

Service Coordination for System Navigation

When Living with a Neurological Condition in Manitoba

by

Monika Y. Wetzel

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University of Manitoba

Winnipeg, MB, R3T 2N2

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## ABSTRACT

The purpose of this thesis is to explore the diverse experiences of accessing health and social services when living with a neurological condition in Manitoba. Using a qualitative research design, I conducted 15 in-depth semi-structured interviews with adults living with a neurological condition in Manitoba. Findings demonstrated how characteristics of patients, and their service providers/systems, either predisposed them to a lack of service coordination or enabled them to successfully navigate health and social services. In the event that those factors contributed to a need or desire for coordination, participants employed strategies to improve their experience accessing services by i. pursuing knowledge to improve access, ii. actively engaging in behaviours to improve services, or iii. mentally coping with inadequate services. To conclude, practical recommendations on possible initiatives to improve the daily experiences of individuals living with neurological conditions are also provided.

*Key Words:*

*Qualitative, interpretive description, service delivery, service coordination, best practices, community organizations, health care, neurological, system navigation, experience, Alzheimer disease & related dementias, Amyotrophic Lateral Sclerosis, brain injuries, brain tumours, cerebral palsy, dystonia, epilepsy, Huntington disease, Multiple Sclerosis, Muscular Dystrophy, Parkinson disease, spina bifida and hydrocephalus, spinal cord injuries, spinal cord tumours, and Tourette Syndrome.*

**ETHICS**

This study was approved by the Joint Faculty Research Ethics Board at the University of Manitoba. As with other health and medical related research, prior to commencing the interview, the participant and I went over the consent form attached in Appendix I, which they signed, dependent on the full understanding of its contents (van den Hoonard, 2012). The consent form outlined the purpose and methodology of my thesis in laymen's terms, as well as the rights of the respondent. In addition to the main sample selected for this study, a few participants requested that family members join them for the interview; whether for company or to assist with recalling events as they occurred (i.e., to compensate for memory loss related to their neurological condition). These family members were provided the same orientation to the research study and required to complete the consent forms to ensure they were informed as participants. Participants have been assigned a pseudonym to guarantee anonymity throughout the process of the study and in any future publications. For confidentiality purposes, all audio-recordings of interviews were saved electronically on a password-protected computer and paper documents, including consent forms, transcripts, any notes, and copy of pseudonyms, in a locked cabinet. In addition, participants were made aware that they could choose not to respond to any questions or withdraw from the study completely at any time without any repercussions or risk to his or her support from the community organization he or she was associated with. Both prior to signing the consent form and throughout the entire research process, participants were given several opportunities to ask questions. This final thesis has been submitted to iThenticate for added assurance of originality and proper referencing.

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## CHAPTER 1: PURPOSE AND NEED FOR SERVICE COORDINATION

Neurological conditions are considered one of the main contributors to disability within Canada (Canadian Institute for Health Information, 2007). Their impact is only expected to rise with population aging, which will contribute to an increased rate of new diagnosed cases of age-related neurological conditions and, in turn, an increased prevalence of people living with those conditions for a longer period of time (World Health Organization, 2006). The predicted continuation of this trend has contributed to a growing interest in the impact of neurological conditions on the Canadian population and our health care systems (World Health Organization, 2006). In addition, recent shifts in the senior population (e.g., increased disposable income of seniors, increased caregiver and community support) have created a movement towards seeking care in non-institutional settings (Darkins, 2006). Although this recent shift allows people with neurological conditions to live more independently at home for longer, their complex health care needs still require them to access a number of services (Darkins, 2006).

Accessing an array of different health services, a reality for many Manitobans living with neurological conditions, requires the involvement of many actors in an individual's care. This has the potential to "result [in] chaos unless there is a high level of coordination" (Hewer, 2013, p. 442). Based on a review by the Agency for Healthcare Research and Quality led by McDonald et al. (2007)<sup>1</sup>, no universal definition exists to define coordination of care, though upwards of 40 definitions and related terminology were identified to develop the following definition:

Care coordination [is] the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the

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<sup>1</sup> Although the review by McDonald et al. (2007) is not the most recent attempt at defining care coordination, the comprehensiveness (yielded 4730 publications, 75 systematic reviews met inclusion criteria) and the quality of the publication in my view represented the best definition of care coordination.

appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care. (p. 41)

As you will see in this thesis, in some cases, this means navigating through a complicated system with a variety of organizations and service providers with little support to help coordinate and make sense of this process. In this thesis, I examined this issue from the perspective of individuals living with neurological conditions in Manitoba, with a focus on the following conditions: Alzheimer disease and related dementias, Amyotrophic Lateral Sclerosis, brain injuries, brain tumours, cerebral palsy, dystonia, epilepsy, Huntington disease, Multiple Sclerosis, Muscular Dystrophy, Parkinson disease, spina bifida and hydrocephalus, spinal cord injuries, spinal cord tumours, and Tourette syndrome.

I decided to address service coordination and system navigation with reference to a range of neurological conditions because, firstly, from an etiological perspective, many of the conditions listed above share in the fact that they are the resulting effect of a compromised nervous system (Standing Committee on Health, 2012) while at the same time being distinct from other chronic conditions. Though each condition expresses itself through different physiological symptoms, these often result in similar impairments and life challenges that will be reviewed in Chapters 1 and 2. Furthermore, there has been a growing aspiration to address neurological conditions from a united approach due to the impact they have on the daily-lived experiences of individuals living with them. This trend is evidenced through the mission and vision statements of several federal departments and national organizations that deal with people living with neurological diseases. Whether through their own inclusive organizations (e.g., Brain

Canada, Canadian Neurological Sciences Federation) or through collaborative partnerships with the notable national organization called the Neurological Health Charities Canada (NHCC)<sup>2</sup> (e.g., National Population Health Study on Neurological Conditions [NPHSNC]; please see Appendix A for the list of current and founding NHCC Member Organizations), many of these groups routinely lead educational, advocacy, and/or research efforts with the aim of supporting Canadians living with all types of neurological diseases, disorders, and conditions. Lastly, by including all conditions, I have attempted to reduce the bias present in qualitative research that has traditionally excluded “diseases that influence verbal communication, such as stroke, amyotrophic lateral sclerosis, Huntington’s chorea, or Parkinson’s disease” (Thorne et al., 2002, p. 444).

I will begin by outlining the current context in Manitoba for people living with a neurological condition, including demographics, services available, as well as the factors contributing to the need for better coordination of services. This chapter will be broken down into five sections. First, I describe what we know about the prevalence of neurological conditions in Canada and Manitoba (1.1), followed by an overview of the experience of living with a neurological condition (1.2), preliminary sources of data that contribute to the case of lack of service coordination (1.3), and the context of service provision in Manitoba (based on my involvement in original research studies) (1.4). Finally, having laid the groundwork for my research question, I present my research objectives for this thesis (1.5). This description will make evident the distinct and increasing need to be able to provide better coordination of health,

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<sup>2</sup> An umbrella organization of 23 national and provincial voluntary health organizations representing Canadians living with neurological diseases, disorders, conditions, and injuries through one voice, in order to provide a “stronger sense of community and influence for positive change” (NHCC, 2010a; 2010b; Canadian Neurological Sciences Federation, n.d.).

social, and other services for a vulnerable and increasing population - those living with neurological conditions in Manitoba.

### **1.1 Prevalence of Neurological Conditions in Canada and Manitoba**

The burden of neurological conditions in Canada is clearly significant. Based on the Canadian Community Health Survey data, over 3.5 million Canadians self-reported as living with one of 18 common neurological conditions in 2010 to 2011, representing approximately 10% of the Canadian population (Statistics Canada, 2012). Amongst the top seven conditions included, migraines/ headaches were documented as the condition most frequently reported, followed by the effects of a stroke, brain injuries, epilepsy, spinal cord injuries, Alzheimer disease and other dementias, and multiple sclerosis.

Yet, it is reasonable to assume that 10% of the population is an underrepresentation of the number of Canadians living with neurological conditions. More specifically, the 3.5 million identified cases included in this 10% were limited to specific neurological conditions, thus excluding the hundreds of other neurological conditions that impact Canadians (e.g., Attention Deficit Hyperactivity Disorder, Autism, Trigeminal Neuralgia) (Canadian Institute for Health Information, 2007; National Institute of Neurological Disorders and Stroke, n.d.), the 170,355 Canadians living with neurological conditions in institutions, those working full-time in the Canadian Forces, or Aboriginals living on reserves (LINC Final Report, 2014; Statistics Canada, 2013). Furthermore, the course of getting a diagnosis is often an extensive process, suggesting that many individuals may not initially attribute their symptoms to the presence of a neurological condition, and therefore would likely not be included in this 10% of self-reported cases (Department of Health Long-term Conditions NSF Team, 2005).

As with the national rates discussed above, after reviewing the literature, it is clear that

few resources exist to identify regional or provincial prevalence and incidence rates of neurological conditions. Canadian Community Health Survey data from the 2010 to 2011 time period indicates that almost 8 thousand Manitobans were living with a neurological condition in an institution in the year 2011 to 2012 (Statistics Canada, 2013). In this case, the most prevalent conditions included Alzheimer disease and other dementias (70.39%), followed by the effect of strokes (21.39%), epilepsy (6.92%), and Parkinson disease (6.70%). In this case, we are limited to extrapolating and applying our national prevalence rate of 10% to the population of 1.272 million Manitobans for a broad estimate of 127 thousand people living with neurological conditions in the province.

## **1.2 Experience of Living with a Neurological Condition**

In reviewing the literature, one's daily-lived experience will likely be affected by acquiring a neurological condition. Although each individual has his or her own environmental context (e.g., extent of access to financial resources) and physiological characteristics (e.g., the type and severity of condition) that shape his or her distinct experience, the existence of comorbidities and common impairments creates a shared experience across neurological conditions. As expanded upon later in Chapter 2 of this thesis, people living with neurological conditions have been known to develop a range of symptoms that promote physical, cognitive, social, and emotional health challenges (NHCC/PHAC, 2014; Cella et al., 2011; Department of Health Long-term Conditions NSF Team, 2005). However, it is not only the challenges that shape an individual's daily life, but also how he or she chooses to confront those challenges. In a recent study, nine common strategies<sup>3</sup> to maintain a sense of self amongst adults living with a

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<sup>3</sup> (1) Avoidance and denial, (2) cognitive reframing, (3) articulation of the self through imagined positive identity, (4) strategies that reconnect to identity in the past, (5) adjusting and altering goals, (6) spiritual activities, (7) humour, (8) comparison with others: identity as shaped through

neurological condition were identified (Roger, Wetzel, Hutchinson, Packer, & Versnel, 2014). Strategies ranged from negative coping where participants would deny the very existence of their condition to more adaptive coping where they would embrace changes by reframing the situation to focus on the positive elements. Though there is no one ideal type of coping or management strategy, research does suggest adaptive coping styles will lead to better emotional adjustment (Anson & Ponsford, 2006).

Therefore, how people live and choose to cope with these symptoms can create common experiences across conditions. Common experiences reported in the preliminary findings of the NPHSNC<sup>4</sup> in Canada include declining perceived health status, facing accessibility issues, increased activity restrictions, financial insecurities, decreased participation (at work, school, community, family, and leisure activities), and an increased need for assistance and health services (NHCC/PHAC, 2014). As stated by Bernard, Aspinal, Gridley, and Parker (2008), “Many quality of life issues which primary health care, social care and other services must address will not be condition specific, but centre round mobility, support, employment, housing and social interaction” (p. 7). As a result, while the physiology of conditions may differ, the literature mirrors my own belief that the symptoms, impairments to health-related quality of life, and other challenges (including the lack of service coordination) are characterized by numerous commonalities, thus requiring a united approach to studying and addressing the needs of people living with any neurological condition (Kirton, Jack, O’Brien, & Roe, 2012).

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social constructs, and (9) creating communities: a reciprocal reflection of self.

<sup>4</sup> A 15 million dollar study, titled the NPHSNC, which was accomplished through a partnership between the Public Health Agency of Canada, Health Canada, Canadian Institute for Health Research, and the NHCC between 2009 and 2014 (NHCC/PHAC, 2014).

### **1.3 Lack of Service Coordination**

In order to cope and manage the symptoms and barriers associated with one's condition, a multitude of resources are made available across different agencies and disciplines. However, research indicates people living with neurological conditions may face unique challenges in the process of accessing and managing services. For example, poor memory, communication problems, or other acquired symptoms have the potential to create challenges when trying to communicate with service providers (Egan, Anderson, & McTaggart, 2010). In addition, as people age, the fluctuating needs that accompany certain conditions can create challenges requiring additional adjustments to needed services (Challis, 2010). The actual physical location, information system, or design of a building can also represent existing factors that influence the process of locating services and the accessibility of those services, while system-based factors within those buildings, such as the professionals' expectations or the organization of services can affect the flow of service provision (McDonald et al., 2007).

In the hope of understanding more about potential gaps in service coordination and support with navigating health and social services, I found in my literature review that systems have been criticized for their inability to offer timely service delivery, local specialists, home visits, disability services, transportation services, as well as coordination and continuity of care (Galushko et al., 2014). Frequent health care users in other provinces have reported feeling "frustrated, confused, and forgotten" as a result of an unorganized health care system that was difficult to navigate (The Change Foundation, 2008; Spragins & Lorenzetti, 2008). England in particular, a country with a similar socialized health care system funded through public taxation (The NHS Constitution, 2013), has begun taking steps to tackle such issues by revamping their entire health care system; making integrated patient-centered care a health care priority for

people living with long-term neurological conditions (Department of Health Long-term Conditions NSF Team, 2005). Additional research has supported more service coordination and assistance with system navigation for those living with neurological conditions on the part of service providers (Almasri et al., 2011; McDonald et al., 2007; The Change Foundation, 2008). These findings suggest it is highly relevant to review existing research and to conduct new research occurring in this area in Manitoba.

To date, few studies in the literature examine aspects of care coordination for adults with neurological conditions in Manitoba. Restall, Leclair, and Fricke (2005) published a report focusing on the influence of coordination on rehabilitation and occupational therapy services. In fact, most studies in the literature also examined coordination within one institution or area of care, rather than investigating access to care across health, social, and community sectors and services, often neglecting the role of not-for-profit community organizations in the delivery of care services. More recent studies by Roger and Penner (2012) and Roger, Mary-Quigley, and Medved (2010) reviewed the factors and supports that shape communication between patients with neurological conditions and care providers, as communication about care is an essential part in health care provision and the larger issue of service coordination. Consequently, further investigation is needed to gain a better understanding of care coordination across the many service providers and sectors in the province. Therefore this study may act as a catalyst that will encourage Canadians to take steps to enhance the process of accessing care for people diagnosed with neurological conditions; and as a result, improve the quality of life of our population plus the overall effectiveness and efficiency of our system.

## 1.4 Manitoba Context

Manitoba is a province made up of approximately 1.2 million people (Government of Manitoba, 2015). As with other Canadians, Manitobans benefit from living in a context where medically necessary basic health care is publicly funded and universally available (Health Canada, n.d.). The health services within the province are regulated by the department of Manitoba Health, Healthy Living and Seniors (MHHLS) and are provided on a “pre-paid basis, without direct charges at the point of service” (Health Canada, n.d., para. 28).

The first point of contact with the health care system typically begins with primary care, at which point patients seek support with health promotion, addressing common illnesses, symptom identification, or managing their chronic conditions. Primary care services are increasingly being delivered by a range of providers, including family doctors, nurse practitioners, pediatricians, or physician assistants, and can be accessed from “a clinic, a family doctor’s office or a community health center” (MHHLS, n.d., para. 1). Several initiatives are currently underway in the province to try and make primary care more accessible, including the Family Doctor Finder program to attach patients without a provider to a family doctor or nurse practitioner; Mobile Clinics and TeleCARE to improve access to primary care for rural and remote populations; QuickCare Clinics to offer primary care with flexible hours; ACCESS Centers to deliver primary care that meets the unique needs of a community; as well as Birth Centres and Midwifery services (MHHLS, n.d.).

Should patients require support beyond this initial care network, a primary care provider must refer them to a specialist. In the case of people suspected of living with a neurological condition, this typically involves a referral to a neurologist who “has extra training or expertise in that area” (MHHLS, n.d., para. 6). In Manitoba, based on a preliminary search, approximately

34 physicians across 16 different facilities are specialized in neurology (including paediatric neurology) and are currently licensed to practice within the province.

If patients are in need of social services, referrals can also be made to community resources. For example, in addition to health services, Community Access Centres offer programs and support related to mental health, home care, employment, and income assistance to Manitobans in general. There are also well over 50 community resources (e.g., organizations, centers, groups) available to serve people with neurological conditions; whether they are tailored to be condition specific or for people living with disabilities in general (please see Appendix B for the full list of Services Related to Neurological Health Offered in Manitoba identified in a preliminary search). Community organizations identified typically offered supports related to information and referral services, education and recreation programs, financial assistance, awareness efforts, research funding, support groups, counselling, and advocacy. Nevertheless, there was a great range in the comprehensiveness of services for conditions, varying from the least amount of services offered to those living with migraines and headaches, to the most supports offered to patients living with cancer (e.g., brain tumour, spinal cord tumour) and Alzheimer disease. That being said, social and health services do not have a combined structure within the Government of Manitoba, which would make it more difficult to support collaborative initiatives whether health and social needs are addressed simultaneously; unlike Quebec's government structure (Gouvernement du Québec, 2015).

Specific to those living with neurodevelopmental disorders and disabilities, social services can be a key resource in living with their condition. The Community Living disABILITY Services (CLDS) offered through Manitoba Family Services is an example of an initiative within the province that supports adults with mental disabilities in taking advantage of

opportunities within the community to build independence based on their abilities (Government of Manitoba, n.d.)(e.g., Residential Services, Day Services, Support Services, In Company of Friends Program).

From this list, we may infer that several services exist to assist people with the management of their condition and daily-life in Manitoba. However, while working as a research assistant, people living with neurological conditions repeatedly expressed concern over difficulties navigating and accessing health and social services (Roger et al., 2014). In this section, I will outline the associated themes from studies, including the LINC Study data (1.4.1), research conducted by Dr. Roger and others in Manitoba (1.4.2), and a Manitoba community consultation that I worked on as a research assistant (1.4.3).

**1.4.1 The LINC study.** One recent national study highlighted the significance of service coordination. The Everyday Experience of Living with and Managing a Neurological Condition (the LINC Study) was one of the 15 studies included in the NPHSNC (Versnel et al., 2013). One of the main goals of this study was to document the overall impact that neurological conditions have on people living with those conditions, their families, informal caregivers, and communities (Versnel et al., 2013). Between April 2012 and June 2014, I was involved with the LINC Study as a research assistant assisting with literature searches, transcribing interviews, and conducting monthly telephone interviews with participants in Manitoba, Ontario, and the Atlantic provinces. In addition, I was able to engage with the LINC data as a research assistant while co-authoring an ensuing peer-reviewed paper led by Dr. Roger, which reviewed the strategies to maintain a sense of self while living with a neurological condition (Roger et al., 2014). It is through this engagement that I became aware of participants' repeated frustrations when navigating health and social services.

In general, it seemed as though participants were struggling internally between feelings of frustration and acceptance of the process required to access services for their condition. Difficulty with navigation and wait times, though resented, tended to be accepted as a new state of normal and as a part of the system that always seemed to “eventually” deliver on needed services. The course of navigation typically commenced in a family physician or general practitioner’s office, which would then instigate participants’ referrals to specialists. Unfortunately, along this route, participants reported facing several hurdles, including going to great lengths to secure proper care and supports (e.g., “jumping through hoops” for financing equipment, acquiring homecare, patient autonomy), unpleasant side-effects from being a “guinea pig” in countless trials, the uncertainty around treatment decision-making and other life obstacles, as well as feeling stigmatized or devalued (e.g., “hypochondriac,” one of many, not taken seriously). In some cases, participants attributed these failures to a lack of knowledge and understanding about neurological conditions on the part of health professionals, insufficient communication between care providers, or just plain incompetence.

Then again, this was not the experience for all people in the study, as some participants reported positive experiences with their provider, care team, or community organization. Accessing services seemed to be a positive experience when participants could build a trusting and cooperative bond with the person delivering and coordinating their care. Such relationships appeared to develop when participants perceived care providers as being knowledgeable, honest (e.g., not concealing health projections, upfront about being uninformed), welcoming (e.g., treating them as a knowledgeable “person” as opposed to a discountable patient), and/or supportively involved (e.g., assistance with care coordination and finding answers).

Finally, outside of relying on service providers, some participants demonstrated efforts to

take control of their own health. In some cases, individuals knew a close friend or family member already engaged with the health care system who could give personal advice with its navigation (e.g., how to present their needs, go to emergency room). In addition, others used past experiences from former trial and error efforts, education, or employment to leverage more confidence, control, and respect when navigating health and social services (e.g., personal research, getting a second opinion). Moreover, the obstacles faced when navigating the health care system sometimes even created a loss of trust and confidence in care providers and the health care system altogether, which could be associated with some of the moves towards non-adherence, alternative medicines (e.g., diet and exercise), or avoiding treatment all together.

Though it is possible to learn to be effective and efficient while navigating the health care system, it seems unreasonable that solving the intricacies to this process should be self-taught while simultaneously dealing with a diagnosis, managing symptoms, coordinating appointments with various experts, and living one's everyday life before receiving access to care. Beyond this, awareness and accessibility of services tended to vary from person to person, with only those who learned the tricks of navigating the health care system or other organizations and those with access to personal resources being able to make full use of the services available. Therefore, as part of the fundamental principles of the Canadian health care system, it is important to address these discrepancies to ensure that everyone truly has universal access to care (Health Canada, n.d.).

**1.4.2 Research conducted by Dr. Roger and others in Manitoba.** Previous research (Roger & Penner, 2012; Penner & Roger, 2012; Roger & Medved, 2010; Roger, Mary-Quigley, & Medved, 2010) identified that there is a need and interest to continue to conduct research in Manitoba with a Manitoba focus on those living with a neurological condition. To begin,

community consultations were held by Dr. Roger in 2008/09 with affiliated staff and organizations, as an initiative to better grasp organizational needs regarding care services to families and couples with long-term neurodegenerative conditions (e.g., Huntington disease, multiple sclerosis, Alzheimer disease, ALS, and Parkinson disease). Responses then clarified the need for research on people's daily-lived experiences and especially a need to better understand their interactions with the health care system. In 2009, the research team received funding to commence Phase II, where they explored decision-making between couples and care professionals. Funding was then received for Phase III in 2010, which was used to further explore what had changed for participants given their daily-lived experiences in the last year. As a result, this research led to Dr. Roger's invitation to being a co-investigator on the LINC study as noted above.

**1.4.3 Manitoba community consultation.** As a follow up to the LINC Study, Dr. Roger (the Principal Investigator in the Manitoba site) hosted a community workshop at the University of Manitoba in January 2014 (for which I was hired as a research assistant), in order to further analyze the barriers affecting people living with neurological conditions within Manitoba. Representatives from 17 Manitoba-based organizations for each condition listed under the NHCC were invited to discuss the social experiences faced by Manitobans living with neurological conditions (Roger & Wetzel, 2014). Based on email responses, brainstorming, and identified dot-voting priorities from 10 community organization representatives at this workshop, it was clear that the main priority for organizations was to address feelings of invisibility while navigating through a complicated system to access services in Manitoba (please see Appendix C for the list of Community Organizations Contacted; Roger & Wetzel, 2014, p. 11). There was a strong agreement among representatives that their members regularly experienced barriers when

trying to access care. Moreover, there was overwhelming consensus that both a lack of awareness of neurological conditions and insufficient care coordination were the main contributing factors to difficulties that arose while navigating the health care system. In fact, participants felt that access to a timely diagnosis, referrals, follow-ups, as well as other services was dependent on a patient's ability to act as his or her own advocate, thereby creating disparities in access to care.

Rather than creating a new service, based on recommendations made at the community organization workshop and previous research, it could be more efficient to investigate developing coordination strategies in each of the community organizations that would connect with members in a holistic manner, cutting across different sectors to provide the best available care, treatments, services, and resources in the health care system and community. As a result, for my thesis, I conducted a qualitative study that investigated the challenge of system navigation, alongside the recommended solution of improved service coordination.

### **1.5 Research Objectives**

The purpose of this thesis is to explore the diverse experiences of accessing care and services when living with a neurological condition, with a specific focus on the benefits and barriers of service coordination in Manitoba. In addition, I intend to make recommendations to future service coordinators and government on possible service coordination initiatives that will aim to improve the daily experiences of individuals living with neurological conditions.<sup>5</sup>

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<sup>5</sup> \*\* Please note, this thesis is not intended to critique the health care system; rather, I am interested in acknowledging the current service gaps, while utilizing prospective opportunities within community organizations to support successful coordination of existing services offered in the community and mainstream health care system for people living with neurological conditions.

The research objectives guiding this study include: 1) to examine the current experience with navigating health and social services to access services for people living with a neurological condition in Manitoba; 2) to describe the current perceived successes and gaps of care coordination within Manitoba; and 3) to develop a better understanding of how service users imagine service coordination might look or not look to improve those experiences.

## **CHAPTER 2: BACKGROUND ON NEUROLOGICAL CONDITIONS**

The nervous system is made up of a few main components such as the brain, spinal cord, sensory organs, muscles, and many types of nerves. Any damage, infection, genetic predisposition, developmental complication, or other impairment to the nervous system could impact anything from people's senses to their learning capabilities in the form of a neurological condition (Standing Committee on Health, 2012). The study of neurological conditions has expanded and led to the discovery of over 600 hundred conditions to date (National Institute of Neurological Disorders and Stroke, n.d.). As it currently stands, the World Health Organization (2014) recognizes a number of neurological conditions affecting the nervous system, including epilepsy, Alzheimer disease and related dementias, cerebrovascular diseases, migraines and headaches, multiple sclerosis, Parkinson disease, neuroinfections, brain tumour, neurotrauma, and neurological conditions from malnutrition. This chapter will first group and review the types of neurological conditions (2.1), followed by an overview of their related impacts to individuals' health-related quality of life (2.2).

### **2.1 Types of Neurological Conditions**

There exists an essential underlying similarity between all neurological conditions, where the seamless connection between the brain, spinal cord, and/or nerves has become compromised. Connections between the central and peripheral nervous systems can become damaged, thus interrupting the flow of information commands and sensory signals, which contribute to an array of associated functional impairments that we see in many neurological conditions (National Institute of Neurological Disorders and Stroke, 2014). Through our awareness of this process, in this section, we will categorize conditions based on how they are believed to develop in the

central nervous system or peripheral nervous system; that is, through trauma, prenatal or childhood development, and degeneration.

While simplified here, in reality there can be much overlap between groups presented (Standing Committee on Health, 2012). For example, while some types of dystonia can be acquired genetically, others are described as idiopathic or acquired through trauma to the basal ganglia (National Institute of Neurological Disorders and Stroke, 2015). In addition, though some neurodevelopmental conditions are caused by trauma or possess degenerative characteristics, they are categorized here with other conditions acquired early in life. This grouping will allow for focusing on a distinct experience, where the individual will have lived with a condition for the entirety of his or her life (i.e., not knowing any other reality) and where much of the service coordination and decision-making is left up to parents or family members throughout the first stages of his or her life. Within this section, I plan to review these three types of neurological conditions, beginning with neurotrauma (2.1.1), followed by neurodevelopmental conditions (2.1.2), and degenerative conditions (2.1.3).

**2.1.1 Neurotrauma.** In some cases, neurological conditions can be acquired suddenly through physical injury to the central nervous system, that is, the brain and spinal cord. Injuries can be the result of both external factors, such as a motor vehicle accident, or internal factors, such as a stroke or tumour (Manitoba Brain Injury Association, n.d.; Turner-Stokes, Sykes, Silber, & Sutton, 2008a). In fact, as these threats can effectively harm both the brain and spinal cord, it follows that studies have shown, more or less, half of spinal cord injury cases sustained also led to a co-morbid brain injury (Macciochi, Seel, Thompson, Byams, & Bowman, 2008).

Though some similarities exist in acquiring spinal cord and brain injuries, this is not to be mistaken with similarities in their functional disabilities. Functional impairments derived from

brain injuries can directly impact parts of the brain contributing to cognitive symptoms (e.g., deficits with attention, information processing, memory, and executive functions), psychiatric symptoms (e.g., depression, anxiety, irritability), and physical symptoms (e.g., weakness, ataxia, balance, sensory abilities, intermittent seizures/ epilepsy) (Cruz, 2010; Konrad et al., 2011; Manitoba Brain Injury Association, n.d.; Ponsford, Draper, & Schönberger, 2008). On the other hand, spinal cord injuries often present themselves distinctly in terms of physical limitations such as problems with sensation, mobility, gastrointestinal system and other activities of daily living (Pobre et al., 2010a). In addition to impairments from the initial injury, additional physical, emotional, and cognitive symptoms may arise from living with functional limitations (Groah et al., 2012; Post & van Leeuwen, 2012).

Unlike most other types of neurological conditions, in many cases there is an opportunity for long-term improvements after the initial onset of the condition. For this reason, it is important that individuals with both non-traumatic and traumatic injuries work with rehabilitation programs to help recover prior functions and well-being; however, projections for rehabilitation and other outcomes will differ for each participant based on the severity of injury and other influential factors (Kennedy & Chessell, 2013; Ponsford, 2013; Restall et al., 2005).

**2.1.2 Neurodevelopmental conditions.** In human development, the central and peripheral nervous systems are very fragile and can be affected by a variety of factors such as infections, trauma, genetic predispositions, or developmental complications. According to the National Institute of Neurological Disorders and Stroke, should a foetus or child be affected in any way, this can lead to neurodevelopmental conditions that can “affect cognitive and/or behavioural development during a lifetime” (Standing Committee on Health, 2012, p. 3; Turner-Stokes et al., 2008a). Infections and illness are known to be potential causes of neurological

conditions such as, in the case of some types of acquired hydrocephalus, where an accumulation of cerebrospinal fluid can be triggered by an infection and create extreme intracranial pressure (Sharma, Sharma, & Raniga, 2013). Trauma to the brain or spinal cord can also contribute to neurologic, motor, and/or postural impairments at all ages, especially when the central nervous system is most vulnerable in early development, as is seen in some types of cerebral palsy (Pobre, Trangco-Evans, & Abramov, 2010b). In addition, it is possible that exposure to or ingestion of specific agents, such as infectious diseases, substance abuse, or chemicals, can create an environment that is harmful to the foetus and risks healthy development, as in the case of Foetal Alcohol Spectrum Disorder or Minimata Disease (Orna, 2011). Furthermore, it is not only exposure to toxic substances but also the absence of required nutrients that can harm the process of development, as demonstrated by the associated increased risk of neural-tube malformations in spina bifida with insufficient levels of folic acid (Pobre et al., 2010b). Lastly, some neurological disorders are hereditary, meaning disorders are genetically inherited by children and can affect how his or her nervous system develops, as with Tourette syndrome, which over time has been characterized by a fluctuation in repetitive and involuntary movements, vocalizations, use of obscene language, and echoing of others' words (McNaught & Mink, 2011). Though a wide range of therapies, surgeries, assistive devices, pharmaceuticals, and care options exist to treat and manage symptoms, such conditions typically cannot be cured.

**2.1.3 Degenerative conditions.** After consulting several national agencies, including Statistics Canada, the Institute of Neurosciences at the Canadian Institute for Health Research, Manitoba Health, and the Centre for Chronic Disease Prevention at the Public Health Agency of Canada, it is clear that no universal definition to define degenerative conditions currently exists and should be addressed in future research. In the meantime, for the purpose of this study,

degenerative conditions will refer to disorders that are characterized by a continuing or intermittent progressive deterioration of cells and organ function. Although neurodevelopmental conditions can also be degenerative, in this sub-section I will be referring to conditions acquired post-childhood, to highlight the unique experience of acquiring a neurological condition after one has already developed a sense of self.

One of the most common types of degenerative conditions in Canada is Alzheimer's disease or other dementias, which is known to generate a continuous decline in individuals' global intellectual functioning and hinders their ability to care for themselves independently (Danila et al., 2014; Statistics Canada, 2012; Statistics Canada, 2013). Other types of degenerative conditions have been linked hereditarily; for instance, parents with Huntington disease are known to genetically pass on a 50% chance of receiving the gene that contributes to brain cell death and the associated mobility, cognitive, psychiatric, and behavioural impairments to their children (Aubeeluck & Wilson, 2008). Various genetic susceptibilities are also suspected to contribute to the risk of developing Parkinson disease, a condition characterized by a progressive loss of neurons containing dopamine in the brain (World Health Organization, 2006). However, it is believed that exposure to risk (e.g., pesticides) and protective factors (e.g., smoking) in one's environment can equally affect the chances of developing this condition (de Lau & Breteler, 2006; Dardiotis et al., 2013). In the case of muscular dystrophies, another group of inherited conditions, individuals experience a progressive deterioration of the muscle cells and tissues that become replaced by fatty deposits and connective tissues, resulting in muscle weakness and associated physical disabilities (Manzur & Muntoni, 2009). People living with ALS and multiple sclerosis also experience similar progressive muscle weakness and disabilities. This process of deterioration occurs in the brain and spinal cord; more specifically, multiple

sclerosis patients experience a loss of myelin protecting the central nervous system, while ALS patients face the destruction of upper and lower motor neurons (Pobre et al., 2010c). In many cases, degenerative conditions are considered to be age-related conditions with no cure, though advances in research are slowly introducing new ways to slow or stop intermittent relapses and/or disease progression with disease modifying therapies or alternative therapies, as well as manage the conditions with assistive technologies and strategies.

## **2.2 Health-related Quality of Life**

HRQL is “limited to the aspects of life that are important to the evaluator in the context of health and illness” (Padilla, Frank-Stromborg, & Koresawa, 2004, p.129) In particular, one’s health-related quality of life (HRQOL) may be hindered by living with the diagnosis, symptoms, or treatments related to the neurological condition (Cella et al., 1995, as cited by Carlozzi & Tulsky, 2013). Based on five sources, including a literature review, expert input, patient and caregiver focus groups, and key word searches, Cella and colleagues (2011) reviewed data on seven groups of neurological conditions<sup>6</sup> in order to select the domains most relevant and important to those specific conditions. In this part of their study, issues that were identified in a minimum of three sources per condition in over half of the conditions were considered generic concepts, indicating a common concern across conditions. In this section, I will review these generic concepts, including physical health (2.2.1), cognitive health (2.2.2), social health (2.2.3), and emotional health (2.2.4), to illustrate the most common impacts experienced while living with a neurological condition.

**2.2.1 Physical health.** The most noticeable influence of symptoms is on an individual’s physical health. Physical health was recognized as the highest concern for the majority of

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<sup>6</sup> Adult conditions: Stroke, multiple sclerosis, Parkinson, Epilepsy, and ALS;  
Pediatric conditions: Epilepsy and muscular dystrophy

conditions<sup>7</sup> in Cella's et al. (2011) study (other than Adult and Paediatric Epilepsy, where physical health was only supported by two sources). Those affected by neurological conditions are commonly faced with physical impairments related to "vision, hearing, hand/finger dexterity, mobility, bladder and bowel control to varying extents," as well as increased pain and discomfort (NHCC/PHAC, 2014, p. 3). Symptoms can then hinder individuals' ability to engage in activities of daily living (Cella et al., 2011). In fact, physical limitations are so commonly experienced when living with a neurological condition that Statistics Canada's follow-up Survey on Living with a Neurological Condition in Canada stated that over 90% of participants reported interruptions to their usual activities (NHCC/PHAC, 2014). Moreover, while symptoms can increase interruptions in activities of everyday life, such as one's ability to work (Hardie & Poole, 2013), these interruptions can also contribute to further consequences affecting the experience of living with a neurological condition (e.g., socioeconomic status and other financial barriers).

**2.2.2 Cognitive health.** Cognitive health is vital to live and thrive in the complex environment that we live in. Cella et al. (2011) identified cognitive health as a second essential component of HRQOL when living with a neurological condition for several of the conditions<sup>8</sup>. As cognitive health focuses on an individual's ability to perform mental processes, it appeared less relevant to conditions characterized by mainly physical impairments, such as ALS or muscular dystrophies. In general, common cognitive manifestations of neurological conditions include impaired communication (e.g., speech, comprehension), general concerns with applied cognition (e.g., memory, attention/concentration), and executive functions (e.g., decision-

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<sup>7</sup> Number of sources: multiple sclerosis (5), Stroke (5), Parkinson (5), ALS (5), muscular dystrophy (4)

<sup>8</sup> Number of sources: Parkinson (5), Adult Epilepsy (4), Stroke (4), multiple sclerosis (3), Pediatric Epilepsy (3)

making, problem-solving, planning, multitasking, reasoning) (Cella et al., 2011; Department of Health Long-term Conditions NSF Team, 2005). As with interferences with one's physical health, impairments to these cognitive functions can also lead to subsequent consequences influencing the experience of living with a neurological condition. For example, brain injuries have the potential to contribute to communication and memory problems (Konrad et al., 2011), which could be a significant barrier to accessing services or living independently. Overall, of all the neurological conditions reviewed in the Survey on Living with a Neurological Condition in Canada, Alzheimer disease and other dementias scored the lowest score associated with cognition impairment with a Health Utilities Index of 0.37, indicating the greatest impact (NHCC/PHAC, 2014).

**2.2.3 Social health.** Amongst all the HRQOL domains in Cella et al.'s (2011) study, social health was the most consistently identified as a high priority across all conditions, with a minimum of support from four sources<sup>9</sup> per condition. Social health may be measured by individuals' ability and satisfaction with participation in social roles and activities, though living with a neurological condition can require individuals to discontinue or rework social roles, relationships, and identities developed in various domains (i.e., work, home, school, leisure) (Carlozzi & Tulsky, 2013). For example, loss of mobility or cognitive functions have been known to restrict the accessibility of social venues or create barriers to effective communication respectively (Kennedy & Adolphs, 2012; Shevil & Finlayson, 2006; Tickle-Degnen, Ellis, Saint-Hilaire, Thomas, & Wagenaar, 2013). Additional concerns related to social health referenced in the literature included reports of being socially isolated or withdrawn (Finlayson, van Denend, & Hudson, 2004; Gibbons et al., 2013; Tickle-Degnan et al., 2013), concerned over social support

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<sup>9</sup> Literature review, expert input, patient and caregiver focus groups, and key word search.

(i.e., access and dependence; Cella et al., 2011; Finlayson et al., 2004; Fong, Finlayson, & Peacock, 2006), as well as feeling stigmatized<sup>10</sup> (NHCC/PHAC, 2014; Carlozzi, Tulsky, & Kisala, 2011; England, Liverman, Schultz, & Strawbridge, 2012; Molina, Choi, Cella, & Rao, 2013).

