
Exploring Patient Needs in Island Health:

A Rehabilitation Perspective

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EXECUTIVE SUMMARY

Understanding patient needs is integral to Island Health's planning for and provision of appropriate and accessible services across our geography. The purpose of this report is to explore patient needs as defined by patients, informal caregivers, and clinicians and to identify the unmet needs. Patient needs assessment is a methodology chosen to assist the client to explore the needs of community based patients.

In order to understand the met and unmet needs for rehabilitation patients, interviews were conducted with patients, caregivers and clinicians. Patients living in the community with some involvement with rehabilitation were invited to respond to questions exploring their experiences with a specific set of needs. As well, caregivers who support patients along with clinicians working in the rehabilitation continuum were interviewed using a similar tool.

The interview tool presents fundamental needs categories developed through a review of patient needs literature. The needs were drawn from the research with the populations of community dwelling elderly, multiple sclerosis (M.S.) patients, general neurologically impaired patients and traumatic brain injury patients. A synthesized list of needs was developed to create the conceptual framework, which guided the research. The conceptual framework articulates the needs of housing, equipment, therapy, social and recreational, vocational, cognition and emotions. The interview tool asks open-ended questions based on these needs to explore experiences among participants.

Twenty patients, fourteen caregivers and fifty-six clinicians were involved in the study and the findings generally reflect the needs identified in other patient needs research studies.

The main themes that surfaced through the focus groups for the clinicians were unanimous in their sense of the issues that clinicians face on behalf of their patients regardless of the community. The clinicians across the island identified significant unmet needs for housing, equipment, supportive care, social and recreational, vocational and cognitive and emotional needs. Availability of services was better in more densely populated areas however challenges were experienced north of the Malahat in obtaining equipment and with patients receiving home support services in a timely way.

The average age of the patient sample was 61.55 years with a significant number of younger participants who noted gaps related to return to work and access to services that meet their needs. Younger caregivers noted more significant issues with burden than their older counterparts. The most significant gap given our younger population was related to vocational needs and cognitive and emotional needs often limiting the ability to return to productive employment.

Patients and caregivers identified six themes within the context of the needs based conceptual framework. These included information, out of pocket, caregiver burden, accessibility and availability, emotional support and transportation.

Patients and caregivers spoke at length about their need for information especially at the transition points between inpatients and outpatients and after they have completed their outpatient program. More than half the patient and caregiver participants identified out of pocket costs associated with equipment and ongoing therapy as well as the patients expressed concern about the burden that is placed on their caregiver. There were a few caregivers who identified the need to ‘fight’ on behalf of their loved ones for services and resources. Accessibility and availability is a large bucket that considered the accessibility of services from therapy to home support and equipment and the issues were similar for patients and caregivers. Transportation was a key issue for patients, often the responsibility falls to the caregivers particularly the spouses.

The study concludes with a number of considerations for the client:

1. There are two system level needs that were identified; these include housing and a more comprehensive equipment program.
2. There is a need to focus on improved supports to provide a combined model of patient and caregiver focused care.
3. In order to provide services that meet the needs of patients beyond the typical three-month period allotted for outpatient therapy, partnerships need to be explored with community programs such as those provided through the community recreation centres as well as non-profit support groups.
4. For clinical services we need to examine the roles of the different provider groups and determine the opportunities to look at the work that each discipline is doing and look at the addition of support roles to improve accessibility and availability.

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INTRODUCTION

Island Health provides health services to its population of 771,660 residents (Island Health, 2014, About Us, Facts and Figures). This population occupies Vancouver Island, the Gulf Islands, Discovery Islands, and extends onto the mainland north of Powell River to south of Rivers Inlet (Island Health, 2014, About Us, para.1).

As a health authority, we are challenged with an aging population in all communities. Based on the Local Health Area profiles produced by the Planning Department, the population aged 75+ is expected to increase in all communities from a low of 77% in Sidney, 127% on the Gulf Islands, 192% in Courtenay and a high of 194% in Sooke by 2034 (Planning and Community Engagement-2-5, 2013, p. 1). As well, we are experiencing significant demand pressures for the publically funded health supports in acute, community and residential sectors across the island.

As we age, there is an increasing possibility of disability resulting from a neurological event such as a brain injury from a stroke or a traumatic head injury or from a progressive neuromuscular disease such as M.S. (Chappell & Cooke, n.d., p. 1). Disability may also result from an amputation, loss of vision, or diseases such as rheumatoid arthritis, among others. These disabilities are generally for life and people must learn to compensate for their limitations.

There are other diseases where the disabilities are more episodic in nature. As an example, we currently provide services to an orthopaedic population, whom has had total hip or total knee replacements. These patients are considered elective, meaning for the most part they have chosen to have the surgery to correct an osteoarthritic condition, which can limit function prior to the surgery. These patients have short-term disability that is generally gone after 3 – 6 months post-surgery and they resume their normal activity. They are the main users of our outpatient physiotherapy resources leaving limited capacity to address the mobility and functional needs of neurological patients such as those who have had a stroke. Neurological patients will have mild, moderate, or severe disabilities that rarely completely resolve. When one overlays the aging process, these issues can require further compensation and management that is often unavailable. So understanding the needs of our patients is an important step in evaluating, planning and reallocating services to meet the expressed needs of our populations.

Rehabilitation is defined as a “goal oriented and often time limited process, which enables individuals with impairments, activity limitations, and participation restrictions to identify and reach their optimal physical, mental and/or social functional level through client focused partnership with family, providers, and the community. Rehabilitation focuses on abilities and aims to facilitate optimal independence and social integration” (Adapted from World Health Organization) (Alberta Health Services, 2008, p. 5). This definition helps to articulate the value that rehabilitation professionals bring to health care.

These services are an essential component of the Island Health's ability to meet the care needs of patients across the continuum of care, from home/community, to hospital, to outpatient settings, to residential facilities.

For the purposes of this project, rehabilitation includes physiotherapy, occupational therapy, recreation therapy, speech language pathology, and social work.

In Island Health, rehabilitation resources are spread across different services and portfolios causing fragmentation of the services for patients.

In 2013, a review was completed by an external consultant, which focused on a high level review of Rehabilitation services as it is organized across Island Health. The review identified a number of recommendations to move toward a new structure for rehabilitation. I have been asked to address one of the recommendations through my work in the health authority; an inventory of services and as part of that a needs assessment of rehabilitation patients. This work is important as we have no evidence that the programs and services, which we are currently providing actually address patient needs in a responsive and effective way.

The purpose of this report is to explore patient needs as defined by patients, informal caregivers, and clinicians and identify the needs that are unmet. Patient needs assessment is the methodology that was chosen in order to assist Island Health to explore the needs of community based patients. Patients living in the community with some involvement with rehabilitation were invited to participate in an interview to respond to questions exploring their experiences with a specific set of needs. As well, caregivers supporting patients were interviewed and clinicians working in the rehabilitation continuum were interviewed in a focus group format using a similar set of questions.

Understanding patient needs is integral to our planning for and providing appropriate and accessible services across our geography. This report provides a summary of these needs from community dwelling patients. Based on the literature the needs that are explored are housing, equipment, therapy, social and recreational, vocational, and cognition and emotions. The findings from the interviews and focus groups are presented and include direct quotations illustrating the needs identified with the target populations. Finally, the relationships and interpretation of the Island Health patient experiences is discussed.

