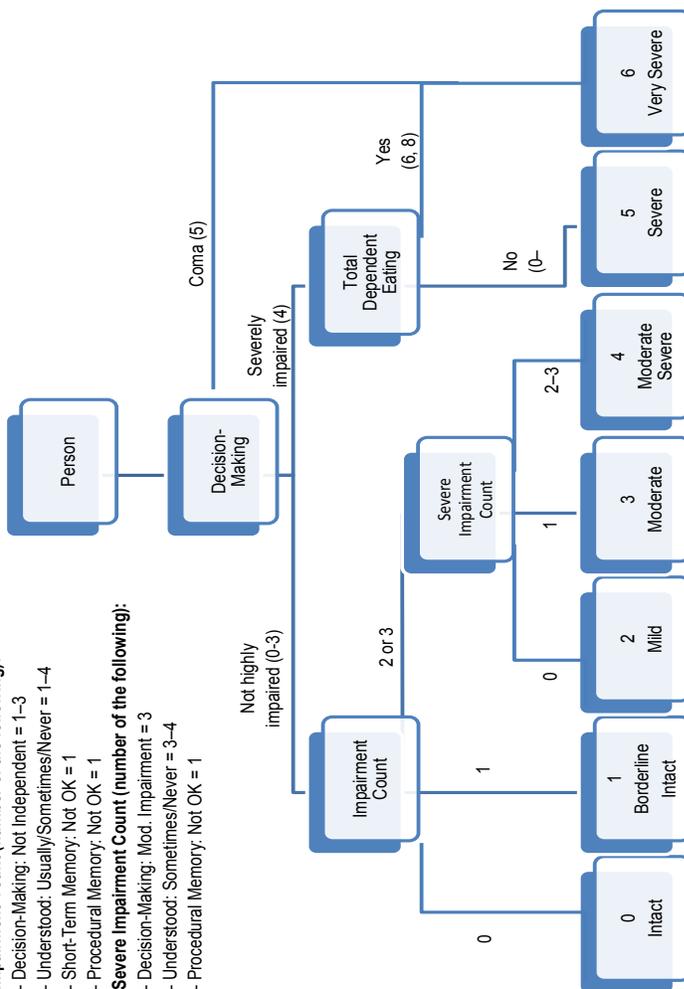**Cognitive Performance Scale : Retrieved from www.interrai.org**

Cognitive Performance Scale

Impairment Count (number of the following):
- Decision-Making: Not Independent = 1–3
- Understood: Usually/Sometimes/Never = 1–4
- Short-Term Memory: Not OK = 1
- Procedural Memory: Not OK = 1

Severe Impairment Count (number of the following):
- Decision-Making: Mod. Impairment = 3
- Understood: Sometimes/Never = 3–4
- Procedural Memory: Not OK = 1

Person

Decision-Making

Coma (5)

Severely impaired (4)

Not highly impaired (0-3)

Total Dependent Eating

Impairment Count

Severe Impairment Count

Yes (6, 8)

No (0–

2 or 3

1

0

2–3

1

0

6 Very Severe

5 Severe

4 Moderate Severe

3 Moderate

2 Mild

1 Borderline Intact

0 Intact

Source: Morris JN, Fries BE, Mehr DR, Hawes C, Philips C, Mor V, Lipsitz L. 1994. MDS Cognitive Performance Scale. *Journal of Gerontology: Medical Sciences* 49(4): M174–M182.

Depression Rating Scale: Retrieved from www.interrai.org

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Depression Rating Scale (DRS)

Score	Item
0–3	Made negative statements
0–3	Persistent anger with self or others
0–3	Expressions (including nonverbal) of what appear to be unrealistic fears
0–3	Repetitive health complaints
0–3	Repetitive anxious complaints/concerns (non-health- related)
0–3	Sad, pained, worried facial expression
0–3	Crying, tearfulness

Range: 0–14

Scoring:

0 = No mood symptoms

14 = All mood symptoms present in last 3 days

Scores of 3 or greater indicate major or minor depressive disorders.

The Depression Rating Scale (DRS) is calculated by summing all seven input items after recoding each input item to a three-point (0, 1, 2) scale. The first two levels, 0 and 1, are rescaled to 0; level 2 is rescaled to 1; and level 3 is rescaled to 2.

Source: Burrows A, Morris JN, Simon S, Hirdes JP, Phillips C. 2000. Development of a Minimum Data Set-Based Depression Rating Scale for Use in Nursing Homes. *Age and Aging* 29(2): 165–72.

CHESS Scale: Retrieved from www.interrai.org

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Changes in Health, End-Stage Disease, Signs, and Symptoms Scale (CHESS)

Score	Item
0–2, 8	Change in decision making
0–3	Change in ADL status
0–2, 8	Change in ADL status
0–4	Health condition — vomiting
0–4	Health condition — peripheral edema
0–3	Health condition — dyspnea
0,1	End-stage disease
0,1	Weight loss
0,1	Insufficient fluid
0,1	Dehydrated
0,1	Decrease in food or fluid
0,1	Fluid output exceeds input

Range: 0–5

Scoring:

0 = No health instability
1 = Minimal health instability
2 = Low health instability
3 = Moderate health instability
4 = High health instability
5 = Very high health instability

The CHESS Scale is calculated by adding sign and symptom variables up to a maximum of 2, then adding three other variables (Change in decision making, Change in ADL status, and End-stage disease), giving a highest CHESS score of 5.

Source: Hirdes JP, Frijters D, Teare G. 2003.The MDS CHESS Scale: A New Measure to Predict Mortality in the Institutionalized Elderly. *Journal of the American Geriatrics Society* 51(1): 96–100.