**2.2.4 Emotional health.** Emotional health represents the final generic component influencing HRQOL and the experience of daily life for the majority of conditions (Cella et al., 2011). Based on the study by Cella et al. (2011), evidence suggests emotional health was recognized as relevant in all adult neurological conditions<sup>11</sup>. Alternatively, there was insufficient evidence, both in the study and in the literature to suggest that emotional health was an issue for many paediatric neurological conditions, such as children with epilepsy, muscular dystrophy, brain injury, or spina bifida with hydrocephalus (with the exception of more depression and anxiety reported in children with autism) (Cella et al., 2011; Mayes, Calhoun, Murray, Ahuja, & Smith, 2011).

According to Carlozzi & Tulsky (2013), emotional health can be defined as negative “feelings of emotional distress (e.g. anxiety, depression, anger, etc.), as well as positive emotional experiences (e.g. happiness, resilience to life challenges, gratitude)” (p. 216). In the case of neurotrauma, negative emotions were reported to manifest in the form of depression, anxiety, or anger (Carlozzi et al., 2011; Craig, Tran, & Middleton, 2009; Wijesuriya, Craig, Tran, & Middleton, 2012). In addition, based on the unpredictable nature of many progressive degenerative conditions, living with a neurological condition can interfere with participants’ envisioned daily activities and future planning, contributing to feelings of fearfulness, frustration,

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<sup>10</sup> Most evidence focuses on the experience of stigma for those living with epilepsy, chronic migraines, brain injuries, and ALS.

<sup>11</sup> Number of sources: Parkinson (4), Epilepsy (4), multiple sclerosis (4), Stroke (3), ALS (3)

insecurity, as well as a loss of control and independence, or missed opportunities (Chen, Miller, Seo, & Mendoza, 2010; Dawson, Kristjanson, Toye, & Flett, 2004; Finlayson, van Denend, & Dalmonte, 2005; Haarh, Kirkevold, Hall, & Østergaard, 2013; Ploughman et al., 2012a).

Emotions developing from the onset of a neurological condition appear to manifest from the disruption to individuals' biographical stories, as a result of disruptions to their sense of self, as seen in Bury's (1982) research on chronic illnesses.

As demonstrated by this chapter, neurological conditions are acquired in a variety of ways; such as through trauma, genetic predispositions, infections, or age; yet, they all remain alike, as they commonly result from the impairment of the central and/or peripheral nervous system, the "control centre" of the body that connects and coordinates one's mind and bodily functions. Whether this contributes to similar symptoms or barriers in everyday life, there is no denying that there is a relationship between neurological conditions that should be acknowledged. In particular, this thesis will focus on the barrier of accessing services both within a health care and community setting, as the amount and complexity of services required is sometimes just as complicated as the conditions, symptoms, and treatments themselves.

### **CHAPTER 3: LITERATURE REVIEW**

In this chapter, I will discuss the process and findings from my literature review of existing research on service coordination for people living with neurological conditions to inform the selected objectives of this study and ensure their novelty. This process commenced the research design phase with a systematic search for both qualitative and quantitative reports published over the past decade. My search was conducted in May 2014 and was limited to articles published in English and will be focusing on service coordination in developed countries. Multiple variations of search terms using “AND” and “OR” were used in a variety of databases (i.e., Academic Search Complete, CINAHL, Family & Society Studies Worldwide, Social Sciences Full Text (H.W. Wilson), SPORTDiscus, MasterFILE Premier, PsycInfo, PubMed, Medline, Scopus). Sample key search terms included “neurological” or the name of each specific condition (e.g., multiple sclerosis or MS), followed by terms such as “service” or “care” and “coordination” or “coordinator.” In order to better grasp the distinction in concepts related to patient autonomy, additional searches were also conducted, especially related to patient autonomy in treatment decision making, using terms such as “locus of control,” “empower,” “patient autonomy,” “shared decision-making,” “patient-physician relationship,” and “access to information.” Moreover, to further complete the list of literature, reference lists from studies examined were also screened for additional recent work in the area. During the review process, peer-reviewed articles, as well as organization and government reports were chosen at face-value based on the title and abstract, then reviewed and narrowed down to the 89 articles included in this review (please see Appendix D for the Literature Review Matrix).

In reviewing the literature on coordination of services, the topic of service coordination was consistently presented as a best practice by service users and providers to assist the ability of

patients to access services and navigate health, social, and community systems. According to this review, several existing concepts appear to be interrelated with coordination of care, including multidisciplinary care, collaborative care, person-centered services, and continuous care. When describing coordination of care, much of the literature on provision of care shows the interchanging of these terms, as well as other similar ones (e.g., care management, discharge planning, shared care, disease management; Brustrom, Thibadeau, John, Liesmann, & Rose, 2012; Haggerty et al., 2003; Kodner, 2009; McDonald et al., 2007; Reid, Haggerty, & McKendry, 2002).

While these concepts are not synonymous (Jansen, Krol, Groothoff, & Post, 2007), it is easy to sometimes mistake one for another as they play such an essential part in the context of care coordination. In fact, existing in the midst of such dynamic health and social systems, it became clear that coordination was frequently interlinked and influenced by these other best practices, to the extent that it was difficult to support one without influencing the others. In this section, I will outline the four main best practices of service provision that emerged from my literature review in order to illustrate the experience of service use in developed countries, including multidisciplinary care (3.1), collaborative care (3.2), person, patient, or family centered service integration (3.3), and continuity of care (3.4).

**3.1 Multidisciplinary care.** The process of service provision begins prior to an official diagnosis at the first inquiry about symptoms and often continues until death (Gibson, 2008). This suggests that the time allocated to service provision for someone living with a neurological condition can vary from an average of 14 months for those diagnosed with a motor neurone disease, up to decades for people living with multiple sclerosis (Department of Health Long-term Conditions NSF Team, 2005). Outside of routine primary care provided by a general practitioner,

people diagnosed with a neurological condition can also access specialized health services, such as neurology, neurosurgery, occupational therapy, psychiatry, psychology, rehabilitation and/or palliative care to name a few. These specialized health services can be accessed through centers or institutions explicitly focused on the patients' condition or facilities dedicated to a variety of complex disabilities (Siegert, Jackson, Playford, Fleminger, & Turner-Stokes, 2014; Stillman, Frost, Smalley, Bertocci, & Williams, 2014; Turner-Stokes, Sykes, & Silber, 2008b).

Beyond the treatment of symptoms, as mentioned in Chapter 2, living with a neurological condition can also mean confronting physical, social, financial, and psychological barriers. These obstacles can be addressed through community support services, independent contract services, or community-based services commissioned and delivered locally (Surrey County Council, 2011; Department of Health Long-term Conditions NSF Team, 2005). Available services could include anything from family education, to respite care, homecare, financial services, information services, advocacy, long-term care, mental health and addiction services, and more. For example, a Canadian study reviewing community and health services for people living with an acquired brain injury in Ontario believed this population was at an increased risk of depression, anxiety, and other psychopathologies, thereby adding a layer of behavioural and mental health services needed in their care plan (Munce, Laan, Levy, Parsons, & Jaglal, 2014). Moreover, this study found services gaps in services available for comorbid mental health conditions. As a result, multidisciplinary care should be implemented not only to address the complexity of the condition itself but also the multifaceted barriers that manifest while living with a neurological condition on a daily basis for a more comprehensive and holistic approach to service delivery (Breitlow, 2007; Peel, Thomas, & Worth, 2013).

By employing multidisciplinary care teams, it sets the stage for an intricate context where several health care professionals must be in continuous communication with one another and with service providers in the community. In their study, Turner-Stokes et al. (2007) found that, as a result of efficient intercommunication between service providers, patients would benefit from greater access to services and a wider range of expertise. With such value attached to communication between team members, Brustrom et al. (2012) developed recommendations for spina bifida clinics to promote intra-team communication, including instigating pre and post-clinic meetings, standard protocols for communication, and written briefs on cases.

According to the UK Department of Health Long-term Conditions NSF Team (2005), two types of multidisciplinary care exist. In many cases, diverse disciplines operate independently while incorporating multidisciplinary efforts by establishing common goals and respective roles, as demonstrated in a study by Turner-Stokes et al. (2007; 2008b) on the interface between the area of neurology, rehabilitation, and palliative care. Another enhanced model of multidisciplinary care also exists, where service delivery emphasizes integrated team collaboration, as demonstrated in the Comprehensive Care Clinics model for children with hypothalamic obesity (due to treatment of brain tumours; Rakhshani et al., 2010).

Team approaches to multidisciplinary care are wide-ranging, since composition and strategies of each team may vary depending on the care context and goals (Suddick & Dee Souza, 2006). While not always possible, the more integrated comprehensive types of multidisciplinary care was said to contribute to improvements in children's total HRQOL, physical functioning, and school functioning in an Ontario study (Rakhshani et al., 2010). Furthermore, positive outcomes, faster functional gains, and shorter hospital stays were reported in a study by Turner-Stokes (2008) as effects of coordinated intensive multidisciplinary

rehabilitation for patients with acquired brain injuries in England. Stroke patients were also found to benefit from multidisciplinary care teams, with Marsden et al. (2010) describing potential long-term benefits to HRQOL and physical functioning for community dwelling chronic stroke survivors. Lastly, Langhorne et al. (2005) reported shorter hospital stays, reduced death and dependency, increased ease in activities of daily living, and in turn, the opportunity to live at home independently with these supports when discharged from the hospital.

In relation to patients' experience with care coordination, multidisciplinary care models have been said to contribute to increased ease and patient satisfaction when navigating services (Spragins & Lorenzetti, 2008). In a study by Preen et al. (2005), patients reported improved quality of life and better satisfaction with discharge after receiving a multidisciplinary discharge care plan, as opposed to being discharged using standing hospital discharge procedures. The Change Foundation (2008) also reported improvements to care coordination, while acknowledging one particular challenge to that type of service delivery. More specifically, while multidisciplinary care allows patients to access a greater number of quality services, findings from their report propose that some participants reported confusion in identifying the main health professional who they should turn to, in order to discuss their service coordination.

According to the National Institute of Health and Clinical Excellence (NICE) guidelines, secondary care practitioners (e.g., neurologists) would be responsible "to co-ordinate holistic multidisciplinary care" for participants with Parkinson disease (as cited by Agha et al., 2012). Initial audits of this study indicated that such areas were sometimes forgotten in secondary care, though compliance was improved to 100% when checklists were implemented to remind practitioners of these steps (Agha et al., 2012).

While it appears that this checklist would bring Parkinson disease service provision up to

speed in terms of the NICE guidelines, I see a gap in the fact that the health professional (i.e., nurse specialist) most involved with the participant's continual support was not at the very least consulted in the creation of the patient's care plan, as was done in the care for children with spina bifida from Dunleavy's (2007) study. Furthermore, the checklist only considered four types of health services for referrals (i.e., occupational therapy, rehabilitation, vocational, palliative services), which neglects the coordination of "holistic" and "personalized" care that could also require social, psychological, emotional, occupational therapy, and financial services to name a few. Lastly, there is also the possibility that neurologists are not available for discharge or care planning, as was seen in 77% of encephalitis patients leaving the hospital with ongoing complications (Easton, Atkin, & Hare, 2007). Instead, in a follow-up study, Easton and colleagues (2007) found that almost three quarters of patients identified the Encephalitis Society, a community organization, as "their only source of comprehensive information" about their neurological condition (p. 643).

**3.2 Collaborative care (patient autonomy).** Historically, when faced with critical health conditions, patients and families found themselves in a paternalistic relationship where they would assume a submissive role and obediently adhere to the physician's orders (Deber, Kraetschmer, Urowitz, & Sharpe, 2007). Though it is still possible to encounter this type of service delivery model, new ethical standards require health professionals to go beyond promoting what is in the best interest of patients to also ensure they are well educated on the benefits and risks of interventions and autonomous in their treatment decision-making (Lee & Lin, 2009; Rubin, 2014; Solari et al., 2010). In fact, research suggests that patients living with chronic conditions, and particularly those with multiple sclerosis (except for one Italian study), desire more autonomy and control when making decisions about their care, in the form of

increased participation, involvement, and collaboration in the patient-physician relationship (Deber et al., 2007; Giordano et al., 2008; Hamann et al., 2007; Heesen, Kasper, Segal, Köpke, Mühlhauser, 2004; Heesen, Köpke, Solari, Geiger, & Kasper, 2013; Kasper, Köpke, Mühlhauser, Nübling, & Heesen, 2008; Solari, Geiger, & Kasper, 2013). As a result, extensive research has gone into creating decision-making aids, curricula, and programs (Heesen et al., 2007; Heesen, Solari, Giordano, Kasper, & Köpke, 2011; Little, 2013; Solari et al., 2010; Solari, 2014), and resource lists (Frank, Feldman, & Schulz, 2011; Franklin, 2006) to better inform patients. Furthermore, the Multiple Sclerosis Society and Parkinson Disease Society have evolved to prioritize patient autonomy and collaboration in their service frameworks, as well as to advocate for them in the health care setting (personal communication, Ellen Karr, May 26<sup>th</sup>, 2014; Grimes et al., 2012).

With an undeniable shift towards patient autonomy, there are associated influences on participants' experiences while navigating health and social services. Patients are becoming more self-reliant and involved in their own care, engaging in increased behaviours such as self-management, information-seeking (e.g., peer support, internet, research), verifying trustworthiness of their physician (e.g., reputation), or questioning inadequate medical services (Langhorne, Thomas, & Kolaczkowsk, 2013; Lee & Lin, 2009; Versnel et al., 2013; Wilson, Seymour, & Perkins, 2014). Yet, the question is whether they are engaging in such behaviours out of desire or necessity. On the one hand, participants reported taking health care matters into their own hands when faced with inadequate care coordination, suggesting their efforts were a means of achieving proper care in spite of the system rather than as a preference (The Change Foundation, 2008). Alternatively, Sixsmith (2012) also recognized this shift as "a more equitable [patient-physician] relationship where both experiential and professional knowledge are both

valued” (p. 51). Furthermore, patients in other studies demonstrated an eagerness to become more engaged in the management of their condition, since living with it for many years enabled them to become experts of their condition and more confident in acting as their own advocates (Lee & Lin, 2009; Ploughman et al., 2012b). But even so, most patients (and families) are seeking collaboration and a shared partnership not full autonomy (Aspinal, Gridley, Bernard, & Parker, 2012; Davies, Rennick, & Majnemer, 2011; Deber et al., 2007; Giordano et al., 2008; Rubin, 2014; The Change Foundation, 2008) and have expressed an overwhelming preference to be asked about their treatment preferences (Ryan & Sysko, 2007).

Ultimately, physician-patient partnerships that share responsibilities and strike a balance between patient self-sufficiency and health practitioners’ involvement will benefit patients. This type of “collaborative autonomy model” allows people living with a neurological condition the experienced guidance of an expert when making critical health decisions, while being able to emphasize the importance of their personal values and preferences throughout the decision-making process (Aggarwal, Davies, & Sullivan, 2014; England et al., 2012; Rubin, 2014, p. 317). However, participants still have the option to refuse advice and choose an “isolated autonomy approach,” which could mean choosing what is in line with their values rather than health (e.g., refusing life-sustaining treatment for cultural reasons; Rubin, 2014, p. 315). As a result, a patient’s context is critical in determining the proper balance in a patient-physician relationship.

The Behavioral Model presented by Andersen (1995) suggests that predisposing characteristics (e.g., health beliefs) and enabling resources (e.g., family) can influence health behaviours and needs, such as younger, more educated, and female populations demonstrating increased rates of patient participation in medical decision-making (Kaplan & Frosch, 2005;

Ryan & Sysko, 2007). In addition, acquired knowledge of the condition and health care system, uncertainty or pressure of a shortened anticipated lifespan, or existing co-morbidities are examples of factors that can influence personal preferences. Therefore, what is considered supportive care planning and advocacy for a newly diagnosed ALS patient who expects rapid health deterioration could be experienced as overbearing and paternalistic for someone else who has lived with and managed a stable spinal cord injury for many years.

Ultimately, collaborative care can have great impacts on patients' outcomes. For instance, as identified by a comprehensive review by Kiesler et al. (2006), "mismatches" to patient preferences related to service delivery contributed to an increased report of dissatisfaction, decreased emotional well-being, and less effective treatments. As insinuated by Kachuk (2011), the success of a treatment is dependent upon improvement to a patient's life, which itself is dependent upon patients' perceptions of improvement. This raises the importance that doctors "listen to patients" and "acknowledge the power of the patient's narrative" (p. 206).

**3.3 Person, patient, or family centered service integration.** Three types of care integration are included in the literature. Though they all refer to service integration for the individual with a condition, articles with a medical focus tended to discuss participants as patients. In addition, integrating services for "families" rather than for a "patient" or "person" was frequently used when family members played an important role in caregiving, treatment decision making, or care planning, as family members tend to be fundamental in service provision and informal caregiving as a disease progresses (Dyke, Buttigieg, Blackmore, & Ghose, 2006; King, Teplicky, King, & Rosenbaum, 2004; Tan, Jennings, & Reuben, 2014). According to Dunst (1997), service coordination contributed to the delivery of integrated support for patients and their families and thus, is fundamental in the delivery of family-centered care.

Committing to such caregiver tasks can lead to missed workdays or caregiver strain; however, using service coordination can ease the process of care delivery by improving communication with health care professionals, access to resources, understanding of the condition, and ultimately by approaching care provision in a way that acknowledges and addresses the family's needs (Palfrey et al., 2004). Ultimately, participants within this study found the integrated system provided by the Pediatric Alliance Care Coordination not only improved satisfaction with care but was also associated with "some indications of improved health as well as decreased burden of disease" (Palfrey et al., 2004, p. 1507).

Though there has not been a universally accepted definition for person-centered services, references across the literature have implied that person-centered care refers to the delivery of "individualized, needs-based" services that are strategically integrated, co-informed, and centralized for the person or family living with the neurological condition (Almasri et al., 2011, p. 131; Department of Health Long-term Conditions NSF Team, 2005). There are two main components that can be interpreted through this definition. The first component is the provision of personalized services based on the importance of addressing an individual's or the family's "unique" needs (King et al., 2004, p. 79). In other words, the mere fact a service is being offered does not mean that it is addressing a need. In fact, some remain speculative about the universality of the benefits even attributed to integrated care, suggesting that the "merits of service changes depend[] on the needs of [the patient]" (Dickinson, 2008; Kaehne & Catherall, 2013, p. 601). This only reinforces the belief that it is not only the integration of services but the focus on patients' particular needs that is significant. Therefore, as an alternative to disease-focused care, this approach to service delivery allows patients to self-identify and prioritize their needs (Olsson, Jakobsson Ung, Swedberg, & Ekman, 2012; Spragins & Lorenzetti, 2008; Reuben et

al., 2013). According to King et al. (2004), “developmental gains/skills development and psychosocial adjustment” were the two main outcomes for children when receiving family-centered services (p. 80).

A study by Reuben et al. (2013) utilizes the process of co-management with health professionals to identify patient-centered goals, which they hope will “maximize function, independence, and dignity; minimize caregiver strain and burnout; and reduce unnecessary costs through improved care” (p. 2215). Consequently, cooperative communication between health care professionals and patients is encouraged to give patients the opportunity to become informed, convey their preferences for an individualized approach in adapting services to patients’ needs (Galushko et al., 2014; Kaplan & Frosch, 2005; King et al., 2004; Olsson et al., 2012), as well as to build relational continuity (Freeman et al., 2007). Though families of children with spina bifida have sometimes been reluctant to communicate needs, Brustrom et al. (2012) recommended that clinic staff continue to provide written summaries or designate time after their clinic hours to contact or communicate with families. Research has shown that the length of consultation time is important in service delivery for people living with neurological conditions, both for physicians to learn more about their patients for patient-centered support, as well as patients who are able to ask more useful questions about their condition and management skills (Kirton et al., 2012; Penner & Roger, 2012). For example, parents have reported a positive association between contact hours with service providers and positive family-centered outcomes (Sloper, Greco, Beecham, & Webb, 2006). Furthermore, a study by Trute, Hiebert-Murphy, and Wright (2008) found that the extent that service coordination was family centered greatly determined the likelihood of families’ resource needs over time (i.e., psychosocial support resources).

Alternatively, the second component of the definition was to integrate services. In recent years, England has emerged as a leader in this area since the UK Department of Health incorporated person-centered services as the core “quality requirement” to their National Service Framework for Long-term Conditions in March 2005, which was later solidified by the White Paper the following year (Department of Health, 2006; Department of Health Long-term Conditions NSF Team, 2005). Similar to community consultation delivered in January, this framework also identified a need for improved service coordination for people living with long-term neurological conditions. Sample recommendations for more integrated services included providing care planning that would regularly review and organize services and communications across agencies for patients through “a single point of contact” (p. 22), which was later re-emphasized in other studies (Pomeranz, Shaw, Yu, & Moorhouse, 2008; Russell, Roe, Beech, & Russell, 2009; Turner-Stokes et al., 2008b). According to a case study by Perla, Jackson, Hopkins, Daggett, and Van Horn (2013), a veteran afflicted by a traumatic brain injury was able to receive services centered around his particular needs, which reportedly improved his sleep patterns, headaches, and improvements in the home environment. Furthermore, according to the authors, the receipt of comprehensive care coordination and case management was associated with decreased anxiety in war veterans when reintegrating back into the community.

As with most other health care users, there are points throughout a condition when patients living with neurological conditions must access emergency and acute health services (Department of Health Long-term Conditions NSF Team, 2005). And yet, as was described earlier, the complexity of neurological conditions means also accessing an array of services, especially after leaving the hospital setting. Research conducted on the Ontario health services suggested that, while processes and procedures within the hospital setting appeared to be well

integrated and connected, the flow of care seemed to become fragmented when returning back to the community or a long-term care facility (The Change Foundation, 2008). With services being comparatively less integrated in the community as compared to hospital settings, the onus then falls on the patient to assemble the scattered services in a variety of settings without the adequate skills or supports (Spragins & Lorenzetti, 2008). As a result, patients unaware of the care process must learn to navigate the system, figuring out whom to contact and what questions to ask for each separate issue, which at its worst can lead to patients losing out on care because they are lost and forgotten in the transition if barriers are left unaddressed (The Change Foundation, 2008; Egan et al., 2010).

Communication issues represent another theme of a disconnected system, especially when transitioning between locations or providers (Kaehne & Catherall, 2013; Spragins & Lorenzetti, 2008). The extent of collaboration amongst service providers in both the health and social fields is key to the delivery of integrated and coordinated services (Almasri et al., 2011; Department of Health Long-term Conditions NSF Team, 2005). Without proper integration of primary care and mental health services, physicians may be unaware of the necessary services external to their field (i.e., behavioural and mental health services) from inadequate dissemination of information (Bitsko et al., 2013). If the transfer of information between providers becomes hampered, this can likely be associated with issues of “repetition, redundancy and delay” (The Change Foundation, 2008, p. 7). For instance, in a review conducted by Spragins and Lorenzetti (2008), patients were required to reiterate medical histories and symptoms, repeat unnecessary tests, and face appointment delays or cancellations when the service providers received inadequate or inaccurate information. Beyond inconveniences, such discrepancies were also reported to contribute to safety hazards, potentially leading to

“inappropriate or absent follow-up care” (p. 24). Alternatively, those service providers who integrated multidisciplinary neurological services through teamwork and communication saw benefits to the “effectiveness and efficiency of the service” (Brewah, 2013; Suddick & Dee Souza, 2006, p. 80), by providing treatments that complemented one another (Department of Health Long-term Conditions NSF Team, 2005). In a study conducted by Parent, Barchi, LeBreton, Casha, and Fehlings (2011), patients with spinal cord injuries who were promptly referred to an integrated multidisciplinary team even saw decreases in mortality and complication severity.

Service integration and service coordination are inherently linked. In one way, service coordination is made easier if services are already integrated (McDonald et al., 2007). For instance, according to Spragins and Lorenzetti’s (2008) review, how patients perceive their care coordination is strongly associated with the success of communication amongst health care professionals. On the other hand, service coordination can also be used to address gaps in services when service integration is unavailable. More specifically, services can be brought together either physically by co-locating services in the form of a one-stop-shop multi-centre (e.g., Winnipeg Specialized Services for Children and Youth, <http://www.sscy.ca/>) or abstractly through official programming where information and referrals are streamlined (e.g., Outpatient programs at Deer Lodge Centre, <http://www.deerlodge.mb.ca/programsOutpatient.html>) (Bernard et al., 2008; Munce et al., 2014; The Change Foundation, 2008).

While ideal, acquiring and maintaining the funds and capacity to implement initiatives outside of a hospital setting is often a key barrier straining service delivery, especially for the development and maintenance of such costly integrated service proposals (Bahn & Giles, 2012; Bernard et al., 2008; Crack, Turner, & Heenan, 2007; Easton et al., 2007; Knapp, Iemmi, &

Romeo, 2013; Munce et al., 2014; Palsbo & Diao, 2010), which can be revenue neutral at best for some conditions (e.g., spina bifida; Brei, 2007). In addition, strategic planning will also take time to develop and implement an integrated care pathway with a focus on multidisciplinary and coordinated care, which was actually identified as a core barrier to implementation of an integrated care pathway for people living with Parkinson disease in Peel's et al. (2013) study. In the event that initiatives are too costly or time consuming, support from service coordination and care planning can be used to substitute formal integrated networks by connecting patients with the services they need through referrals, information services, support, and advocacy (Bernard, Aspinal, Gridley, & Parker, 2012; Egan et al., 2010).

**3.4 Continuity of Care.** The final theme exposed in the literature review as a best practice for service provision is continuity of care. The concept of continuity explicitly emerged in medical specialties related to disease management in the late 1980s, as a reflection of rising numbers of chronic conditions with complex care needs (Haggerty et al., 2003). As people with neurological conditions are living longer, developing a strategy to provide access to prolonged synchronized timely care is becoming progressively more and more valuable. In fact, national bodies, such as the Canadian Health Services Research Foundation and the UK Department of Health have identified continuity of care for patients, caregivers, and family members as a research priority (Reid et al., 2002). Though a universal definition does not exist, research has identified continuity of care as a multifaceted concept. This subsection will outline informational continuity (3.4.1), relational continuity (3.4.2), and management continuity (3.4.3), as these represent the main dimensions of this concept, which are referred to the most consistently in the literature (Aspinal et al., 2012; Bernard, Aspinal, Gridley, & Parker, 2010; Freeman et al., 2007; Haggerty et al., 2003; Reid et al., 2002).

**3.4.1 Informational continuity.** As discussed for other best practices, communication between health providers is paramount in providing integrated person-centred services. Therefore, it is of little surprise that informational continuity, which promotes information transfer and sharing (e.g., patients' medical history, values, and preferences) between service providers, was identified as one of the main dimensions of continuity of care and essential to self-management (Cheng et al., 2004; Freeman et al., 2007; Haggerty et al., 2003; Ray, 2005). Based on the literature, informational continuity occurs when one care provider has access to and uses relevant written or oral information on prior events when making current care decisions (Reid et al., 2002). Systematic documentation is a clear mechanism used to communicate information (Brustrom et al., 2012; Cheng, et al., 2004). In one study, having access to formal structured electronic records of a patient's complete health history was said to enable physicians (or any provider in the case of an unscheduled visit) to provide sound and effective health care decisions for their patients (Darkins, 2006).

The key elements in this definition include both the transfer and the uptake of information, as research demonstrates that information transfer alone is insufficient to improve care delivery (Freeman et al., 2007). As a result, the degree of informational continuity achieved is ultimately determined by the extent of integration between providers (Aspinall et al., 2012). In Wensing's et al. (2011) study, connectedness between health care professionals was dependent on caseloads (with more patients with Parkinson disease leading to more connections with other health care professionals), as well as location of care (with hospitals demonstrating more connections than primary health care settings), which in turn translated into higher competence in treating Parkinson disease and enhanced coordination of care. In a Manitoba-specific context, "high caseloads, limited resources, and a general lack of system service integration" limited

service coordinators' ability to provide family-centered services, such as meeting with families and fellow providers or completing administrative tasks (Wright, Hiebert-Murphy, & Trute, 2010, p. 125). In addition, when transitioning between different sectors, informational continuity was not an automatic process; rather, some respondents reported unnecessary redundancy, rescheduling, and/or the burden of transferring information falling on patients themselves when information was not transferred properly (Davies et al., 2011; The Change Foundation, 2008).

**3.4.2 Relational continuity.** Sustained quality relationships represent the second component of continuity of care, which has been defined as “an ongoing therapeutic relationship between a patient and one or more providers” (Haggerty et al., 2003, p. 1220). Though literature on primary care mainly illustrates continuity as a relatively permanent relationship between one patient and his or her general practitioner, the context changes in the delivery of secondary care. Since general practitioners do not have the expertise or resources to deliver services in all care settings (e.g., rehabilitation, neurology), patients with unique needs related to their neurological conditions must be referred out to receive such services. However, even when referrals result in inconsistent relationships with specialists, this is offset by the predictability and sustained relationship that is built with a patient’s main provider or core team (Haggerty et al., 2003). In their review of a comprehensive Service Delivery and Organization program in England, Freeman et al. (2007) recommended that patients should be seen by the same practitioner over time, where appropriate, to allow for the relationship to build trust and therapeutic benefits. In a study by Russell and colleagues (2009), building a strong trusting relationship with patients was seen as one of the main advantages to the role of community matrons when providing services over time. Trust in interactions with one’s health provider is known to contribute to improved health outcomes through mechanisms of patient compliance, disclosure, placebo effect, and

physician's caring behaviour (Lee & Lin, 2009). From participants' perspectives, having a relationship made the difference between understanding "them" versus "their condition" (Apsinal et al., 2012, p. 2314).

In addition, continuity and coordination can lead to improvements in communication, which is associated with patient empowerment, service provider involvement, and reductions in repetition (Aspinal et al., 2012; Palfrey et al., 2004; Reid et al., 2002). In a study by Roger and Penner (2012), a continuous relationship meant health professionals had a better grasp on their patients' condition (i.e., Huntington disease) and personal characteristics, placing them "in a much stronger position to assess how an individual [was] doing" (p. 518). Alternatively, in a study by Davies et al. (2011), strong partnerships and parents' confidence in the paediatric health care team were replaced by feelings of abandonment, loss, fear, and uncertainty when young adults with neurological conditions were required to transition to adult services. At this point, parents in the study were required to rebuild a connection with their child's new physician within the adult setting, as without this relationship "No one knew [them]," and they were just "a number" waiting without services for their first appointment (p. 35). In another study, some patients with spinal cord injuries refused to attend clinics because of their discontent with the inability to visit the same physician more than once, thus demonstrating a strong desire for relational continuity (Williams, 2005).

Indeed relational continuity is not only the onus of health professionals, as visits tend to be either initiated by the patients or dependent on their voluntary attendance. While this could mean sporadic attendance for some patients, it remains important to maintain a reliable point of contact, as some users prefer to have the control and choice to only return to access services when it is needed (e.g., life transition, obstacles) (Aspinal et al., 2012; Easton et al., 2007;

personal communication, Ellen Karr, May 26<sup>th</sup>, 2014), while others may prioritize early access over this continuity due to difficulties or delays (Freeman et al., 2007).

**3.4.3 Management continuity.** Finally, the last dimension of continuity of care is management continuity, which focuses on the treatment of the neurological condition. As with any person, treatment needs and desires will evolve over time for patients with neurological conditions. This will mean facing transition periods, whether from child to adult services (Binks, Barden, Burke, & Young, 2007; Brustrom et al., 2012; Davies et al., 2011; Restall et al., 2005), life cycle changes (Pomeranz et al., 2008), or moving to a new setting due to functional declines or improvements (e.g., when discharged from the hospital or admitted to long-term care facilities) (Chevignard, Toure, Brugel, Poirier, & Laurent-Vannier, 2010; The Change Foundation, 2008).

According to findings related to the National Service Framework implementation in England, service providers sometimes do not possess the financial and staff resources required to provide “on-going and comprehensive rehabilitation,” thereby forcing them to terminate these services upon return to community settings despite patients’ ongoing needs (Sixsmith, Callender, Hobbs, Corr, & Huber, 2014). In one study, services that were received for over a decade were “abruptly terminated” without the proper steps to confirm the availability of future care, causing a fragmentation in the management continuity (Davies et al., 2011, p. 35).

Transitioning between settings to receive services has been referred to as a specific factor that frequently interrupts the experience of management continuity, possibly leading to detrimental outcomes to quality and provision of services, and in turn patients’ health (Reid et al., 2002; Sixsmith et al., 2014; Spragins & Lorenzetti, 2008). Beyond being introduced to an unfamiliar system, participants in qualitative studies described themselves during their

transitions from paediatric and adult settings as being “unprepared for their roles in the next health care setting,” missing knowledge about “the essential steps in managing a chronic illness,” and being limited in terms of their “access to appropriate health care practitioners for guidance” (p. 1068).

As a result, planning for management continuity is encouraged to enable the service provision of timely, seamless, coherent care, which is amenable to the fluctuations in patients’ needs and consistent even when crossing between service providers or organizational boundaries (Aspinal et al., 2012; Binks et al., 2007; Chevignard et al., 2010; Freeman et al., 2007; Haggerty et al., 2003; Perla et al., 2013; Pomeranz et al., 2008; Reid et al., 2002). In fact, research reporting on the implementation of recent care management initiatives in England indicates “having access to a named person, able to co-ordinate care within and across different sectors, improves continuity of care for people with long-term neurological conditions” (Bernard et al., 2010, p. 79; Russell et al., 2009). While six weeks of post-hospital discharge may assist with some of the transitional challenges highlighted earlier, it appears that it was insufficient to support the potentially lifelong chronic needs of stroke patients discharged from the hospital in a study by Mayo and colleagues (2008). However, by employing lifelong “advocacy, communication, education, identification of service resources, and service facilitation” in the form of case management, case managers have been reported to be successful at promoting patient wellness and autonomy for such complex patient (Pomeranz et al., 2008, p. 324).

As with other types of continuity, this dimension is influenced by how integrated and coordinated services are (Haggerty et al., 2011), which is supported by the assessment, planning, facilitation, and monitoring of care planning activities (Challis, 2010). Such plans can vary greatly, ranging from small-scale interventions (e.g., short-term rehabilitation) to plans that map

out flexible management goals for the remainder of a patient's life (Challis, 2010; Reid et al., 2002). At this point in time, rehabilitation teams, nurse specialists, and day opportunities have been identified as existing vehicles for promoting continuity of care in England through a research project commissioned by the Department of Health Policy Research Programme, which warrants further investigation to capture their full impact on patients' experience with care coordination and coherence of services (Aspinal et al., 2012; Bernard et al., 2012; Freeman et al., 2007; Gridley et al., 2011; Haggerty et al., 2011).

Otherwise, teleassessment, telesupport, telecounselling, teleeducation, telehealth, telemedicine, teleradiology, telerehabilitation, and similar technological initiatives have also been proposed for people with neurological conditions to facilitate a revolutionary way of delivering services (Brewah, 2013; Galea, Tumminia, & Garback, 2006; Singh et al., 2009; Timpano et al., 2013). More specifically, in a study by Stillman et al. (2014) symptoms made access to health care and other services challenging at times, such as inaccessible exterior doorways that affected one third and 27% of primary and specialty care visits respectively. Therefore, measures have been taken to think of new innovative ways to address accessibility barriers that may interfere with management continuity, though current technology in service delivery is limited and cannot substitute regular onsite neurological input (Hewer, 2013; Hoffman & Cantoni, 2008).

### ***Literature Review Conclusion***

Before addressing the issue of service coordination, it was necessary to describe the system in which patients were accessing their services to provide context to the issue at hand. By combining themes identified in the literature review with McDonald's et al. (2007) definition of care coordination, this study will define service coordination as:

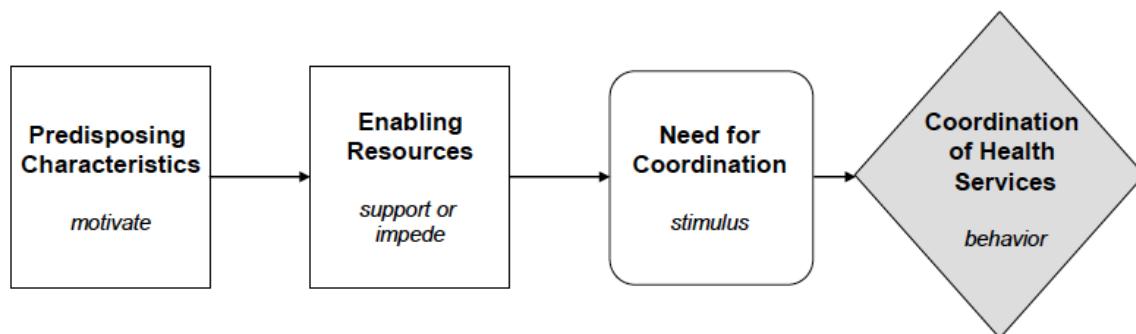
The collaborative exchange of information among participants involved in a patient's care (including the individual or family affected by a neurological condition themselves) to enable marshalling of personnel and resources required, in a way that best facilitates the delivery of reliable person-centered services.

In particular, this definition identifies patients as people and families, refers to services holistically (including more than just care or treatment), and gives more emphasis to the patient's involvement in the process of decision-making and planning. As you can tell by this definition, service coordination is a dynamic behaviour. While multidisciplinary care, collaborative care, integrated person-centered care, and continuous care all represent a context or state of being, service coordination represents that behaviour that occurs as a result of their existence or in spite of their absence. It can be both a consequence of a successful system or an intervention on its own to ensure that patients can focus on living rather than solving the puzzle that is their care plan.

## CHAPTER 4: CONCEPTUAL FRAMEWORK

Several conceptual models exist to hypothesize how care coordination, and outcomes from such interventions, can be realized (McDonald et al., 2007). Out of these alternatives, the model that came closest to my interpretation of the literature was McDonald et al.'s (2007) adapted version of Andersen's (1995) Behavior Framework (for McDonald et al.'s Care Coordination Framework, please see Figure 1). Andersen's framework was initially developed in 1968 to predict and assist in understanding the use of health services by patients and their families (Andersen, 1995). In 2007, McDonald and colleagues adapted this model "to focus on the coordination behaviours of health care delivery participants," demonstrating the linear process leading up to the actual behaviours of care coordination, and will be referred to as the Care Coordination Framework for the remainder of this thesis (McDonald et al., 2007, p. 111). In this chapter, I will explain all the components of the Care Coordination Framework that were used in framing my data analysis (4.1), as well as explain what Care Coordination Interventions have appeared in the literature (4.2).

**Figure 1. Care Coordination Framework**



\*\* Figure from McDonald et al. (2007, p. 111), which was originally adapted from Andersen's (1995) Behavior Framework.

#### 4.1 Care Coordination Framework

The model begins with “Predisposing Characteristics,” otherwise known as factors existing prior to service delivery, which determine the level of motivation generated for care coordination (Andersen, 1995). According to Andersen (1995), this component includes mainly personal and system characteristics, as well as other external environmental factors.