LITERATURE REVIEW

An assessment of needs is described as a “systematic approach to ensure that the health service uses its resources to improve health of the population in the most efficient way” (Wright, Williams, and Wilkinson, 1998, p.1). This definition is relevant to a health care system where we have certain constraints such as availability of dollars and human resources, which drive a match between need and service availability.

A need is a subjective concept that is “felt by the person” (Talbot, Viscogliosi, Desrosier, Vincent, Rousseau, and Robichaud, 2002, p.2). Therefore, understanding the patient’s subjective experience is an important factor in exploring the current services and how they are accessed and utilized. According to Talbot et al. (2004) a need is a function of the characteristics of the individual and their environment, the service providers and of the organization (p.2). Over time, the needs for an individual change based on what programs are being accessed and what other supports are available in the individual’s life (Ibid., p. 2). Unmet needs are a challenge to assess as evidenced by Diwan and Moriarty (1995) who describe needs as “elastic and relative” (p. 49). A need can be values based and so difficult to examine in populations.

Heinemann, Sokol, Garvin, and Bode (2002) describe the concept of “service deprivation” (p. 1052) as the result of needs not being met by available services. For the purpose of this study, I define felt, unfelt, expressed and normative needs as articulated in the articles by Heinemann et al. (2002) and Vincent, Deaudelin, Robichaud, Rousseau, Viscogliosi, Talbot, and Desrosiers (2007).

Heinemann et al (2002) distinguish between felt and unfelt needs; a felt need is a “perceived want” (p. 1052) whereas an unfelt need is one that an individual lacks awareness of (Ibid., p.1052). This apparent lack of awareness is present for a variety of reasons including: not being aware of the services available, a lack of confidence in the individual’s own abilities resulting in the individual limiting their activity participation causing them to fail to seek help (Ibid., p.1052). This lack of confidence supports the social isolation and compromises the patients’ community integration.

Expressed needs are the felt needs that are turned into action. The action can be reflected through a wait list for a service, which according to the authors is a measure of the unmet need (Vincent op. cit., p.3). A normative need is described through the eyes of the expert health care providers (Ibid., p.3).

Diwan and Moriarty (1995) explore patient needs in a community dwelling elderly population. These authors describe unmet needs as issues that are not being served by the program and services available. The authors present a conceptual framework that categorizes needs into six themes including basic maintenance, supportive, rehabilitative, treatment, preventative, and promotive (p. 53). These needs are aligned against four possible barriers and are explored with the consumer, the provider and the informal caregiver (Ibid., p.50 & 53).

The study sample included 11 patients with brain injury: 10 stroke patients and 1 traumatic brain injury patient and 6 multiple sclerosis patients. These diagnostic groups are explored in the patient need literature and a summary is presented here.

Brain Injury

Brain Injury can be due to a stroke or a traumatic head injury. In the case of stroke, it most commonly happens in adults over seventy years of age however there is evidence that the number of adults suffering a stroke in their fifties is increasing (Heart and Stroke Foundation, 2014, para. 4). Stroke is one of the leading causes of death and disability in British Columbia (Cloutier- Fisher, 2005, p. 221).

Younger patients with stroke present some unique challenges that are not seen in the older population. Most specifically patients with speech, cognitive, and mobility issues are challenged by residual impairments to return to employment. Kersten, Low, Ashburn, George, and McLellan (2002) found that in a group of young stroke patients, they had needs related to assistance with family concerns, “intellectual fulfillment” (p. 865) and needing a break from their situation.

With patients who experience stroke, 60% of them will have neurological impairment requiring rehabilitation (Cloutier – Fisher, 2005, p. 221). Patients vary in their presentation of disabilities including weakness or paralysis on one side of the body, speech and cognitive impairment, and depression resulting in varying levels of dependence in daily activities (Ibid., p. 221). All of these aspects have significant impacts on the individual and their support system and create perceived needs.

A population of older stroke patients and their caregivers living in the community as well as health care professionals and managers identified themes of behavior, language, motor abilities, and intimacy in a needs assessment by Vincent, *op. cit.*, p. 6.

There were four environmental factors considered by participants, as having unmet needs including health system factors such as medical and rehabilitative care; the education system, which focuses on information; and “public infrastructure and community organizations” (Vincent, *op. cit.*, p. 6).

Participants talked about the issue of “scarcity of resources” (p. 6), which related to the money to pay for services and the lack of health care providers to offer the services (Vincent et al., 2007). This issue is visible through waitlists and inequities between communities.

Some studies highlighted the issue of continuity within the system of services accessed by patients and the lack of access to supports such as peer support groups and respite as well as short-term housing opportunities (Ibid., p. 7). As well, the patients and their caregivers further identified two concepts - “the lack of continuity and coordination of care and the lack of information about services aids and adaptations” (p. 663).

The need for information has been identified in a number of studies. Needs related to education involved the need for information to be provided to the caregiver when and where it is needed (Vincent, op. cit., p. 7).

McLean, Roper-Hall, Mayer and Main (1991) interviewed 20 patients and 20 caregivers and found there were needs for information through education to ready caregivers to be able to cope with their loved one's care especially those who require significant amounts of support (p. 562).

Garratt and Cowdell (2005) conducted a study regarding patients' need for information and found that patients' needed information about their illness related to diagnosis and prognosis as well as referrals and information about services. The authors also identified a need to review the information provided to patients and caregivers with them on a few occasions in order "to build on it or to make sense of it" (p. 3). It was felt that patients in the midst of recovery from a traumatic event such as a stroke would benefit from returning to the information a number of times to ensure that it is retained (Ibid., p. 3)

Within the Heinemann et al. (2002) study, specific to the Traumatic Brain Injury (TBI) population, they identify 27 needs which are functionally based such as "feeling part of my community" (p. 1054). The results of this study, demonstrate that the most common unmet needs amongst TBI patients to be "emotional, cognitive and social needs" (p. 1058). At the same time the least common are the needs related to household tasks, personal care activities and transportation (Ibid., p. 1058).

Multiple Sclerosis

Multiple Sclerosis in Canada has a high prevalence compared to other countries (Beck, Metz, Svenson, and Patten, 2005, p. 516). Of the five regions considered in this study, British Columbia was second last in prevalence in terms of M.S. per 100,000 (p. 517). M.S. is a chronic disease that eventually disables the adult depending on the type of M.S. that they have been diagnosed with (Finlayson, 2004, p. 54).

Turner Stokes, McCrone, Jackson, and Siegert (2013) conducted a study to explore the needs of patients with long-term neurological disability living in the community. These authors utilized the Needs and Provision Complexity Scale (NPCS) to examine met and unmet needs in this population (Ibid., p. 1). Patients demonstrated significant gaps in relation to accessing rehabilitation in the community, equipment aids and support for social interaction (Turner Stokes, op. cit., p. 7).

The study by Marcia Finlayson examined a M.S. population stratified into three age groups. The younger group with an average age of 62 years was found to be making decisions at an age younger than most of their peer group and which adds to their level of perceived stress (Finlayson, op. cit., p. 60).

In a study by Kersten, McLellan, Gross-Paju, Grigoriadis, Bencivenga, Beneton, Charlier, Kelelaer, & Thompson (2000) the authors developed a tool called the International Services and Needs Assessment (SUN), and used it to interview M.S. patients in five different countries. They identified six groupings of needs including basic needs, equipment, service, information, financial, and self-actualization (p. 46-47).