Demographic characteristics (e.g., age, gender), social structures (e.g., education, occupation, ethnicity, social networks, social interactions, culture), and health beliefs (e.g., attitudes, values, knowledge) are all personal characteristics in the model that typically influence need and use of health services (Andersen, 1995). Dependent on these characteristics, one’s knowledge of and stance on service coordination will differ. According to McDonald et al. (2007) this can influence the role patients play in their own care coordination. For example, some people could be intrinsically motivated in their daily-lives, which would inspire similar tendencies when diagnosed with a condition, thereby creating patients who inherently desire to be autonomous and involved in the coordination of their own care.

The qualities of the system and “context of care coordination” itself are also recognized as predisposing characteristics (Andersen, 1995; McDonald et al., 2007, p. 112). The structure of medical professions can be particularly influential for service delivery and coordination, as this creates “expectations about who has responsibility for specific care activities” (McDonald et al., 2007). For instance, if an organization was structured based on neoliberal policies, this would lead to a pattern of transferring the responsibility of service coordination to patients and their families. Relatedly, health professionals would be less inclined to perform these coordination tasks, as they would no longer feel a responsibility to do so. However, according to McDonald et al. (2007), with creativity and significant enabling resources (i.e., investments, intervention),

steps could be taken to reduce such barriers (e.g., training, new organizational structure, culture), thereby changing what was once a predisposing characteristic into an enabling resource.

Therefore, the distinguishing factor of predisposing characteristics is that they represent current characteristics that are not easily altered without the appropriate enabling resources (McDonald et al., 2007).

“Enabling Resources” is the second component of the Care Coordination Framework, though still existing prior to the act of care delivery. Enabling resources signify both personal/family resources (e.g., income, insurance, travel), as well as community/organizational resources (e.g., “requisite information systems, organizational structures, or productive relationships with others providing care to the same patient”; Andersen, 1995; McDonald et al., 2007, p. 112). These resources represent facilitators of system navigation, given their tendency to enable participants in addressing need for coordination. When available, enabling resources provide patients and service providers the “means and know-how” to access and coordinate services, in place of the need for coordination existing in their absence (Andersen, 1995, p. 3).

McDonald and colleagues (2007) further explain the “classification of predisposing characteristics and enabling resources [as] a function of point of view” (p. 112). Whether acting as a system-level (e.g., government policymakers) or service-level (e.g., community service provider) decision maker, participants will have access to different enabling resources that can be used to influence service coordination. For example, organizational boundaries and government health care policies can impede community organization representatives from influencing a particular service integration initiative in the health care system, making its absence a predisposing characteristic from the point of view of the community organization. On the other hand, the same representatives could have access to resources and authority within their own

organization, allowing them control over the delivery of the services (and therefore the enabling resources) they offer to people with neurological conditions and health care providers participating in service coordination. Therefore, the same factors can be perceived as either predisposing characteristics or enabling resources depending on the eye of the beholder.

The third element to the Care Coordination Framework, the “Need for Coordination,” is a straightforward requirement that most would find familiar in this area of research. When someone faces a diagnosis of a neurological condition, he or she faces the prospect of accessing services. At this point, depending on “the patient’s health and functional state, and his/her perception of need,” a need for coordination may be stimulated (McDonald et al., 2007, p. 112).

Once a need for coordination is determined, one or more participants in the patient’s care must voice this need to generate the final stage of engaging in the actual behaviours of Coordinating Services (McDonald et al., 2007). Based on the need for coordination indicated, specific steps to improve care coordination can be identified (McDonald et al., 2007). In some cases, improving coordination of care can be as simple as reinforcing current best practices, while in other cases it may involve the development of new guidelines, new coordination interventions, or new policies to support coordination, dependent on the enabling resources available to the individual conducting the situational analysis (McDonald et al., 2007).

## **4.2 Care Coordination Interventions**

Based on a comprehensive review by the Agency for Healthcare Research and Quality, 43 reviews directly related to the coordination of care were identified in the literature (McDonald et al., 2007). Amongst this list, 20 different types of interventions were identified, of which “multidisciplinary teams,” “disease management,” and “case management” were the most frequently used (see Table 1 for Types of Care Coordination Interventions). The two former

types of care coordination interventions consistently contributed to improved health outcomes; yet, the authors could not identify what intervention was the most efficient, as studies were overwhelmingly heterogeneous in terms of the populations being reviewed, the definition used for coordination of care, and the variety or lack of measures. Furthermore, the literature focuses on specific patient populations including congestive heart failure diabetes mellitus, and other mental health illnesses (e.g., depression, anxiety), demonstrating a gap in the literature.

Table 1

*Types of Care Coordination Interventions*

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• Assertive community treatment</li> <li>• Case management</li> <li>• Collaborative care</li> <li>• Disease management</li> <li>• Geriatric assessment/evaluation and management</li> <li>• Integrated programs</li> <li>• Interprofessional education</li> <li>• Key worker assigned coordination function</li> <li>• Multidisciplinary clinic</li> <li>• Multidisciplinary program (comprehensive)</li> </ul> | <ul style="list-style-type: none"> <li>• Multidisciplinary teams</li> <li>• Navigation program</li> <li>• Nurse-doctor collaboration</li> <li>• Organized specialty clinic</li> <li>• Organized cooperation</li> <li>• Shared care</li> <li>• Specialist outreach clinic</li> <li>• System level interventions</li> <li>• Team coordination and delivery</li> <li>• Team coordination</li> </ul> |
|--|--|

*Note.* Modified table from McDonald et al. (2007), p. 62.

In fact, only one study within the list of reviews directly related to coordination of care was related to a neurological condition. This review by Langhorne et al. (2005) examined care coordination offered by multidisciplinary teams for older stroke patients in the process of early supported hospital discharge, including rehabilitation and community support. The findings demonstrated that weekly team meetings encouraged coordination of care that contributed to a reduced rate of mortality and dependency in stroke patients.

To conclude, based on the literature review and McDonald's et al. (2007) comprehensive

meta-analysis, there has yet to be a coordination intervention that has been proven most effective. In part, this provides support for future research to develop an official definition for the term “coordination.” In addition, this is also the result of different conditions having different levels of service needs, thus benefiting from different types of interventions. That being said, although interventions may differ, the goal consistently remains to provide the most appropriate, complete, and timely care possible, which itself contributes to improvements in “clinical outcomes, adherence outcomes, other patient experience outcomes, and utilization outcomes” (McDonald et al., 2007, p. 62).

This conceptual model is both clinically-based and facilitates an applied theoretical inquiry, which is very much in line with the research objectives of this thesis. As a result, I expand on its components in my discussion and recommendations in Chapter 8, where I explain what participants from my study identified as their hopes for future interventions for service coordination within Manitoba.

## CHAPTER 5: METHODOLOGY

This chapter will describe the methodological approach of my thesis, including the research design (5.1), data source or study sample (5.2), data collection methods (5.3), data analysis based on Morse's (1994) four analytic procedures (5.4), as well as the best practices that were following based on Tracy's (2010) eight criteria for qualitative research (5.5).

### 5.1 Research Design

The choice of research design and methodology is dependent on how appropriate those methods are for answering the study's research objectives (van den Hoonard, 2012). This study uses a qualitative approach to learn about processes and experiences of system navigation and service coordination (Patton, 2002) by the individuals who utilize them. The types of questions asked in data collection require inductive reasoning, as the "experience" of accessing services is not a concept that can be quantified (Thorne et al., 1997). In this case, qualitative research was able to account for those variations in personal contexts, which supported gaining an in-depth understanding of multiple perspectives, rather than trying to generalize findings to a single truth (van den Hoonard, 2012). By asking "how" questions in semi-structured interviews, I was able to increase the richness of my data regarding participants' subjective realities, relationships, and contexts, in order to further contributed to my understanding and ability to provide person-oriented recommendations (van den Hoonard, 2012).

Based on my research objectives, I utilized Thorne, Reimer Kirkham, and MacDonald-Emes's (1997) "interpretive description" research design to guide the methodology of my thesis. Interpretive description was chosen to generate knowledge for both theoretical and clinical purposes in applied health disciplines (Hunt, 2009). More specifically, I have located my study within the strand of theoretical development of applied health. Firstly, I did so to justify

conclusions drawn from my literature review and the purpose of my study as a whole “within a discipline’s knowledge base.” Next, I “used [MacDonald’s et al. (2007)] theory to guide and direct the various phases of the research process,” with the goal of advancing that theoretical position (Thorne et al., 2002, p. 441). This design was chosen to facilitate myself, as the researcher, to go beyond the systematic description of the experiences and analysis of human phenomena to theorize and apply recommendations to real-life contexts (Thorne Con, McGuinness, McPherson, & Harris, 2004). This involved “interpretation and explanation in the context of qualitative credibility criteria” (Thorne et al., 2004, p. 8). Therefore, in line with the goal of this study, interpretive description allowed me as the researcher to go beyond describing the experience of accessing services to understand, interpret, and explain how and why these experiences are influenced by living with a neurological condition in Manitoba.

In addition to contributing to the literature, interpretive description focuses on participants’ subjective experiences, with the ultimate goal of guiding future change to improve implementation (Thorne et al., 2008). Interpretive description was said to be especially beneficial in health care, as it generates findings that are not only directly relevant to the setting by engaging those involved in the clinical-context (in this case the patients), but frames it in a way that is “accessible and coherent” (Hunt, 2009, p. 1291). Specifically in this study, stories of accessing services derived from participants provided me with a better understanding of how Manitoban’s living with neurological conditions view the successes and gaps of the current system, which I then translated into recommendations for future policy and practice in Chapter 8.

## **5.2 Data Source: Study Sample**

As with other community organizations in the literature, we can assume that those within Manitoba act as a primary source of support for those living with neurological conditions and

their families (Crack et al., 2007; Easton et al., 2007; Girach, Hardisty, & Massey, 2012). In fact, not-for-profit community organizations have successfully become an essential part of not only the social welfare of the population but also their care provision, as demonstrated by the thousands of registered members and touch points reported by Manitoba community organizations themselves (please see Appendix E for the Estimated Number of People Supported by MB Community Organizations). Given the prominent role community organizations play in serving people with neurological conditions, their expressed investment in the topic, existing connections, as well as the self-governance of those organizations, these community organizations were selected as the vehicle for addressing the issue of service coordination in Manitoba. As with other types of qualitative research, interpretive description contends that people are experts of their own experiences (Thorne et al., 1997). Since the goal of this research is to improve coordination of services related to neurological conditions in Manitoba through not-for-profit community organizations, it is paramount that data sources for this study included the perspectives of those stakeholders currently accessing such services (Sixsmith, 2012; Sixsmith et al., 2014).

Using purposive sampling, I strategically selected 15 adults living with neurological conditions in Manitoba. These individuals were selected because they represent the conditions discussed earlier in my introduction. Building on existing relationships with community organizations in Winnipeg, staff representing these groups assisted me in the dissemination of my poster and promotion of my study via message boards, social media, newsletters, and word-of-mouth (please see Appendix C for the list of Community Organizations Contacted, Appendix F for the Recruitment Letter, and Appendix G for Recruitment Poster). In addition to these efforts, snowball sampling and word-of-mouth were key in soliciting community members

outside of community organizations.

Eligibility was dependent on participants being over 18 years old, living in Manitoba with a neurological condition, and having accessed some level of services from community organizations or the health care system over the past year, thereby capturing the most recent context of service utilization. Otherwise, recruitment efforts focused on maintaining sample diversity by recruiting adults from different backgrounds for “theoretical sampling,” a concept borrowed by interpretive description from grounded theory (Bryman, 2012, p. 418; Glaser & Strauss, 1967; Thorne et al., 1997). This meant trying to ensure a variety in demographic characteristics, such as participants’ condition, age (over 18 years old), time since diagnosis, sex, education, and geographic location (i.e., urban vs. rural), ethnicities, and socioeconomic status when possible, as these factors have the potential to influence access to care. The diverse sample promoted variability in terms of the perspectives on service coordination, thus adding to the significance of themes that emerged from the data regardless of different backgrounds and experiences (Patton, 2002; Thorne, 2008). Table 2 breaks down the demographic and health characteristics of study participants.

<i>Demographic and Health Characteristics of Study Participants</i>	
Demographic Characteristics (N=15)	Summary Statistics n (%)
<u>Age</u>	
Mean	50.6 years
Range	20 to 74 years
20 to 34 years	2 (13.3%)
35 to 49 years	5 (33.3%)
50 to 64 years	4 (26.7%)
65 + years	4 (26.7%)

<u>Gender</u>	
Female	8 (53.3%)
Male	7 (46.7%)
<u>Marital Status</u>	
Married	10 (66.7%)
Unmarried	4 (26.7%)
Divorced	1 (6.7%)
<u>Ethnicity</u>	
Canadian/ European	11 (73.3%)
Metis	2 (13.3%)
Jewish	1 (6.7%)
Mennonite	1 (6.7%)
<u>Employment/ Education Status</u>	
Full-time Student	1 (6.7%)
Full-time Work	6 (40.0%)
Part-time/ Casual work	2 (13.3%)
Retired	4 (26.7%)
Unemployed/ Not Student	2 (13.3%)
<u>Highest Education</u>	
Incompleted High School	1 (6.7%)
High School	2 (13.3%)
Certificate/ Diploma	10 (66.7%)
University	2 (13.3%)
<u>Household Income (Dollars)</u>	
0 to 30,000	5 (33.3%)
30,000 to 60,000	3 (20.0%)
60,000 to 90,000	2 (13.3%)
90,000 +	5 (33.3%)
<u>Place of Residence</u>	
Urban	14 (93.3%)
Rural	1 (6.7%)

<u>Primary Neurological Condition</u>	
Neurodevelopmental	5 (33.3%)
Neurotrauma	5 (33.3%)
Neurodegenerative	5 (33.3%)
<u>Time Since Diagnosis</u>	
Under 1 year	2 (13.3%)
1 to 4 years	2 (13.3%)
5 to 9 years	3 (20.0%)
10 to 14 years	2 (13.3%)
15 to 19 years	1 (6.7%)
20 + years	4 (26.7%)
<u>Private Insurance</u>	
Yes	11 (73.3%)
No	4 (26.7%)
<u>Self-reported General Health</u>	
Excellent	3.5 (23.3%)
Good	7.5 (50.0%)
Fair	2.5 (16.7%)
Poor	1.5 (10.0%)
<u>Self-reported Mental Health</u>	
Excellent	4 (26.7%)
Good	7.5 (50.0%)
Fair	3 (20.0%)
Poor	0.5 (3.3%)

*Note.* Half points in self-report health sections were included to represent the daily fluctuations in participants' perceived health status reported where participants felt they found themselves between two categories.

In addition to the main sample selected for this study, a few participants requested that family members join them for the interview; whether for company or to assist with recalling events as they occurred (i.e., to compensate for memory loss related to their neurological condition). Family members participated to varying degrees, with some jointly participating throughout the interview and others waiting on the periphery to answer questions directed to

them as they arose. Given that family members were key supporters and companions in participants' experiences while navigating the health care system, their data greatly enriched the findings of this study. Pseudonyms were assigned to both main participants and family members, but have been kept separate from demographic characteristics for confidentiality purposes. Table 3 includes each participant's pseudonym and neurological condition for the reader's convenience.

<i>Participant Pseudonyms and Conditions</i>		
<u>Pseudonym</u>	<u>Condition</u>	<u>Subtype</u>
Victor	Brain Injury	From Trauma
John Wayne (J. Wayne) <i>Dad: Clyde</i>	Cerebral Palsy	Maternal Toxemia
Andy <i>Wife: Molly</i>	Parkinson Disease	Idiopathic- Vocal Tremor
Julienne <i>Husband: Gaston</i>	Alzheimer Disease	Early-stages
James	Spina Bifida and Hydrocephalus	Congenital
Lena	Hydrocephalus	Arrested
Olive	Epilepsy	From Brain Injury
Shelly Vollant (Shelly V.) <i>Dad: Big Bird</i>	Epilepsy	From Trisomy 8
Jacks Teller (Jacks T.) <i>Wife: Lulu Belle</i> <i>Daughter: Sadie Tahoe</i>	Muscular Dystrophy	Limb-girdle
Oliver Twist (O. Twist)	Spinal Cord Injury	Paraplegia
Jane Brock (Jane B.)	Dystonia	Blepharospasms
Suzy	Dystonia	Cervical Dystonia

Sherri	Multiple Sclerosis	Primary Progressive
John <i>Wife: Emily</i>	Huntington disease and Stroke	Adult-onset
Leslie	Tourette Syndrome	Mild

### 5.3 Data Collection

I emailed questionnaires to confirmed participants to yield preliminary descriptive information of the population (Please see Appendix J for Questionnaire). Otherwise, I utilized a semi-structured interview guide as the primary data collection tool in face-to-face interviews (please see Appendix H for the Interview Guide). Questions outlined in the interview guide were linked to the conceptual framework and research questions to provide consistency and ensure collection of pertinent information. Questions were written in plain language and in English to enhance the participants' understanding. Clarifications were always available.

All interviews were audio-recorded and took place at a time and private location chosen by the participant to promote convenience and comfort for them when discussing their experiences (e.g., their house, a familiar coffee shop). Participants were asked to reflect on the coordination of care, as well as their overall experience, when accessing services through the health care system or in the community. In addition, they were asked to share their perspective of the different systems, the effectiveness or gaps of service coordination initiatives, as well as suggestions for any future changes. The length of interviews ranged between just over a half an hour to nearly four and a half hours, averaging at about 1 hour and 15 minutes per interview.

All semi-structured interviews contained open-ended questions as well as optional probes to elicit further information when clarification was needed (van den Hoonard, 2012). Participants were allowed to provide as much or as little about their experiences as they saw fit. In addition, the flexibility from open-ended questions respected participants' answers, allowing them to lead

the interview in the direction that they saw as most meaningful, including areas that were not previously considered in the interview guide and future data collection (van den Hoonard, 2012).

#### **5.4 Data Analysis: Morse's (1994) Analytic Procedures**

As described by van den Hoonard (2012), the process of data analysis is often one that should occur concurrently with data collection due to their reciprocal influence (though it is important to avoid premature data coding). Since interpretive description was chosen to guide this study, data analysis followed the steps outlined in the existing work by Morse (1994) as recommended by Thorne (2008), which has assisted in ensuring rigorous analytic procedures. In this section, I explain how I followed Morse's (1994) steps of data analysis, through comprehending (5.4.1), synthesizing (5.4.2), theorizing (5.4.3), and recontextualizing (5.4.4), which enabled me to identify patterns within the data, relationships between those patterns, and finally recontextualize those relationships to have meaning in the world of applied health research.

**5.4.1 Comprehending.** In terms of Morse's (1994) first phase of data analysis, as with other types of qualitative studies, I immersed myself in the data to enhance my comprehension by performing an extensive literature review. In line with this process, interpretive description of health research recommends authors situate themselves within existing knowledge of other experts in the field to assist in orienting the inquiry (Thorne et al., 1997). As demonstrated in Chapters 1 to 4, I sought out knowledge of the current context of service coordination, relevant concepts (e.g., best practices in service provision), existing theoretical frameworks (e.g., Care Coordination Framework), as well as all relevant literature in the area to prepare myself for this study. However, these merely represent starting points for data analysis, for which I was required to “challenge[] as the inductive analysis proceed[ed]” (Thorne et al., 1997, p. 173).

Initially, I supported this process of data comprehension by engaging in “active inquiry,” where I used probes included in my interview guide (e.g., who, what, when, why, where, how) to investigate both what emerged as obvious and meaningful to participants, as well as to inquire about anything that appeared out of the ordinary (which I captured in my memos and field notes for future reference) (Morse, 1994, p. 28; Thorne et al., 1997). In addition, as identified in my literature review, concepts related to service provision tended to be used interchangeably (e.g., multidisciplinary care, collaborative care, integrated care, patient-centered care). Therefore, by utilizing existing knowledge of concepts, routine reviews of memos and codes, and member-checking, I was able to assess whether the concepts utilized by participants mirrored those in the literature (Mauthner & Doucet, 2003), and whether I interpreted those meanings as they were meant to be understood (van den Hoonard, 2012).

**5.4.2 Synthesizing.** Building on this knowledge, I synthesized the data, the second analytic procedure identified by Morse (1994). This phase involved transcribing interviews verbatim, cross-referencing the accuracy of interview recordings and transcripts, organizing the data, as well as re-reading transcripts in full a minimum of six times, two of which included using rigorous line-by-line analysis (Morse, 1994; Tracy, 2010).

Beyond avoiding the replication of existing studies, being well versed in all areas related to my topic improved my ability to draw on commonalities and contrasts between participants’ responses and what was reflected in the literature, as well as identify novel themes (Morse, 1994). Though multiple realities are acknowledged in the practice of interpretive description, with thoughtful analysis of participants’ subjective experiences and data sources I believe I was able to link themes and identify unconventional cases and apply these “common themes to an infinite set of unique cases” (Thorne et al., 1997; Thorne et al., 2002, p. 443). I also found it

valuable to focus on maintaining an open-mind when considering new concepts that could be viable to the topic and true to the context from which they were collected. I accomplished this by not restricting the research focus or trying to force findings into pre-conceived theories (Maxwell, 2013).

In addition, to further enhance my comprehension, re-reading interviews multiple times provided me the opportunity to build on my set of personal memos by addressing a different question for each reading in my journaling (i.e. What is happening here? What is the participant saying?) (Morse, 1994; Thorne et al., 1997). It is my hope that the development of this type of “audit trail” will allow future researchers to follow my cognitive development as I worked through the process of data analysis beyond the theory’s simple “emerg[ence] from the data” (Halpern, 1983, cited in Morse 1994, p. 24). These personal reflections were then merged and organized with the words of participants, allowing me to identify main themes presented within the data (Coffey & Atkinson, 1996). At this point, I coded interviews by summarizing themes and similar concepts, applying them to the transcripts of readings that followed (Morse, 1994). In this process of coding, I paid special attention to question the codes developed, redefine ambiguous codes, and collapse redundant codes, which were verified by the members of my research committee to obtain unanimous validation. I also discussed emerging themes with my supervisor on two occasions so as to review their efficacy with another expert.

**5.4.3 Theorizing.** Continuing with the inductive approach to analysis, my goal for this research was to exceed a simple description of themes to engage in the third phase of theorizing about complex relationships between meaningful concepts in my findings (Morse, 1994). In this process, I produced “data driven” interpretations about the common experience when accessing services related to neurological conditions (Sandeloswki & Barroso, 2003, p. 909; van den

Hoonard, 2012). By combining applicable concepts from the literature and those developed in my thematic analysis, my thesis captured both participants' common experiences as well as "multivocality" (Tracy, 2010, p. 844). Furthermore, through my immersion in the data, I felt I was able to link seemingly unrelated facts to theorize how those experiences were influenced by support with service coordination and how that knowledge could be used to improve the future system navigation of health services (Morse, 1994; Sandelowski & Barroso, 2003).

**5.4.4 Recontextualizing.** Once complete, in addition to ongoing knowledge dissemination of these findings at conferences and in publications, it is my greatest hope that I ensure the application of my findings to improve future practice (Thorne, 2008). This research generates knowledge for both theoretical and clinical purposes in applied health disciplines (Hunt, 2009). In addition, it offers a unique understanding of service coordination beyond what is currently offered by existing theories, which can be transferred to other contexts (e.g., other chronic conditions or other provinces), resulting in a conceptual contribution to the literature (Tracy, 2010). To conclude this thesis, I also offer recommendations to service coordinators and government on possible coordination initiatives that aim to improve the experiences of people living with neurological conditions while navigating health and social services.

### **5.5 Best Practices in Qualitative Research: Tracy (2010)**

In order to ensure best practices of qualitative research in my thesis, I was guided by the eight criteria outline by Tracy (2010), including worthy topic (5.5.1), rigour (5.5.2), sincerity (5.5.3), credibility (5.5.4), resonance (5.5.5), significance (5.5.6), ethics (5.5.7), and coherence (5.5.8). These were chosen for this study to provide standards of quality, while being "more flexible and contextually situated than rigid quantitative criteria" (Tracy, 2010, p. 838).

**5.5.1 Worthy topic.** According to Tracy (2010), worthiness of one's topic is achieved by having a topic that is "relevant," "timely," "significant," and "interesting" (p. 840). As previously demonstrated, the topic of service coordination is one that has recently emerged as a top priority by Manitoba not-for-profit community organization representatives, by Canadians living with neurological conditions in the LINC Study, as well as internationally in research studies. While more is increasingly being done to provide services for those living with neurological conditions, how to manage those services while dealing with a neurological condition remains a timely and relevant topic.

**5.5.2 Rigour.** Rigour is a quality achieved through adequate and proper use of "theoretical constructs," "data and time in the field," "sample," "context," and "data collection and analysis processes" (Tracy, 2010, p. 840). Clearly guided by MacDonald and colleague's meta-analysis (2007), this study makes a substantial effort to include and appropriately use theoretical constructs to promote rich rigour. In addition, though qualitative research tends to suggest that data collection should continue until the point of data saturation, a concept derived from grounded theory (Corbin & Strauss, 1990), interpretive description is based on the assumption that there are infinite realities (Thorne, 2008). Similar to the majority of other interpretive description studies in the literature, my sample sits within the appropriate range of ten to 20 participants, which is based on both the type of knowledge sought and inevitable barriers (i.e., time, resource, ethical constraints). In addition, particular attention was paid to consider alternative explanations at various points in the data analysis that will be reviewed by my thesis committee.

**5.5.3 Sincerity.** Being reflexive about my own "subjective values, biases and inclinations" and transparent about my methods and challenges were the two main criteria

outlined by Tracy (2010) in order to demonstrate sincere research (p. 840). Though the perception of completely objective research is artificial, my goal for my thesis was to decrease biases as much as possible and provide complete transparency (Tracy, 2010). As a part of this process, throughout the course of data collection and analysis, I engaged in active and continuous reflexivity by situating myself in the data (Pillow, 2003). I wrote my thesis with an open-mind all while being frank about my exposure to existing data (e.g., the LINC Study), potential strengths and biases that arise (e.g., personal background), and limitations of my study (presented in Chapter 8). Furthermore, as my analysis of all data sources was based on my personal intuition, member-checking, being self-critical, and honest with the reader were all key tools I engaged in to increase trustworthiness of conclusions drawn, and reduce potential biases.

**5.5.4 Credibility.** Tracy (2010) highlights the importance of demonstrating concrete detail through “triangulation or crystallization,” “multivocality,” and “member reflections” (p. 840). In this case, credibility was fulfilled by providing an in-depth illustration and detail of all events from multiple perspectives (Tracy, 2010, p. 844). In other words, I included different points of view from a diversity of participants and the literature to provide a complex understanding of service coordination and system navigation while comparing the trends and dissimilarities (Tracy, 2010). Lastly, as with other best practices, I was transparent and collaborated with participants to ensure that the data was written as they presented it.

**5.5.5 Resonance.** Delivering moving and transferable research were considered measures of research that resonates with one’s audience. In my own research, I am personally driven to make changes locally to improve the experience of individuals living with a neurological condition and their families. It is my hope that my thesis will evoke emotions and attentiveness from readers, potentially motivating others to make a change as well. Through the use of detailed

journaling and memo writing, I have created an “audit trail” so that readers will be able to follow my thought process (Halpern, 1983, cited in Morse 1994, p. 24). This level of detail will enable others to transfer my findings and recommendations to their context, should they find themselves in a similar situation, such as in service coordination in other Canadian provinces.

**5.5.6 Significance.** As with all interpretive description, it is my goal to go beyond mere description of the data and reapplication of an existing theory. As mentioned earlier, the significance of my topic comes from the application of my findings to improve future practice (Thorne, 2008), both “practically” and “conceptually” (Tracy, 2010, p. 840). More specifically, I offer contributions to the literature from my reinterpretation of existing models and overview of current experiences within the province. In addition, I propose recommendations in Chapter 8 to government and community organizations on future service coordination initiatives, such as a development of a “one-stop-shop” resource manual or comprehensive multicenter for those living with neurological conditions in Manitoba.

**5.5.7 Ethics.** In addition to the procedural ethical guidelines met for the Joint Faculty Research Ethics Board at the University of Manitoba, I attended to ethical interpersonal issues that arose along the way. I truly allowed participants to take the reins during their interviews, by agreeing to their preferred time and location for the interview, the inclusion of family members, as well as their desired focus for the interview. In addition to providing anonymity, I also made a concerted effort to write up findings in a way that both demonstrates the struggles faced by participants, while also portraying them in a position of strength. Finally, I have and will continue to share updates on the progress of my thesis with participants, providing them a copy of the final product.

**5.5.8 Coherence.** Lastly, the eighth and final best research practice outlined by Tracy (2010) includes meaningful coherence. In her work, Tracy outlines coherence as connecting all aspects of a study (i.e., literature, methods, research questions, findings, interpretations) that align with one's stated goals. With the expertise of my thesis committee, when conducting my thesis, I have used theories, methods, and procedures that complement each other, as well as the research objectives of this study. While being considerate of the uniqueness of the literature and my findings, I have considered how my literature review is mirrored in the theories I selected, as well as how my findings are mirrored both in the literature review and the theories. I have kept in mind that 'coherence' suggests the emergence of a clear thread being followed from the first page of my thesis to the last – conceptually, evidence wise, and in relation to the literature and the methods.

## CHAPTER 6: FINDINGS

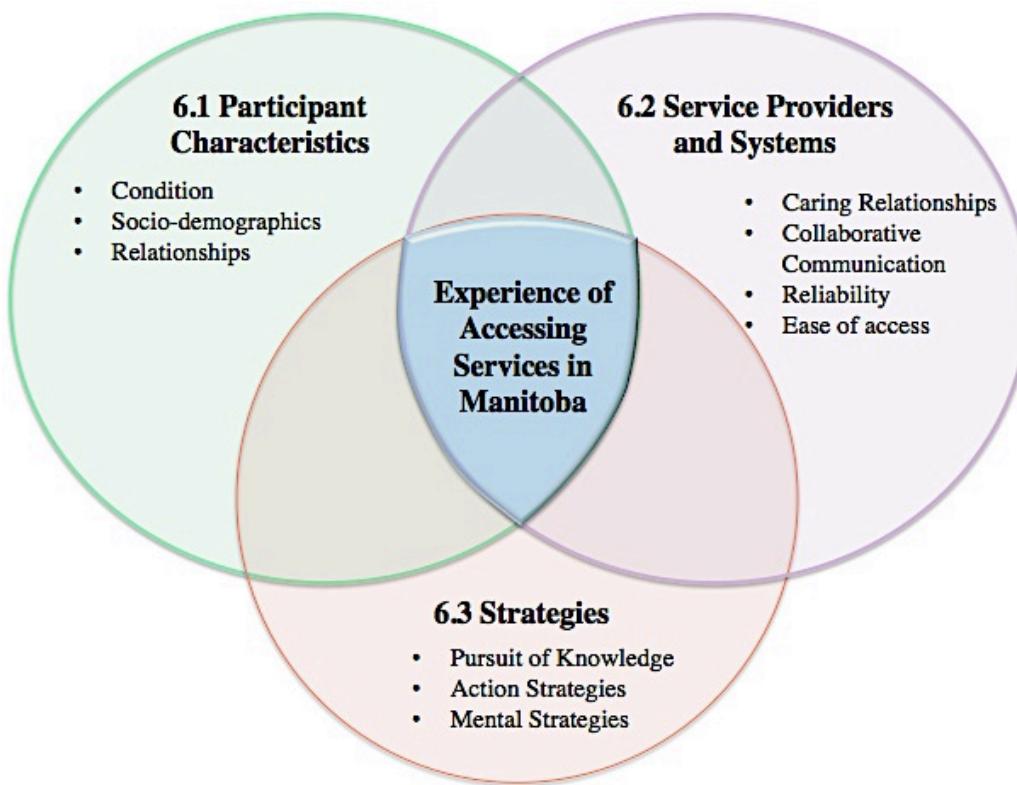
My participants articulated a range of experiences navigating health and social services while living with a neurological condition in Manitoba. While their stories differed, and they sometimes demonstrated opposite accounts of the same matters, an analysis of the fifteen semi-structured interviews resulted in the emergence of three superordinate themes, including:

Theme 1, the influence of “Participant Characteristics” which reviews how the complexity and uncertainty of one’s condition, personal circumstances, and access to supportive relationships varied from one participant to the next, thereby setting the tone for their future needs for services and support with service coordination. Simply put, this theme indicates what factors were influencing participants “going into” the system.

Theme 2, the influence of “Service Providers and Systems” explores how participants’ experiences of navigating the health and social services in a variety of systems depended on service providers’ caring relationships, reliable care, collaborative communication, and facilitated access to services. This theme demonstrates what was influencing them “in” the system.

To conclude, Theme 3, “The Strategic Patient,” will describe the art of improving one’s experience accessing services. Strategies participants engaged in to improve their experience while accessing services ranged from i. pursuing knowledge to improve access ii. actively engaging in behaviours to improve services, and iii. mentally coping with inadequate services. In other words, this theme reviews the actions participants took as a result of (in)adequate care “after the fact” to improve their experiences.

For a summary of the themes, please see the Themes presented in Figure 2 below.

**Figure 2. Themes**

### **6.1 Participant Characteristics**

“Participant Characteristics” reveals how a person’s traits and context contributed to diverse experiences accessing services. Each member was influenced by his or her type of neurological condition (6.1.1), socio-demographic characteristics (6.1.2), and relationships (6.1.3) prior to the act of care delivery, which ultimately influenced their access to services. These variances in personal contexts contributed to the fact that participants were starting from different places in relation to their need for services and support with service coordination.

**6.1.1 Condition.** The type of neurological condition a participant was diagnosed with, in and of itself, acted as a significant influential variable in this study. In other words, the type of condition participants were diagnosed with influenced the combination and severity of their symptoms greatly, thus contributing to a range in the amount and complexity of services needed.

These three examples show that for some, requiring services immediately is essential, whereas for others, a later entry into the system is more helpful.

Faced with the abrupt occurrence and complexity of a spinal cord injury, O. Twist described a greater need for services when admitted to the rehabilitation unit shortly after his accident, “there was a lot of learning to be done, a lot of education, seminars, [...] patient groups every week, you know, it felt like a lot of time, but you know it was very important information.” In turn, he later elaborated how this need slowly decreased once the condition stabilized, saying “from the time that you leave the hospital [...] I think it’s every year you get a follow-up [...] then eventually you know if things are stable, you move to a two year kind of a schedule.” Along the same lines, according to Emily, her husband, John “would use more services in the past, especially after he had his stroke,” a point when his condition was seemingly most complex.

Alternatively, Sherri faced a more gradual increase in her need for services. As her multiple sclerosis advanced, she received services in a way that was timely and relevant to the stage of her condition. She explained this process through her encounter with her neurologist: “I asked ‘Should I go to the [Specialized Outpatient Clinic]?’ Well when I first went to him he said ‘No. You’re not ready.’ And I wasn’t ready. And then eventually I went to the [Specialized Outpatient Clinic].” This quote demonstrated a positive correlation between the growing complexities of Sherri’s condition with her need for the increasingly complex assortment of services offered to her. It also shows that her care provider was knowledgeable about her condition and was able to tune into her unique stage-related needs.

In addition to timing of services, was a change in the types of services accessed over time. Big Bird spoke of his experience trying to meet his daughter’s numerous physical needs as a child: “we did use resources for the Trisomy 8 because Shelly V. had many physical needs;

limitations of her hands and feet and eyes. So we did use those extensively in the early years.” With time, Shelly V.’s needs evolved, as her developmental condition required less physical care, thus allowing her to focus on and seek out alternative supports for her other priorities, including finding employment and supporting her emotional and social well-being. Post hospital discharge, O. Twist and Victor shared a similar sequence of events. With growing stability in their own conditions, there was a detectable increased focus on “reintegrate[ing] into the community” based on the services they accessed. This is the case for some people who are able to stabilize their conditions, while others are facing a longer downward trajectory.

By stark comparison, when asked about her utilization of health services over the past year, Leslie shared, “not for me [...] I got diagnosed and that was basically it.” In Leslie’s case, there was an absence of treatment-seeking behaviours all-together, as she explained how her Tourette syndrome paled in comparison to her other conditions. Also on the lesser end of the spectrum, Julienne and Gaston described Julienne’s condition as the preliminary stages of a mild Dementia that had even further improved “since [...] taking her pills.” Being in the early stages, their responses suggest Julienne’s condition had yet to cause debilitating symptoms in their everyday life, thereby not motivating a need for services. Her husband Gaston spoke of an “alarming” visit they had from the [Community Organization X] and an occupational therapist, stating, “it’s still preliminary so... [the service provider] said ‘we have all kinds of programs’ but... she never mentioned any because it’s not at that stage yet.” As Gaston explained in this quote, “right now [there was] no need for [services],” as Julienne’s condition had not advanced to a point where there was a need.

Uncertainty of the future also played an important role in the services needed for one’s condition. Most neurological conditions include an element of uncertainty when considering the

future, as experienced by Jacks T. who faced uncertainty in the future of his Muscular Dystrophy. However, he reported his condition to be “not as severe” and relatively static in terms of its progression, stating: “Well if there’s nothing new then what’s the point of going for me? ‘Cause that was the question from them after a while. ‘So why are you here? Why did you come here?’”; an experience that could certainly discourage the use of services. On the other hand, when confronted with the realities of Parkinson disease, Andy and his wife engaged in two hours of preplanning with an occupational therapist, by way of ensuring their access to all services that “Andy might need in the future.” On the one hand, “maybe it won’t even happen”; and yet, this heightened uncertainty triggered their desire to prepare for the worst, so they are “not trying to get in when [they] need it.” To conclude, Molly and Andy experienced increased uncertainty in their imminent futures, as opposed to Jacks T. who expected little change on a daily basis.

**6.1.2 Socio-demographics.** Beyond one’s condition, participants defined themselves by social and demographic characteristics. Through their stories, it became clear that each member’s collection of characteristics influenced his or her experience navigating health and social services. Responses appeared to highlight the influences of age (6.1.2.1), personality (6.1.2.2), socioeconomic status (6.1.2.3), and employment (6.1.2.4) on accessing services.

Language, ethnicity, and geographic location were expected to play a role in the experience with service coordination. However, based on the largely urban, Caucasian, and English speaking sample selected, these personal characteristics were not presented by more than one participant as greatly influencing experiences of accessing services.

**6.1.2.1 Age.** Age was a significant factor influencing the experience while accessing health and social services. Participants affected by neurodevelopmental conditions faced distinctive challenges when transitioning to adult services. Specifically, four of the five

participants with such conditions acknowledged the disparity in services from one age category to the next. For instance, Leslie said “Kids don’t usually get dropped,” identifying the superior effort that typically goes into care for children because of their age. However, this preferential treatment and services in general “dropped off” after the age of 18, which James explained was his disappointment, and what he believed to be the disappointment of many. His response was “I’m sure other people have said the same thing, that services for children and youth [...] are a lot better and a lot more accessible than they are for the adults.” While James acknowledged that he continued to be on the “list” of service users with a variety of different organizations, he disclosed, “they can’t really offer me anything.” Similar grievances were shared by J. Wayne and his father Clyde who identified the lack of services as “the one problem” they had while trying to manage J. Wayne’s symptoms from the cerebral palsy. He further explained that, other than for surgery, “since [J. Wayne’s] transition to adult care, he goes to see a family doctor and that’s about it.” Not for lack of a need, a clear difference in the pattern of service delivery for adults was detected, as J. Wayne used to receive a multitude of therapies “through school” that were later discontinued “once [he] graduated.” Now, “There’s nothing,” according to Clyde.

Not only does this transition from youth to adulthood present a new challenge of locating services to meet one’s needs, but it was done at a point when the young adults were seeking to build independence and gradually take control of their own health care. O. Twist acknowledged the support he received from his family, though he described how being a young adult at the time of his accident left him “pretty stubborn,” “pretty hardheaded,” and “wanting to be independent,” meaning he “didn’t really... like to ask for help.” Illuminating the inequity between services, O. Twist was able to coordinate much of his services post-injury as a young adult with the

assistance of his local community organization, a system that offered very coordinated and multi-disciplinary services.

James eloquently described his feelings when transitioning to adult services, saying “It sort of feels almost like you dive off the deep end,” since when you turn 18 “nobody tells you [...] how to get in touch with these [...] other things that are available.” He then echoed this thought in different ways, saying, “now that you’re an adult, you’re just expected to navigate the system on your own, and [...] I bet you 99 % of the population out there... would not, would not be able to do that.” Based on this quote, while children’s services are generally coordinated for them by their parents, by the time they are supposed to inherit this role as adults, they have not been provided the necessary knowledge base to do so. For J. Wayne, he described his attempt at navigating health and social services as, “Very, very frustrating because [he] can’t find out stuff on [his] own that [his parents] don’t already know.”

On the other hand, Shelly V. perceived her age as an advantage, as she and her father Big Bird compared her experience to that of other seniors trying to seek out services for their neurological conditions. “[A]ge has a big thing to do with it” Big Bird began. Both he and Shelly V. explained how the younger populations typically have the ability to be more “proactive in [...] berating out what they need, as opposed to somebody who is [...] in their late 60s and 70s,” especially if they are not “computer” or “electronic[ally] savvy.” Andy and his wife Molly continued on this point when they described accessing information for the disability tax credit. In their interview they highlighted the fact that “everybody doesn’t go on the website”; rather, they, and others within their social circle, alternatively “would have never gone and looked” would it not have been for the benefit of their engagement in their local community organization.

Consequently, in some cases age created a biased experience for some older individuals when accessing services in an increasingly technological world.

**6.1.2.2 Personality.** Participants' experiences navigating health and social services was also greatly influenced by a particular social characteristic, that is, their personalities. In fact, most participants labeled themselves in their description of service-seeking behaviours.

"I would say I'm a survivor." (Victor)

"I'm an outgoing person, ok... I'm stubborn." "I have an attitude like [...] you have to be a fighter." (Olive)

"I don't take no for an answer." "I'm very proactive." (Shelly V.)

"I'm not going to stop fighting until something gets done with this." (J. Wayne)

The way that participants identify themselves in these quotes demonstrates a strong sense of self, which later appeared to be an important resource when confronted by adversity in accessing services. Even in cases when participants did not specifically identify these traits, they presented these types of characteristics in different ways. For example, Sherri shared strategies she used to stand her ground when faced with inadequate services that will be reviewed later in Section 6.6. Similarly, Lena shared her response to both positive and negative treatment in the system, stating: "I'm a huge letter writer [...] Well it goes both ways. If I've gone somewhere and I've been treated badly, I'm going home and writing a letter. If I've gone somewhere and I've been treated really well, I'm going home and writing a letter."

On the other hand, participants also shared points where their personalities were unable to protect them from feelings of vulnerability, such as the "helplessness" and frustration felt by J. Wayne when he tried to manage homecare and disability services. James also recognized how in some cases his personality held him back from being able to access services. In one situation, he

was required to try to persuade his neurosurgeon that he needed an MRI. In this scenario, he described himself as “one of those people” who has “trouble being assertive … without going into being aggressive.” At that point, he engaged his mother who he felt possessed this type of personality skill-set in order to influence progress.

Although personality characteristics were predisposing, one would imagine that being faced with a life-altering condition alone would require resilience. According to James, through the process of living with Spina Bifida and Hydrocephalus, he “developed a certain mindset about what it [was] like, you know, to live and to cope with a disability.” This helped him in his advocacy efforts, as we will see many others use their personalities as the foundation to other strategies used in accessing services reviewed in Section 6.6.

**6.1.2.3 Socioeconomic status.** Financial barriers and resources, by far, represented one of the most discussed topics across all interviews. As demonstrated in Table 2, there existed a range in terms of participants’ monetary affluence. Regardless of one’s financial stance, most participants reported struggling with balancing costs and benefits associated with out-of-pocket expenses. In Sherri’s case, she listed off several out-of-pocket expenses she was required to pay for; including, their new “ramp at the back of the van” that “[they]’re going to be paying for [...] for a long time.” In turn, she also mentioned the many services that were simply “too expensive,” including the Movement Centre that was “500 dollars for 6 months of therapy.”

What was most striking about participants’ ability to pay for out-of-pocket expenses was that it did not seem to depend on his or her income specifically, but rather his or her “insurance coverage,” whether through work or the Pharmacare program. In Suzy’s case, being of a lower socioeconomic class, but not low enough to qualify for Pharmacare was described as particularly challenging. Her following quote depicts her frustration with not being able to access coverage:

“What I need is the benefit, what everybody needs is the benefits. Like I have to pay for my own meds. I have to pay for... whatever else I need,” “I said ‘OK, all I want is that little health card’ and they wouldn’t give it to me.” Without coverage, Suzy and others in similar predicaments were forced to engage in strategies to obtain the services they needed, which will be reviewed in Section 6.6 of this thesis.

Although those with coverage expressed appreciation for those items that were covered, in many cases, participants described the extensive process associated with asking the pre-emptive question, “is this covered, and or, how do we access this?” (Clyde). Emily revealed her specific challenge with accessing “liquid thickner” through her insurance company, an expensive product recommended by John’s speech therapist, the application of which would reduce his chance of choking, a known risk for those living with Huntington disease. She stated, according to the insurance company, “if we get a prescription from his doctor, [...] then, they said, I could submit the prescription with receipts, passed receipts, and they’ll think about it. They’ll think about covering it. [...] So... I may or may not be covered.” On the one hand, coverage was perceived as a positive resource; and yet, coverage was also assessed as inadequate or difficult to utilize.

In the end, even with the best coverage plans, gaps in coverage continued to persist:

Our insurance will cover the mobility devices but they won’t cover anything that makes it easier to move. Like for the Scooter, they won’t provide a ramp, they won’t provide a lift, it’s up to the individual to actually get the scooter into the vehicle. (Lulu B.)

So they paid for the scooter but nothing to get it into the van. (Jacks T.)

Benefited by their marital status, Jacks T. and Lulu B. reported being able to rely upon two incomes and sometimes two insurance plans. By having coverage from several insurance plans,

Jacks T. received coverage for 100% of costs of assistive devices that promoted his mobility. However, this coverage was constrained by the plan's limitation for ramp and lift coverage, thereby requiring the family to fund this service themselves.

**6.1.2.4 Employment.** Lastly, the final socio-demographic factor frequently reported as influencing participants' ability to access services was their current and past employment. In line with the previous subsection, employment was a large determinant of socioeconomic status and insurance coverage for some. Though six of the participants were able to continue full-time work, some were retired, faced reduced hours, or were unemployed, leaving them to collect Employment Insurance, Disability Pension, or nothing.

To add to the financial benefits of employment, formal education and relevant experience gained were identified as benefits by some participants. As health-care workers, Suzy, Lena, and Olive explained the benefit they reaped from having previously worked in health-related fields. For Olive and Suzy, this experience provided them with the knowledge to think about health alternatives and to advocate for themselves. Unrelated to the health care fields, Jacks T.'s current employment also proved beneficial, as he was involved working with taxes full-time. More specifically, while access to the tax credit offered by the province was considered a resourceful program, four participants identified the significant barrier that people face when trying to "fight" to get access to this benefit. This was a challenge Jacks T. did not face, according to his quote:

Well if you didn't fill out the form properly they reject it. So then they send the form back, or they just say the form was incomplete. So then you got to go to your doctor again. But you can only see your doctor like every two to three months. And then you

don't know what was wrong on the form. So,... I knew what had to be on that form for the bastard.

Here, Jacks T. clarified how his experience was comparably different from others who had less experience with taxes.

**6.1.3 Relationships.** Very much intertwined with social characteristics identified in the previous section, each participant was subject to a range of relationships that were resourceful when navigating health and social services. This section will review relationships, again pre-existing to the act of care delivery, as well as the many ways they played a role in influencing the experience of accessing services for participants living with neurological conditions, including relationships within the participant's family and social networks.

In particular, the support participants felt they received from their families was overwhelming in these interviews. Thirteen of the fifteen participants referred to how their families played a role in managing their health care. For example, J. Wayne explained, "Everything that I know, either I self-taught myself just from going through it or my dad and my mom have done research." For two participants, being recipients of this support contributed to feelings of guilt of inconveniencing their families, but for the most part, participants were mostly grateful for family members' guidance with navigating health and social services, advocacy, as well as more functional support (i.e., transportation, physical support).

Most pronounced, Victor repeatedly described, and was sometimes left speechless, by his appreciation for the emotional, physical, and financial support his family provided him from the time he was affected by a brain injury in the hospital, to his rehabilitation process, and still today. Based on his interview responses, Victor's parents acted as proxies for most of his decisions and

guided him through much of the process of reintegrating into the community, ultimately filling many of the gaps experienced by other participants.

I: Ok... And how about the homecare? Would you know how you initially were referred to the homecare or did you ask for homecare?

V: My, my parents.

I: Your parents?

V: My parents did everything for me. Ya.

I: And same with the rehabilitation services?

V: (laughs) My parents.

This quote represented a repeated scenario in Victor's interview, where his issues with connecting to community services or coping with inadequate homecare staff did not resonate as a concern for him, as it did for other participants. Alternatively, his parents were always there to resolve the issues. "Ya someone always took care of me and it's haaahhh (*Speechless*)," which he said with a sense of confidence.

On the flip side, the absence of family was seen as a factor that would be a disadvantage. Pinpointed as a source of inequity Victor said, "You know, the thing is with me, like I said earlier, I have my family but not everybody has family." J. Wayne, Shelly V., and Sherri actually articulated experiencing significant fears of losing their loved ones that they depended on. "I thought, what if something happens to my mom or my dad, I'm basically ignorant [of] the system," J Wayne explained.

Beyond family, the next system of support (in terms of proximity to participants) was from their social networks. It is important to note that although engagement in community organizations, online communities, and most other communities of support were identified in

participants' social networks, they were excluded from this section; the reason seemed to be that most networks did not exist prior to the access of care. Alternatively, in many cases participants connected with these contacts and groups, in part, as a strategy to access more information, and therefore will be reviewed later in Section 6.6. Even for participants who knowingly lived with their neurological conditions since birth, any existing long-term connections that better situated them in "the community of people living with similar conditions as them," would have presumably been executed by their parents.

The two exceptions to this rule included church communities and close friendships. For James, this meant the "convenience" of having access to "counselling and therapy services" from a "satellite office [in his] church," thus filling a gap that he originally identified in adult services. Likewise, J. Wayne attributed his knowledge of "the Tabs program," a needs-based program designed to fund specialty chairs, to attending his church. "I wouldn't even know about the program if we didn't go to church that week, [...] someone volunteered me and then I got really aware about what it's all about" he said. Amongst the five interviews of participants who used wheelchairs, four of them identified the limitations of the wheelchair access programs funded by the province. J. Wayne was able to address this through being interconnected with his church network, in combination with his father's subsequent support with researching and coordinating those services.

Big Bird spoke more generally about the support Shelly V. received from their "inner social circle" or "church circle," metaphorically comparing the benefits to "a domino effect." "'Oh try this', and then the domino effect occurs. And once you touch one... then well... ok got me to phone this number or contact this person and so [on].'" Lastly, in Sherri's case, she goes as far as to insinuate that "moving into another apartment that would be more accessible for a

bathroom” would have had accessibility benefits, but was ultimately outweighed by the support she received from her friend and neighbour.

## 6.2 Service Providers and Systems

The second theme, “The Influence of Service Providers and Systems,” goes beyond participants’ initial context to capture qualities commonly referred to by participants’ as significant in their experience of navigation within the actual system. These influential qualities included, service providers’ establishment of caring relationships (6.2.1), collaborative communication (6.2.2), reliability (6.2.3), and ease of access to services (6.2.4). Value in services was determined using participants’ own words, which shed light on both qualities received and appreciated, as well as desired in past or future services.

**6.2.1 Caring relationships.** One of the most obvious themes that emerged from interviews was participants’ desire for service providers to “care” about them and their case. Oftentimes, caring seemed to be correlated with service providers’ level of effort (e.g., “trying”) or relationship with patients. For Olive, this was a concern she had with her initial general practitioner following her first Grand Mal. During this encounter, she recalled he “just kind of gave [her] meds,” “that’s it,” thereby giving her the impression that “he just didn’t care.” Whilst trying to cope with the “thought [that her] career and life [were] over” and gain a fresh “outlook” on her future, she felt her general practitioner was unaware of resources available to her, and ultimately “He didn’t even care” to find out.

With the exception of his current caseworker, J. Wayne sensed a similar deficiency with his homecare services. J. Wayne asked, “what happened to the ‘care’ in homecare? What happened to helping people out when they need help [...]?” The difference lay in that, in general, homecare workers remained focused on his case, saying “call me when you’re doing something

with your life.” This relationship was then contrasted with the one J. Wayne had with his current caseworker who “shows [...] an interest” in him and would be more likely to say, “keep me up to date in your life, whether you’re doing something or you’re not.” J. Wayne explained that he simply wishes to be seen “as a client” and “a human being,” rather than labelled as “a number” or treated as “another pay check.” He said, “Get to know us. We don’t bite.”

According to Clyde, a “revolving door” was to blame for these types of relationships. Ultimately, a lack of consistency inevitably left homecare workers unable to become accustomed to J. Wayne’s case or needs. J. Wayne also explained how “flip flopping caseworkers like underwear” meant he could never build “stability” or “a rapport with a worker,” thus causing him “stress and anxiety.” In the same sense, Andy and Olive said continuity in the relationship with their main health professionals made “a hell of a big difference, because then they know you” (Olive) and have “a feel for my situation” (Andy).

For Sherri, she felt a deep sense of caring from her main provider from her local community organization. “I mean you listen to [her] line [...] she says, ‘Eventually [...] we will end MS.’” Based on this message and the community organization’s effort to “try to do as much as they possibly [could],” Sherri sensed “the trying [and] the caring.” She was given a similar impression by her neurologist, who she said “tries to do anything and everything he possibly can.” Through Sherri’s comments, there was a resounding message that suggested that she was appreciative of service providers’ investment in her health concerns; but even more so, for the special relationships she built with them, as demonstrated in the following comment: “I said to him ‘you’re my favourite doctor’. He said ‘you’re my favourite patient.’” Victor also shared a strong relationship with health professionals caring for him in the hospital following his brain injury. “Instead of doing it themselves, [...] help them out like you’re their big brother or sister

[...] show that you care.” In his metaphor Victor compared the help he received from nurses in the hospital to that from a sibling. Based on participants’ interviews, building relationships, such as this, were very meaningful in their experience to create a sense of reassurance.

**6.2.2 Collaborative communication.** Participants also identified a strong desire for communication with service providers both as a means for collaboration, keeping participants informed, and ensuring that service delivery is conducted in a way where patients’ felt respected. Participants classified how staffs’ communication skills greatly contributed to their experience with care; ranging from being “positive” (Shelly V.), “very easy to talk to” (Emily), “Very friendly, communicative” (Jacks T.), “nice and helpful” (Clyde), as well as “very informative [and] nice” (Lulu B.), to “not very communicative” (Jacks T.), not “very helpful” (Sherri), or even non-existent. “I never saw him until I left” Sherri resentfully said about her experience with a surgeon. In one case, J. Wayne’s homecare worker even went to the extent to outline her job requirements, stating, “I’m not paid to listen to you.”

Collaboration with nurses was a key component of Emily’s experience while coordinating John’s stroke rehabilitation process. By telling “the staff [...] it was probably Huntington disease,” they were then able to work out “that he not come home for a couple of weekends because it was too hard on [Emily].” Olive, in particular, verbalized her appreciation for her neurologist who “listens a lot more” than other doctors when she provided suggestions, such as the operation for “Temporal Nerve Stimulation” and “Vagal Nerve Stimulation.” Lastly, Shelly V. valued “good advice” from her health professionals, such as when her “good [family] doctor” said, “If something ends with ‘ulose’(sic)... put it back. Or if it says ‘additives’ or ‘seasoning’... put it back. You can’t have it.” This type of communication allowed Shelly V. to engage in the self-management of her epilepsy, something she appreciated.

In addition, without sufficient communication while coordinating her services, Julienne and Gaston described their experience navigating health and social services as “overwhelming” and left Julienne asking the question “am I going crazy or what?” For J. Wayne, “That’s where the gap comes in.” In his account, J. Wayne says that he was “willing to work” with his homecare staff and incorporate “communication” to achieve his ideal service experience. On the one hand, since his transition to self-managed homecare, J. Wayne appreciated being able to “make phone calls” “to organize his own workers.” However, this level of collaboration was clearly not present in his other service interactions, as he crafted a request for other service providers: “listen to what we have to say, we’ll listen to what you have to say, let’s come compromise here.” He then further described the communication in his “ideal homecare and care” with adjectives associated with transparency, including “be open, be honest, stop with the lying, stop with the excuses.”

**6.2.3 Reliability.** Based on their interviews, participants also valued dependability and reliability in their services and service providers. That being said, several comments were related to experiencing unreliable services, which was a type of experience mentioned most frequently in relation to homecare.

With the exception of Emily, all participants using homecare described it “as a regular event” of “uncertainty” (O. Twist), “clue[lessness]” (J. Wayne), and “never kn[owing]” (Clyde). Participants repeatedly described dealing with workers not showing up for their shifts when “they [were] supposed to be there,” and “last minute” calls from the agency to tell them “so and so is not coming in today, we couldn’t get a replacement, good luck” (J. Wayne). The quality of homecare workers also appeared to create uncertainties for service users, as some would be

“really good” while others would engage in behaviours that made them uncomfortable, such as “sleeping” (Victor), “sneak[ing] medication” (J. Wayne), or saying rude comments (J. Wayne).

Outside of homecare, participants valued a sense of “know[ing]” that resources and service providers would “[be] there” for them in the event that they needed them. “They need someone in their corner” Victor explained. For Leslie, O. Twist, Andy, and Molly, this was a feeling associated with their respective outpatient clinics, when stating, “I have somebody I can call” (O. Twist), “anytime I’d needed anything I felt like it’s never an issue” (Leslie), “you can call anytime and they’ll answer” (Andy), and “Oh they’ll fit you in” (Molly). Sherri and O. Twist echoed similar values in relation to their particular not-for-profit community organization being “there” for them, including “she’s just there,” “she’s gone through this beginning to end with me” (Sherri), and “before I even knew that I had questions… I knew that [Community Organization X] was there” (O. Twist).

Emily and John also felt an unwavering sense of confidence not only in the existence of services provided by their specialized outpatient clinic, but also their quality, “we knew they were the right people to go to in regards to Huntington’s because [...] they’re the experts.” All in all, the sense of certainty in quotes presented showed participants’ sense of “confidence [...] that they’re going to get the information they needed” (O. Twist), something that O. Twist identified as a basic goal of service delivery. Big Bird and Shelly V. went further to agree that patients’ doctors are “too busy” and that there should be “advocates [...] outside the medical field” who are “knowledgeable on where to go, what to do, and what to say.” “[T]here should be somebody out there” Big Bird said.

**6.2.4 Ease of access.** The final quality participants valued greatly in service provision, was the “ease” with which they could access services. Based on their interviews, the way

participants would discuss services became more optimistic when they were coordinated and free from obstacles. Ease of access to services was the characteristic that varied the most amongst participants. First of all, ease of access was influenced by the availability of a family doctor, whether it was a general practitioner, neurologist, or specialized clinic, as this was a fundamental step in how participants accessed care. General practitioners represented the “first doctor you see [...] for everything because they have to refer you” (Olive). Being the first point of contact in the health care system, family doctors ultimately molded participants’ trajectory while accessing care and services. Olive and James reflected on this in a similar way. “It just depends on the doctor” (Olive), and “if they’re able to find a family doctor, that makes a big difference as well, because your family doctor really should be one of the people that you should be able to go to” (James). Without them, patients were generally limited in the services they could access, especially from the health care system.

James described his experience when his family doctor retired as being “sort of dropped out of [...] the system for a while.” Without the approval of her family doctor, Leslie faced a similar obstacle when her doctor would not provide her with a referral to a clinic for a diagnosis, thereby compelling her to self-refer. In turn, at the clinic she was told, “you can’t send yourself here, you need to have a referral from a GP.” For O. Twist, these were not challenges he personally faced, since he would “just call the [spinal cord] clinic [to] make an appointment when he had “a spinal cord related issue.” He stated with assurance, “Who do I call? Well you call [Community Organization X], and [Community Organization X] will connect you” and “before I even knew I had questions... I knew that [Community Organization X] was there.” Sherri also demonstrated confidence in her specialized outpatient clinic in her comment: “If they don’t get anything through their GP and they’re still very frustrated then... go to the MS Clinic.”

Alternatively, O. Twist compared his experience to that of a friend living with spina bifida who could not “find a doctor who [would] take him on as a patient.” Like Leslie and James, O. Twist’s friend was unable to receive basic services and referrals from a family doctor, nor could he rely on the safety net of a specialized outpatient clinic, since “there’s no such clinic, there’s no equivalent,” leaving him to “go to a walk-in clinic or an ER somewhere” (O. Twist). In this situation, we see how, in addition to having access to a family doctor, participants’ diagnosis determined the systems and range of services available to them.

For O. Twist and Victor, having endured a traumatic injury established their admission to a hospital within the health care system, where a holistic collection of services was coordinated on-site. In this scenario, without research or complex applications, O. Twist and Victor did not have to look far to access supportive services. In fact, subsequent to the process of being treated and diagnosed, O. Twist met with service providers who helped him with “planning for discharge and home environment [...] service needs, transportation, financement (*sic*), equipment, supplies, homecare... all that stuff.” Furthermore, according to O. Twist, it was the formal “ongoing follow-up” that represented the “real value from that program,” where they made “a concerted effort to monitor the health needs [of] people with spinal cord injuries.”

One specialized outpatient clinic similarly provided a multidisciplinary approach to treating Huntington and Parkinson disease that was both internally integrated and closely connected with related community organizations. According to Molly, from the point of diagnosis, “set[ting] up appointments with everyone there” all happened within a month. From their comments, Andy and Molly gave the impression that the clinic left nothing to be desired, as “every aspect [was] covered” and they received “the works.” Not only was the list of services comprehensive, but according to Emily, “everything seem[ed] to be [...] central,” leaving her

without any complaints in terms of navigation. In addition to scheduled follow-ups, according to Molly and Emily, patients also had the option to “approach each one” of the health professionals within the clinic. “It’s easy,” Molly said, “There’s [...] the nurse you can go to and she probably would send you in the direction you need to go.” On top of that, Andy pointed out that “everyone there is on the same wavelength”; meaning, though they “all coordinate their individual service,” the constant communication between providers allowed them to “relay” information, thus further adding to the inherent coordination in the delivery of services. Emily described the ease with which she was able to adjust her husband’s anti-depressant medication when his anger issues were “getting to be pretty serious” with his Huntington disease. “He just called the pharmacy for some incidences. So yes, as far as that goes, right on top of it. He was wonderful that way,” she said.

As a comparison, Jane B. stated that she had “never been so offended by the medical community as when [she] was subjected to psychiatry,” where no one even “recognized dystonia.” They assumed that her referral from her general practitioner meant “all was well.” She then explained, “they all look at this from a very narrow perspective [...] there’s not this integration,” which forced her to become her own advocate. Jane B. identifies the “disconnects” in the system as one of the main elements driving her to “raise money and awareness of dystonia” through Dystonia Support Group, so they can be “diagnosed and treated with dignity,” rather than having “to go to specialist after specialist after specialist.”

Many other participants also expressed longing for some of the characteristics described in integrated systems. In different ways, participants identified co-locating information and services, in order to “remove some of the confusion,” as a potential model for all organizations. Participants recommended doing this either by co-locating services physically “in one building”

or “one ginormous department” (J. Wayne), or conceptually through “one portal,” “one contact,” “one connection,” or “one place to get information,” as with “an agency or a call center” (O. Twist). Describing it as “nice just to have one person that you call and you say ‘what do I do’ and she knows who to go to,” Leslie shared her experience with receiving coordination from a case-coordinating nurse.

With services being centralized at the one specialized outpatient clinic, Emily and John had no difficulties with navigation. Conversely, James faced a scenario where he was responsible for facilitating communication between his neurosurgeon and neurologist. He believed this incidence would not have come to be if “those doctors would [have] be[en] in the same building everyday,” rather than being based in different clinic settings. Although he was able to resolve the issue through the Patient Relations Office, “it’s just another step to go through,” he said. Both he and Olive referred to scenarios where a lack of communication between health professionals led to unnecessary action on their part, which they described as the “run-around” (Olive) or “hoops [...] to jump through” (James). “Integration and coordination between the services is definitely (*emphasis*) definitely one of our missing links right now,” “even the integration of... our doctors with let’s say non-traditional services like the massage therapy... is important as well,” according to James.

As a specific example, for Sherri, accessing physiotherapy was anything but easy. Initially, Sherri personally located and began participating in an exercise program within her community, only to have it later discontinued due to a lack of resources. Following this interruption in services, any of the potential alternatives Sherri explored were either too far, too expensive, or inefficient. “[I]t’s so hard for me to get out all the time,” she said, “It’s easier for me for somebody to come here and do physio with me.” To no avail, she requested support with

determining the level of coverage for physiotherapy services, only to be further disappointed with a lack of support with coordination. This scenario, like other examples, demonstrated the convoluted process that participants must sometimes endure to locate services when coordination was unavailable.

According to Jacks T. and his family, while accessing services from his community organization was characterized by this type of a long process in the past, Jacks T. and Lulu B. acknowledged the shift in recent years towards delegating more responsibilities to the local groups, thereby contributing to “short-cuts” and a less “bureaucratic” process (Jacks T.).

### **6.3 The Strategic Patient**

This third and final section aims to highlight the strategies participants engaged in, after the fact of having received initial services, to improve their experience. In most cases, participants engaged in the pursuit of knowledge to gain information to make better use of the system available (6.3.1); action strategies to mitigate the effects of inadequate services (6.3.2); or mental strategies that had no effect on their access to the service, but rather their ability to cope through inner strength (6.3.3). Overall, though strategies have elements that overlap with one another, it is not necessarily the case for all participants and therefore have been separated into the specific subsections included below.

**6.3.1 Pursuit of knowledge.** While very intertwined with the next section on action strategies, as the pursuit of knowledge represents an action in itself, the “pursuit of knowledge” represents the process of searching for information prior to taking action to improve services. Based on participants’ stories related to this topic, there was a strong positive relationship between participants’ access to knowledge and having a positive experience navigating health and social services. The simple factor of knowing what questions to ask, who to call, where to

go, what was available, as well as how and when to access services, was a significant theme in the findings. In some cases, one piece of information resulted in a “domino effect” that led to a long line of other services. This subsection will review the main ways participants pursued knowledge including preplanning, seeking research, connecting with communities of support, or through community organization involvement.

Commonly referred to, being proactive and preplanning were some of the steps participants took to anticipate and prepare for the worst. Molly described her strategy in the interview; she shared, “you have to get yourself in front of things if you can.” Even when services were not inadequate, participants described not wanting to wait for something bad to happen. In this sense, although Shelly V. was unable to predict the future of her condition, she took steps to apply to a disability advocate for tax credits and benefits. Through these steps, she was able to acquire a Registered Disability Savings Plan and ensure her future financial security. Likewise, Andy and Molly acknowledged that “it’s just an automatic, if you have Parkinson it’s not going to improve.” By anticipating Andy’s eventual decline, the couple was able to access anything “that [he] might need in the future,” to avoid the “pressure” of locating resources themselves at a stressful time in the future.

In a recent example, Shelly V. was confronted with the negative experience of having her clinic close down without warning, leaving all personal health files inaccessible, unattended, and visible through a glass window. That being said, Shelly V. described herself as taking “immediate” action, through a long list of steps, “to get those files put somewhere safe” and to locate “a new GP.” At the time, Shelly V. was still waiting on a response to her first efforts, but she described being ready to take her efforts to “the next level” if she had to. Though there was no immediate need for her to see a GP, nor was it her responsibility to take action, Shelly V.’s

prompt behaviours meant that she, and many others from that clinic, would face less of an interruption in services when transferring clinics in the future.

In the hopes of “managing [her] condition,” Shelly V. and other participants also demonstrated a great investment in the pursuit of knowledge related to their condition and treatments (Big Bird). For Olive, she described how it was the patient’s responsibility to “dig information out yourself.” Indeed, this was how Olive “came about” her knowledge of new treatments, by “looking [it] up,” and how Shelly V. stayed informed through online searches and social media groups. Shelly V. and Big Bird agreed that “you have to go and look,” “then you can find the resources,” but qualified this statement by saying “But you shouldn’t have to look so hard.”

In some cases, use of online research was combined with “phoning around and trying to get some information,” such as when Emily found herself contacting the insurance provider and pharmacies to access “liquid thickener” for John. For Clyde and J. Wayne, it was a common occurrence that they needed to explored several local community organizations outside the scope of his condition, given that those initiatives were “individual[ly] run things that you actually have to phone around to try and find.” In fact, Clyde believed that “the only reason [J. Wayne] got such an elaborate chair [was] because [he] made a bunch of phone calls getting ahold of people around Canada” when trying to access the Tabs Program. However, when emotional supports were not available for J. Wayne, Clyde was required to expand his research tactics to seek services from organizations not tailored to his condition, due to the lack of specialists available in the city to work with individuals with cerebral palsy.

J. Wayne, James, and O. Twist provided wonderful examples of how knowledge was proactively exchanged through communities of support. For James, it was the case that he felt

“For 34 years, I have been trying to navigate the system myself”; therefore, he said, “if someone comes from out of province, I can try to help them.” Describing a more reciprocal sharing of information, J. Wayne mimicked a conversation he had with his friends where he said, “O.K. if you know something let me know because I want to know that too.” Through trial and error, J. Wayne and his family came to realize how specific terms could be used with service providers to gain access to services. Being a safety issue, his worker who had originally declined J. Wayne’s request for a door with a window, all of a sudden came to oblige. “O.K. if it’s a safety issue, we can get you the window.” In turn, J. Wayne, as per their agreement, happily shared this tactic with his friend in the following quote:

One of my friends was saying, “You know I can’t get a faster wheelchair [...].” And my mom said that: “Oh well can you get across the street?” And he’s like, “Barely before the light changed.” And my mom says, “So it’s a safety issue.” And he says, “Yes.” And mom said, “Well use that.” And low and behold, he got a new wheelchair within a month. Similarly, O. Twist shared his experience trying to “work around” the process of vehicle modifications:

I needed some equipment modified and usually [...] it’s a lengthy process but... [My friend] said, “Well just call the worker directly?” And I said, “Well can you do that?” He said, “Ya! I do it all the time.” I called the worker directly and we made an appointment and I was all done within a week [... S]ometimes you feel you need to, to take advantage of that. I try to be respectful of processes that these places have in place... but sometimes the temptation is too great.

Similar to close friendships that enabled each party to gain better access to services, sharing information was also a big component of the success of community organization

engagement. Emily in particular felt that “the [Community Organization X was] very helpful,” as she was able to benefit from “a lot of referrals [and ideas] through the group,” a comment echoed by Molly in relation to her support groups. Similarly, following her first diagnosis, Lena left the physician’s office with a strong need for more information. “Want[ing] to be informed,” she took to the Internet, to “pick and choose” the most reputable sites. As a consequence of these efforts, she came upon a local community organization website related to her condition and was able to reach out to the group, saying, “I need information!” When referring to her local community organization, Leslie said “I didn’t know that they existed until I found it online.” This desire to be informed was something that Lena felt was standard across patients.

**6.3.2 Action Strategies.** In this study, 14 of the 15 participants chose to take their care into their own hands by engaging in action strategies. Action strategies included specific actions taken by themselves to improve the inadequate services received or to alleviate their effect. Although this could have been accomplished in several ways, this section includes those strategies repeatedly discussed by participants only, including using financial resources and being an advocate.

Amongst participants, the use of personal resources was identified as a way that participants could by-pass obstacles in accessing services. If there was one thing that participants agreed on, it was that “living with a disability is expensive” (O. Twist). Across interviews, we see a trend of participants having to pay for vehicle modifications, mobility devices, pharmaceuticals, and other types of treatments not covered by insurance plans. In the scenarios below, we see first hand examples of participants and their families doing cost-benefit analyses of accessing supports.

Such analysis was evident in Sherri's comment, as she shared how she struggled to justify paying 70 dollars for a new exercise program. While "the camaraderie was very nice," she came to the conclusion that it did not seem "worth it" to pay "to do arm exercises" when what she really desired was leg exercises. In addition, though "the new TNS or VNS" treatments Olive was seeking were still unavailable in Canada, she admitted how over time she too became "the type of person who would pay for tests." In her mind, the benefits would be worth the expense if it meant trying to stop her seizures, and in turn, stop taking medications.

For James and others who "could afford it," it was sometimes "easier and quicker to" use personal financial resources and purchase a suitable wheelchair or other assistive device "out-of-pocket." Otherwise, he explains he "would have had to have waited two years" for coverage, which just simply "wasn't going to cut it." Having purchased "just a transport wheelchair," Molly and Andy were able to avoid that process of applying for coverage, since they could cover those costs. And yet, should Andy need a wheelchair with bigger wheels in the future, Molly admitted that they "would probably access [those supports] then, because then you're getting into more money." In this situation, participants were willing to accept the cost of services that are affordable based on their socioeconomic status, in order to avoid the lengthy process required to access them. However, once services became relatively more expensive, participants began choosing to endure those procedural complications.

In addition to wait times, another compounding issue was what participants would "qualify for," as there were no "guarantee[s]" (James). Although James "could have [qualified for a] wheelchair through [Community Organization X]," this would have entailed an entire process involving being "assessed by an occupational therapist" to determine what he "would qualify for." O. Twist similarly argued "there are things in place through government that are

helpful”; however, “they still resist making options [...] available so that [people] can choose the kinds of [chairs] that they need to be independent” in the community. This is very telling of the main theme in J. Wayne’s interview, where he and his father explain the many ways the province refuses to cover any services beyond what is “basic and/or adequate,” which by their standards has been anything but adequate. In James and O. Twist’s case, this meant potentially waiting to qualify for “an O.K. chair,” such as the “Quickie Q7 wheelchair,” which would not have met their needs (O. Twist). In the end, as stated by O. Twist, the chair simply did not provide the same options or adjustability options that he could buy on his own to allow for a “mobile and independent” lifestyle. This was a similar challenge faced by Jane B., who was able to pay for an “integrative medical practitioner” and an 11 thousand dollars for medical tourism to investigate all aspects related to her health, a comprehensive service providing her a “wealth of information” she did not feel she was receiving from the medical system.

When unable to afford these financial strategies, or in addition to them, advocacy seemed to be a way in which participants took action to improve their experience accessing health and social services. In his interview, O. Twist illuminated how heavy workloads put on community organizations were “ridiculous because there are so many people out there who need help.” As a result, when “people [were] calling [...] with questions and needing help,” counselors’ time became limited, thereby contributing to the general “tendency to not... make that call to the other guy who, who hasn’t called.” In this scenario, although O. Twist did not blame patients for not following up with the community organization, there was a clear bias suggesting that if they did not advocate for themselves, they too will “get left behind.” Sherri shared a similar storyline when she never received a follow-up in the process of trying to access housing services from a local community organization for seniors.

From a health care point of view, while Lena appreciated the communication she received from her physician, she shared how she was reciprocally “very good about ... contacting him” and “believe[d] in ‘you have to take some of the ... responsibility yourself.’” While “no news is good news,” she continued, patients should take responsibility and follow-up with their health professional if they are concerned. In some cases participants gratefully took on the responsibility to advocate for themselves, even to the point that they would manage their own care. For example, faced with a lack of reliability in “community homecare” services, J. Wayne and O. Twist “got away” from that and chose to apply for “self-managed homecare,” where they now coordinate their own team of staff members.

A similar point was raised by Jane B., Leslie, J. Wayne, and O. Twist who said, they had to be their own “advocates” to receive the services they wanted (Jane B., Leslie), “If we don’t know what to ask for, how can we ask” (J. Wayne), “you really have to be able to ... know how to ask for things, because if you don’t... they’re not going to come out and find you” (O. Twist), and “it’s easier to get left behind when you’re not really calling and trying to advocate for yourself” (O. Twist). As for a specific example, Shelly V. described the lack of action on the part of her physicians in recent years. In fact, she said “for any doctors that I had or any procedures that I had [or] wanted done, I actually asked for [it].” Along the same line, this concern also resonated in Jacks T.’s interview when he said, “If I don’t initiate it, it doesn’t happen.” Jane B. also cautioned against putting too much trust in authority figures like doctors after previously being let down.

Rather than a lack of action on the part of service providers, Sherri was required to act on her own behalf to rectify inappropriate treatment from providers, which she experienced while undergoing surgery to have her bladder lifted. Following repeated surgeries, Sherri was faced

with a gamut of upsetting events, including long lasting complications, her request for a catheter being ignored, and being yelled at by a nurse in the recovery room. According to Sherri, the nurse turned to her and said, “Stop crying! You don’t have a catheter! Suck it up.” Though unable to reverse the lifetime of numbness that she will now experience in her abdomen from the surgery, Sherri later submitted a complaint to address how she was treated.

Finally, when unable to advocate for themselves, some participants involved another party to demand accountability. For Leslie and James, this meant seeking out a second opinion from another health professional and the hospital’s Patient Relations Office when they felt they were not being heard. For instance, Leslie defended her choice to by-pass her family doctor by getting a referral to a specialized outpatient clinic from a walk-in clinic. In her response, she felt she was left with “no choice,” since “every time I called [...] the nurse was just really aloof.” For James, J. Wayne, and Victor, this also meant involving a family member, such as when Victor found his homecare worker sleeping on his couch. Although he did not say anything to the worker himself, he felt comfortable telling his father, who then ensured that Victor be assigned a new homeworker.

**6.3.3 Mental strategies.** Lastly, though less common, mental strategies represented another approach demonstrated by participants. These strategies were implemented for the purpose of coping or providing mental confidence, as opposed to improving access to services. For example, O. Twist would not “worry” about accessibility of his services because he knew he could access services through his specialized outpatient clinic.