The most significant needs that were not being met were related to finances and the need for information and services. Some of the caregivers in two of the countries identified a need for respite services (Ibid., p. 47).

Multiple Sclerosis is an unpredictable disease and can challenge an individual's ability to be future focused and fulfill certain roles they play (McCabe, Ebacioni, Simmons, McDonald, and Melton, 2014, p. 4). These authors researched the role of support groups for M.S. patients and identified a perceived need for appropriate supports that assists them to feel they are not alone and helps families to support the person with M.S. through adjustment to changes in function (Ibid., p. 4).

Finlayson and Cho examined M.S. support resources to understand how and why these types of resources are used. The authors found that age and community size was influential when it comes to utilization of the group. Younger M.S. patients had attended these groups recently seeking new information and support (Ibid., p. 488).

To develop my conceptual framework for this study, four articles, from the literature, were utilized to distill my list of patient needs incorporated into my interview tool. These articles include Turner Stokes et al. (2013); Heinemann et al. (2002); Kersten et al. (2002) and Diwan and Moriarty (1995). By examining these articles and comparing their needs, I developed the key needs that form the foundation of my interview tools for this project. Please see Appendix to view the table that describes the needs identified in each article illustrating the differences and commonalities across the articles.

WORKING CONCEPTUAL FRAMEWORK

Assessment of need is a challenging area to attempt to address due to the subjective nature of needs (Heinemann, op. cit., p. 1052). In order to understand the met and unmet needs for rehabilitation patients, I conducted interviews of patients, caregivers and clinician focus groups. For the patient group, I am particularly interested in this from the context of their home community.

I explore this through the use of an interview tool that presents some fundamental need categories. These categories were developed through a literature review presented earlier and include community dwelling elderly, M.S. patients, general neurologically impaired patients and traumatic brain injury patients. Upon reviewing these articles, a synthesized list of needs was developed to create the conceptual framework, which will guide my research. The key concepts, which I will use in examining this area, are included in Chart #1.

Chart #1

1. Housing <ul style="list-style-type: none">• Adapted housing, Supportive housing, Residential care
2. Equipment <ul style="list-style-type: none">• Basic ADL• Specialty – including power mobility, prosthetics
3. Therapy <ul style="list-style-type: none">• Services received by Physio, OT, SLP, SW, Rec. Therapist, Neuropsychologist• Intensity of services
4. Supportive Care <ul style="list-style-type: none">• Personal care, homemaking, meal preparation, supervision, transportation
5. Social/Recreational <ul style="list-style-type: none">• Recreation centres for exercise/activities, hobbies, Senior centres, societies
6. Vocational <ul style="list-style-type: none">• Employment either paid or volunteer
7. Cognitive/emotional

The first category is housing as a basic need and includes the broad spectrum of shelter including rental units, supportive housing, adaptive housing and residential care. For the purpose of this study supportive housing describes assisted living, mental health housing, group homes, etc.

Housing is important as a social determinant of health and as such, housing is seen as “a necessity” (p. 29) for healthy living. Individuals are at increased risk from a health perspective when living in “unsafe, unaffordable, or insecure housing” (Mikkonen & Raphael, 2010, p. 29).

Equipment is the next category and describes equipment supporting an individual’s activities of daily living, e.g. transfer tub bench, wheelchair. There is also the area of specialized equipment, which includes items such as tilt in space wheelchairs and prosthetics.

Equipment is important as supports to independence. As an example, a patient who has had a mild stroke with some residual paralysis on one side of their body may be dependent for bathing unless they have a transfer tub bench that allows them to sit on the edge and slide across into the tub.

The next category is Therapy and addresses the services provided by professions listed in Chart #1. These services can be measured by intensity of service and whether there is a cost associated. Therapy enables patients to reach their optimal level of function; it is strength based and works toward community integration (Alberta Health Services, 2008, p. 5).

Supportive Care explores a number of services including activities of daily living (ADL) support for personal care and instrumental activities of daily living (IADL) including meal preparation, housekeeping, laundry, the need for supervision, and transportation. Typically personal care is supported through Home and Community Care whereas the IADL services are purchased by the patient or caregiver and are important to maintain the individual in their home.

Social/Recreational is an important need that looks at community re-integration. This category looks at the development of programming in the community to support patients and their caregivers through diagnostic specific societies such as the M.S. Society or adaptive fitness classes through recreation centres. This is important for patients with disability to “increase quality of life and decrease mortality after a stroke” (p. 1) and improves community integration (Venna, Xu, Doran, Patrizz, & McCullough, 2014).

Vocational needs involve supportive services that assist the individual to return to work post injury or illness. Work is considered a therapeutic activity and promotes “physiological survival and psychological well-being” (Lee, 2010, para. 1). Vocational rehabilitation is important to assist those with disabilities to find employment after a major illness or injury. There are several aspects to vocational rehabilitation including assessment and evaluation, on the job training and accommodation to name a few (Ibid., p. 4).

Cognitive/Emotional needs are characteristics such as memory, problem solving, judgment and executive functioning for cognition and for emotional needs it encompasses depression, grief, loss due to disability or bereavement, sadness, or anxiety.

Cognition refers to “mental activities such as seeing, attending, remembering, and solving problems” (Cognifit, 2015, para. 1). It is these processes that assist us to interact with others and is what determines our intelligence and who we are as people (Ibid., para. 1)

Emotional health is very important and stressors can impact our emotional well-being. The stress of a major illness and resulting disability can trigger depression and anxiety. Researchers highlight that almost 30 % of patients with stroke will suffer from depression resulting in impaired recovery and decreased quality of life (Paolucci, 2008, p. 145).

METHODOLOGY

Research Question

What do patients, caregivers, and rehabilitation clinicians identify as needs of patients in their home community?

Research Design

I have chosen an exploratory, semi-structured interview design, which will be delivered through patient and caregiver interviews and clinician focus groups.

Research Objective

As described earlier, the purpose of this study is to explore the patients' needs from three different perspectives – patients, caregivers, and clinicians. The objectives identified below will help to detail the need from these perspectives and further identify the gap between the perceived needs of patients and caregivers and what is available.

1. To explore needs of the rehabilitation patient using the interview tool developed through the conceptual framework.
2. To understand the gap between perceived needs and services available in the community.

Sampling

This study was approved by the Joint Ethics Review Board for Island Health and the University of Victoria. The study was conducted with patients in Island Health who have had an inpatient rehabilitation unit stay, patients seen in the M.S. Clinic and patients who have participated in the outpatient programs in acute rehabilitation.

Patients and caregivers were recruited through the nurse leaders on the rehabilitation units as well as the coordinators for the outpatient departments across the acute care sites. As well, patients were approached through the M.S. Clinic in Victoria. All patients and caregivers over a period of two months were provided with an invitation to participate, directing them to contact the primary investigator if interested in participating in the study.

The clinicians were recruited through the managers for the programs where they work. Using the services of an administrative assistant, a request was sent to the managers asking them to provide the email addresses for their therapy and social work staff to the administrative assistant. The assistant sent the study invitation to the clinicians via email requesting that interested clinicians contact the primary investigator.