When faced with wait times during the process of getting diagnosed, Lena spoke of her “belie[f] that [the health care system] works.” She said, “I have to believe that when you are in dire straits, people will move.” Based on her various quotes, Lena explained how her

experience “working in the health care system helped.” In this role, she witnessed first hand the prioritization of services, which helped her to validate the time that patients spent waiting for appointments. Lena shared how mentally she became invested in the belief that if she or anyone else was to “really need something, there are ways to get things done.”

In a similar sense, some participants seemed to modify their expectations, thus narrowing the gap with the existing situation. For instance, based on their interview, Shelly V. and Big Bird agreed that accessibility of information was key for patients in the management of their condition; however, Big Bird acknowledged the fact that “the medical doctor [...] doesn’t have to know ... a lot about epilepsy or a lot about these things,” as information is “changing so rapidly” that “you can’t expect every professional to be on top of everything.” Lena equally recognized how doctors could be “inundated with pamphlets,” making it difficult to keep track of resources for people with different neurological conditions. As with Lena, many other participants also modified expectations related to timeliness of services when they stated, “I know he’s a busy doctor” (Olive) or “at least I have somebody I can call” (O. Twist). Leslie’s experience with wait times was interesting in the following train of thought:

*Leslie: [T]hey get me in right away. I mean sometimes it’s a bit of a wait, I know, but [...] it’s not so terrible. So I would say ya the only tough thing is wait times. But other than that [...]*

In this quote, Leslie mentally moved back and forth between her discontent with wait times and her willingness to accept them as a norm in our society, where she saw her situation as comparatively better than what others must deal with. In reality, “there will always be ways to improve” (O. Twist); however, for O. Twist he acknowledged that even with funding and timeliness issues he never felt like “there were any services that were lacking.”

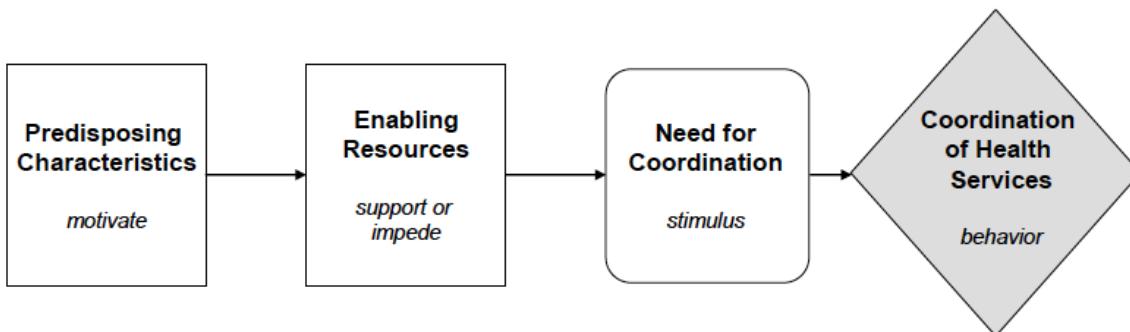
## CHAPTER 7: DISCUSSION TO ADVANCE THE CONCEPTUAL FRAMEWORK

The first two research objectives explored “how participants experienced navigating health and social services,” and “what participants viewed as current successes and gaps of care coordination within Manitoba.” What was most notable from the findings was not a repeated set of experiences when accessing services; but rather, a continuum of experiences that varied depending on a consistent set of influences in one’s life. As a result, what was experienced as a gap in the system by one, may not have been experienced by the next, but was similarly valued.

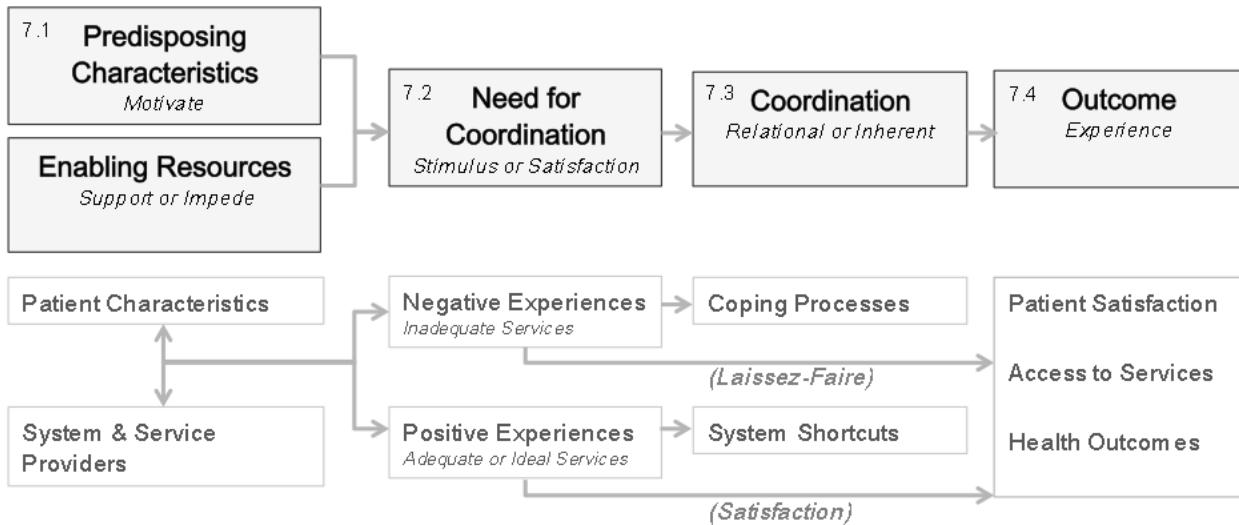
Significant influences to participants’ experiences were subdivided into the three main themes identified in the findings (i.e., participant characteristics; service providers and system qualities; and choice and/or ability to employ strategies), which shared prominent similarities with the literature and McDonald’s et al. (2007) Care Coordination Framework. I combined my interpretations of the interview data with the literature to adapt this conceptual model, which I will discuss phase by phase in this section. A visual representation of McDonald’s et al. (2007) original Care Coordination Framework and my adapted version are presented below in Figure 3.

**Figure 3. Adapted Conceptual Model**

a) Original Care Coordination Framework (McDonald et al., 2007)



b) Adapted Care Coordination Framework



### **7.1 The Hand We Were Dealt: Predisposing Characteristics and Enabling Resources**

“The Hand We Were Dealt” was written to revisit the first two components of the Care Coordination Framework, Predisposing Characteristics and Enabling Resources. Most recognizably, participants’ characteristics (theme 1; 7.1.1) and system and service providers (theme 2; 7.1.2) correspond with these categories as these factors are baseline factors setting the stage for a participant’s future experiences navigating health and social services.

**7.1.1 Participant Characteristics.** Firstly, participants’ conditions, socio-demographic characteristics, and relationships, are discussed in relation to existing literature.

**7.1.1.1 Condition.** For this present study, participants were of a similar self-reported health status as other Canadians living with a neurological condition based on the proportion reporting fair or poor general health on the 2010/2011 Canadian Community Health Survey, 26.7% and 25.4% respectively (NHCC/PHAC, 2014). If migraines were removed, at which point, “the proportion of Canadians with a neurological condition reporting ‘fair’ or ‘poor’ general health [would] jump[] to 46.2%” (p. 16), suggesting the population sampled was, for the most part, indicative of a population of a higher functioning status. Nevertheless, diagnoses

ranged from stable non-debilitating conditions to conditions with complicated symptoms and care plans. In the end, no two care plans were the same, since each was tailored to participants' unique needs for knowledge, skills, and services from their physicians.

Based on the "inverse therapy rule," the number of services one has access to is indicative of the severity of one's disability, since the scarcity of resources requires services to be focused on patients with the most severe needs (Siegert et al., 2014, p. 13). Similarly, as the complexity of chronic conditions increases, more providers become engaged in a participant's care, contributing to a greater need for assistance with service coordination (McDonald et al., 2007). On that note, Canadians living with a neurological condition were recently reported to access more services related to their condition than those living without a neurological condition or with other types of chronic conditions (e.g., hospital, physician visits, prescriptions, residential care; NHCC/PHAC, 2014). This would suggest that, on average, neurological conditions are considered comparatively more complex and require more support with service coordination than most other chronic conditions. According to related research, explanations for this trend could include the information and processing requirements with complex service needs (Aspinal et al., 2012, NHCC/PHAC, 2014; Davies et al. 2011; Dunleavy, 2007; Heesen et al., 2007; Siegert et al., 2014, McDonald et al., 2007; Wilson et al., 2014), lack of research and awareness of condition (NHCC/PHAC, 2014; Jaglal et al., 2014), the progressive nature (Byrne, McNamara, Seymour, & McClinton, 2009; Hughes, Sinha, Higginson, Down, & Leigh, 2004; Fitzpatrick et al., 2010), and the potential influence on cognitive competency associated with selected neurological conditions, contributing to more challenges with coordination of services (Harris, Chodosh, Vassar, Vickrey, & Shapiro, 2009).

Even so, with the exception of a handful of neurological conditions, there appears to be a

significant lack of awareness compared to most chronic conditions. On behalf of the Health Council of Canada Health Outcomes Steering Committee, recent research states “there is growing awareness of the increase in prevalence of chronic health conditions and the impact of these conditions on health status and healthcare utilization,” both in Canada and abroad (Broemeling, Watson, & Prebtani, 2008, p. 71); yet, there continues to be an important shortage of knowledge and awareness for most neurological conditions among both the general population and service providers, which was reported to greatly affect the quality of coordination and patients’ access to health and community services (Doug et al., 2009; Jaglal et al., 2014, p. 7; Kroll & Neri, 2003). More specifically, a national study identified Canadians’ desire for greater knowledge surrounding the “etiology, prevention, management, and services and supports available in the community” when living with a neurological condition (Jaglal et al., 2014, p. 8).

In the Manitoba-specific context with this study, lack of awareness seemed to be even more prominent for specific types of neurological conditions. For instance, service coordination and accessibility seemed to be positively related to the complexity of the condition for participants affected by neurotrauma. Similar to findings in the literature, this group experienced a greater need for service coordination following the incident, which typically tapered off with time and rehabilitation (Elliott & Parente, 2014; Kennedy & Chessell, 2013). In turn, for neurodegenerative conditions, participants generally expected their condition to progress with time, requiring greater access to a range of services nearing the end of their disease trajectory. This trend would expectedly be even more pronounced if conditions were in their critical stages, when uncertainty is highest, as with long-term, hospice, or palliative care (Byrne et al., 2009; Galushko et al., 2014; Jaglal et al., 2014; Oliver & Waston, 2013, p. 121). However, though equally as debilitating, people living with neurodevelopmental conditions experienced a drop in

the quality of their care after the age of 18. This is a unique challenge for members of this age group, with such a high proportion of children compared to other chronic conditions, who must later face a “transition cliff” when moving to adult services (Jaglal et al., 2014, p. 6). In this case, though the desire for service coordination increased when transitioning to adult services, the opposite was said to occur resulting in a lack of continuity, integration, coordination, and absence of services also seen in the literature.

As a possible explanation for this irregularity, provincial coverage for any non-medicalized services, mainly emotional therapy and physiotherapy, were said to be cut-off or greatly limited after transitioning to adult services, unless “hospitalized or in institutional care” (MHHS, n.d.). Additionally, organizations geared towards these particular types of conditions were said to receive significantly less funding because the organizations were not geared towards vocational rehabilitation, and thus do not receive related funding from the provincial government (i.e., O. Twist). This lack of funding translated into substantially less community and social supports offered to adults living with neurodevelopmental conditions. Furthermore, technological and medical advances have extended the life expectancy of people living with neurodevelopmental conditions, making coordination of services for this group an unfamiliar challenge to the adult sector (Doug et al., 2009).

Based on the prevalence of neurological conditions in the general community and institutions presented in Chapter 1, only those participants with the most prevalent conditions had access to health and community organizations that offered their participants the most in terms of services and service coordination. For instance, there was a glaring discrepancy between the integrated multidisciplinary approach organized for O. Twist’s spinal cord injury in specialized outpatient clinics and Leslie’s need to fight for a diagnosis at a clinic specialized in

conditions other than her own. In line with McDonald's (2007) Care Coordination Framework, with greater prevalence would also come greater pressure on system-level decision-makers to invest financially and conceptually into supporting related local community organizations and supports, which likely contributed to this discrepancy over time.

To conclude, the neurological diagnosis that someone receives would inevitably be considered a predisposing characteristic, as there is typically no cure for most neurological conditions. Hence, the condition they are diagnosed with will determine which resources are made available to them. On the one hand, community organizations can represent enabling factors when contributing to enhanced care coordination or, alternatively, predisposing characteristics when an absence of services creates additional barriers to receiving optimal care.

**7.1.1.2 *Sociodemographics*.** Similar to one's condition, participants were characterized by a range of social and demographic characteristics that translated into a range of experiences navigating health and social services. As described, age was mainly discussed as a predisposing factor for people living with neurodevelopmental conditions, acting as gatekeeping criteria for health and social services. Alternatively, personality, socioeconomic status, and employment acted as foundational characteristics that participants could utilize in their future strategies to gain access to services.

At the beginning of each interview, I asked participants to tell me about themselves for a better understanding of their self-perceptions. Participants overwhelmingly portrayed themselves in relation to their families and as resilient patients who took the initiative to self-advocate. Due to the convenience sampling method used in recruiting participants, a direct comparison to all individuals living with a neurological condition in Manitoba cannot be made. Rather, since recruitment predominantly took place in community-based organizations and was dependent on

respondents' willingness to participate, it is assumed that there is a proportional bias towards more engaged and research-oriented participants.

That being said, research findings suggest that personality variables (e.g., health locus of control, assertiveness, conservatism, self-efficacy) greatly predict patient preferences with regards to patient-physician relationships (Braman & Gomez, 2004; Hamann et al., 2007; Heesen et al., 2004; Solari et al., 2013;). Most participants from this study demonstrated a preference for respect and egalitarian relationships with their physicians through information seeking and active participation in their care coordination or treatment-decision making. In the literature, whether or not the system they engaged with aligned with these preferences played a large part in determining patients' satisfaction with service delivery and whether or not a need was stimulated (Kiesler et al., 2006; Rubin, 2014).

Some participants were able to gain knowledge and experience while working and volunteering, which was deemed as resourceful when coordinating their own services. Aside from connections to their main service providers, participants who were professionally involved with the health care system, tax agencies, or community organizations advantageously gained knowledge about those systems through their employment or volunteer positions. This additional source of information enabled them to build resourceful networks and a knowledge base of how to access services through experiential learning. Hence, as involvement increased, so did participants' knowledge of services from that system, which was helpful when trying to mentally cope with wait times, proactively accessing services, or self-advocating after the receipt of inadequate services. Clark and Wilson (1961) identify this as a material benefit or a tangible reward to volunteering (as cited by Chinman & Wandersman, 1999). I was unable to locate research supporting increased utilization of services in an organization by its own employees or

volunteers. That being said, Hughes et al. (2005) and van der Roest et al.'s (2009) both provide research on people with progressive neurological illnesses and their families, which identifies knowledge of services as a predictor for service uptake and unmet needs respectively. "Where knowledge of services is low, take-up is likely to be similarly low" (Hughes et al., 2005, p. 72).

A coinciding benefit from employment included financial security and health benefit plan coverage. Based on the National Health Population Study on Neurological Conditions in Canada, people living with neurological conditions comparatively incurred higher health care costs than those with other conditions, resulting in substantial out-of-pocket expenses (NHCC/PHAC, 2014). Along with knowledge of services, van der Roest's et al (2009) study proposed that the extent of unmet needs was explained more by access to services and having a health care insurance plan than the actual need itself (p. 961). Participants with conditions that affected their cognitive well-being were most impacted by a reduction in employment prospects. According to NHCC and PHAC (2014), a quarter of adult Canadians living with a neurological condition other than migraines were permanently incapable of working, compared to 1.7% of those without a neurological condition. Without employment, participants relied upon disability pensions and employment insurance, for which the payout varies depending on specific criteria; that being, how the disability was incurred (e.g., work, car accident), whether the individual contributed to the Canada Pension Plan before the disability, or is a war veteran (Jongbloed, 2003). For those who did not qualify, they were required to rely upon informal familial supports for financial assistance to cover out-of-pocket expenses, similar to other Canadians living with long-term disabilities and health problems (Duncan, Shooshtari, Roger, & Fast, 2013). However, as a single mother, Suzy was without a partner to share insurance benefits or to help provide economic protection, thereby demonstrating the added benefit of a marital "safety net," enjoyed by 10 of

the other study participants (Stack & Eshleman, 1998, p. 528). Without family supports, Suzy's experience navigating health and social systems focused on her inability to access services that she needed because of the financial strain of out-of-pocket expenses, as well as her inability to navigate and qualify for complex government assistance programs.

Across all interviews, participants also struggled with the process of qualification, whether it was for social assistance, disability pension, or coverage for publicly or privately funded services. In some cases, participants used their income to bypass what they believed to be a complicated and timely process of qualifying for services. As with other disabilities, taking on care-related expenses meant incurring costs that represented a large portion of participants' household income, especially when living with less financial means (Duncan et al., 2013). Based on the General Social Survey (Cycle 21), Canadians caring for someone living with long-term disabilities or health problems incurred care-related out-of-pocket expenditures, which ranged from under 500 dollars (80.2%) to more than 2,000 dollars (3.2%) per month (Duncan et al., 2013). In this sense, socioeconomic status was a predisposing characteristic for all participants to some extent, but also an enabling resource for those who were able to afford financial strategies that solved their problems accessing services. Even so, participants who were exceptionally well off faced limitations in the services they could afford out-of-pocket, thus compelling them to face the woes of system navigation along with others when purchasing larger-ticket items.

Though other socio-demographic characteristics were reported in this study, they did not play a meaningful role in the findings or conclusions drawn. This likely reflects the biased and small sample size of this study as opposed to a lack of significance and should be considered in future studies. Although this study focused on an urban population, in the literature, rural communities have been known for their absence of care coordination and lack of services

(Aspinal et al., 2012; Bahn & Giles, 2012; Morgan et al., 2009). In a study by Sanmartin and Ross (2006), although routine care was equally accessible to Canadians living in rural areas, they reported significantly more difficulties with accessing immediate care than their urban counterparts. In northern, rural, and remote locations, accessing necessary services was reported as quite challenging in the NPHSNC and therefore should be considered in future research.

In relation to sex and gender differences, research on patient personalities and success with care coordination remains limited. In some cases, studies suggest that women are more inclined to participate in their care (Hamann et al., 2007; Ryan & Sysko, 2007). Personal barriers built on traditional gender roles also means that men have been less likely to use primary care health services than women (Talbot & Tudiver, 1999). Focusing on the personalities of the seven men participating in this Manitoba study, the qualities they used to described themselves or the actions they took to ensure proper care in no way suggested that they were less inclined to engage in coordination strategies than women. However, given that this is a preliminary study and existing research supports the potential for gender differences, it should be considered in future research.

Language barriers (Ayanian et al., 2005; Ngwakongnwi, Hemmelgarn, Musto, King-Shier, & Quan, 2012; Sanmartin & Ross, 2006) and ethnicity (Ayanian et al., 2005; Zambrana, Molnar, Munoz, & Lopez, 2004) understandably have also been identified as influential variables in relation to service coordination and accessibility. The NPHSNC recently highlighted the importance of increased awareness and consideration of First Nations and Métis populations, as well as “cultural background[s] and language[s]” when serving Canadians living with neurological conditions (NHCC/PHAC, 2014, p. 49). In this current study, language barriers had no influence over themes and only one participant identified ethnicity as potentially influencing

one's connection to and receipt of community supports, following the departure from the hospital setting, for First Nations populations in the province (a challenge identified second-hand as a counsellor rather than from personal experience). Currently, the jurisdiction over Aboriginal people's health care is a public health concern across Canada, as the federal government maintains legislative authority over "Indians and Indian Bands", while provinces authorize control over health care legislation (Lavoie & Forget, 2008, p. 108). Due to a lack of cooperation and coordination between the two levels of government, First Nations people face barriers in accessing health services (Lavoie & Forget, 2008). The "ambiguity about the level of government responsible for care provision and the need for better cultural competence among care providers" were identified as issues faced by Canadians living with a neurological condition (NHCC/PHAC, 2014, p. 4). Due to Manitoba and Saskatchewan's high and increasing Aboriginal population, this is an issue that holds particular relevance in these provinces and warrants attention in future research.

**7.1.1.3 Relationships.** Lastly, familial relationships and social networks, represent the third type of personal characteristic influencing participants' navigation of health and social services. According to a study by Galushko et al. (2014), some participants living with multiple sclerosis saw a decrease in their social networks as their condition progressed. No such trend was present in the findings of this study, with experiences that ranged from adjusting social networks to befriending people in similar life circumstances to absolutely no change in one's network.

Typically, family engagement in service delivery seemed anticipated or "normal" for many participants. Much of the family-centered research related to neurodevelopmental conditions focuses on parents' active involvement with service planning from birth, thus resulting in a continuation of involvement into their adult years that follow (Almasri et al., 2011;

Binks et al., 2007; Brustrom et al., 2012; Davies et al., 2011; Dyke et al., 2006; King et al., 2004). Otherwise, family involvement was more a matter of patients' increased need for support due to impairments (e.g., support accessing services, health care decisions-making; Golla, Galushko, Pfaff, & Voltz, 2011; Oliver & Watson, 2013; Wilson et al., 2014).

Informal family caregivers are increasingly being depended upon to meet the augmented demands of caregiving and organization of care (e.g., correspondence for aids and rehabilitation, facilitate access to services) (NHCC/PHAC, 2014; Purkis et al., 2008). From a practical perspective, shifting caregiving responsibilities and expenses from the health system onto families is cost effective. Trying to coordinate professional contacts on top of a caring role has been reported as potentially burdensome and overwhelming for family members (Oliver & Watson, 2013). Caregiver strain is a multi-dimensional construct defined in terms of burdens associated with the need to provide care or assistance to another (Robinson, 1983 as cited by Higgins, Duxbury, & Lyons, 2007). However, in my interviews, conversations focused on the mutually positive relationship participants had with their family members or their appreciation for family support provided (likely since most participants were relatively high-functioning).

What was apparent was the “domino effect” that relationships had on coordination of services, with one resourceful connection leading to another and so on. Given that knowledge of services was said to predict the use of services, participants’ connections filled the gaps of the system by connecting their loved-ones to the necessary resources when the system failed to do so. In a study by Chapleski (1989), having connections to “nonkin advisers, membership in clubs, and contacts with other community agencies, along with availability of moderate-size kin networks” was identified as positively increasing the elderly’s awareness of services. According to the Care Coordination Framework, these relationships supported continuity of services and

would be considered enabling resources, used as a foundation for the pursuit of knowledge or action strategies.

**7.1.2 Systems and Service Providers.** The following section includes a discussion integrating themes related to the service provider and system characteristics from the findings with those identified in the literature review of this study. Given the fact that this thesis is focused on the perspective of people living with a neurological condition, all organizational or system-based characteristics are considered fixed because participants are perceived as having a general lack of power over resources to develop systemic interventions or invest in services.

Based on my literature review, I identified four best practices for service delivery, including 1) multidisciplinary care, 2) collaborative care, 3) integrated person-centered services, and 4) continuity of care. As explained in Chapter 4, these concepts represent structures of care that support coordination of services in their presence, and a need for it in their absence. Striking resemblances existed when comparing these four best practices to what participants valued in their systems and service providers, including 1) ease of access, 2) collaborative communication, 3) caring relationships, and 4) reliability, the four themes from participant interviews. In this section I highlight these similarities and how the concepts support one another.

First of all, participants appreciated or desired a system that was “easy” or convenient to navigate. Similar to best practices of service delivery, they found the navigation experience easier when they had uninterrupted access to the services they needed with relatively little effort. These needs were complex, ranging from physical to mental, emotional, and social, oftentimes extending beyond what a general practitioner can provide, thus requiring the expertise of a variety of specialists in multidisciplinary care teams (Breitlow, 2007; Bitsko et al., 2013; Doug et al., 2009; Galushko et al., 2014; Langhorne et al., 2005; Parent et al., 2011; Suddick & Dee Souza,

2006; Wilson et al., 2014). In this study, although there were elements of multidisciplinary care for all participants, the delivery of services by specialized outpatient clinics demonstrated a clear medical advantage, allowing patients to receive a broad range of services from experts specialized in their condition with ease.

Equally as important as the delivery of a range of services is the integration of these services based on patients' and families' specific needs to ensure a "seamless" "eas[e of] access and navigation" (Kodner, 2009, p. 8; Spragins & Lorenzetti, 2008). As with the literature, teamwork and communication between professionals for the betterment of the patient contributed to participants' receiving services without having to take personal measures to facilitate coordination (Almasri et al., 2014; Spragins & Lorenzetti, 2008; The Change Foundation, 2008).

According to Kodner (2009), collaboration both within and between "the 'cure' and 'care' sectors" must occur for the integration of services; by doing so, "easy links" are created for seamless transitions "between primary, secondary and tertiary care; between ambulatory, home- and community-based and institutional care; and between medical/acute care, long-term care, mental health care, social services, and so forth" (p. 13). In this study, when clinics established connections with community organizations, patients benefited from being connected directly to an even greater range of services tailored to their condition in a timely fashion (e.g., tax, housing, recreation, transportation). Research suggests that the incorporation of and coordination between statutory health care and community-based services, as well as non-statutory services, are important in the delivery of health services (Aspinall et al., 2012; Doug et al., 2009; NHCC/PHAC, 2014). This held true in the present study, as many participants benefited equally, if not more, from community services, as opposed to health care services.

By easing the process of service navigation, patients are believed to be able to take charge of their own care, a trend also demonstrated in the current study (Spragins & Lorenzetti, 2008). Amongst the interviews with participants who accessed services from more integrated systems, there was a clear trend of greater acceptance towards engaging in tasks required to navigate the system on their own, including approaching service providers to communicate their needs as they arose. Consequently, integrated service delivery facilitated both collaborative communications with service providers (a theme Manitoba participants valued in their care), as well as patient autonomy (a best practice identified from the literature).

When compared with existing research, participants portrayed a similar desire to be informed and engaged in treatment-decisions (Galushko et al., 2014; Kaplan & Frosch, 2005; King et al., 2004; Olsson et al., 2012). Through collaborative communication efforts, participants reported negotiating services with their service providers, which seemed to provide them more control and autonomy over their services. In research, patient-physician communication has been related to patient empowerment, increased service provider participation, and reductions in repetition in participants' care (Aspinal et al., 2012; Palfrey et al., 2004; Reid et al., 2002). Franklin (2006) also raised the importance of early patient education to ensure people facing brain injuries received the proper information and do not "slip through the cracks" (p. 503). According to Ong, de Haes, Hoos, and Lammes (1995), patient-physician communications achieved three main goals, which were to establish a relationship, information exchange, and patients' participation in care-related decision-making (as cited by Kiesler et al., 2006). Nevertheless, regardless of their engagement, participants sometimes found themselves in a system that could not accommodate their requests or collaborating with a service provider who was unwilling to alter services to accommodate participants' preferences.

Participants often interpreted their providers as poor or unwilling to collaborate when communication was negative, limited, or absent from patient-provider interactions. By comparison, participants noted their appreciation for positive exchanges with service providers, as well as any ensuing caring relationships. For some, relationships with their service providers influenced participants' self-identities and would build up participants' confidence, such as when they would use pet names to describe each other (e.g., favourite patient). Contrastingly, participants tried to ward off negative self-concepts when interactions were insensitive or unkind (e.g., just a number or a pay check). This effect seemed less important when interactions were with an occasional or intermittent service provider. Specifically, participants who were hospitalized or frequently visited a particular health professional were more inclined to develop relationships with those providers. By comparison, patients whose services consisted of the acute health care system or yearly follow-ups shared less time with their service providers, giving them less reason to interact on a personal level. According to Haggerty et al. (2003), although multidisciplinary care often contributes to inconsistent relationships with specialists, long-term relationships with a main provider or core team provides sufficient predictability to offset what would otherwise be an unpredictable navigation experience.

Based on participants' interviews, whether or not service providers showed signs of caring for participants or made an effort to coordinate services was also telling of how reliable participants would perceive them to be. Through these indicators, physicians demonstrated a particular investment in their patients' well-being, which in turn seemed to comfort participants by validating that they could rely on their service providers to do all that was possible. With the exception of one, participants accessing publicly funded homecare services perceived these as consistently unreliable. Performance and interactions with caseworkers were persistently

negative, and were thus labelled as untrustworthy and unpredictable. In ideal cases, longer-term relationships were interpreted as translating into service providers' greater awareness and knowledge of participants' personal contexts and preferences. However, with the level of turnover experienced in homecare services, building relationships was particularly challenging for participants. Findings from the research also suggest that building patient-physician relationships contributed to continuity in care (Freeman et al., 2007), which itself is considered the fourth and final best practice identified in the literature review.

Specifically, in the literature, continuity in a relationship is termed relational continuity, which is believed to support a sense of trustworthiness and related therapeutic benefits (Aspinal et al., 2012; Freeman et al., 2007). Within a trusting relationship, patients are described to be more willing to adhere to treatments and disclose health information, while physicians are more willing to engage in caring behaviours (Lee & Lin, 2009). Furthermore, a holistic approach to service delivery combined with relational continuity (i.e., more listening and time spent with patients) contributed to a patient-centered approach (as opposed to a disease-centered approach), which was greatly appreciated by people living with neurological conditions in the literature (Aspinal et al., 2012). Overtime, consistency in these relationships enables service providers to learn more about their patients and use information from prior service interactions to modify patients' care more appropriately to suit future circumstances, also known as informational continuity (Reid et al., 2002). This is again interrelated with another type of continuity, management continuity, which is the process of providing "timely and complementary services that are responsive to changing needs" (Reid et al., 2002, p. 9). In a systematic review, patients themselves were "prepared to trade off delays in access for routine check-ups for chronic conditions, against increased continuity for serious conditions or those where there was a high

level of uncertainty" (Parker, Corden, & Heaton, 2011). As neurological conditions contribute to ongoing and complex service needs and uncertainties, implementing continuity would be even more imperative for effective outcomes.

To summarize, though the literature focused on best practices, some of the most fundamental and basic practices were not met in participants' services. For example, some participants struggled accessing services when they did not have access to a general practitioner, even though they represent the first point of contact and are the main organizers of participants' health-related services. Rather these practices and the themes that are identified in this section represent an ideal that should be sought. In fact, when comparing the literature with the findings of this thesis, regardless of whether patients have a neurological condition, chronic condition, or neither, they appear to want the same things in their care. The difference, however, is the extent to which these are needed due to the highly complex nature of neurological conditions. Unlike other chronic conditions, many neurological conditions have a great impact on one's cognitive manifestations of well-being, making it difficult to communicate with providers or actively participate in service planning (Department of Health Long-term Conditions NSF Team, 2005). Furthermore, the emergency associated with neurotrauma or fast progressing neurodegenerative conditions also creates a sense of urgency, typically not seen in other chronic conditions.

## **7.2 Need for Coordination vs. Patient Satisfaction**

McDonald et al. (2007) encourage the identification of patients' in greater need of coordination including those with "complex medical or social problems, multiple health care providers involved in care, services received at multiple sites, and patients with specific diseases" (p. 134). Both patients and their service providers were said to be able to perceive a need for coordination and stimulate action. In other words, patients themselves can self-identify

if the complexity of their condition categorizes them within a group requiring complex care, and therefore, more care coordination.

Furthermore, the extent to which predisposing patient characteristics and system qualities are compatible also gauges the “Need for Coordination” that is stimulated (McDonald et al., 2007). For example, if a person’s condition is only moderately complex but he or she has no supportive enabling resources (e.g., no relationships, lives in a rural area, low socioeconomic status, poorly coordinated system), he or she may require more care coordination than someone with a very complex condition protected by many enabling resources (e.g., much family, insured, Type A personality, very integrated system). In these cases, patients or caretakers could raise this concern in hopes of increasing coordination of services.

My recruitment was limited to people living with neurological conditions; and yet, the Care Coordination Framework says little about the actual Need for Coordination from the patient’s perspective. In addition, given the current encouragement for patient-centered care, their input should be considered rather invaluable. Therefore, this section will only address this topic from patients’ perspectives (as well as in the stories shared earlier in my findings section). Given the diversity in participants’ characteristics as well as the quality of serving systems, there was a corresponding range of resulting experiences. In the likelihood of oversimplifying the complexity of participants’ experiences, they will be discussed based on a continuum from negative to positive. This section identified ways in which I distinguished between how participants’ presented these experiences in their interviews.

Firstly, participants identified services that generated negative experiences, whether personally or by someone in their social circles. In their interviews, only J. Wayne and Clyde described themselves as requiring additional support “all the time.” However, all participants

were able to identify something that could be improved in the system, and 12 of the participants were able to identify at least one instance in their care that was inadequate and led to a negative experience. More specifically, participants and their family members most frequently described negative experiences accessing services for themselves, or for others with the same condition, as frustrating. Such words were used to represent underserving systems, where participants received services that they believed to be inadequate, thus stimulating a need for coordination.

Negative experiences often occurred when participants reported being faced with being dropped by a provider, having no support from their providers, or facing other types of uncertainties while receiving unreliable care, especially in the case with publicly funded homecare services. In some of these cases, the participants' and service providers' perception of their needs did not align. Otherwise, there was not a "good fit" between the participants' needs and what the system was able to provide (McDonald et al., 2007, p. 116). Consequently, what patient autonomy or interdisciplinary patient-centered services looks like will vary with each participant's context and the resources available to him or her.

Alternatively, amongst the 15 participants, there were five who identified themselves as having received ideal services where "everything [was] positive" (Molly). These participants applauded the services they received at every possible point in the interview. And yet, across the board, other participants also mentioned at least one area of their care that they felt was adequate and appreciated, regardless of how negative experiences from other systems had been. For instance, J. Wayne and Clyde frequently cited the many ways the system failed them but also took the time to acknowledge his caseworker and his other "great" and "fantastic" supports. J. Wayne described these as "the very few people that actually want to see us succeed." When describing adequate to ideal service coordination, participants used words such as "excellent"

(Molly, Andy, Emily), “impressed” (Emily), “wonderful” (Sherri, Emily), and “Cadillac” (Andy) to name a few and told of positive experiences navigating health and social systems.

Participants who identified as receiving ideal service experiences typically did so when coordination was inherent in the existing predisposing characteristics. In these cases, information and services were readily coordinated and available, leaving no service needs unmet and no questions unanswered, thus surpassing needs, expectations, or desires and not triggering strategies to rectify the situation. Furthermore, ideal services were typically characterized by support beyond expected physical care, with many appreciating services from local community organizations even more, since “it’s almost a given, because that’s what we expect.”

While Canadians benefit from a system that provides exceptional physical care for acute health care needs, the future for most living with a neurological condition is left filled with uncertainties (Chen et al., 2010; Davies et al., 2011; Heesen et al., 2013). Based on participants’ interviews, community organizations replaced this uncertainty with a reliable community of supports, personal goals, and a positive outlook that some did not expect following the diagnosis of a neurological condition, thereby raising the significance of integration between health and community organizations.

### **7.3 Strategic Coordination**

Ultimately, participants reported a spectrum of positive to negative experiences when accessing health and social services. When services delivered met participants’ needs, they typically reported satisfaction and positive experiences. In ideal cases, knowledge and services were readily available through inherently coordinated systems, leaving no service needs unmet or questions unanswered and thus not triggering a need for additional service coordination behaviours. In turn, when receiving adequate services, though not to the same extent, participants

were similarly content and satisfied with services. Consequently, participants were able to achieve the goal of system navigation (i.e., access to services, patient satisfaction, and possible positive health outcomes), while bypassing the stage of coordination behaviours.

Interestingly, even when needs were met, participants receiving adequate services were sometimes tempted into using similar strategies as those receiving inadequate services. In these cases, rather than triggering coordination behaviours out of need, they did so out of desire for shortcuts to access services and bypass system obstacles. One participant expressed his feelings of guilt for engaging in these actions; another participant felt it represented abuse of the system; while the majority explained how their actions were completely justified. For instance, one participant stated, “the system is broken, I only do it when I have to, I get special treatment because I’m different from the rest – I don’t whine”.

Alternatively, inadequate services<sup>12</sup> or negative experiences were often associated with a poor fit between a participant’s needs and what the system or their service providers could offer them, which in turn triggered a need for coordination. McDonald et al.’s (2007) model generally refers to coordination, as a behaviour performed by system-level policy-makers and service providers. However, the authors also state that the “general concept of coordination, applies to any behavior related to coordination” (p. 113). Furthermore, Porteous, Wyke, Hannaford, and Bond (2015) report that the origins of the Care Coordination Framework (i.e., the Behavioral Model) can be used to predict self-care behaviours, and even encourage its application to different conditions, systems, and types of self-care. Therefore, in my model, I focus on patients’

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<sup>12</sup> The term “inadequate services” was inspired through J. Wayne’s interview, where he and his father frequently referenced provincially funded services as being “basic and/or adequate”. Though these terms on their own refer to meeting a standard level of care, the way they were used in J. Wayne and Clyde’s stories demonstrated how what was believed to be basic or adequate in the system was not adequate for his personal needs, further reinforcing the need for person-centered services.

utilization of coordination behaviours while accessing health and social services. Explicitly speaking, in my findings I identified how participants strategically improved their access to health and social services through a pursuit of knowledge, action strategies, and mental strategies.

The fundamental message underlying the first strategy is that information is power, separating the knowers from the lost souls. The knowers are a separate class of patients that strategically used knowledge to ease the process of accessing health and social services they needed in the face of the uncharted territories of a neurological condition. Some pursued knowledge in anticipation of difficulties navigating the system. They identified the benefits to preplanning as being able to access necessary knowledge and services prior to needing them, strategically coping with system obstacles. Otherwise, during the act of service delivery, if systems and services did not meet participants' needs or expectations, the pursuit of knowledge was also used as a strategy executed in preparation for advocacy efforts. For instance, many participants desired more information or access to available services or treatments (out of need or in the hope of a better treatment or service), which triggered them to pursue knowledge outside of their relationship with their service providers, in preparation to ask service providers for a referral or even to self-refer.

Based on existing research, the strategies outlined could be considered, "information-seeking behaviours" (Braman & Gomez, 2004; Hu, Bell, Kravitz, & Orrange et al., 2012). In some cases, this meant actively researching the Internet or service directories for new knowledge; connecting with communities of support, in order to learn from others affected by the same condition; or becoming involved with community organizations where knowledge of services could be learned through accessing or delivering services (or by being in close contact

with others who deliver them, e.g., secretary). According to a study by Bishop, Frain, Espinosa, and Stenhoff (2009), similar numbers of people living with multiple sclerosis used the Internet (27.94%) and local or national agencies (21.64%) as their primary source of information, as compared to using health professionals (31.69%) (p. 111). Porteous et al. (2015) also reported that those who have knowledge of services are more likely to use them, regardless of the source of knowledge (e.g., media, service providers, past experience).