Specific inclusion criteria for patients included 1) involvement with therapy along the continuum, 2) living in their home community, and 3) the capability to answer questions. Caregivers who were currently supporting a family member receiving rehabilitation services and clinicians representing each of the communities on the island as well as

representing acute care, home and community care, seniors' health and residential care and work in the area of rehabilitation and social work were invited to participate.

Across the island, 20 patients participated in interviews and were visited in their homes by the primary investigator (n=20). Fourteen caregivers were recruited to participate (n=14), three of which were independent of the patients. Of the remaining 11 caregivers, four caregivers were interviewed together with their respective patient/family members. This was due to the level of speech impairment and was an attempt to improve the quality of responses interviewing the caregiver and the patient together.

Chart #2 describes the distribution of age and gender for the patient sample. The overall average age for the patient group was 61.55 years with a range of 41 – 85 years. The average age for the brain injury patients is 72 years with a range of 42 to 85 years while the average for the M.S. patients is 55 years with a range of 41 to 66 years.

Chart # 3 describes the diagnoses for the patients with over 75% of the sample population having a neurological diagnosis.

Chart #4 describes the home locations of the patients and caregivers.

Fifty-six clinicians were interviewed (n=56), 54 clinicians across 12 focus groups and two clinicians were interviewed individually. Chart #5 summarizes the number of clinicians involves by discipline and which sector they represented.