In turn, using existing or newly accrued knowledge, participants would engage in action strategies to access necessary or desired services. For those receiving adequate services, advocacy efforts were most often utilized to avoid wait times for services, whereas those faced with inadequate services were more often faced with addressing a lack of services. For both of these groups, this meant using financial strategies, to bypass the systems' obstacles. Financial strategies were often biased towards those of a higher socioeconomic status, unless participants relied on credit or had access to other financial supports (e.g., Pharmacare, family members).

Advocacy efforts were another type of action strategy used to overcome system obstacles (e.g., being persuasive, using resourceful connections). According to William L. Roper, patient advocacy drives positive change by applying “pressure to initiate and follow through on the needed changes in our health care system” (Earp, French, & Gilkey, 2008, p. xii). The goals of patient advocacy are to include patients in the provision of services to foster safety and patient-centeredness (Earp et al., 2008). Other research refers to this deeper involvement in care as “patient activation”, which itself has been associated with improved care coordination and health outcomes (Maeng, Martsolf, Scanlon, & Christianson, 2012; Mosen et al., 2007). Across 14 of the 15 interviews, responses frequently reflected the importance of taking responsibility over their own care through advocacy efforts.

Even in the case where individuals receive adequate or inadequate care, there is always the chance that they choose to forgo engaging in care coordination behaviours, and adopt a laissez-faire approach, thereby allowing their predisposing characteristics to fully determine their experiences. No participants in this study personally experienced this; though, O. Twist referenced the difficulty one of his friends faced while trying to access health-related services while living with spina bifida. Without a family doctor, O. Twist's friend was left "to go to a walk-in clinic or ER somewhere. And he says he just doesn't do it, he doesn't go." Otherwise, a few participants chose to engage in mental strategies to influence their interpretation of the type of service they received (e.g., trusting in the system). Strategies identified in participants aligned very well with strategies to maintain a sense of self, reported by Roger et al. (2014). Specifically, cognitive reframing, adjusting and altering goals, as well as comparing oneself with others equally applied to participants in this study (Roger et al., 2014). Though these strategies did not facilitate access to services, participants used them to mentally cope with services that did not match with their expectations or needs, thus contributing to the ultimate goal of improved patient satisfaction while navigating systems.

To conclude, strategies represent ways that participants react to the fit between their personal characteristics and the systems available. When participants had the perfect constellation of enabling resources, engaging in strategies was made easier. For example, although engagement in community organizations supported participants' awareness of services, they continued to be limited in the degree to which community organizations were established and offering services. For instance, Jane B. explained the limited supports her support group could offer members, compared to other community organizations. This section does not intend

to suggest that the engagement in a strategy results in assured improvements in service navigation outcomes; rather, the success strategies fluctuated, as did the outcome of those efforts.

#### 7.4 Outcomes

The ultimate purpose of service coordination in the literature has been “based on the assumption that integrating and coordinating services will result in better outcomes than would be the case if service are provided in a non-integrated manner” (Dunst & Bruder, 2002). The Care Coordination Framework demonstrates a linear process from baseline characteristics leading to the receipt of coordinated services (McDonald et al., 2007). However, as mentioned earlier, it is not necessarily the access to health and social services itself that is significant but the effectiveness of that access. In fact, both the goals to improve coordination and the ways of achieving access to services will vary by participant and the specific service or coordination problem at hand.

According to Andersen (1995), “‘effective access’ is established when utilization studies show that use improved health status or consumer satisfaction with services” (p. 6). Similarly, Donabedian (2005) identified quality and effectiveness of care as measured by the level of health and satisfaction achieved or produced. As a result, though there is limited literature to support the positive effects of coordination, based on the work that does exist, the authors support that coordination contributes to patient satisfaction, health outcomes, and access to services (McDonald et al., 2007). Therefore, I added a final stage in the adapted model as “Outcomes” that includes all three of these outcomes.

In this study, patient satisfaction was largely represented by positive experiences navigating health and social systems from good fit between patient characteristics and system qualities. In the literature, multidisciplinary care models are said to contribute to increased ease

and patient satisfaction when navigating services (Spragins & Lorenzetti, 2008). A greater degree of patient satisfaction was also reported by more activated patients (Mosen et al., 2007) otherwise described as someone with greater “organizational and self-lobbying capabilities” (Maeng et al., 2012, p. 1963). Patients’ perception of provider-patient communication was greatly associated with satisfaction and improvements in health (e.g., emotional health, symptom resolution, function, physiologic measures, pain control; Beaulieu et al., 2011; Stewart, 1995). Patient-centeredness was identified in multiple studies as improving “patient satisfaction, quality of care, and health outcomes” (e.g., emotional well-being, build trust, social support), all while reducing associated costs and disparities experienced (Epstein, Fiscella, Lesser, & Stange, 2010, p. 1489). For patients living with other types of chronic conditions, integrated care systems were greatly associated with coordination of care and patient satisfaction (Wang et al., 2015). In a study by Freeman et al. (2007), relational, informational, and management continuity were identified as contributing to patient satisfaction in participants living with diabetes and cancer.

Though some participants of this study were hopeful for cure, health outcomes were not largely discussed. Unlike patients with acute health conditions, when living with a neurological condition, most patients are unlikely to recover completely; rather, some experience continuous health deterioration. As a result, expected health outcomes have focused more on “personal comfort,” “social and economic participation,” and “autonomy,” which were identified by Spiers et al. (2014) as outcomes desired by people living with long-term neurological conditions using integrated health and social care (p. 4).

Lastly, whether achieved inherently through enabling resources, or strategically through relational coordination, this thesis in its entirety has been dedicated to increasing accessibility of health and social services through coordination. Dunst and Bruder (2002) identify “systems

coordination, information and referral, family support and resources, family-centered practices, and teaming” as the five specific benefits families desire from service coordination (p. 369). In this thesis, with such a range in participants and baseline characteristics, there was a resulting range in experiences with accessing services. However, though there seem to be several ways of accessing knowledge and services, most seem to be based on baseline characteristics. In other words, based on the Manitoba participants sampled, the services a patient could access were biased towards those who had the most common condition, best connections, most activated personalities, most awareness, and/or more money. Unfortunately, this makes knowledge and services commodities that are not made available equally to all sectors of the Manitoba population. Andersen (1995) defines “equitable access” as variation in access to services being determined by demographic (e.g., geographic location) and needs variables (e.g., complexity of condition), as opposed to social structures (e.g., age), health beliefs, and enabling resources (e.g., system; p. 4). According to the outcomes of this study, it would seem that “equity is in the eyes of the beholder” (Andersen, 1995, p. 4).

## CHAPTER 8: RECOMMENDATIONS FOR PRACTICAL APPLICATION

For this study, data collection included a range of conditions. Side by side, inconsistent distributions of successes or gaps in systems became apparent. The findings of this thesis provide evidence of a need for service coordination and continued research to evaluate types of interventions and any subsequent outcomes of these. Existing systematic reviews study the application of coordination interventions, providing guidance for action (please see Table 1 for Types of Care Coordination Interventions); however, the literature consistently recommends the input of stakeholders in determining the criteria and design of services (Freeman et al., 2007; Haggerty et al., 2011; McDonald et al., 2007; Sargent, Pickard, Sheaff, & Boaden, 2007). Involving these groups allows opportunities for enhanced patient autonomy, as well as an increased likelihood of addressing the health and social needs of a larger audience by considering their experiential knowledge (Sixsmith, 2012). From the perspective of the Client Services Coordinator of the MS Society Manitoba Division, “the great ideas we think of fall flat if we do not include stakeholders” (personal communication, Ellen Karr, May 26<sup>th</sup>, 2014). As a result, for the final component of my thesis, I address my third and final research objective, which is to describe “how participants [living with neurological conditions] imagined service coordination might look or not look to improve experiences” accessing health and social services. This objective involves participants’ input and simultaneously fulfills the practical approach required in interpretive description, by supporting recommendations for future initiatives.

According to a recent survey on patient experience by Laberge et al. (2014), “continuity and coordination” were rated as the most important aspects, while “communication” and “patient-centered care” were the most frequently rated amongst the top 10 aspects of primary

care in Canada (p. 5). Overall, primary care providers in Manitoba and other provinces were ranked highly for each of these criteria, though Manitoba scored marginally lower for ease of obtaining “a referral to a medical specialist” (p. 18). Comparatively, based on findings of this thesis, Canadians living with a neurological condition face unique challenges not experienced by the general population. Some challenges seemed to be contextually related to the service providers themselves (i.e., being disorganized, rude), while others were more system-oriented, for which participants offered recommendations. Based on research and participants’ feedback, the following initiatives are recommended to address the most commonly reported barriers to service coordination: patient-centered training (8.1), uniform access to organized specialty clinics (8.1), system-level interventions (8.2), individualized funding (8.2), streamlined referrals (8.3), and information resources (8.3).

### **8.1 Patient-centered Training & Organized Specialty Clinics**

Firstly, participants identified the lack of coordination of services while transitioning to adult services as a gap for people living with neurodevelopmental conditions from childhood. Based on related-resources, a Healthy Child Manitoba (2008) report clearly describes the protocol for transitioning students with exceptional needs from their school setting to living in the community. Students are entitled to services from the first year that they enter high school until their 21<sup>st</sup> birthday or when they graduate, whichever occurs first. A complex coordination plan is outlined in the report, combining the efforts of Manitoba Family Services and Housing, Child and Family Services authorities, school divisions and educators, designated agencies and service providers funded by government, as well as the individual’s personal support network. The level of detail in this document is indicative of the efforts made by the province to guarantee students’ access to uninterrupted multidisciplinary care; and yet, a need for coordination persists.

Once these services were no longer accessible, following the completion of the transfer process, participants were faced with the realities of adult health and social services. They described adult services as less integrated or patient-centered, making them feel unprepared to independently navigate systems. Therefore, while the initial transition to adult services can be well integrated, ensuring connections to the proper supports, as needs change over time and supports pull out, participants are left to rely on their families for guidance. As a result, making minor changes to the personal training on system navigation for future generations is recommended. This will allow for an efficient use of services, as it does not require the development of a new initiative but rather the use of existing resources. This approach will ensure that in addition to delivering information to the students' support networks (e.g., parents), a distinct personalized effort is made to prepare emerging adults for the transition. In addition, though not directed solely to people living with neurodevelopmental conditions, as described in Chapter 1, MH HLS currently has several initiatives underway to ensure access to primary health care. As mentioned earlier, such initiatives, at minimum, provide patients with a first point of contact from which future referrals and health care services can stem from.

Furthermore, given the exceptional level of service coordination offered through specialized clinics, having such establishments consistently or similar models of care across neurological conditions should be consistent to avoid service inequities. Research findings provided evidence of optimal coordination of services by specialized clinics (Brustrom et al., 2012; Dunleavy, 2007; Morgan et al., 2009; Rakhshani et al., 2010; Williams, 2005). These initiatives focus on easing the process of navigating of services through the use of a staffed coordinator position and/or an approach to patient care that is integrated and continuous. In turn, as identified in the findings of this study, when accessing services is straightforward, patients

will feel more confident with navigating on their own. In that case, the current transition process occurring in secondary education would suffice by connecting students to an integrated system, as they could rely on subsequent service providers to guide and collaborate with them in their new environment.

Staffing and financial issues were noted in the research as potential obstacles to this type of large-scale initiative (Brustrom et al., 2012; Williams, 2005). Therefore, undertaking this initiative would be a long-term goal to allow sufficient time to gather funding and stimulate other enabling resources. Furthermore, reviews yet to demonstrate the added benefit of this coordination intervention over another (McDonald et al., 2007). According to McDonald et al. (2007), further research is needed for “patient populations that have obvious coordination needs, such as patients with multiple complex medical problems, the frail elderly living independently, patients transferring between care settings, or physically disabled persons” (p. 132). Although patient autonomy was not identified in the top 10 rated values for Canadians, it is clear that individuals living with neurological conditions appreciate the opportunity to be empowered in the provision of services (Laberge et al., 2014). Ultimately, given the size of the project and the lack of additional research evidence, it would be suggested to undertake a pilot study that engages patient stakeholders and ensures the efficiency and effectiveness of this initiative.

## **8.2 System-level Interventions & Individualized Funding**

The following recommendation is to address the gaps identified with provincially funded homecare systems. In repeated scenarios across multiple interviews and in the research, homecare workers were identified as unreliable and disconnected from their patients. Both of these gaps are associated with a system overwhelmed with demand. The home care sector in Canada has been characterized by a combination of low wages, sub-optimal working conditions,

and staffing issues (Statistics Canada, 2002). A combination of insufficient wages, benefits, and job security, as well as fluctuating hours and work environments make it difficult to recruit and retain workers (Statistics Canada, 2002). Frequent staff turnover in this study interrupted relational continuity and prevented the development of a patient-provider relationship for participants. In combination with the high demand and workloads in this field, these factors contribute to absenteeism and a lack of punctuality and, in turn, dissatisfied clients who are helplessly underserved (Vaulto & Maurée, 1996 as cited by Haussman & Sauer, 2007).

In the long-term, hiring more homecare workers would relieve pressure from the system; though, like other funding initiatives, is somewhat unrealistic to hire sufficient staff to relieve this pressure in the short-term given limitations to provincial funds available to pay for staff and a potential cap to the number of staff graduating from homecare programs. In the long-term, workforce planning by the province could make this a priority; however, balancing priorities related to primary health care, public health and other sectors of MHHLS must simultaneously be considered.

On the other hand, facilitating a transition to the Self and Family Managed Homecare Attendant Program, for participants willing and able to do so, would relieve pressure from the main homecare system, as well as support greater patient autonomy, patient-centeredness, and reliability in their care, by providing patients with the support needed to manage their own homecare staff. Piloted in 1991 and permanently implemented in 1993, this program receives funding from the Ministry of Health and is administered by the Regional Health Authorities (Spalding, Watkins, & Williams, 2006). Currently the program is available to Manitoba clients who have a stable medical condition and received provincial home care services for a minimum of one year (Spalding et al., 2006). As a result, it is recommended that providers be provided

with tools and resources to facilitate screening for eligible patients that would benefit from such a program. Like the Self and Family Managed Homecare Attendant Program, research demonstrates benefits of other individualized funding programs in Canada, which could be considered in future initiatives to improve the quality of life of clients (Lynch & Findlay, 2007). Future research is also required to uncover the possible causes and solutions that might help to address the overburdened system, which is likely to become more overloaded by an aging population (Statistics Canada, 2002).

### **8.3 Streamlined Referrals & Information Resources**

Next, based on the findings of this research, the importance of connecting people living with a neurological condition to community organizations is greatly emphasized. Overall, participants were quite happy with physical care received but identified gaps in mental and social services. Integration is regularly referenced as important in the delivery of health services in existing research (Aspinal et al., 2012; Doug et al., 2009; NHCC/PHAC, 2014). Those able to connect to an established community organization said that it greatly contributed to their well-being, by way of social, recreational, counselling, and coordination opportunities. In fact, many participants benefited equally, if not more, from their community services, as opposed to health care services. Some even went on to volunteer with local community organizations, which was associated with the three categories identified by Clark and Wilson (1961) including “material, solidary, and purposive” benefits (as cited by Chinman & Wandersman, 1999, p. 48). Even community organizations that were less developed provided a continuous community of support that some participants relied on.

Integrating health and community organizations also provide mutual benefits to both the community organization itself and service providers. In a health care context, coordinating care

to ensure holistic needs are met involves time that many physicians and neurologists cannot schedule into their busy days, and for which they are not generally reimbursed (McDonald et al., 2007). In addition, growing needs are “occurring in an environment in which cost containment efforts result in decreased access to social support,” adding additional pressure to an already loaded system (McDonald et al., 2007, p. 132). At the same time, since community organizations’ success is built on memberships, from fundraisers to advocacy efforts, they actually benefit from a large membership base.

There are many approaches to integrating services. Due to the wide array of conditions and health professionals, co-locating services would be unmanageable. Alternatively, organizations could designate coordination responsibilities to a key worker, streamlining connections to community organizations; a role typically played by nurse specialists in research (Aspinal et al., 2012; Bernard et al., 2012; Freeman et al., 2007; Gridley et al., 2011; Mayo et al., 2008). As it currently stands, privacy laws limit most community organizations from obtaining lists of prospective members (Manitoba Ombudsman, n.d.); however, if there were a formalized approach to inform participants of these programs prior to departing the health care setting, participants could access services on their own volition. As a result, it is recommended that MHHLS, regions, and fee-for-service clinics collaborate to redefine system processes, in order to facilitate agreed upon streamlined connections to community organizations. This would mean that patients’ connections to such resources would not be left up to chance, thus eliminating potential service inequities.

As problems with change management from competing system ideologies might well result in the rejection of this recommendation, creating tools and resources to inform service providers and patients about community resources at minimum provides a more accessible

process for those who wish to identify resources should they choose. The development of a resource manual and website with all the community-based resources available for people living with neurological conditions is a possible example of this. To enhance the user-friendliness of this resource, it should be comprehensive with all main conditions, inclusive of a range of services (i.e., not necessarily health-related), and easy to understand and navigate (i.e., concise, contact information, resource description, outlined application process, accessible online). This would situate the manual as an undemanding “one-stop-shop” handbook for physicians and their patients to simplify coordination. In the long-term, a designated body would update and distribute this resource to relevant service providers on a routine basis to maintain its relevancy and utility. Furthermore, it would serve well to include service providers in the development of such a resource, to ensure that it meets the needs of both the patients and the distributors of knowledge.

Rather than providing the solution to existing problems, the recommendations provided in this chapter are intended to spark a conversation and demonstrate the array of context-specific recommendations that could be used to enhance service coordination in Manitoba based on research and participants’ feedback. Some represent projects that can be done in the short term, while others may take more time and resources. For future service coordinators and government, the most paramount message this thesis presents, is that “one size does not fit all.” Therefore, though approaches to coordination interventions may differ, the goals remain constant, that is, to provide equal opportunity to health by ensuring equitable access to quality health and social services.

## CHAPTER 9: CONCLUSION

Neurological conditions occur when there is impairment to one's central or peripheral nervous system, thus contributing to symptoms, lost health-related quality of life, and everyday life challenges that can be similar across conditions. In particular, based on recent initiatives in Canada and Manitoba, one of those challenges includes accessing and managing services related to their condition. Similar to those with acute health care needs, introductions into the health care system and navigating within a single organization may be accomplished with familiarity. However, when conditions advance and people are required to navigate across multiple health and social systems on a long-term basis, personal characteristics and lack of coordination have a profound impact on system navigation.

The aim of this qualitative study was to explore the diverse experiences of accessing care and services when living with a neurological condition, with a specific focus on the benefits and barriers of service coordination in Manitoba. In particular, 15 people using a range of different systems and characterized by a diversity of personal characteristics were interviewed. Using McDonald et al.'s (2007) Care Coordination Framework, I was able to uncover multiple elements that either facilitated or impeded access to health and social services.

On the one hand, the main two themes, personal characteristics as well as system and service providers, aligned with the predisposing and enabling characteristics in McDonald et al.'s (2007) Care Coordination Framework. These baseline factors determined both one's need for coordination and represented the quality of systems accessed. Based on the literature review, in order to support the complex needs of people living with a neurological condition, multidisciplinary care, collaborative care, integrated person or family-centered services, and continuous care (as related to information, relations, management) were revered as the best

practices in service provision for this population. Participants from this study similarly appreciated these characteristics but described them with qualities that they recognized; including ease of access, caring relationships, collaborative communication, and reliability.

In McDonald's et al. (2007) model, it is the compatibility of patients' needs and the quality of systems that determined their overall satisfaction. In this study, I similarly found that when services delivery inadequately supported participants' needs, a need for coordination was stimulated to rectify negative experiences through coping strategies. These types of strategies were outlined in the third theme of this thesis, strategies, which included strategies related to the pursuit of knowledge, action strategies, and mental strategies. I also found that even in the event that services were adequate, participants would also use comparable strategies as shortcuts to further ease their experience of navigating systems and achieve better patient outcomes, whereas when participants were receiving ideal services, no needs were stimulated, as existing services supported participants' access to services, satisfaction, and related health outcomes.

This analysis demonstrated the many qualities that participants identified as successes and gaps in the health and social systems they were navigating. Based on that, a selection of context-specific recommendations were made for future service coordinators in the province, the provincial government, and future researchers. Specifically, the gaps experienced by children transitioning to adult-services could be addressed through more student-focused training to ensure they are imparted with the necessary knowledge to navigate a fragmented adult system; otherwise, participants recommended physically integrating services into a specialized outpatient clinic, which would directly ease the process of navigation internally within the system itself. Next, to address lack of patient autonomy and continuity in homecare, system-level interventions were recommended for long-term improvements; in the meantime, participants recommended

substituting this service for self-managed services with individualized funding, for those who are able and willing. Lastly, participants disagreed with the inconsistency in the referral process to community organizations. As a result, they recommended investing in efforts to integrate health and social services that provide a streamlined approach to referrals, as well as to develop an easy to use information resource that covers all services. This process of standardization acts as a step towards health equity, so that access to services is less likely to be determined solely by patients' knowledge of services.

### **9.1 Limitations**

While my thesis exhibits many strengths, I also intend to be transparent about its limitations. For instance, given that a few participants requested that family members join them for the interview, it must be noted that their presence may have also introduced bias in the findings, leading to an over-emphasis of the importance of family and friends or the omission of challenges related to these relationships in one's experience navigating the health care system.

Furthermore, most studies in the literature examined coordination within one institution or area of care and often neglected the role the community organizations in the delivery of care services. Unfortunately, this limits my ability to use prior studies as a comparison when identifying barriers and facilitators to improved navigation across services for this vulnerable population.

Though the recommendations were based on existing research, the context-specific recommendations from this study were from a small sample that cannot be representative of all Manitobans living with a neurological condition. These insights remain subjective but should be considered with a larger sample and with more detail in future research. In addition, cost restrictions may make it challenging for some systems to afford some of the recommendations

provided. Furthermore, the recommendations failed to include the perspective of service providers, which would have increased the significance given the fact that much coordination occurs “behind the scenes.”

Unfortunately, thesis time constraints would not allow for looking into the elements of service provision that are specific to each condition. Therefore, though an effort was made to look at individual conditions and groups of neurological condition types (i.e., neurotrauma, neurodevelopment, degenerative), the focus of this thesis remained on investigating people with neurological conditions as a whole. Moreover, those conditions included in this study will only be included from the perspective of those members who access health and social services, which neglects to include those who do not have access to such services (e.g., Aboriginals), those who do not want services, or those who were lost in the health care system before they could be properly diagnosed or referred to a related community organization. Nonetheless, while the sample may not be representative of all people with neurological conditions, their viewpoints remain essential contributions to any advancement in this area.

## TIMELINE

The proposed study was completed over the course of one year, between May of 2014 and August of 2015 and has been outlined below.

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**Appendix A: Neurological Health Charities Canada Member Organizations****Current Members**

1. ALS Society of Canada
2. Alzheimer Society Canada
3. Alzheimer Society of Ontario
4. Brain Injury Association of Canada
5. Canadian Alliance of Brain Tumour Organizations
6. Canadian Epilepsy Alliance
7. Canadian Neurological Sciences Federation
8. Centre for ADHD Awareness Canada
9. Dystonia Medical Research Foundation Canada
10. Headache Network Canada
11. Heart & Stroke Foundation of Canada
12. Huntington Society of Canada
13. March of Dimes Canada
14. Mood Disorders Society of Canada
15. Multiple Sclerosis Society of Canada
16. Muscular Dystrophy Canada
17. Ontario Federation for Cerebral Palsy
18. Ontario Neurotrauma Foundation
19. Ontario Rett Syndrome Association
20. Parkinson Society Canada
21. Spina Bifida & Hydrocephalus Association of Ontario
22. The Foundation Fighting Blindness
23. Tourette Syndrome Foundation of Canada

(NHCC, 2010a)

**Founding Members**

1. ALS Society of Canada
2. Alzheimer Society of Canada
3. Epilepsy Ontario
4. Huntington Society of Canada
5. Multiple Sclerosis Society of Canada
6. Muscular Dystrophy of Canada
7. NeuroScience Canada/ Brain Canada Foundation
8. Ontario Federation for Cerebral Palsy
9. Ontario Neurotrauma Foundation
10. Parkinson Society Canada
11. Spina Bifida & Hydrocephalus Association of Ontario
12. Tourette Syndrome Foundation of Canada

(Brain Canada Foundation, n.d.; Canadian Neurological Sciences Federation, n.d.)

**Appendix B: Services Related to Neurological Health Offered in Manitoba**

**Memo, June 10<sup>th</sup>, 2014:** When compiling the list of services available within Manitoba, it was fairly easy to locate those services available in hospital setting, as these services were integrated and easily identifiable through the Winnipeg Directory and online. However, this process became much more difficult when searching for additional community resources for when patients leave the hospital setting; for instance, home care, respite care, rural services, long-term care homes, disability services). In many cases, services were not specifically labelled as being available to those with neurological conditions, which could create confusion around eligibility. In addition, as some of these services must be paid out-of-pocket, cost-comparison is also made challenging from locating pricing on each separate provider's site. Through this preliminary search, it became clear that much effort and resources go into creating such an abundance of services in the province; however, the full potential benefit of these services will not be met if the public feels they are too difficult to access.

**Neurology Specific**

1. **Health Sciences Centre, Department of Internal Medicine (Neurology)**, AE308, GE248, GF535, & GF543-820 Sherbrook St.
2. **St. Boniface General Hospital, Department of Medicine**, Neurophysiology Lab & C5014- 409 Taché Ave.
3. **Clinique St. Boniface Clinic**, 343 Taché Ave.
4. **Children's Hospital**, AE308- 840 Sherbrook St.
5. **Deer Lodge Centre, Movement Disorders Clinic**, 200 Woodlawn St.
6. **Markham Professional Centre**, 303-2265 Pembina Hwy.
7. **Victoria General Hospital, Adult Medical Clinic**, 2735 Pembina Hwy.
8. **Medical Arts Building**, 908 & 1516-233 Kennedy St.
9. **Rehabilitation Centre for Children**, 633 Wellington Cres.
10. **Winnipeg Clinic**, 425 St. Mary Ave.
11. **Thomson House**, 1835 Corydon Ave.
12. **Neurology Associates**, 101-698 Corydon Ave.
13. **Rehal Medical Clinic**, 1763 Portage Ave.
14. **Naturopathic Family Medicine Inc.**, Unit 10, 1200 Waverley St.
15. **Brandon Regional Health Centre**, 150 McTavish Ave. E. (Brandon)
16. **Dr. Tang-Wai**, 429 Princess Ave. (Brandon)

**General**

- Health Sciences Centre, Department of Internal Medicine (Neurology), 820 Sherbrook St.
  - Pain Management Centre
  - Rehabilitation Day Program
  - Stroke Prevention Clinic
  - Respiratory Clinic
  - Oncology
  - Spinal Cord / Amputee / Neurolocomotor
  - Ambulatory Care Clinics
  - Multiple sclerosis Clinic
- St. Boniface General Hospital, Department of Medicine, 409 Taché Ave.
  - Neurophysiology Lab

- Neurology (Brain) Services, Neurology Clinic, Prevention Clinic, EMG Clinic
- Oncology
- Victoria General Hospital, 2735 Pembina Hwy.
  - Adult Medical Clinic
  - Oncology
- Clinique St. Boniface Clinic, 343 Taché Ave.
- Children's Hospital, AE308- 840 Sherbrook St.
- Deer Lodge Centre, 200 Woodlawn Street
  - Movement Disorders Clinic
  - Assistive Technology Products and Services
  - Department of Communication Disorders
- Markham Professional Centre, 303-2265 Pembina Hwy.
- Medical Arts Building, 908 & 1516-233 Kennedy St.
- Rehabilitation Centre for Children, 633 Wellington Cres.
  - Out Patient Clinics
- Winnipeg Clinic, 425 St. Mary Ave.
- Thomson House, 1835 Corydon Ave.
- Neurology Associates, 101-698 Corydon Ave.
- Rehal Medical Clinic, 1763 Portage Ave.
- Naturopathic Family Medicine Inc., Unit 10, 1200 Waverley St.
- Brandon Regional Health Centre, 150 McTavish Avenue E. (Brandon)
- Dr. Tang-Wai, 429 Princess Avenue (Brandon)
- CancerCare Manitoba Foundation Inc., 675 McDermot Ave.
- Concordia Hospital, CancerCare/Oncology Clinic, 1095 Concordia Ave.
- Grace General Hospital, Cancer/Oncology Services, 300 Booth Dr.
- Seven Oaks General Hospital, Oncology (Cancer) Department, 2300 McPhillips St.
- Movement Centre of Manitoba Inc., 1646 Henderson Hwy.
- Manitoba Riding for the Disabled Association Inc., 145 Pacific Ave.
- SMD Self-Health Clearinghouse Inc., 825 Sherbrook St.
- Wellness Institute, Health Education, 1075 Leila Ave.

### **Alzheimer Disease and other dementias**

- Alzheimer Society of Manitoba, 120 Donald St., Unit 10
  - Community awareness
  - Education
  - Support Counselling
  - Support Groups
  - Advocacy
  - Research Funding
  - First Link Referral Program for Health Care Professionals
  - Medic Alert Safely Home Program
  - <http://www.alzheimer.mb.ca/we-can-help/>
  - (Frank et al., 2011)  
<http://www.cfp.ca/content/57/12/1387.full.pdf#page=1&view=FitH>

- Actionmarguerite, St. Boniface, 185 Despins St.
- Actionmarguerite, St. Vital, 450 River Rd.
- Golden Links Lodge, 2280 St. Mary's Rd.
- Manor Adult Day Club (Lions Housing Centres), 320 Sherbrook St.
- River East Personal Care Home Ltd., 1375 Molson St.
- Riverview Health Centre, Personal Care Home, 1 Morley Ave.
- Winnserv Inc., 960 Portage Ave, St.

### **Amyotrophic Lateral Sclerosis (ALS, Lou Gehrig's Disease)**

- Amyotrophic Lateral Sclerosis Society of Manitoba, 493 Madison Street
  - Awareness & Education Events
  - Education
  - Provision of equipment
  - Advocacy
  - Bereavement support
  - Home visits
  - Programs
  - Raise funds for client services and for research
  - Information services about local and provincial health care services as well as social and community services
  - <http://alsmb.ca/index.php?page=als-manitoba>

### **Brain/Head Injury**

- Manitoba Brain Injury Association, 825 Sherbrook St.
  - Awareness and Education Events
  - Support Group
  - Peer interactions
  - Social & Recreation Programs
  - Education services
  - Library resources
  - Multimedia resources (books, videos, and computer programs)
  - Advocacy & relations w/ government agencies, health services and rehabilitation centres, and funding agencies)
  - <http://www.mbia.ca/wp/about-us/who-we-are/>
- Parachute, Manitoba Chapter, Health Science Centre
- St. Amant, 440 River Rd.
- Transitional Living Centres, 1010 Sinclair St.
- Riverview Health Centre, Geriatric and Rehabilitation Inpatient Care, 1 Morley Ave.

### **Brain Tumours & Spinal Cord Tumours**

- Canadian Cancer Society, Manitoba Division, 193 Sherbrook St
  - Peer Support Program, 415 1<sup>st</sup> St Brandon
  - Smokers' Helpline, 193 Sherbrook St.
- Optimist Clubs Foundation of Winnipeg Inc.
- Rady JCC, Active Living for Older Adults 123 Doncaster St.

- Terry Fox Foundation, 1214 Chevrier Blvd, Unit A
- Wellness Institute, Health Education, 1075 Leila Ave.
- Brain tumour foundation of Canada: Support group: Winnipeg, Manitoba
  - Peer Support Groups
  - Information Services on treatment options, support tools, community resources
  - Enhance coping skills
  - Online Community Braintumour.ca, blog, social media, newsletters
  - 1 on 1 Emotional Support
  - Educational awards for brain tumour survivors
  - <http://www.braintumour.ca/293/winnipeg-manitoba>

### **Cerebral Palsy**

- The Movement Centre, 1646 Henderson Hwy, Winnipeg, MB R2G 1N7
  - Conductive education
- Cerebral Palsy Association of Manitoba Inc., 500 Portage Ave.
  - Awareness Events & Fundraising
  - Information Services & Newsletter
  - Grants for assistive devices
  - Scholarships
  - Education
  - Peer Support
  - Advocacy
  - <http://www.cerebralgalsy.mb.ca/index.htm>

### **Dystonia**

- Dystonia Chapter and Support Group of Manitoba
  - Support Group
  - Information Services
- Dystonia medical research foundation Canada
  - Awareness Events & Fundraising
  - Research
  - Information Services
  - Advocacy
  - <http://www.dystoniacanada.org/manitobawebpage>

### **Epilepsy**

- Epilepsy and Seizure Association of Manitoba Inc., 4-1805 Main St.
  - Awareness and fundraising events
  - Community Education & School Awareness Programs
  - Information and referral services
  - Support Groups
  - [http://www.manitobaepilepsy.org/#!about\\_us/csgz](http://www.manitobaepilepsy.org/#!about_us/csgz)
  - [http://media.wix.com/ugd/e6c86e\\_7ca3606636c944fbae3a66b6a9feea15.pdf](http://media.wix.com/ugd/e6c86e_7ca3606636c944fbae3a66b6a9feea15.pdf)

### **Spina Bifida Hydrocephalus**

- Spina Bifida and Hydrocephalus Association of Canada, Manitoba Division, 647-167 Lombard Ave.
  - Awareness/Fundraising Events
  - Determining needs
  - Physical and emotional support,
  - Information services on legal, educational, financial and vocational opportunities
  - Student Bursaries (national)
  - Referral to local services (information, educational materials, support group details, encouraging personal insights, therapies, adaptive sports)
- <http://www.sbhams.ca/>

### **Huntington disease**

- Huntington Society of Canada (Kitchener)
- Manitoba Huntington Disease Resource Centre/ Huntington Society
  - Information / consultation
  - Short term counselling
  - Referral to community resources / mutual support
  - Educational presentations
  - Information / consultation to health and social service professionals.
  - Fundraising/Awareness events
  - Huntington disease Support Group
  - <http://huntingtonsociety.ca/wp-content/uploads/2013/10/MANITOBA-Winter-14.pdf>

### **Muscular Dystrophy**

- Muscular Dystrophy Canada, Manitoba Division, 204-825 Sherbrook St.
  - Connecting
  - Financial Assistance
  - Support (Members & Family)
  - Educational Events
  - Fundraising/ Awareness
  - Advocacy
  - Information Services
  - Assistive Devices
  - <http://muscle.ca/we-can-help/>

### **Multiple Sclerosis**

- The Movement Centre, 1646 Henderson Hwy, Winnipeg, MB R2G 1N7
  - Conductive education
- Multiple Sclerosis Society of Canada, Manitoba Division, 100-1465 Buffalo Pl.
  - Government Relations & Advocacy
  - Information and Referrals (e.g., housing, transportation, Drug cost reimbursement, income support, accessibility)
  - Programs for Caregivers
  - Research & Publications & Student Bursaries

- Recreation Programs
- Social Groups
- Support and Self-Help Groups
- Education Programs
- Support for families
- Funding Services
- <http://mssociety.ca/manitoba/Client%20Services.htm>

### **Migraines/ Headaches**

- Headache Network Canada
  - Provide educational services to the headache sufferer and his/her family
  - Raise the awareness level among the general public of the nature and impact of headache disorders
  - Assist the medical profession and other health disciplines in the management of headache disorders
  - Co-operate and work with governments at all levels to advance knowledge about all aspects of headache disorders and to encourage governmental assistance in this field to maintain and operate an educational website on the subject of headache disorders.
  - <http://headachenetwork.ca/about-hnc/>

### **Parkinson Disease**

- Parkinson Society Manitoba, 7-414 Westmount Dr.
  - Regular support group meetings throughout MB
  - Caregivers sessions
  - Educational meetings and an annual Regional Conference
  - Resource lending libraries in Brandon and Winnipeg with a variety of books, DVDs, and videos
  - Counselling with clinical nurse
  - Exercise classes
  - Alternative therapy sessions including massage
  - Regional Newsletter, *Talk Among the Tulips*
  - Advocate efforts on behalf of People Living with Parkinson by actively engaging government and its agencies on relevant issues
  - Referral Centre (national phone line)
  - [http://www.parkinson.ca/site/c.qIIZIdNYJwE/b.5472727/k.C8CA/About\\_Us.htm](http://www.parkinson.ca/site/c.qIIZIdNYJwE/b.5472727/k.C8CA/About_Us.htm)
- Reh-fit Centre, 1390 Taylor Ave.
  - Young Parkinson Exercise Program
  - Educational Workshop, Exercise to Fight Parkinson Disease
  - <http://globalnews.ca/news/858870/winnipeggers-design-new-exercise-program-to-help-people-with-parkinsons/>
  - <http://www.reh-fit.com/keeping-well/stroke-exercise/>
- St. James-Assiniboia 55+ Centre, Parkinson Support Group, 3-203 Duffield St.
- PRIME, Winnipeg Health Region, <http://www.wrha.mb.ca/wave/2010/10/prime-time.php>

**Spinal cord injury**

- Canadian Paraplegic Association Inc., Manitoba Chapter/ Manitoba Paraplegia Foundation Inc., 825 Sherbrook St
  - Rehabilitation Counselling
  - Service Coordination: (coordination for the rehabilitation process, from onset through community integration)
  - Vocational/ Employment Services
  - Peer Support
  - Community Advocacy (eliminate barriers to community participation & leadership in prevention efforts)
  - Information Services for individuals with spinal cord injuries, families, employers, community agencies, insurers and governments.
  - <http://www.cpamanitoba.ca/services.htm>
- Parachute, Manitoba Chapter, Health Science Centre, 820 Sherbrook St.

**Spinal Cord Tumours**

- Canadian Cancer Society, Manitoba Division, 193 Sherbrook St.
  - Information Service
  - Financial Help
  - Support Groups
  - Transportation
  - Online community (CancerConnection.ca)
  - Peer Support Services
  - Community Services Locator
  - (Directory helps in finding the services they need. Over 4000 cancer-related services listed.)
  - Smokers Helpline
  - Wigs and Hair Donations
  - <http://www.cancer.ca/en/support-and-services/support-services/how-we-can-help/?region=mb>
- Optimist Clubs Foundation of Winnipeg Inc.
- Rady JCC, Active Living for Older Adults 123 Doncaster St.
- Terry Fox Foundation, 1214 Chevrier Blvd., Unit A
- Wellness Institute, Health Education, 1075 Leila Ave.