Chart # 2 – Characteristics of Patients

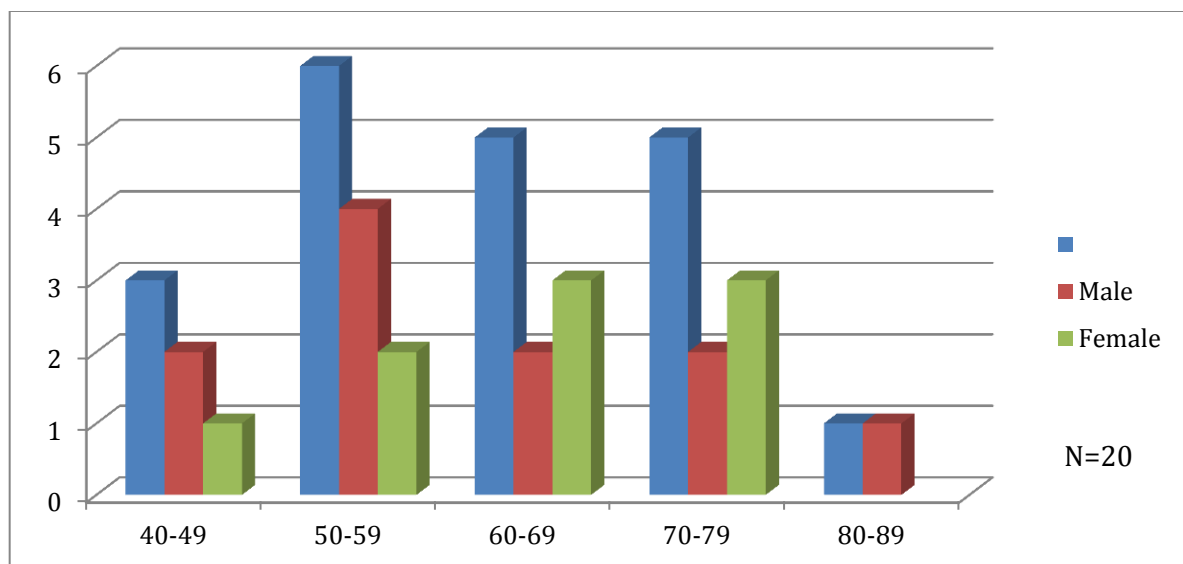


Chart #3 – Diagnosis of Patients

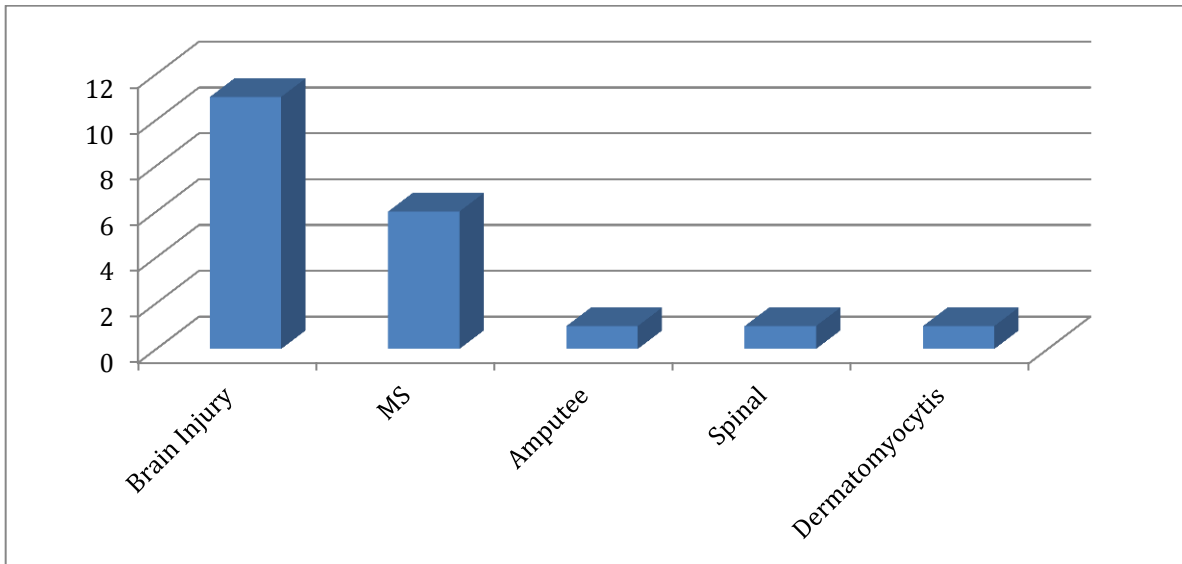


Chart #4 – Home Location by Community for Patients and/or Caregivers

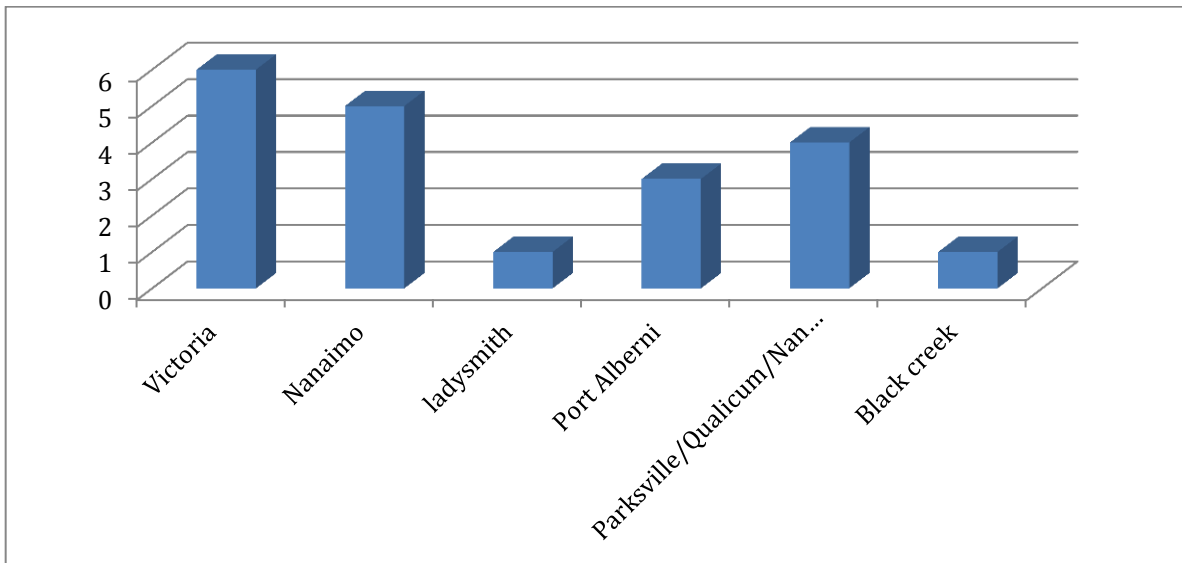
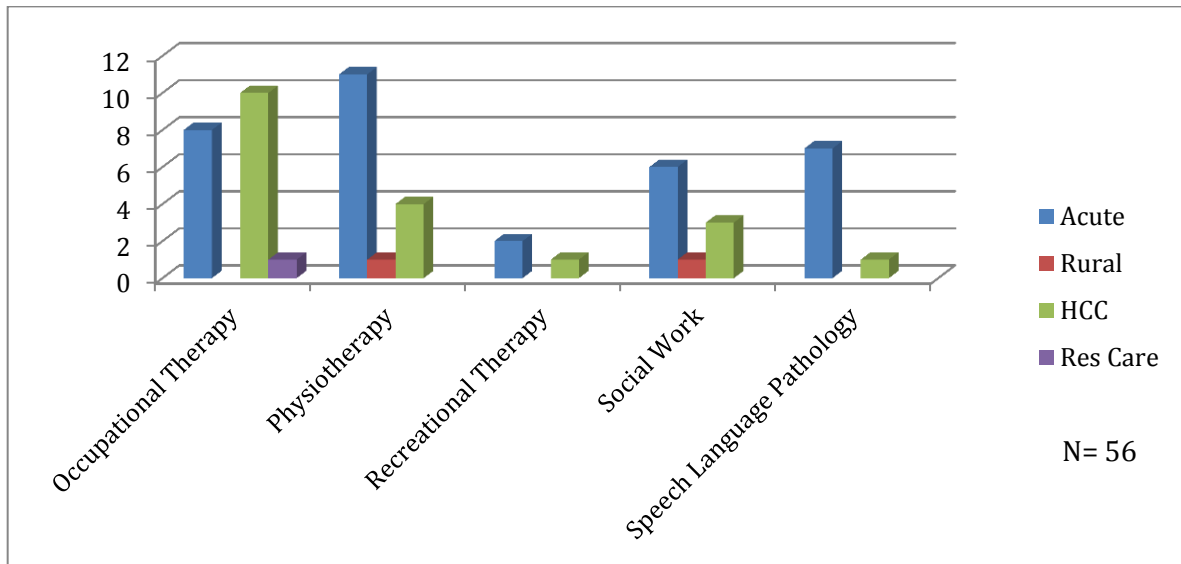


Chart #5 – Clinician Participants by Discipline and Health Sector



Interview Design

Due to the subjective nature of needs, a semi structured interview process was chosen as the method of data collection. The use of this process provides participants with the time to explore topics guided through open-ended questions (Social Research Skills, n.d., p. 1). This technique is useful when the investigator is attempting to understand the points of view of the target populations (Ibid., p. 1). The questions were based on the conceptual framework and were developed to explore participant experiences with the needs identified. The tool consists of eight questions; one for each need. Each question asks the participants(s) to describe an example and identify what went well and what didn't go well. The three participant groups 1) Patients, 2) Caregivers, and 3) Clinicians were asked the same questions with slight wording changes to reflect their context. An interview script was developed and used to guide the discussions and further probing was done to improve the understanding of the concepts or ideas.

Below is an example of a question from the interview tool for the patients:

Describe an example of what services you have accessed within your home community related to your illness/disability.

What went well?

What didn't go well?

See Appendix B for a copy of the interview tool

Methods of Analysis

Interview responses were recorded electronically with the investigator taking notes on an Island Health laptop. These notes were supplemented by an audio recording of each interview. Audio recordings were reviewed and compared to the investigator's notes to ensure a comprehensive transcript for each interview and focus group. The notes were

coded using guidelines of Braun and Clarke (2006) using a semantic approach for coding the data. The data was explored at the surface level in order to identify individual experiences (Braun & Clarke, 2006, p. 84). These authors present a guideline for conducting thematic analysis with five phases beginning with a review of the data to become familiar with the detail (p. 87). As the primary investigator, I conducted the interviews and focus groups personally taking notes and then reviewing the audio recordings. This allowed me to immerse myself in the data, which further progressed the coding and the theming (Ibid., p. 87). The second phase was to develop the initial codes, which involved grouping the data by concepts. Phase three takes the list of ideas or concepts and begins to put them together into broader themes (Ibid., p. 89). The fourth phase involves going over the themes with an eye for refinement followed by the fifth phase of creating the definitions for the themes (Ibid., p. 92).

FINDINGS

Clinician Focus Groups Results

Twelve focus groups and two single interviews were conducted with clinicians from acute rehabilitation, home and community care, and residential care. The single interviews were due to scheduling issues with the clinicians; one clinician from Tofino and one clinician from Mount Waddington. There were four focus groups in south island, three groups in Nanaimo, two groups in Cowichan Valley, and one group on the West Coast, in Campbell River and in Comox/Courtenay.

The information that follows is a summary of the clinician input through the needs based interview tool. The clinician focus groups produced an enormous amount of data and in order to optimize sharing this information it was decided to present the highlights from each of the key needs that were asked about in the focus groups.

Clinicians identified problems as opposed to needs. With their involvement as a health care provider, the clinician has a more ‘behind the scenes’ viewpoint – patients do not directly experience these issues. These themes discussed in this section were unanimously identified across all the focus groups.

Housing. Housing is defined as any type of shelter that people live in and includes, single-family homes, rental units, supportive housing, transitional care and residential care. According to the focus groups, housing is an issue regardless of where you are on the island. The clinicians describe several challenges in working with patients in acute care in preparation for discharge. These problems include lack of brain injury housing in the health authority and what is available has significant wait lists. This shortage impacts the length of stay of these patients within acute care while they wait for options to be identified. All communities have identified the need for affordable and accessible housing however often only one of these elements is available.

“Happens all the time in acute, housing is an issue for discharge planning and for taking patients to rehabilitation, for those who are cognitively impaired or globally aphasic-they are no longer able to live on their own.”

If renovations are required to their housing, this can impact length of stay in acute care. In some communities there are no transitional beds for patients to go to while waiting for the renovations to be completed.

In most communities, clinicians identified some Assisted Living resources and then residential care services with nothing in between.

“It is such a jump to move psychologically through those transitions in your mind it is too quick, too fast and it is a very difficult process and then if the caregiver gets sick in all this then you are really hooped and people don’t understand.”

Residential services are designed for the elderly not for the younger brain injury population who often experience behavioural issues. As well, the clinicians, indicate they are built around single diagnoses such as dementia rather managing patients with multiple and complex issues.