**Effects of Stroke**

- Heart and Stroke Foundation in Manitoba, Provincial Office, 6 Donald St.
- The Movement Centre, 1646 Henderson Hwy, Winnipeg, MB R2G 1N7
  - Conductive education
- Canadian Stroke Network
  - Awareness campaign,
  - Stroke prevention clinics
  - Stroke Rehabilitation Program
- Stroke Recovery Association,
  - Referral Services

- Information Packages
- Educational Materials
- Volunteer Opportunities
- Visitation Program
- Speaker's Bureau or Stroke Panel (Community presentations)
- Newsletter
- Post-stroke exercise program (\$5.00 per half-hour session)
- Art Class
- Taiji: Functional Fitness For Stroke Survivors
- SAM Auxiliary: projects and activities (e.g. Knits for Charity, fundraising & special events).
- Moving Forward: To create clear and concise projects that would benefit the Association and its members and have fun doing.
- Support Groups (different types and locations)
- <http://www.strokerecovery.ca/services.html>
- Riverview Health Centre, Geriatric and Rehabilitation Inpatient Care, 1 Morley Ave.
- Stroke Association of Manitoba Inc., 247 Provencher Blvd., Unit B
- St. James-Assiniboia 55+ Centre, Stroke Recovery Support Group, 3-203 Duffield St.
- Youville Centre, St. Vital, 4-845 Dakota St.
  - Nutrition Services
  - Pathways Program

### **Tourette Syndrome**

- Tourette syndrome Foundation of Canada, Winnipeg Chapter
  - Support group for child w/ Tourette syndrome
  - School liaison and consultation,
  - Specialized groups (e.g., handwriting/fine motor)
  - Assessment (psychiatric, psychological, educational, and occupational therapy),
  - Individual and family treatments,
  - Medication management,
  - Public education about Tourette syndrome to individuals, groups, schools, and the community.
  - [http://tourette.ca/connect-chapters.php?entry\\_id=2988](http://tourette.ca/connect-chapters.php?entry_id=2988)
  - St. Boniface General Hospital, Tourette Disorder Service, 409 Taché Ave.

**Appendix C: Community Organizations Contacted****1. Diana Rasmussen**

ALS Society of Manitoba  
Executive Director and Client Services Coordinator  
493 Madison Street  
Winnipeg, MB R3J 1J2  
Contact: [drasmussen@alsmb.ca](mailto:drasmussen@alsmb.ca)

**2. Jennifer Ricardo**

Alzheimer Society of Manitoba  
Education Coordinator  
10 -120 Donald Street  
Winnipeg, MB R3C 4G2  
Contact: [alzeducation@alzheimer.mb.ca](mailto:alzeducation@alzheimer.mb.ca)

**3. David Kron**

Membership and Program Director  
Cerebral Palsy Association of Manitoba Inc.  
105 – 500 Portage Ave. Winnipeg, MB R3C 3X1  
Contact: [davidk@cerebralgalsy.mb.ca](mailto:davidk@cerebralgalsy.mb.ca)

**4. Barbara Crow & Brian Crow**

Dystonia Chapter and Support Group of Manitoba  
27 Royal Salinger Road  
Winnipeg, MB R2J 2P1

**5. Sara Bettess**

Epilepsy and Seizure Association of Manitoba  
4 – 1805 Main Street  
Winnipeg, MB R2V 2A2  
Contact: [epilepsy.seizures.mb@manitobaepilepsy.org](mailto:epilepsy.seizures.mb@manitobaepilepsy.org)

**6. Dr. Anthony Michael Kaufmann**

Director  
Centre for Cranial Nerve Disorders (Stroke, Brain Injury, Headaches, and Migraines)  
University of Manitoba, Winnipeg Regional Health Services  
GB137 Health Sciences Centre  
820 Sherbrook Street  
Winnipeg, MB R3A 1R9  
Contact: [akaufmann@hsc.mb.ca](mailto:akaufmann@hsc.mb.ca)

**7. Stephanie Bevacqua**

Community Outreach Coordinator  
Multiple Sclerosis Society of Canada, Manitoba Division  
100- 1465 Buffalo Place  
Winnipeg, MB R3T 1L8  
Contact: [stephanie.bevacqua@mssociety.ca](mailto:stephanie.bevacqua@mssociety.ca)

**8. Averill Stephenson**

Services and Community Development Coordinator – Manitoba  
Muscular Dystrophy of Canada, Winnipeg Community Office  
204 – 825 Sherbrook Street  
Winnipeg, MB R3A 1S1  
Contact: [averill.stephenson@muscule.ca](mailto:averill.stephenson@muscule.ca)

**9. Howard Koks**

Chief Executive Officer  
Parkinson Society Manitoba  
7 – 414 Westmount Drive  
Winnipeg, MB R2J 1P2  
Contact: [howard.koks@parkinson.ca](mailto:howard.koks@parkinson.ca)

**10. Brenda Savilaakso**

President  
Tourette Syndrome Foundation of Canada, Winnipeg Chapter  
PO BOX 49077 RPO Garden City  
Winnipeg, Manitoba R2V 4G8  
Contact: [tsfc@tourette.ca](mailto:tsfc@tourette.ca)

(\*: Made contact but unable to attend)

(\*\*: New contact to be invited to participate in this thesis)

**11. David Sullivan\***

Executive Director  
Manitoba Brain Injury Association  
204-825 Sherbrook Street  
Winnipeg, MB R3A 1M5  
Contact: [david@mbia.ca](mailto:david@mbia.ca)

**12. Marsha Oeste\***

President

Spina Bifida and Hydrocephalus Association of Canada, Manitoba Division  
The Winnipeg Foundation  
647-167 Lombard Avenue  
Winnipeg, MB R3B 0V3

**13. Jackie Shymanski\***

Director, Public Affairs & Communications

CancerCare Manitoba

Room ON 4053

675 McDermot Ave. Winnipeg, MB R3E 0V9

Contact: [communications.publicaffairs@cancercare.mb.ca](mailto:communications.publicaffairs@cancercare.mb.ca)

**14. Dr. Doug Hobson\***

Assistant Professor, Department of Internal Medicine (Neurology) University of Manitoba

Co-director Movement Disorder Program and Movement Disorder Neurologist

Deer Lodge Centre

200 Woodlawn Street

Winnipeg MB R3J 2H7

Contact: [contact\\_us@mdc-dlc.ca](mailto:contact_us@mdc-dlc.ca) / [research@deerlodge.mb.ca](mailto:research@deerlodge.mb.ca)

**15. Sandra Funk\***

Director

Manitoba Huntington Disease Resource Centre

200 Woodlawn Street

Winnipeg MB R3J 2H7

Phone: 204-772-4617

Contact: [sfunk@huntingssociety.ca](mailto:sfunk@huntingssociety.ca)

**16 Society of Manitobans with Disabilities (SMD)\***

825 Sherbrook Street

Winnipeg MB, R3A 1M5

Contact: [www.smd.mb.ca/](http://www.smd.mb.ca/) / [info@smd.mb.ca](mailto:info@smd.mb.ca)

**17 Ron Burky\***

Executive Director

Canadian Paraplegic Association (Manitoba) Inc.

211-825 Sherbrook Street

Winnipeg, MB R3A 1M5

Contact: [rburky@canparaplegic.org](mailto:rburky@canparaplegic.org) / [winnipeg@canparaplegic.org](mailto:winnipeg@canparaplegic.org)

### Appendix D: Literature Review Matrix

	Purpose	Country	Sample	Findings	Main Theme
1. Agha et al. (2012)	The National Institute of Health and Clinical Excellence issued guidelines for diagnosis, follow-up, and multidisciplinary care. This project sought to measure and improve the compliance of service provision for people with Parkinson Disease against guidelines.	UK	N= 20 patients' with PD.	<ul style="list-style-type: none"> <li>- Use of a checklist can have a lasting improvement on compliance with NICE guidelines, even if the intervention itself is transient.</li> <li>- Guidelines led to improvement of 100% compliance by secondary care practitioners, though the process of auditing didn't affect it.</li> <li>- Without guidelines secondary care tended to focus on diagnosis and treatment, but sometimes forgetting the "latter criteria [of] referral behaviour and multi-disciplinary teamwork after the initial diagnosis."</li> </ul>	Continuity of Care
2. Almasri et al. (2011)	To review determinants of family need for families with children with Cerebral Palsy.	US	N= 579 parents of children with CP.	<ul style="list-style-type: none"> <li>- Recommend individualized and needs-based family-centered care for families of children with Cerebral Palsy.</li> <li>- Determinants of Family Needs: Access to services, service coordination, processes of care, and family relationships.</li> <li>- Determinants of specific types of needs: Child adaptive behaviour, communication problems, gross motor function, and family income.</li> <li>- Service providers are encouraged to: <ul style="list-style-type: none"> <li>a. Engage families in expressing needs</li> <li>b. Collaborate in identifying resources</li> <li>c. Guide families in navigating complex service systems</li> <li>d. Assist families in accessing and coordinating various services.</li> <li>e. Act as family's advocate</li> </ul> </li> </ul>	Integrated Family-Centered Care
3. Aspinal et al. (2012)	To identify service models that provided care co-ordination for people with long-term neurological conditions in the UK.	UK	N= 71  PD MS MND BI SCI Epilepsy Neuro-muscular conditions Co-morbidities Other	<ul style="list-style-type: none"> <li>- Neurology nurse specialists contributed to all elements of continuity of care across health and social service sectors with expert knowledge of condition and local services, holistic/ personalized approach, proactive management, and real involvement.</li> <li>- Main outcome from integration is continuity of care, which led to patient empowerment (access when they needed it), trust, and improved communication.</li> <li>- Complexity with integration: changing needs over time, need for simultaneous multidisciplinary care (professionals,</li> </ul>	Continuity of care

				services, and sectors), juggle appointments, repeat story, navigation in a timely manner.	
4. Bahn & Giles (2012)	This paper details a 2009–2010 evaluation of the Neurodegenerative Conditions Coordinated Care Program commissioned to determine if they were the right ‘fit’ for delivery of the program as well as to improve the program service delivery as it progressed.	AU	N= 123 Neurodegenerative Conditions  MND BT HD MD MS Many Others...	<ul style="list-style-type: none"> <li>- Purpose of Neurodegenerative Conditions Coordinated Care Program: to provide in-home care, equipment + respite for as long as possible to allow for the client to live and die in their own home rather than in a clinical hospital setting wherever possible.</li> <li>- Issues with program (Predisposing Factors): <ul style="list-style-type: none"> <li>a) Accessing services in rural areas,</li> <li>b) Program eligibility criteria,</li> <li>c) Effective service provision for children and young people with rapidly degenerative conditions</li> <li>d) Need for funding</li> </ul> </li> </ul>	Lack of Funding
5. Bernard et al. (2008)	This paper reports on part of the preliminary scoping phase of a study designed to evaluate the impact of the National Service Framework for long-term neurological conditions on integrated care in the UK.	UK	N/A  Long-term neurological conditions	<ul style="list-style-type: none"> <li>- Progress for National Service Framework is will eventually contribute to “integrated service provision,” though for now it is patchy and slow</li> <li>- Neurological conditions traditionally were marginalized in government’s health care policy and in initiatives supporting people with long-term conditions (focus on other chronic conditions).</li> </ul>	Integrated Patient-Centered Care
6. Bernard et al. (2010)	Part of larger evaluation of Primary Care Trusts, to look at the integration and continuity of services provided for people with long-term neurological conditions.	UK	118 primary care trusts  Long-term neurological conditions	<ul style="list-style-type: none"> <li>- Prevalence of models of good practice varied widely across and within primary care trust areas.</li> <li>- A little over ½ completed a needs assessment including long-term neurological conditions</li> <li>- ¼ had no arrangements for long-term neurological conditions.</li> <li>- “The complex interplay between strategy, organisational structures and models of delivery, in a context of competing priorities, may account for this variation and patchy progress.”</li> </ul>	Continuity of Care
7. Bernard et al. (2012)	Report on findings relating to strategy, organization, and practice models promoting continuity of care for people with long-term neurological	UK	118 primary care trusts  Long-term neurological conditions	<ul style="list-style-type: none"> <li>- Lack of knowledge and awareness: prevalence of long-term neurological conditions, comprehensive care plans, caseloads, wait times, how interventions were rationed (or not)</li> <li>- A) Community interdisciplinary neurological rehabilitation teams: not available in over ½ of PCTs</li> <li>- B) Nurse specialists: depend on</li> </ul>	Continuity of Care

	conditions in the UK.			- condition C) Day-opportunities: depend on geography, condition, access to care coordination (not commonly available) - Flexibility has led to inconsistency in provision. Best care when “front-line champions” are coupled with systems that can accommodate innovative practice and enable influence on decision-making.	
8. Binks et al. (2007)	To identify barriers, outline key elements, review empirical studies, and make clinical and research recommendations related to the transition from child-centered to adult-centered health care for people with cerebral palsy and spina bifida.	US	N= 149 articles on CP and SB.  Discussions, case series, database or register, qualitative or, survey articles.	- Key elements that support a positive transition to adult-centered health care: a) Preparation, b) Flexible timing, c) Care coordination (Integrated communication about adult-centered services, planning for continuity of care) d) Transition clinic visits, e) Interested adult-centered health care providers.	Integrated Adult-centered Services to Achieve Continuity of Care
9. Bitsko et al. (2013)	To document the impact of Tourette syndrome on the health care needs of children and access to health care among youth with Tourette syndrome.	US	TS  Parent-reported data from the 2007-2008 National Survey of Children’s Health	- When compared to children without Tourette syndrome, children with Tourette syndrome had: a) More co-occurring mental disorders b) Health care needs equal to or greater (especially with co-occurring mental disorders, though they were least likely to receive effective care coordination) - Integration of behavioural health and primary care may be needed to improve care coordination.	Multi-disciplinary Care Integration
10. Brewah (2013)	To understand how health care integration is managed in Kaiser Permanente (a private health care provider in the US) and how this might help patients in the UK with motor neurone disease.	US/ UK	MND  1 clinic	- Robust Communications systems to communicate with patients at diagnosis, care planning and service delivery levels (e.g., technology) - The UK health service has a lot to offer but there is room for improvement - Neurological services in the UK should identify a cohesive multidisciplinary team service for MND patients - Kaiser Permanente offers care that is: personal, simple, and timely to empower decision-making by service users and increase innovation.	Integrated Multi-disciplinary Care  Telehealth
11. Brei (2007)	Review the challenges to multidisciplinary care in the	US	N/A  SB	- Multidisciplinary program remains the best model for health care delivery to people with spina bifida. - Existence and effectiveness is	Multi-disciplinary

	provision of services to people with spina bifida.			dependent on challenges to multiple programmatic, personnel, and financial factors.	
12. Brustrom et al. (2012)	This study examined several aspects of care coordination in the multidisciplinary spina bifida clinic setting.	US	SB  <i>N= 81</i>  (Clinic staff, focus groups with caregivers)	- Care coordination available in several clinics to coordinate services to ease family burden and is seen as beneficial  - Reported benefits of care coordination: increasing access to care, taking the overall needs of each child and family into account, increasing continuity of care, and reducing the burden on families.	Communication
13. Challis (2010)	Workshop of international specialists discussing the organizational and economical context, the professional practices and the specific clinical tools related to Alzheimer's disease and related dementias.	UK	N/A  AD & related Dementia	- The origins of case management  - Impact of case management in social and health care settings in the UK.  - Factors associated with positive outcomes in case management.  - Key factors to be addressed in case management development  - Research questions/development issues for case management in dementia care are identified.	Case Management
14. Cheng et al. (2004)	To present a set of quality indicators for care provided to veterans with Parkinson disease.	US	PD 29 indicators  (Structured review of the medical literature)	- Of indicators with the highest potential value for subsequent quality improvement interventions in PD, coordination of care, medication use, and recognition/treatment of depression scored some of the highest.  - For example, for continuity/coordination of care, it was important for veterans to have a point of contact that they would call if in need of medical care, document newly prescribed medication at follow-ups or in out-patient care, document reason for consultations, as well as document updates on follow-up of diagnostic tests.	Continuity of care
15. Chevignard et al. (2010)	To describe a model of care for children with acquired brain injury and the characteristics of children followed up, the type/amount of services provided and general outcomes.	FR	ABI  Children: Hospitalized ( <i>N</i> = 116), Assessed Vocational guidance unit' ( <i>N</i> = 131)  Followed up by the outreach program	- Co-ordinated multidisciplinary rehabilitation is recommended in the initial phases.  - Most of the children were discharged home with coordinated long-term personalized care plan for ongoing rehabilitation and school adaptations, regardless of injury severity.  - Outcome improved dramatically between admission and discharge.  - More challenging issues arising in late adolescence-early adulthood,	Continuity of Care

			(N = 268)	reintegration must be well prepared and organized and require long-term follow-up care.	
16. Crack et al. (2007)	This paper contributes a micro-level analysis of voluntary welfare providers, an under explored avenue of geographical research.	NZ	N=10 Key informants  N=115 Questionnaire  N=10 centers Participatory observation	- History and reform of voluntary sector - Current Challenges: Funding a) Improvement to sustain advocacy role. b) Recommend shift to client-centered contracts, flexible to changing needs. c) Equitable State funding regime (target in voluntary sector and drop-in centers in general and project specific)	Funding
17. Darkins (2006)	Changing the location of care: Management of patients with chronic conditions in Veterans Health Administration using care coordination/home telehealth	US	Chronic Conditions (Diabetes, Chronic heart failure SCI, PTSD, Depression, COPD, Stroke, MS, Hypertension)	- Veterans Health Administration designed its Care Coordination Home telehealth programs for non-institutional long-term care services. - Important to incorporate patient preference, assesses patient's health care needs, and ensures safe and efficient provision of care for patients with chronic diseases - Can deliver to rural areas	Telehealth
18. Davies et al. (2011)	The objective of this study was to identify salient issues confronting parents of children with complex neurological disorders.	CA	N=17 parents of 11 young adults  Complex Neurologic Disorders and Intellectual Impairment (Most with a seizure disorder)	- Perceived abandonment in transition - Sense of loss, fear and uncertainty - Transition hindered by insufficient coordination/ communication between health professionals, vulnerability of the young adult, lack of appropriate resources in the adult health care system, and parents' poor health status. - Transition felt facilitated by parents' resourcefulness, family support and ability to establish new relationships within the adult health care setting.	Integration during Transition
19. Deber et al. (2007)	Examine the role patients indicate they would prefer in making treatment decisions across multiple clinical settings.	CA	N= 2754 Outpatients (Breast cancer, prostate disease, orthopaedic, MS, HIV/AIDS, ... many others)	- Few respondents preferred an autonomous role - Most preferred shared decision making or a passive role - Familiarity with a clinical condition increases desire for a shared (as opposed to passive) role (Multiple Sclerosis). - Older and less educated individuals were most likely to prefer passive roles.	Patient Autonomy
20. Dunleavy (2007)	To describe the complex role of nurse coordinators in multidisciplinary spina bifida clinics	US	SB	- Key role in hospitalization. - Role in prenatal period - Paediatrician may not have taken care of a newborn with SB, so the nurse coordinator is the person on whom they rely for sharing medical information and education on important issues - Most knowledge about a family	Nurse coordinator

21. Dyke et al. (2006)	To examine family and service providers' perceptions of family-centered services being implemented by a paediatric disability service provider for children with cerebral palsy and to pinpoint areas for improvement.	AU	N=158 families  CP	- Family centered care = important - Services provided not be tailored to meet parents' needs - Respectful and supportive care rated highest by families - Showing interpersonal sensitivity rated highest by physicians. - In need of improvement: a) Written information to families b) Continuity of care, c) More involvement of family d) Detail info about therapy issues e) More general support to families.	Family-centered care
22. Easton et al. (2007)	To describe the role and challenges faced by voluntary organizations in serving the needs of people with neurological disorders, with a special focus on the work of the Encephalitis Society.	UK	N= 339 (members affected by encephalitis)  N= 76 (Postal survey of recent contacts)  N= 22 In-depth telephone interviews  Encephalitis	- Society's helps ensure advocacy with health care agencies - Provide helpful support services, especially information services (reduce feeling isolated, acceptance of condition, symptoms, future, improve self-management) - Many use service and return at transitional or difficult points - Must re-interpret its role in relation to changing needs &context of care provision- relationship to facilitate coordination but distance for advocacy purposes - Limited resources - Not constrained by the bureaucracies	Voluntary organizations
23. Egan et al. (2010)	To describe and evaluate a Community Stroke Navigation program developed by the Stroke Survivors Association of Ottawa.	CA	N= 61  Stroke  N=35 (Stroke survivor) N=26 (Care partner)	- Plan of action developed with OT included coaching, case coordination and education etc. - Assessment 4 months later indicated: a) No impact on community reintegration of the care partner b) No alteration in physical or emotional health for survivors or partners c) Effective for the stroke survivor	Support with Navigation
24. England et al. (2012)	To examine the public health dimensions of the epilepsies.	US	Epilepsy	Focus on: - Public health surveillance and data collection and integration - Population and public health research - Health policy, health care, and human services - Education for providers, people with epilepsy and their families and the public.	Health care delivery, Patient autonomy, Stigma
25. Fitzpatrick et al. (2010)	This report describes a project to assess experiences of health and social care services for patients with Motor Neurone Disease	UK	N= 3 (Lit reviews)  N=46 (QUAL interviews)  N=1 (Advisory)	- The survey indicates many aspects of services that are satisfactory for the majority of respondents - Some experience care coordination, others not - Progress is extensive but inconsistent - Efforts have been made to address the issue of measurement and monitoring	National Service Framework Progress

	(MND), Multiple Sclerosis (MS) and Parkinson Disease (PD), and their carers.		group) <i>N=2661 (surveys)</i> MND MS PD	- to support service developments for neurological conditions. - Need now to build the evidence base for long term neurological conditions in terms of identifying services that work	
26. Frank et al. (2011)	To summarize services provided by the Alzheimer Society and discuss other supports and resources available for the management of dementia.	CA	N/A AD and related dementias	- Existing resources - Other resources such as respite care and day programs should be used when appropriate and can be coordinated with assistance from the Alzheimer Society.	Multi-disciplinary services
27. Franklin (2006)	To outline information about mild traumatic brain injury, including community resources, useful books, articles, and web sites that can assist physicians in the treatment of patients.	CA	N/A BI	- Patient education - Support Services (Psychological intervention, OT, Other therapy) - Community Resources (Outreach, child and youth program, early response service, self-management programs, community programs, concussion clinic, psychiatry programs, worksafeBC program) - Rehabilitation resources (health centre, community therapists) - Regional resources	Awareness of resources (physicians)
28. Freeman et al. (2007)	This program has been the largest and longest of its kind, with particular focus on the experiences of patients and their carers for the NHS Service Delivery and Organisation (SDO) Research and Development Program.	UK/ CA	<i>N= 6 SDO projects</i> (Diabetes Primary care Cancer Learning disability Stroke Mental health)	- A common thread across projects was the disadvantage of vulnerable groups to negotiate better continuity or care. - Other aspects of quality care: access to services, and the interpersonal and perceived technical skills of providers. - Patients saw their role as adherence, self-management, and advocacy, but not all were willing to play active roles - Systems to facilitate info transfer were found to be necessary but not sufficient in improving care delivery. - Continuity impacts: satisfaction, quality of care, and functioning (esp. vulnerable)	Continuity of Care
29. Galea et al. (2006)	To discuss the outcomes of a new customized telerehabilitation program.	US	<i>N=14</i> SCI	- Accepted by patients and - Appreciated by caregivers. - Office visits have increased, - Hospitalizations, and more importantly length of stay, have decreased. - Coordination of the team and relative poor technology are some of the obstacles we have identified - Provides easily accessible multidisciplinary care	Technology
30. Galushko	To explore the subjectively unmet	DE	<i>N=15</i>	Unmet needs: - Support of family and friends	Integrated multi-

et al. (2014)	needs of patients feeling severely affected by MS.		MS	<ul style="list-style-type: none"> <li>- Health care services (Improve /link services, more coordination, support professional patient relationships, more accessible multi-professional services, All services should have an individual approach to provide needs-tailored support, integrate relatives)</li> <li>- Manage everyday life</li> <li>- Maintain biographical continuity</li> </ul>	disciplinary person-centered services
31. Gibson (2008)	This paper looks at various roles and responsibilities of GPs in the management of patients with long-term neurological conditions.	UK	N/A  Long-term neurological conditions	<ul style="list-style-type: none"> <li>- Diagnostics: Many of neurological condition are uncommon; therefore, GP awareness might be limited. Should detect early symptoms and signs and refer to a neurologist</li> <li>- Supportive: secondary prevention, depression, support, follow-up and education</li> <li>- Palliative role</li> </ul>	GP responsibilities
32. Giordano et al. (2008)	To cross-culturally adapt and validate the Italian version of the Control Preference Scale (CPS) subsequently used to assess preferences of people with MS.	IT	N=140  MS	<ul style="list-style-type: none"> <li>- A collaborative role was preferred (61%), followed by passive (33%) and active (6%) roles.</li> <li>- Education and length of follow-up at referral center were associated with choice of an active/collaborative role in the logistic model.</li> <li>- The Italian CPS was well accepted by our MS population.</li> <li>- Our data indicate that a high proportion of Italians with MS prefer a more passive role and this should be considered during the clinical encounter.</li> </ul>	Patient autonomy
33. Gridley et al. (2011)	To understand what helps or hinders the commissioning and provision of integrated services for people with Long-term neurological conditions; identify models of best practice from the perspectives of people with LTNCs and professionals; and develop a benchmarking system to assess the extent to which these models are available.	UK	N/A  Long-term neurological conditions  (Systematic literature review of evidence, in-depth case studies of 6 neurology 'service systems', and survey)	<p>7</p> <ul style="list-style-type: none"> <li>a. Service models for continuity: Community interdisciplinary neurorehabilitation teams</li> <li>b. Nurse specialists and proactive</li> <li>c. Holistic day opportunities services</li> <li>- Systematic approach to delivering treatment and care for people with LTNCs has not yet been achieved.</li> <li>- The survey results reinforced many of the case study findings, particularly around the varying levels of service available depending on diagnosis and location, and problems of access even where high-quality services existed</li> </ul>	Continuity of care
34. Haggerty et al.	To provide insight into how well management	CA	N= 432 adults	<ul style="list-style-type: none"> <li>- 5 validated subscales</li> <li>- Sub-dimensions:</li> <li>a. Coordination actions (by the primary</li> </ul>	Continuity of Care

(2011)	continuity is measured in validated coordination or integration subscales of primary health care instruments.			b. care physician in transitioning patient care to other providers) Coherence (efforts by the primary care physician to create coherence between different visits both within and outside the regular doctor's office) - Mostly positive, but in one, 83% reported having one or more problems on the Overall Coordination subscale and 41% on the Specialist Access subscale.	
35. Haggerty et al. (2003)	To provide common definitions to help health care providers evaluate continuity more rigorously and improve communication.	CA	N/A	- Emphasis of continuity depends on the context (Nursing, primary care, disease management, mental health) - Three types of continuity: informational, management, relational - Continuity is the degree to which a series of discrete health care events is experienced as coherent and connected and consistent with the patient's medical needs and personal context	Continuity of care
36. Hamann et al. (2007)	To study whether participation preferences vary according to the type of disease.	DE	<i>N</i> = 1393  (Hypertension, Depression, Breast cancer, Schizophrenia, MS, minor traumas)	- Factors affecting a greater desire to participate: Younger, education, female gender - MS participants exhibited significantly higher participation preferences than the other diagnostic groups. - No major differences between the other diagnostic groups.	Patient autonomy (participation)
37. Heesen et al. (2004)	To evaluate prerequisite factors for shared decision making, we studied patients' decisional role preferences in medical decision making, knowledge on risks, information interests and the relations between these factors in MS.	DE	<i>N</i> =219  MS	- Most patients (79%) indicated that they preferred an active role in treatment decisions giving the shared decision and the informed choice model the highest priority. - MS risk knowledge was low but questionnaire results depended on disease course, disease duration and ongoing immune therapy. - Measured knowledge and perceived knowledge only weakly correlated with preferences of active roles.	Patient autonomy
38. Heesen et al. (2007)	Trial 1: The effects of a 4-hour education program on relapse management versus an info leaflet to provide information on treatment for MS relapses and increase the recognized options for the treatment of	DE	<i>N</i> =56  Pre-study patients  <i>N</i> =113  Phase 2 Relapse-remitting  <i>N</i> =100  Phase 2 primary progressive	- Decision role preferences: paternalistic style, a professional as agent style, a shared decision style, an informed choice style and a concept of pure autonomy. (79% of patients preferred active roles- autonomous, informed choice or shared decision) - MS risk knowledge was low (knowledge about treatment and side-effects) - In a modeling and piloting phase we studied possible prerequisites of SDM	Patient autonomy

	relapses.  Trial 2: To study the effects of an evidence-based patient information on immunotherapy on decisional role preference and performance in the patient physician encounter.		MS	<p>in MS. It is not entirely clear whether patients really want to participate, whether they really do share decisions or whether they just want to feel they are involved.</p> <ul style="list-style-type: none"> <li>- MS patients claim active roles with positive effects on disease outcome, if only on psychological factors, regardless whether this hypothetical preference may lead to a real autonomous decision or not.</li> </ul>	
39. Heesen et al. (2011)	To summarize recent trials on patient education and decision aids, as well as develop a modular program for all relevant decisions in multiple sclerosis to increase patients' self-management and empower patients to develop their individual approach with the disease.	DE IT	5 studies <i>N1= 150 N2= 305 N3= 120 N4= 190 N5= 150</i>	<ul style="list-style-type: none"> <li>- Interventions: Combinations of brochures, education group session, add-on personal interview with a physician using a navigable CD, take-home booklet.</li> <li>- Inform choices,</li> <li>- Increase MS knowledge,</li> <li>- Improve satisfaction with care,</li> <li>- Preferred and realized roles</li> <li>- Reduced relapses and treatments (unclear)</li> <li>- Enhanced risk knowledge</li> </ul>	Patient autonomy
40. Heesen et al. (2013)	To overview measurement issues in studying decision making in MS, categorized according to prerequisites, process measures and outcomes of patient autonomy.	DE	N/A MS	<ul style="list-style-type: none"> <li>- Prerequisites to decision making:</li> <li>a. Personality, Cognitive style, Coping style, Role preference, Numeracy (ability to work with numbers), Risk knowledge, risk attribution, risk tolerance (depends on illness perception and experience of benefits of a treatment)</li> <li>- Process:</li> <li>a. Internal motivation</li> <li>b. Uncertainty perception</li> <li>c. Patient involvement/participation</li> <li>Medical decision outcomes:</li> <li>d. Health outcomes</li> <li>e. Preference match</li> <li>f. Satisfaction</li> </ul>	Patient autonomy
41. Hewer (2013)	This paper describes the current situation for provision of neurological services in UK, and contains a number of suggested ways in which the situation might be improved.	UK	Long-term neurological conditions	<ul style="list-style-type: none"> <li>- Shortage/ uneven distribution of neurologists</li> <li>- Shortage of neurological rehabilitation services</li> <li>- Lack of national and local leadership</li> <li>- Lack of outcome measures, making it impossible to assess the cost-effectiveness of neurological services.</li> <li>- Future: increased collaboration, involving-non-doctors, need increased coordination and leadership</li> </ul>	Addressing barriers with "non-doctors"

42. Hoffman & Cantoni (2008)	To identify the nature of OT services for neurological rehabilitation in areas of Queensland, the barriers to service delivery, and the current uses of various information and communication technologies between OTs.	AU  BI PD MND MS AD	N= 39	- Telephone, email, fax, internet, videoconferencing, other  - Barriers to service provision included travelling distance to clients, large workloads and limited resources  - Telehealth provides direct home-based client services. It's limited, but is a growing area for rural and remote areas  - Few participants used the Internet or videoconferencing for purposes other than continuing professional development.	Technology
43. Jansen et al. (2007)	To review recent integrated care initiatives and their significance for MS patients.	NL	MS	- Integrated care appears to offer potential for eliminating fragmentation and discontinuity in health care, as well as improved efficiency and effectiveness of health care  - Few published studies have evaluated its implementation with MS patients.  - Interchanging concepts creates problems for substantiating empirical evidence.	Integration
44. Kasper et al. (2008)	To evaluate the effects of an evidence-based patient decision aid (DA) on multiple sclerosis (MS) immunotherapy.	IT	N= 294  MS	- Preferences for autonomous interactions were remarkably high in both groups  - % of preference matches and immunotherapy choices did not differ between groups  - Intervention group was more critical of immunotherapy and rated information as more helpful (Feeling of being better informed, getting important questions more adequately answered, and being better supported in finding their preferred role)	Patient autonomy
45. King et al. (2004)	This article defines family-centered service and outlines a conceptual framework of the premises and principles underlying this approach to service delivery.	CA	N/A  CP	- Family-centered care is considered best practice when providing services to children with cerebral palsy  - Parents who perceived more family-centered services reported less effort in coordinating services.  - Information sharing between physician and family is important for proper collaboration	Family-centered care
46. Kirton et al. (2012)	To explore patients and carers views and experiences of the impact of the Generic Neurology Nursing Service.	UK	N= 65  PD Epilepsy Brain tumour Other	- Longer consultation times:  a. Can talk freely about symptoms b. Can ask more questions c. All patients/carers were satisfied with the Generic Neurology Nurse Service, with the majority highlighting improvements it made in their life	Nurses in service delivery

				<ul style="list-style-type: none"> <li>- Knowledgeable specialist nurse:</li> <li>a. Bridge the gap in the provision of a bespoke service for patients who currently receive sub optimal care.</li> <li>b. Timely service can be suggested as preventing clinical emergencies, maintaining patients' self-management and resulting in the best level of care.</li> </ul>	
47. Knapp et al. (2013)	A systematic literature review was conducted to review the cost-effectiveness/ value of prevention, care and treatment strategies in relation to dementia.	UK	<p>N= 56 literature reviews</p> <p>N= 29 single studies</p> <p>ADRD</p>	<ul style="list-style-type: none"> <li>- Barriers to better cost-effective care:</li> <li>a. Scarcity and low methodological quality of available studies,</li> <li>b. Difficulty of generalising from available evidence,</li> <li>c. Narrowness of cost measures,</li> <li>d. Reluctance to implement evidence</li> <li>e. Poor coordination of health and social care provision and financing.</li> </ul>	Funding barriers
48. Langhorne et al. (2005)	This is a paper presenting the meta-analysis of data from patients with stroke in hospital to receive either conventional care or early supported discharge intervention with rehabilitation community support with the aim of shortening their hospital stay.	US  AU CA NO SE TH UK	<p>N=1597 (11 trials)</p> <p>Stroke</p>	<p>Early supported discharge mostly by multidisciplinary teams</p> <ul style="list-style-type: none"> <li>a. Can substantially shorten hospital stays</li> <li>b. Reduce risk of death or dependency</li> <li>c. Improve scores on the extended activities of daily living scale and in the odds of living at home and reporting satisfaction with services.</li> <li>d. The greatest benefits were seen in the trials evaluating a coordinated multidisciplinary early supported discharge team and in stroke patients with mild to moderate disability.</li> </ul>	Integrated multi-disciplinary care
49. Langhorne et al. (2013)	This study investigates the online search practices, perceptions, and usability of web-based information among multiple sclerosis patients.	US	<p>N= 39</p> <p>MS</p>	<ul style="list-style-type: none"> <li>- Prefer neurologist-supplied info, but frequent health-related websites.</li> <li>- Specific sites visited vary according to both type (MS organization's sites, general health websites, social networking sites) and frequency.</li> <li>- Rarely searched caregiver credentials</li> <li>- Searched for drug therapies, alternative therapies, side effects, emerging research, and new treatment options.</li> <li>- Patients' motivations for searching MS-related information online include preparation for upcoming doctor visits.</li> </ul>	Patient autonomy
50. Lee & Lin (2009)	This paper argues that increased trust does not necessarily imply decreased autonomy and presents a framework to understand the interactive process between these two	TW	<p>N/A</p> <p>Chronic disease</p>	<ul style="list-style-type: none"> <li>f. Framework argues policy makers and health care providers should: foster</li> <li>a. Patients' trust</li> <li>b. Preferences for autonomy</li> <li>g. Trust contributes to: <ul style="list-style-type: none"> <li>a. Compliance</li> <li>b. Patients' Disclosure</li> <li>c. Placebo Effect</li> <li>d. Physician's Caring Behavior</li> <li>h. Thereby leading to best health-related</li> </ul> </li> </ul>	Patient autonomy and trust

	preferences.			outcomes.	
51. Little (2013)	This paper considers ways in which integrative health care could be incorporated into nursing curricula as a means to prepare nurses for this important challenge.	UK	General	<ul style="list-style-type: none"> <li>- Shift to integrative health care reflects the public's desire for complementary and alternative medicine</li> <li>- Spirit of client-responsive health care</li> <li>- To interact with patients health professionals need to understand its underpinning concepts</li> <li>- Prepares nurses to engage with a modern client base, supports patient choice, and encourages a contemporary focus in nurse education</li> </ul>	Patient autonomy
52. McDonald et al. (2007)	To develop a definition of care coordination, apply it to a review of systematic reviews, and identify theoretical frameworks that might predict or explain how care coordination mechanisms are influenced by factors in the health care setting and how they relate to patient outcomes and health care costs.	US	<i>N= over 40 definitions</i>  <i>N= 75 systematic reviews evaluating care coordination interventions</i>  Mental health Heart failure Diabetes Cancer Palliative care Rheumatoid arthritis Stroke Others...	<ul style="list-style-type: none"> <li>- Care coordination definition</li> <li>- Care interventions</li> <li>- Conceptual frameworks: Andersen's, Donabedian's framework, Nadler/Tushman, Wagner's Chronic Care Model, and Gittell's Relational coordination framework</li> <li>- Strongest evidence shows benefit of care coordination interventions for patients with congestive heart failure, diabetes mellitus, severe mental illness, recent stroke, or depression.</li> <li>- Evidence about key intervention components is lacking.</li> </ul>	Definition Interventions Conceptual structures
53. Marsden et al. (2010)	To explore whether a group program for stroke survivors and carers is feasible and effective in the long-term in a rural settings.	AU	<i>N= 25 chronic stroke survivors</i>  <i>N=17 carers</i>  <i>N= 7 sessions</i>  <i>N= 3 settings</i>  Chronic stroke	<ul style="list-style-type: none"> <li>- Between-group trends favoured the intervention group for most outcome measures</li> <li>- The majority of measures remained above baseline at 12 weeks post program for stroke survivors.</li> <li>- Physical activity, education and social interaction by a multidisciplinary stroke team.</li> <li>- This program may improve and maintain HRQOL and physical functioning for ppl and their carers.</li> </ul>	Rural Multi-disciplinary
54. Mayo et al. (2008)	To review for 6 weeks following hospital discharge a nurse stroke care manager maintained contact with patients through home visits and telephone calls designed to coordinate care with the person's	CA	<i>N=190</i>  Stroke	<ul style="list-style-type: none"> <li>- There were no differences between groups on primary outcome measure (health services utilisation), or any of secondary outcome measures</li> <li>- No evidence that passive case management offered alone (w/o multi-disciplinary team approach to rehabilitation) was successful.</li> <li>- Compared to people receiving post-hospital care, 6 weeks isn't long enough</li> </ul>	Case management

	personal physician and link the stroke survivor into community-based stroke services.					
55. Munce et al. (2014)	To conduct a systems analysis on community and health services for individuals with acquired brain injury in Ontario, Canada.	CA	ABI  N=17 Community-based organizations  N= 6 CCACs  N=10 Community Associations  N=9 Rehabilitation hospitals	- Influences to ABI program/ service: Funding, physical space, staffing, other - Lack of services for children/ adolescents - Service gaps: co-existing mental health, children/adolescents, employment services - Need for integration of care across services - Need more organizations to track patient outcomes, report indicators, and/or use benchmarks for evaluation and/or accountability purposes.	Service delivery	
56. Palsbo & Diao (2010)	To analyze the financial performance of a care coordination program.	US	N= 245 beneficiaries  Adult disabilities  (SCI CP MS BI Stroke Other)	- People with physical impairments arising from stroke or other brain injuries appeared to have the greatest access disparities prior to enrolment. - Care coordination leads to higher program expenditures for participants with moderate physical impairments who encounter access problems, but has little impact on participants who are already getting 24-hour care. - This disability care coordination may not be financially sustainable over the long term.	Funding	
57. Palfrey et al. (2004)	Objectives were to characterize children with special health care needs in the Pediatric Alliance for Coordinated Care intervention, assess parental satisfaction with the intervention, assess the impact on hospitalizations and emergency department episodes, and on lost parental work and child's school.	US	N= 150 Children with special healthcare needs  6 practices  (Neurological, Mental disorders, Congenital anomalies, Prenatal conditions, Ill-defined conditions, Organ-specific conditions)	- Coordinated care made care delivery easier for families: better communication and relationship with health professionals, connections to community resources, understanding of the condition and goals for care, and reduced caregiver strain - Pediatric nurse practitioner was especially helpful to families of children who were rated "severe" - Satisfaction with primary care delivery was high at baseline and remained high throughout the study. - Statistically significant decrease in parents missing >20 days of work and in hospitalizations	Continuity of care	
58. Parent et al. (2011)	To improve care and neurological recovery of patients	CA	N= 15 articles  SCI	- Timely transfers to integrated multidisciplinary specialized center decreases:	Integrated multi-disciplinary	

	suffering from spinal cord injury.			a. Overall mortality b. Number and severity of complications c. Length of hospital stay	care
59. Peel et al. (2013)	This article outlines the steps taken to create an integrated care pathway for people living with Parkinson.	UK	N= 96  (Advisory group Stakeholders Living with PD Carers)  PD	- Core barrier to implementation being the perceived time required to undertake the work and resources  - Changes required locally are broad and often require more significant changes to professional attitudes and styles of working than to services  - Integrated Care Pathway is more than a care pathway integrated across the various tiers of health and social care; it is a means of mapping out a pathway to holistic, person-centred care from diagnosis to the end of life	Service delivery
60. Perla et al. (2013)	The purpose of this article has been to describe the collaborative case management between the Department of Defense and Veterans Affairs which ensures SMs and veterans receive their entitled health care services.	US	N= 2 case studies  (Polytrauma TBI Psychological trauma, Painful Musculoskeletal injuries)	- Case management is the central component that ensures seamless patient transitions throughout the rehabilitation and recovery continuum  - The complex care needs of these returning service members requires astute case management skills across a range of military branches and government agencies.  - Identification of a lead case manager ensures clear communication during these times of transition and helps to ease the anxiety for patients and families as they progress and reintegrate back into their community.	Veteran transition
61. Pimouquet et al. (2010)	Systematic review to analyze the cost-effectiveness of community-based care management programs for people living with dementia and carers, in relation to health care cost, institutionalization and hospitalization.	FR	N= 12 RCT  ADRD	- Among the 6 good quality studies, 4 reported positive impact on institutionalization delay, institutionalization length or nursing home admission rate.  - No evidence from good quality studies found for savings in health care expenditures or reduction in hospitalization recourse.  - No conclusion about efficacy of case management on costs and resource utilization	Funding
62. Pomeranz et al. (2008)	To introduce the life care plan as an established and successful approach for meeting the complex and comprehensive needs of individuals with polytrauma.	US	N= 5120  TBI Amputations SCI Burns Blind	- Life care planning: assess lifetime disability-related needs to organize current and future medical and rehabilitation services. (To maximize potential, prevent complications, save financially, enhance QOL)  - Need multidisciplinary care  - Needs change with age  - Case management: Advocacy, communication, education, identification of service resources, and service facilitation used to achieve	Continuity of care for veterans

				client wellness and autonomy (identify services and ensure available resources)	
63. Rakhshani et al. (2010)	To evaluate outcomes of a comprehensive care clinic for children with hypothalamic obesity due to treatment for brain tumours.	CA	N= 39  BT	- Significant increases for child total HRQoL (not for parents), physical functioning and school functioning. - Parents significantly improved responses in coordination of care and understanding of their child's disease. - While attending the clinic patients gained less weight and exhibited improved HRQoL.	Intensive multi-disciplinary care
64. Ray (2005)	Secondary analysis to determine parents' view of the mechanisms used to allocate health, education, and social services to children with chronic illness and disability and their caregiving families	CA	N=43  Parents of children with conditions	- Repeatedly express how critical it is for providers to give them information and education to enable them to self-manage the condition - 11 mechanisms that were used to determine eligibility and/or to ration services: diagnosis, age, technology dependence, severity, functional ability, guardianship status, geographic location, financial resources, judged parental coping, failure to inform parents about available services, and cyclical funding	Patient autonomy
65. Restall et al. (2005)	Identify effective OT and physiotherapy interventions for adults delivered in primary health care in Winnipeg, develop a conceptual framework and service delivery model, and propose a pilot project for such services in one community access model	CA	N= 13 OTs  N=18 PTs  N=13 Health and social administrators  (TBI Stroke PD MS Other chronic diseases)	- OT: a. Stroke: early and continued supported discharge by multidisciplinary community rehabilitation team improved independence with ADL, IADL, and community integration. b. TBI: Multidisciplinary community rehabilitation led to gains in ADL, community integration, psychological well-being and self-organization. c. MS: wellness program improved self-management d. PD: improved functional status and QOL - PT: a. Stroke: improves independence with ADL and reduces risk of deterioration in ability, fewer deaths, increased independences. b. PD: improved ADL Components of Conceptual Framework: a. Integrated interdisciplinary teams b. Promote accessible services and a continuum of care c. Taking a population health perspective d. Identifying core service roles using a multi-faceted approach e. Systematically evaluating services	Current Services and Resources

				<p>Focus groups/ Interviews:</p> <ul style="list-style-type: none"> <li>- Need integrated patient-centered care (including integration of government and education)</li> <li>- Transition challenges</li> <li>- Ensure people don't fall though the cracks of program criteria</li> </ul>	
66. Reuben et al. (2013)	This report describes the clinical aspects of the program's operation and its experience with the first 150 individuals.	CA, US	N=150  ADRD	<ul style="list-style-type: none"> <li>- The Alzheimer and Dementia Care program utilizes an adapted co-management approach in a university-based health care system to provide primary and specialty care for a large population, most of which is covered by Medicare.</li> <li>- Goal to maximize function, independence, and dignity; minimize caregiver strain and burnout; and reduce unnecessary costs through improved person-centered care.</li> <li>- Ongoing study, waiting for results.</li> </ul>	Co-managed person-centered care
67. Rubin (2014)	To present a history of the principles of autonomy and beneficence and then present a shared medical decision-making model, collaborative autonomy, to provide guidance to neurologic critical care providers in how to resolve such dilemmas.	US	N/A  Medical conditions	<ul style="list-style-type: none"> <li>- Studies show the patient wanting to be informed and be part of the decision-making process but also wanting the physician to have a significant role.</li> <li>- Ultimate decision is up to the patient</li> <li>- Collaborative autonomy model as it allows a disclosure of relevant information and treatment options while at the same time including the opinion of the physician. <ul style="list-style-type: none"> <li>a. Paternalist perspective</li> <li>b. Isolated autonomy perspective</li> <li>c. Collaborative autonomy perspective</li> </ul> </li> </ul>	Patient autonomy
68. Russell et al. (2009)	To identify and describe the structure of services for people with long-term conditions, and future developments (and related issues) based on strengths, gaps, overlaps and opportunities of service provision.	UK	PCT 1: <i>N=11 (initial)</i> <i>N=7 (follow-up)</i> PCT 2: <i>N=3 (initial),</i> <i>N=11 (follow-up)</i> Service leads <i>N=4 (initial)</i> <i>N=3 (follow-up)</i> Action Learning <i>N= 15 (Event 1)</i> <i>N=20 (Event 2)</i> Long-term conditions	<ul style="list-style-type: none"> <li>- Matron (community nurse) supporting people with long-term conditions demonstrated benefits to patients.</li> <li>- Provide case management, key point of contact, relationship and trust, cross professional boundaries, proactive preventative work.</li> <li>- Challenges: <ul style="list-style-type: none"> <li>a. Funding challenges: ensure caseload is not too much, or else defeats the purpose of role, need resources to connect acute and non-acute services (e.g., obtaining equipment for non-cancer patients).</li> <li>b. Role challenges: identify role, appropriate training, realistic expectations, including patient satisfaction and carer experiences, unpredictable workload</li> </ul> </li> </ul>	Case management
69.	To investigate	US	<i>N= 2,765</i>	<ul style="list-style-type: none"> <li>- Patients overwhelmingly preferred to</li> </ul>	Patient

Ryan & Sysko (2007)	under what conditions patients prefer to be actively involved in their treatment decisions, the underlying theoretical reasons that may account for decision-making preferences, and what medical decision-making model can guide physicians and medical policy makers.			be asked their opinions about their treatment, and a significant majority preferred that final medical decisions not be made unilaterally by their physician  - Patient preferences for participatory medical decision-making can be influenced by age, education and gender. - Participation is higher for younger, more educated, and female patients.	autonomy
70. Sargent et al. (2007)	To describe case management from the perspective of patients and carers to develop a clearer understanding of how the model is being delivered for patients with long-term neurological conditions.	UK	N= 72 patients N= 52 carers	- Emphasize the importance of seeking patient and carer input when designing new case management programs.  - Community matrons provide five types of care: clinical, care coordination, education, advocacy, and psychosocial support.	Case management
71. Siegert et al. (2014)	To pilot the use of a register to identify and monitor patients with complex needs arising from LTNC.  To determine the extent to which patients' needs for health and social services are met following discharge after inpatient rehabilitation.	UK	N=256 (responses after 4 weeks)  Long-term neurological conditions	- Significant unmet needs were identified within the first year following discharge (especially rehabilitation, social work support and provision of specialist equipment)  - Patients whose needs for community-based rehabilitation were met were more dependent, and demonstrated fewer gains in integration at 12 months post discharge than those with unmet needs.  - Likely explanation reflects resources are limited and services will be focused on patients with the severest problems who have the greatest need.	Service utilization
72. Singh et al. (2009)	To describe the experience with technological initiatives to improve the clinical care and outcome of stroke patients.	SG	N/A  Stroke	- Timeliness is essential with diagnosis and access to treatment.  - Specialist and resource limitations sometimes force people with neurological conditions to be treated by people not specialized in that area  - Utilize lower cost webcams and videoconferencing and emails as a substitute image transfer system.	Technology
73. Sixsmith (2012)	To reveal the ways in which services provided for people with Long Term	UK	N=? , Service users and providers	- Lack of experience amongst health and social care professionals involving service users integrally in their service design and development.	Person-centered

	Neurological Conditions can enhance well-being rather than simply reveal or address their health and social care needs.		PD MS CP Stroke, ADRD Epilepsy MND MD TBI, Others	- Service user involvement in health and social care service design= integral to service development with positive outcomes for service users, health and social care research and service provision  - Equitable relationship where both experiential and professional knowledge are both valued.  - Involvement is empowering and producing more responsive, person-centred services.	
74. Sixsmith et al. (2014)	To explore the experiences of service users and providers during the implementation of the National Service Framework for Long-Term Neurological Conditions.	UK	N= 50 service users  N= 45 service providers  MS ABI Stroke SB PD Epilepsy CP Other	- Diagnosis and treatment a. Delays in diagnosis b. Access to specialist care - Better connected services a. Breakdowns between services during referral to treatment b. Implement integrated services - On-going rehabilitation a. Lack of continuing rehab b. Resource restrictions c. Power imbalances - Treatments terminated even with ongoing need due to lack of support and resources for continuous care.	Funding continuity of care
75. Solari et al. (2010)	Patients report information deficits in the period surrounding diagnosis of multiple sclerosis. We assessed the effectiveness of an add-on information aid for newly diagnosed MS patients.	IT	N= 120 newly diagnosed  MS	- The information aid was safe and significantly associated with attainment of the primary outcome at 1 and 6months.  - It is noteworthy that the components differ in terms of reliability and resource consumption: the booklet and CD are reproducible one-off cost items, whereas the personal interview is more variable and resource-demanding  - Assists in fulfilling ethical obligations to provide information to the patient	Patient autonomy
76. Solari et al. (2013)	The Control Preference Scale is the most frequently used measure of patients' preferred roles in treatment decisions, which was revised into a new computerized patient self-administered version. This study used the new measure to assess role preferences, and their	IT DE	N= 26 patients  MS	- The newly revised Control Preference Scale was well received and considered easy to use by MS patients.  - Reliability was in line with that of the original version.  - Role preference appears affected by cultural characteristics and (borderline statistical significance) education.	Patient autonomy

	determinants, in people with multiple sclerosis.					
77. Solari (2014)	This paper reviews studies that have assessed the experiences of people with multiple sclerosis in the peri-diagnostic period and have evaluated the efficacy of interventions providing information at this critical moment.	IT	N= 9 RCTs MS	<ul style="list-style-type: none"> <li>- Emotional burden at diagnosis was high, and emphasized the need for careful monitoring and management of mood symptoms (esp. anxiety).</li> <li>- Information provision did not affect anxiety symptoms but improved patients' knowledge of their condition, the achievement of 'informed choice', and satisfaction with the diagnosis communication.</li> <li>- It is vital to develop and implement information and decision aids for, but this is resource intensive, and international collaboration may be a way forward.</li> </ul>	Patient autonomy	
78. Stillman et al. (2014)	To identify from whom individuals with spinal cord injury seek health care, the percentage who receive preventative care screenings, and the frequency and types of barriers they encounter when accessing primary and specialty care services; and to examine how socio-demographic factors affect access to care and receipt of preventative screenings.	US	N = 108 SCI	<ul style="list-style-type: none"> <li>- Individuals with SCI face remediable obstacles to care and receive fewer preventative care screenings than their nondisabled counterparts.</li> <li>- Clinical staff should be properly trained in assisting individuals with mobility disabilities, and take a proactive approach in discussing preventative care screenings.</li> <li>- Recent contact with primary and specialty providers (within 12 months)</li> <li>- Most prevalent barriers were inaccessible examination tables and lack of transfer aids.</li> </ul>	Multi-disciplinary care	
79. Suddick & Dee Souza (2006)	The present study investigated therapists' experiences and perceptions of the reasoning behind the team approach in neurological rehabilitation, the structure and composition of the team within which they worked and the team working process	UK	N=5 OTs N=5 PTs Stroke	<p>Teamwork: diverse benefits to patients, the team, individual team members and in improving the effectiveness and efficiency of the service.</p> <ul style="list-style-type: none"> <li>- Composition, activities, and strategies were diverse (example: whether patients were included within the team) depending on the aims and context of the team effort</li> <li>- Interdisciplinary team approach not been consistently adopted</li> <li>- Team approach reasoning supported perceived benefits of teamwork.</li> </ul>	Multi-disciplinary	
80.	Reviewed the	US	N= 519	<ul style="list-style-type: none"> <li>- The program seeks to improve care by</li> </ul>	Funding	

Tan et al. (2014)	Alzheimer's and Dementia Care program.		ADRD	<p>addressing: lack of support and training for caregivers, poor care transitions, and inconsistent access to community-based services.</p> <ul style="list-style-type: none"> <li>- Post-visit surveys showed high levels of caregiver satisfaction</li> <li>- Aim: better care, better health, lower cost and utilization</li> <li>- Ongoing study</li> </ul>	
81. Timpano et al. (2013)	To focus on the use of Tele-Health in neurological practice, and potential benefits of applying information and communication technology to psychosocial and educational aspects of neurological diseases treatment.	IT	N/A  AD Stroke Epilepsy PD Migraines	<ul style="list-style-type: none"> <li>- Telerehabilitation, telesupport, telecounselling, teleeducation</li> <li>- Eliminate unnecessary traveling of patients and their helper.</li> <li>- Allow patients, living in remote areas or physically limited to move, to access to health care services, assuring continuance to health care delivery and reducing economic and social costs.</li> <li>- Reduce stress of caregivers and allows patients to stay longer at home, thus reducing costs.</li> <li>- Improve equity of access to health care, the quality of that care and the efficiency by which it is delivered</li> </ul>	Technology
82. Turner-Stokes (2007)	To explore the tensions between politics and payment in providing affordable services that satisfy the public demand for patient-centered care.	UK	N/A  Long term neurological conditions	<ul style="list-style-type: none"> <li>- Approaches to reduce costs in UK:</li> <li>a. Focus development in priority areas</li> <li>b. Introduction of a fixed-tariff episode-based funding system to cap spending</li> <li>- Whilst responding to public demand for person-centered care, we must recognize the current financial pressure on health care systems.</li> <li>- Clinicians will have greater credibility if they collect and share outcomes that demonstrate the economic benefits of intervention, as well the impact on health, function and quality of life.</li> <li>- Cost-efficiency has to be made in the wider political arena, rather than at local service level.</li> </ul>	Patient-centered
83. Turner-Stokes (2008)	To assimilate the published evidence for the effectiveness of multidisciplinary rehabilitation following acquired brain injury in adults of working age.	UK	N= 6463 (total)  (Early and post-actual rehabilitation; Specialist inpatient rehabilitation for (very/) severe; Behaviour modification programs; etc.)	<ul style="list-style-type: none"> <li>- RCTs: Strong evidence of early post-acute rehabilitation that early co-ordinated multidisciplinary rehabilitation leads to better outcomes and reduced length of stay in hospital, although severity or injury and comorbidity were inevitable confounders.</li> <li>- Non-trial-based studies provided strong evidence for the cost-benefits of rehabilitation, the impact of early or late rehabilitation, the effect of specialist programmes (e.g. vocational or neuro-behavioural rehabilitation),</li> </ul>	Multi-disciplinary

			ABI		or cost-effectiveness.	
84. Turner-Stokes et al. (2007)	To report a parallel survey of consultants working in the fields of neurology, rehabilitation and palliative medicine, and explore the interface between them when serving people with long term neurological conditions.	UK	N= 82 Neurology  N= 149 Palliative care  N= 53 Rehabilitation	-	Agreement with core contributions offered by each specialty and need for collaborative working practice. Each specialty reported greater ease of access to services in their own field Important areas of overlap (e.g., symptom management) Lack of coordination between services for both palliative care and rehabilitation services. Too few referrals to services (esp. palliative services) from shortage of facilitates and unwillingness to engage	Integration of multi-disciplinary care
85. Turner-Stokes et al. (2008a)	Describe guidelines and interface between rehab palliative and neurological care.	UK	N/A  Long term Neurological conditions	-	Neurology, rehabilitation and palliative care should develop closely coordinated working links to support people with neurological conditions Support from diagnosis to death Proper flow of communication and information for patients and their families Designated point of contact for each stage in the pathway A needs assessment identifying the patient's individual problems	Multi-disciplinary
86. Wensing et al. (2011)	To analyze connectedness in a regional network of health professionals involved in ambulatory treatment of patients with Parkinson disease.	NL	N= 104 health professionals  PD	-	Connectedness between professionals may influence clinical decisions and the coordination of patient care. Professional connectedness varied across professionals. A higher caseload and an affiliation with a hospital were associated with stronger connectedness with other health professionals.	Integration
87. Williams (2005)	To provide advice on ongoing care issues and identify/address problems earlier to prevent or reduce length of hospital stay.  To identify what input from the spinal rehabilitation team is required.  To assess if a nurse-led service improved attendance figures	UK	N= 6 clinics  SPI	-	Benefited from up-to-date expert knowledge Management of care through the outpatients clinics, involving carers to supplement the lack of district nurse input, thus avoiding hospitalization from pressure ulcers Satisfaction with care The pilot 'nurse-led' clinic sessions have highlighted both the value and need of this service, which now needs to be extended to meet the continuing needs of this group of patients. Non-attenders said they never saw the same doctor twice, and that advice was sometimes inconsistent or lacking practical problem-solving.	Continuity of Care
88. Wilson et al. (2014)	Discussing the provision of care for people with	UK	N/A  HD	-	Caring for people with HD is challenging, complex and requires multidisciplinary, patient, and family	Multi-disciplinary care

	Huntington's disease			<p>input.</p> <ul style="list-style-type: none"><li>- There are concerns that the National Service Framework in the UK for Long-term Conditions has not been adequately implemented.</li><li>- Insufficient data to assess the effectiveness of services or provide evidence of best practice.</li></ul>	
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### **Appendix E: Estimated Number of People Supported by MB Community Organizations**

Condition	Service Utilization
ALS Society of Manitoba	274 clients living with ALS
Cerebral Palsy Association of Manitoba Inc.	Approximately 330 members.
Dystonia Chapter and Support Group of Manitoba	75 members.
Centre for Cranial Nerve Disorders	30 new Trigeminal neuralgia patients per year. Surgery for approximately 20 Trigeminal neuralgia patients per year.
Multiple Sclerosis Society of Canada, Manitoba Division	4324 touch points in 2012. 2659 participants in programs offered in 2012.
Muscular Dystrophy of Canada, Winnipeg Community Office	Approximately 350 clients. Approximately 250 active clients (received service in last year).
Parkinson Society Manitoba	Approximately 225 participants in programs. Two conferences (Brandon and Winnipeg) attract 300+ people (60% estimated to have PD).
Huntington Society of Canada in Manitoba	64 people living with HD using services. Also see people who are at risk and have tested gene positive but are not yet symptomatic, family caregivers, and other family members.
Canadian Paraplegic Association (Manitoba) Inc.	Rehabilitation service staff completed 10618 client service outputs during the 2012/2013 year for 486 clients.

\*\* Note: This data was collected when I was a research assistant under the advisement of Dr. Roger. I was asked to follow up with all organizations invited to the January workshop in February 2014 to inquire about what numbers they use as provincial prevalence and/or incidence rates, as well as the number of members using their services at the time. This data includes some is not consistent, as some estimates include people living with a neurological condition and others include family, caregivers, or total number of touch points, and does not account for duplication. Furthermore, not all organizations were able to provide a response at the time of contact, but future follow-ups could yield more recent, specific, and accurate counts. For the purpose of this proposal, this simply provides a general estimate of people supported by community organizations in Manitoba.

**Appendix F: Recruitment Letter**

(Weekday, Date)

**RE: SERVICE COORDINATION FOR SYSTEM NAVIGATION WHEN LIVING WITH A NEUROLOGICAL CONDITION IN MANITOBA**

Dear XXXX,

My name is Monika Y. Wetzel and I am a Master's student exploring the different experiences of accessing care and services when living with a neurological condition. My study has recently been approved by the Joint Faculty Ethics Review Board and I would greatly appreciate your input and time to consider participating in this study.

At a workshop hosted in January at the University of Manitoba, there was overwhelming consensus among not-for-profit community organizations that people living with a neurological conditions were experiencing challenges navigating health and social services. As a result, I hope to learn about the benefits and barriers of support provided by (member's community organization) in relation to service coordination and other supports related to system navigation in Manitoba.

If you agree to participate in this study, you will be asked to participate in a face-to-face interview that is expected to last from 45 to 90 minutes, at a time and private location of your choice. Prior to the interview, you will be asked to sign a consent form outlining the study's process and your rights as a participant (such as, withdrawal, confidentiality), contingent upon your understanding and approval of the consent form contents. In turn, you will be provided with an interview guide to outline the types of questions that will be asked of you, though I welcome and encourage you to discuss all experiences, observations, and feelings that you find meaningful around accessing services or navigating health and social services, even if they are not outlined on the interview guide. All interviews will be audio-recorded and transcribed verbatim by myself.

A total of 15 people living with a neurological condition in Manitoba who have accessed services from community organizations or the health care system over the past year will be asked to participate in this study. I hope to work with community organizations to solicit participants living with a neurological condition, using social media and newsletters, snowball sampling, as well as word-of-mouth.

The open-ended interview questions will be based on the specific objectives of this study, which include: 1) to examine the current experience with navigating health and social services (e.g., health care, community organizations) to access services for people living with a neurological condition in Manitoba; 2) to describe the current perceived successes and gaps of care

coordination within Manitoba; and 3) to develop a better understanding of how service users and providers imagine service coordination might look or not look to improve those experiences.

If you are interested in participating in this study, have questions, or wish for more information, please do not hesitate to contact me anytime by phone ([REDACTED]) or email ([REDACTED]).

Sincerely,

A large rectangular area of the page has been completely blacked out, obscuring a handwritten signature. A small, irregular white shape is visible within the blacked-out area, likely representing a portion of the signature that was not fully redacted.

**Appendix G: Recruitment Poster**

**PARTICIPANTS NEEDED!**

**EXPERIENCES ACCESSING & MANAGING SERVICES**

We are seeking adults living with a neurological condition in Manitoba to participate in a 45 to 90 minute interview at a time and location of your choice.

In this interview we hope to learn about your experiences with accessing or managing healthcare and community services, the support you receive from community organizations, and what else you think can be done to improve your experience of accessing services in Manitoba.

ALS/Lou Gehrig's Disease  
Alzheimer's disease  
Brain Injury  
Brain Tumour  
Cerebral Palsy  
Dystonia  
Effects of stroke  
Epilepsy  
Headaches/Migraines  
Huntington disease  
Hydrocephalus  
Multiple Sclerosis  
Muscular Dystrophy  
Parkinson Disease  
Spina Bifida  
Spinal Cord Injury  
Spinal Cord Tumour  
Tourette Syndrome

**MY CONTACT INFORMATION:** **Monika Wetzel**

 **UNIVERSITY  
of MANITOBA**

This study has been approved by the Joint Faculty Ethics Review Board at the University of Manitoba.

 **family social sciences**

### **Appendix H: Interview Guide**

The purpose of this thesis is to explore the diverse experiences of accessing care and services when living with a neurological condition, with a specific focus on the benefits and barriers of service coordination in Manitoba. In addition, I intend to make recommendations to future service coordinators and government on possible service coordination initiatives that will aim to improve the daily experiences of individuals living with neurological conditions.

Here we will go through the interview guide that I shared with you prior to this interview. It will outline the types of questions that will be asked of you, but I welcome and encourage you to interrupt me at any point to discuss all experiences, observations, and feelings that you find meaningful around accessing services or navigating health and social services, even if they are not outlined on the interview guide.

1. Could you tell me about yourself?
2. Could you explain how you have and continue to locate community or health care services you need for your condition and what that experience was like for you?
  - a. Do you remember having any distinct observations, reactions, comments, or feelings when interacting with service providers?
  - b. From your perspective, what helps a person with your condition be successful at navigating the health care system and community organizations?
  - c. Do you feel that you have access to any particular resources that help you access or manage your care?
3. Can you remember at any point, feeling the need for additional support with accessing or managing services? If yes, how? If no, could you explain?
4. Could you explain what types of support (if any) you have received to help manage and coordinate your care or services?
  - a. How would you say these supports changed your experience when accessing services?
  - b. How do you feel additional service coordination could have changed your experience when accessing services?
5. Can you explain how you might envision the ideal support with service coordination to help with system navigation?
6. Thank you for all your valuable information, is there anything else you would like to add before we end?

#### **Additional topics**

- Integrated person-centered care
- Multidisciplinary care
- Continuity of care
- Patient autonomy
- Are there any other factors (e.g., resources, coping) that you believe have influenced your ability to navigate the health care system?

- Communication
- When we discuss navigating through the health care system or other systems of service providers, what does that mean to you?

**Prepared Prompts:**

- You mentioned \_\_\_\_\_, did this surprise you?
- You mentioned \_\_\_\_\_, could you tell me more about that?
- You mentioned \_\_\_\_\_, what was that like for you?
- You talked about \_\_\_\_\_, describe that experience in as much detail as possible.
- Could you give me an example?
- Could you explain what you mean by...?
- Anything else?
- Can you explain what else happened?
- What were your feelings about that?
- It sounds as though you had a pretty strong reaction.
- It sounds like you're saying ...

## Appendix I: Consent Form

### SERVICE COORDINATION FOR SYSTEM NAVIGATION WHEN LIVING WITH A NEUROLOGICAL CONDITION IN MANITOBA

For questions about the study please contact:



**Sponsors:** Manitoba Graduate Student Scholarship  
University of Manitoba Graduate Student Fellowship

Hello and thank you for your interest in learning more about this research study. Please take your time to review and consider this consent form. Please feel free to ask any questions you may have, including meaning of words, information, or steps that you might not understand.

#### Purpose of Study

The purpose of this thesis is to explore the different experiences of accessing care and services when living with a neurological condition. In particular, I will focus on the benefits and barriers of support provided by community organizations with coordinating those services. With the findings of this study, I hope to make recommendations to future service coordinators and government on possible initiatives that will aim to improve the experience of navigating through the health care system and related organizations.

#### Sample

About 15 adults living with a neurological condition who have accessed services from community organizations or the health care system over the past year will be asked to participate from this study.

For example, some of the community organizations could include:

- ALS Society of Manitoba
- Alzheimer Society of Manitoba
- Canadian Paraplegic Association (Manitoba) Inc.
- CancerCare Manitoba
- Centre for Cranial Nerve Disorders
- Cerebral Palsy Association of Manitoba Inc.
- Deer Lodge Centre
- Dystonia Chapter and Support Group of Manitoba
- Epilepsy and Seizure Association of Manitoba
- Manitoba Brain Injury Association
- Manitoba Huntington Disease Resource Centre
- Multiple Sclerosis Society of Canada (Manitoba Division)

- Muscular Dystrophy of Canada (Winnipeg Community Office)
- Parkinson Society Manitoba
- Society of Manitobans with Disabilities
- Specialized Services for Children and Youths
- Spina Bifida and Hydrocephalus Association of Canada (Manitoba Division)
- Tourette Syndrome Foundation of Canada (Winnipeg Chapter)

### **Study Procedures**

If you agree to participate in this study, you will be asked to participate in a face-to-face interview that is expected to last from 45 to 90 minutes, at a time and private location of your choice. Prior to the interview, you will be provided with an interview guide to outline the types of questions that will be asked of you, though I welcome and encourage you to discuss all experiences, observations, and feelings that you find meaningful around accessing services or navigating health and social services, even if they are not outlined on the interview guide. All interviews will be audio-recorded and transcribed verbatim by myself.

### **Risks, Benefits, and Costs**

Participants will not be compensated for participating in this study. Though I hope that participation will lead to improvements in future navigation of services, this cannot be guaranteed.

There is minimal risk involved in participating in the research study. In the event that abuse and/or neglect is disclosed during an interview, I will be required to report the disclosure to authorities. If you experience any distress throughout the course of the study, you will be provided with numbers to contact a professionally trained counsellor at Klinik (204-786-8686 or 1-877-435-7170) or the Psychological Association of Manitoba (204-487-0784).

### **Confidentiality**

Your confidentiality is my main priority. As a result, all audio-recordings of interviews will be saved electronically on a password protected computer and paper documents, including consent forms, transcripts, any notes, and copy of pseudonyms, will be saved in a locked cabinet. When analyzing data, all identifying information will be removed, to the best of my ability. All participants will be assigned a pseudonym that will be stored in locked file cabinets and in password protected computers at the University of Manitoba until the project is complete. After 3 years, all audio-recordings and documents containing confidential information will be destroyed for your privacy. Your individual privacy will be maintained in all published and written data resulting from the study.

### **Data Utilization**

I intent to use data for several publications, including my Master's thesis, two peer reviewed publications prepared for qualitative or health oriented journals, as well as a report of findings and recommendations to community organizations listed above and Manitoba Health.

### **If I sign, can I revoke it or withdraw from the research after?**

Your decision to participate in this study is voluntary. Should you choose to participate, you can decline to answer any question. If you answer a question you are free to withdraw authorization regarding the use of any information that you have disclosed. In addition, you have the option to

withdraw yourself completely from the study at any point without any repercussions. If you chose to withdraw authorization for information provided, that data will no longer be included in the data analysis or publications of the study. Any level of participation will not affect you in any way; including the support or services received and/or employment status through the organization you are associated with or were contacted through. If you wish to withdraw from the study, you may do so by calling or emailing myself (Monika Y. Wetzel) at [REDACTED] or [REDACTED]. If you are not satisfied with the manner in which this study is conducted or simply desire further information on your rights as a participant, you may contact the University of Manitoba, Fort Garry Campus Research Ethics Board Office at 204-474-7122.

**Statement of Consent**

My signature hereby indicates that I am 18 year of age or older and that I: have read and understand the contents of this consent form; had the opportunity to discuss this study and all questions with the primary investigator; understand that I will be given a copy of this consent form after signing it; freely agree to participate and know that my participation is completely voluntary; and am aware that I may choose to withdraw selected or all information or myself completely from the study at any time.

Although all measures will be taken to protect my personal identity, I understand that confidentiality cannot be guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board, for quality assurance purposes. By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Signed,

Participant's signature: \_\_\_\_\_ Date: \_\_\_\_\_

Printed name: \_\_\_\_\_

---

I, Monika Y. Wetzel, hereby attest that all required explanations with all relevant details of this research study have been provided to the participant named above. I believe that the participant has understood all the information provided and has knowingly given informed consent.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix J: Questionnaire**

Pseudonym: \_\_\_\_\_ Date: \_\_\_\_\_

**Questionnaire: Participant Information**

I hope to collect information from all of our participants so I can better describe the group of people involved in this study. Below, please check the boxes or fill in the answers that best describe you. Please note: all questions are optional and if you have any questions or concerns feel free to contact me at [REDACTED].

1. **Age:**  \_\_\_\_ years
2. **Gender:**  Male  Female  Other: \_\_\_\_\_
3. **Language:**  English  French  Other: \_\_\_\_\_
4. **Marital Status:**  Divorced  Separated  Single, never married  
 Common-law  Married  Widowed  Other: \_\_\_\_\_
5. **Ethnicity or Cultural Group (please feel free to check more than one box):**  
 European  First Nations/Aboriginal  Asian  African  Oceania  
 Caribbean  Other: \_\_\_\_\_
6. **Current Schooling or Employment Status** (work includes unpaid work in the home):  
 Part-time Student  Full-time Student  Retired  Self-Employed  
 Work Part-time  Work Full-time  Other: \_\_\_\_\_
7. **Please include your current or previous occupation:** \_\_\_\_\_
8. **Highest Level of Education Completed:**  
 Grade \_\_\_\_  Certificate or diploma  Undergraduate Degree  
 Graduate School  Other: \_\_\_\_\_
9. **Household Income:**  0 to \$30,000  \$30,001 to \$60,000  
 \$60,001 to \$90,000  \$90,001 and up
10. **Area of Residence:**  
 City of Winnipeg  
 Other: \_\_\_\_\_ (incl. communities outside of Winnipeg)
11. **In general, would you say your health is:**  
 Excellent  Good  Fair  Poor
12. **In general, would you say your mental health is:**

Excellent      Good      Fair      Poor

**13. Have you been diagnosed with any of the following conditions:**

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> ALS/ Lou Gehrig's Disease      | <input type="checkbox"/> Effects of stroke   | <input type="checkbox"/> Muscular Dystrophy |
| <input type="checkbox"/> Alzheimer or Related Dementias | <input type="checkbox"/> Epilepsy            | <input type="checkbox"/> Parkinson Disease  |
| <input type="checkbox"/> Brain Injury                   | <input type="checkbox"/> Huntington Disease  | <input type="checkbox"/> Spina Bifida       |
| <input type="checkbox"/> Brain Tumour                   | <input type="checkbox"/> Hydrocephalus       | <input type="checkbox"/> Spinal Cord Injury |
| <input type="checkbox"/> Cerebral Palsy                 | <input type="checkbox"/> Migraines/Headaches | <input type="checkbox"/> Spinal Cord Tumour |
| <input type="checkbox"/> Dystonia                       | <input type="checkbox"/> Multiple Sclerosis  | <input type="checkbox"/> Tourette Syndrome  |
| <input type="checkbox"/> Other: _____                   |  |   |

**14. Beginning with the condition that you consider to be your primary diagnosis,**

**when were you diagnosed with your condition(s)?**

- Condition #1: \_\_\_\_\_  \_\_\_\_ years ago (primary diagnosis)
- Condition #2: \_\_\_\_\_  \_\_\_\_ years ago
- Condition #3: \_\_\_\_\_  \_\_\_\_ years ago

**15. In the past 12 months, have you accessed services for your condition?**

Yes      No

**16. Do you have Private Health Insurance?**

I have private health insurance      I do not have private health insurance

**17. Please indicate all the services you have accessed from the health care system for  
your condition:**

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> Doctor's office     | <input type="checkbox"/> Walk-in clinic          | <input type="checkbox"/> Case Coordinator      |
| <input type="checkbox"/> Neurology           | <input type="checkbox"/> Rehabilitation Services | <input type="checkbox"/> Physiotherapy         |
| <input type="checkbox"/> Addiction Services  | <input type="checkbox"/> Occupational Therapy    | <input type="checkbox"/> Long-term Care        |
| <input type="checkbox"/> Homecare            | <input type="checkbox"/> Mental Health Services  | <input type="checkbox"/> Vision care           |
| <input type="checkbox"/> Emergency Room      | <input type="checkbox"/> Outpatient Clinic       | <input type="checkbox"/> Assistive Devices     |
| <input type="checkbox"/> Audiology           | <input type="checkbox"/> Community health centre | <input type="checkbox"/> Telephone Health Line |
| <input type="checkbox"/> Disability Services | <input type="checkbox"/> Nurse Specialist        | <input type="checkbox"/> Social Worker         |
| <input type="checkbox"/> Others: _____       |  |  |

**18. Please indicate all the services you have accessed from your local Society, Association, Groups, or community organization for your condition (such as the Parkinson Society, Dystonia Support Group, CancerCare, etc.):**

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Information Services       | <input type="checkbox"/> Referral Services    | <input type="checkbox"/> Education Programs     |
| <input type="checkbox"/> Social/Recreation Programs | <input type="checkbox"/> Financial Assistance | <input type="checkbox"/> Home visits            |
| <input type="checkbox"/> Awareness Efforts          | <input type="checkbox"/> Research Funding     | <input type="checkbox"/> Support Groups         |
| <input type="checkbox"/> Counselling                | <input type="checkbox"/> Advocacy             | <input type="checkbox"/> Provision of Equipment |

**19. Please indicate all the OTHER services you have accessed for your condition.**

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> Vocational training | <input type="checkbox"/> Naturopath              | <input type="checkbox"/> Financial Services    |
| <input type="checkbox"/> Legal Services      | <input type="checkbox"/> Transportation Services | <input type="checkbox"/> Alternative Therapies |
| <input type="checkbox"/> Other: _____        |  |  |
- 
- 

Thank you for time and consideration in answering these questions! Without you this study would not be possible. When you have completed this form, please e-mail your answers to [REDACTED] or bring it with to the interview.