The clinicians note that there are two levels in residential care that patients and their families are not aware of prior to their selection and admission to a facility. There are facilities that provide equipment and rehabilitation staff and these are often Island Health owned and operated. The private paid facilities and the affiliates to Island Health typically do not provide equipment or rehabilitation staff. In these situations families must buy the needed equipment for their family member and may also need to purchase private rehabilitation services to address their functional needs. A few of the focus groups spoke of the lack of awareness of types of resources and services available to patients as noted in this quotation *“I also think there is something to be said that families and patients don’t know, what they don’t know.”*

Equipment. Clinicians state that it is easier if the person is going home with basic equipment needs because they typically can access this equipment through Red Cross loan. In south island, there is a perception amongst the clinicians North of the Malahat that there is better access to equipment in Victoria compared to other communities. The Red Cross receives some funding from Island Health to provide an equipment loan program to the communities on the island however there are communities who have nothing. In these cases patients must travel elsewhere to access needed equipment, e.g. Parksville/Qualicum patients travel to Nanaimo.

North of the Malahat the clinicians indicate that the loan cupboards are smaller and the days that this equipment is available are often limited to 2 to 3 days per week with the exception of Nanaimo. Depending on where you are on the island dictates whether the equipment is available and accessible and this contributes to issues in discharging patients home in a timely fashion.

Clinicians from outlying areas note that a lack of equipment in their areas has further impact on home and community care being able to support patients in their homes.

“It puts people at high risk to fall and care workers are at high risk for injury and caregivers are at high risk for reaching their breaking point more quickly, like a lot of times people are admitted to residential care or hospital due to caregiver stress or social situations and that is a lot of times what it is they just can’t deal with it.”

Clinicians identify that specialized equipment like hospital beds, low air loss mattresses, tilt recline wheelchairs among others are difficult to locate on loan and this is more prevalent up island. This results in patients having to rent or purchase the equipment - *“A lot of people in this community can’t afford to purchase or rent so they are at a whole disadvantaged because it is not available and they can’t afford it.”*

Therapists in various communities are often delivering equipment, as there is no delivery service through Red Cross in some communities e.g. Port Alberni and Cowichan Valley.

“There are some frustrations out there for outlying areas where there is more limited equipment available and certainly for delivery of equipment and not having that service in the Cowichan Valley so sometimes therapists are spending time transporting equipment rather than spending time with clients.”

Patients from the North Island have to come to Campbell River in order to access equipment from the vendor.

“Vendors will not go all the way up so they are not offering equipment for trial so patients come to Campbell River and purchase equipment only to get it back and find it does not fit or work in their setting.”

This also occurs on the West Coast and is particularly relevant for communities such as Tofino and Ahousat.

“Getting equipment out there is...I beg borrow and steal I rely on whoever is driving out that way (Tofino) because First Nations Health Authority won't pay for delivery and they won't pay for taking something out there to trial and medical companies don't want to pay for it themselves especially when we have to barge a power wheelchair to Ahousat.”

Therapy. A common theme with all communities had to do with the generalization of the role of therapy in Home and Community Care.

“To me it is an example of them losing sight of what I do and what I bring. All you are wanting me to do is this generalized case management without actually ... I would like to work to the full scope of my practice and people still need treatment when they can't get out of their home or to keep them functioning.”

For communities such as Cowichan Valley some services are not available and patients have to travel to Nanaimo for Intensive Outpatient Program, Speech Language Pathology, splinting, and hand therapy.

“One frustration, I see people having to drive great distances to receive these services when they should be available in their community.”

“It just kills the loved one doing the driving the stress from that is just huge you know not having a five or ten minute drive as opposed to 40 minutes.”

As we move up the island, the numbers of full time equivalents (FTE) are smaller and the populations more dispersed, resulting in a small number of FTE to cover larger geographical areas. For people with longer term needs they have to locate therapy or social work services privately in their community.

“ and in North Island, the far north, we have 1 – 2 FTE of physiotherapy and occupational therapy and have just filled some longer term vacancies those positions cover inpatients, home and community care, and residential care.”

Distances are large and people are dispersed across the geography and some are not seen by the local staff in their communities they travel to CRH to be seen there.”

Therapists talked about:

“front loading of services, not follow-up over time. What we do as clinicians we just give them everything we know and as much knowledge as we can and then based on what they can afford they will go out and do more.”

“We focus so much in the first ten days in hospital when they cost the most and when they are discharged from hospital there is so little left.”

Supportive Care. Clinicians identify that there is a lack of services to meet the IADL needs such as grocery shopping, meal preparation, banking, paying bills, etc. Several clinicians across the island said- *“We make our patients dependent otherwise they can’t access supports so we don’t actually provide what they need.”*

Most if not all of the clinicians spoke of a program called Better At Home and it provides services like transportation to non-medical appointments and other more instrumental activities that patients may have to pay for. One clinician described this as the- *“Crawl up the ladder and change the light bulb for me service.”*

A common theme in the focus groups is the inconsistency of workers going into the home. Patients can have 10 different workers in their home and sometimes more. This variation causes an issue with therapist delegation of tasks, as they have to train multiple workers and then provide them with adequate supervision for the task.

“With rehabilitation we would train the workers but there is a disconnect about supervision because those workers are supervised by a nurse and it is a bit contrary to our practice standards that say we are supposed to provide supervision and training ongoing.”

Transportation was unanimously identified as a huge issue for patients accessing services. If patients have spouses or family members who can drive, they are better off. In outlying areas like Parksville/Qualicum there are limited therapy services available and so people have to travel to Nanaimo for outpatient rehabilitation for example. Clinicians note that this distance to travel impacts the patient’s ability to participate in their therapy as they are more fatigued than if they were living locally.

“Handi Dart is sketchy at best” was a consistent message across the island. Most often it runs only six days per week not into the evening. Some patients do not live in the area where Handi Dart runs. People have to book two weeks in advance of their need. Their booking system is automated which presents a challenge to those who are cognitively impaired. The demand for the program has surpassed its capacity to provide a timely service resulting in patients waiting a long time before and after treatment to be picked up increasing patient fatigue.

Social Recreation. This need is an important aspect in assisting the patient to integrate back into the community. Through the focus groups I explored the partnership opportunities that the various outpatient departments may have initiated. There are a couple of communities that have developed opportunities in the recreation centres for programming that focus on balance, adaptive exercise, cognition and falls prevention. In particular the recreation centre in Ladysmith has worked with the Ladysmith Health Centre to:

“provide an abundance of services and they have different exercise programs with different levels. Basically they saw a need and communicated with us and they took courses with the therapist. They established that program recognizing a need for something more than falls prevention.”

In south island there are a couple of recreation therapists who work with patients to assist them with integration into the community.

“We have the Moving On group to try to fill some needs of the younger stroke and brain injury population connecting them with the community and promoting peer support and learning how to access recreation centre programs.”

Vocational Needs. For the most part clinicians were not aware of any resources for vocational rehabilitation in most areas saying *“The neuro population often has cognitive and language issues and so they present a challenge for us in getting them back to work.”* The outpatient neuropsychologist receives referrals looking for guidance regarding return to work issues.

Cognitive/Emotional

Cognition. The clinicians indicate that they complete cognitive screens and assessments but there is not a lot of intervention *“there is not a lot of supports for the younger people.”* The outpatient neuro program is the main services on the island providing cognitive assessment and follow-up therapy. Home and Community Care occupational therapists up island say: *“I don’t think we manage cognition at all in the community. I think we assess it and try to keep people safe, our caseloads are literally – ‘don’t go there’.”*

Emotional. Clinicians have identified a gap in services with emotional support.

“I don’t think I would have to say that the publically funded services don’t manage that very well. I heard feedback about bereavement from younger people who lose a spouse or partner and they go to the support groups but they say they don’t feel like they fit in.”

Summary of Clinician Focus Group Results

The clinicians across the island identified significant unmet needs for housing, equipment, supportive care, social and recreational, vocational and cognitive and emotional needs. Availability of services was better in more densely populated areas however challenges were experienced north of the Malahat in obtaining equipment and access to outpatient therapy in a timely way to support their needs. Clinicians felt that there are needs related to IADL that if met would support the patient to remain in their community.

The availability of social and recreational programming was dependent on the community with Victoria and Ladysmith having the most collaborative partnerships with recreation centres of all the island communities.

The most significant gap given the subset of younger patients was related to vocational needs and cognitive and emotional needs often limiting the ability to return to productive employment and/or re-integrate into the community.

Patient Interview Results

The thematic analysis has produced 6 themes: Information, Out of Pocket, Caregiver Burden, Accessibility/Availability, Emotional Support, and Transportation.

These themes were common across the 8 needs that were explored in the interviews and focus groups.

Theme: Information. Information is defined as education that is requested by patients and caregivers regarding services that may be part of their community and/or are needed in order to improve function and independence. The information needs are defined based on the context and the person making the request. Six out of twenty patients identify needs for more information across the continuum.

“The thing I think I found most frustrating ... M.S. isn't a new disease it would have been a lot easier if they had a package – newly diagnosed package. What you might be faced to deal with in the future these are the things you need to think about”

“My biggest feeling is that when I left they didn't give us an exit package we didn't know where to look for services”

Patients identified issues with transitions between acute and community and after outpatient therapy has come to an end and shows that patients lack the information about what the next steps are - *“They gave me a lot of brochures that I can't read and a website – I can barely use a computer”* due to his visual impairment.

This quotation illustrates that the information provided needs to be individualized to the patient's need. Information should be offered through a number of media as the learning style for each patient or caregiver will vary. For some it may be a package and for others it may be a website and still others may benefit from both. The other piece that has been mentioned in the interviews is having contact with an individual in order to individualize the information for their context and provide a consistent point of contact.

Theme: Out of Pocket. Out of pocket is defined as the services and equipment that patients have to pay for out of their pocket in order to maintain them in the community. In the context of this study patients potentially pay for housing adaptation, equipment, private therapy, some public home supports and private home services, transportation, and social and recreational pursuits.

Of the 20 patients in this study, three patients were receiving Persons With Disability (PWD) pension through the Ministry of Social Development and Social Innovation (MSDSI) and so for the most part all of their equipment was covered, for three others they had private insurance and they certainly described being relieved they had that coverage.

The fourteen remaining participants would pay out of pocket for services and equipment, transportation, etc. In the case of home adaptation there is a grant that some individuals would be eligible for however they have still incurred costs while going through the application process.

Of those patients with no other coverage each identified their out of pocket costs for wheelchairs and bathing equipment. For the most part the patients did require required significant amounts of equipment beyond what they can get on loan from the Red Cross or borrow from a friend. Red Cross is meant for short-term loan only.

One patient was on a disability pension from his employer and residing with his caregiver. They are in the process of applying for grants in order to fund significant renovations to his suite in the realm of \$10,000 minimum. His caregiver is retired and on a pension and so they both identified significant financial burden trying to move forward with much needed renovations.

“It’s a big burden on me and mom, it makes it difficult to sleep and stuff, just having that extra weight on my shoulders” This patient is experiencing significant functional decline he also noted that *“If there was a package outlining these services you can access*
It could include *“what I was eligible for ...the disability tax credit”*.
“I never really worried about money before ...But now I have to be very careful what I spend”

The added stress of financial worry negatively impacts patients in terms of symptoms as well as to the burden of worry for caregivers.

Of note in the cases of MS patients, they are able to access most equipment through the M.S. Society for loan or through PWD. There are a few diagnoses specific societies like the M.S. Society, which support patients and caregivers through equipment loan, support groups for patients and caregivers as well as other types of programming.

However, participants noted that these societies vary across the island in terms of supports they can provide. For example, the M.S. Society in Victoria provides physiotherapy services through the Society for a nominal fee whereas Nanaimo does not.

Theme: Caregivers. This category is defined as those individuals who ‘informally’ provide care and support to their family member. An informal caregiver is someone providing care and is not being reimbursed financially for his or her assistance.

Of the 20 patient participants, 12 had an informal caregiver involved to some degree in their lives. This involvement varies from providing personal, IADL and emotional support to providing more intermittent supports such as transportation and/or some meal preparation or companionship.

From the patient’s perspective there is recognition that without this person they would not be able to manage at home.

“My disease has really dictated her retirement and that bothers me that she’s worked her life so hard and now she is basically full time caregiver to me.”

“I think the caregiver takes a real hit through this whole thing, yeah probably more so than the person experiencing the illness.”

As well, there are caregiving activities that are assumed by neighbours and friends without being asked, *“Our neighbours are just great, they are a great support and bring food to the door.”* Some patients are proud and wish to be as independent as possible and will only accept help if it is offered *“So far I have been lucky, with friends I don’t ask if they offer to pick up something I will give them a list.”* At the same time this patient also indicated that he has many offers to take him out, *“but I feel like a damn fool and it’s not comfortable so I don’t do it.”*

Theme: Accessibility/Availability. This theme is defined as the ability of patients to access therapy and social work services in inpatients and outpatients, home support services as well as equipment. Twelve out of twenty patients identified issues of accessibility and availability. Once living in their home communities patients may access home and community care therapy or outpatient rehabilitation on the islands.

Patients who received home and community care therapy receive it for home safety assessments and equipment recommendations.

“I was here with the OT yesterday and me and my mom were planning to do a full bathroom reno...I am going to be in an electric wheelchair ...getting one from the OT on loan to feel it out.”

Home care occupational therapists identify the requirements for home modification and assist in organizing the equipment needs. As well, the OT is involved in making recommendations regarding the home support needs.

“Could have used the OT involvement earlier in the process as a part of the Welcome to M.S., this is what your life is going to look like potentially package.”

Some patients require follow up therapy in order to address a further issue that is impairing function. One gentleman had injured his shoulder on his stroke-affected side.

“My doctor said: go see a physiotherapist. She (the physio) is a nice lady but she doesn’t have any idea about stroke...no place for follow-up of stroke with a shoulder problem.”

This quotation speaks to an issue for some patients that of finding a clinician with specific expertise. While he was trying to locate a service he was unable to pursue recreational and fitness activities such as swimming. The same patient describes a similar issue with knowing how to locate a speech language pathologist in his community.

“We had a problem when we got out of hospital there was nowhere to go...how to make speech better didn’t know how to make it better”

Other patients were able to locate the expertise they required and conveniently they were located nearby. One gentleman was paying a private physiotherapist, a specialist in stroke care and was seeing him weekly as well as attending a community hospital physiotherapy and occupational therapy program. The patient describes his experience with the neuro physiotherapist below.

“He’s \$95 an hour. Ouch! But he is good. It is more intense one on one down here...he doesn’t monkey around, he says you are going to do ...and I say I can’t and he says yes you can...he challenges my brain.”

Half the patient participants were receiving some level of home support at the time of the interview and of those, seven expressed needs for improved consistency in the workers. Consistency in this context is referring to the number of workers moving through their care. More often than not a patient will receive 8 – 10 different workers per week.

“Sending different people in all the time is stressful and I have to have a level of confidence in the workers and I wasn’t getting that level of confidence.”

This patient was emphatic about her lack of confidence in these workers and identified that the concern was with the level of fitness of some workers - *“They physically struggle, some are extremely overweight and I am concerned about them hurting themselves and me.”*

Theme: Emotional Support. Depression and loss are a large part of stroke, M.S. and many other conditions that result in a significant change in a person’s independence, physically and cognitively.

Of the 20 participants, 15 admitted to having some level of depression, sadness or anxiety as one of their symptoms to manage. For many of their symptoms were significant enough that they were prescribed medications.

One gentleman suffers from significant emotional regulation issues despite being on medication.

“I was happy before I had a stroke...it took me away from my dogs, I can’t drive, I can’t do my hobbies, and interests that I used to do – that’s how it is really

impacting my life. Depression haunts you, I got like a little demon in my head with an old fashioned slide projector, it flashes happy times and it just drives me up the wall.”

This patient is socially isolated as he is not able to drive and relies on his wife who works during the day. She has hired a driver to take him out to appointments and to visit with him.

“You are depressed every day you can’t go out and do and earn a living and your quality of life is not as good as it was before you can’t do the things that you used to do not only socially but physically. . . .There is a lot of frustration.”

Theme: Transportation. Transportation was a subcomponent of the need for supportive care in the interview tool for this study. It is a theme that impacts a person’s ability to get out and integrate into their community through work or leisure activities and avoid social isolation.

Of the 20 patients participating, seven have returned to driving. Of the 13 not driving, seven have a spouse who drives them, one relies on a friend for transportation, four are signed up for Handi Dart or are regular users and one uses the Granny Go Go service. Fewer patients than expected access Handi Dart. Handi Dart is a public transit resource that has some limitation in terms of routes, availability in the community and the wait times, *“Handi Dart is a lot of waiting around”*

Summary of Patient Interview Results

Patients spoke at length about their need for information especially at the transition points between inpatients and outpatients and after they have completed their outpatient program. More than half the patient participants identified out of pocket costs associated with equipment and ongoing therapy. Over half the participants had caregivers providing some supports and the patients expressed much concern about the burden that is placed on their caregiver. Accessibility and availability is a large bucket that considered the accessibility of services from therapy to home support and equipment. Transportation was a key issue for patients, often the responsibility falls to the caregivers particularly the spouses.

Caregiver Interview Results

Theme: Information. Information is defined as education that is requested by patients and caregivers regarding services that may be part of their community and/or are needed in order to improve function and independence.

Of the fourteen caregivers, five identified the need for information regarding what to expect, next steps for treatment, diagnostic information.

Caregivers describe spending time trying to identify whom to call, where to go, what are the possible resources that may benefit them. Some felt like time was marching on while they tried to navigate the complex health system for answers. This only adds to their stress as a caregiver.

“They proceeded to just pile on the information none of which I currently remember and the only thing I do remember was about Handi Dart, they didn’t know where we lived. Too much, too late and most was not going to be of any use, it was too general and they didn’t know anything about our community. It was the mechanics of discharge.”

Of note there were two caregivers and their spouses who also had a need for information regarding home support. This need appeared to only be recognized when each of the caregivers “*hit the wall*” experiencing significant caregiver burnout.

Theme: Out of Pocket. Out of pocket is defined as the services and equipment that patients have to pay for out of their pocket for in order to maintain them in the community. In the context of this study patients potentially pay for housing adaptation, equipment, private therapy, some public home supports and private home services, transportation, and social and recreational pursuits.

“I’m a pensioner as well and I’m thinking, oh my god, where’s all the money coming from for all this stuff you know you get by and you get a pension and you work your whole life...you’re not rich.”

Of the fourteen caregivers, half identified incurring out of pocket expenses. In a few cases, these expenses were short term while they waited for their insurance coverage to come through. For others out of pocket expenses are significant. Regardless of insurance coverage or grant funding, financial burdens layer on more stress for the caregiver.

Theme: Caregivers. This category is defined as those individuals who ‘informally’ provide support to their family member. An informal caregiver is someone providing care and is not being reimbursed financially for his or her assistance.

The caregivers identified varied experiences in this group. Seven of the fourteen participants had significant caregiving responsibilities with four of these seven working either inside or outside of the home.

“Because they (the patient) are in their own bubble and this is all they do – do their homework, brush their teeth, and eat and keep up their basic healing requirements, whereas you’re like paying bills, cleaning house, driving to appointments, arranging appointments, trying to do your job, ya da, ya da, ya da.”

For a couple of the caregivers from the group of seven their experience was similar and they all felt that a longer stay on the rehabilitation unit would have benefited the patient and the caregiver - “*He was in for 9 1/2 weeks – having him more independent when he came home – felt I had to do absolutely everything for him.*”

Often in these cases the caregivers identified feeling overwhelmed despite in some situations having home support in place for their loved one.

Participants described their advocacy role for their loved one. This is evidenced by the following quote - *“I had to fight to get him into the hospital program...I’m in sales I never give up. No means maybe in my world.”*

“I think again his age and the demographics of someone with stroke is someone in their 60’s and 70’s and not in their 40’s. If I hadn’t been a pushy broad, I wouldn’t have got there.”

These are very compelling quotations illustrating the tenacity required to ensure their loved ones received timely and appropriate services. All but one caregiver articulated an advocacy role, the work that they each did to support and coordinate their loved one’s recovery.

Theme: Accessibility/Availability. This theme is defined as the ability of patients to access therapy and social work services in inpatients and outpatients, home support services as well as equipment.

For the caregiver the experience of accessing therapy is primarily in doing the research to identify the potential resources and in a couple of the cases in this study they pay out of pocket for therapy - *“To get what he needed we would pay out of pocket for OT, Physio, and SLP and they were about \$110 to \$125 per session.”*

Several caregivers commented on the ability to access someone for questions or information about services the process was not straight forward as illustrated in this comment below.

“Access to people in Island Health needs to be made simpler. If I want to get a hold of someone you go through a main central number and it takes you off somewhere that person calls you back and you happen not to catch the call and you are left with a number that takes you into mystery land.”

In home care, home support is provided to patients to meet a personal care need. As mentioned previously, home support cannot be put in for meal preparation, housecleaning, laundry, unless tethered to a personal care need. Even then feedback from patients and their caregivers is that home support is inconsistent with what they will and won’t do and the users of the services do not find it helpful - *“It is way more helpful if they could just do the dishes in the sink, I am not asking them to clean the house.”*

A common theme for the younger population in the study was the lack of fit between them and the services they accessed.

“That is what I was worried about that it would be illness based, people getting together and whining and that he would internalize that. The paraplegic group would be a group to look into because they are younger.”

Theme: Emotional Support. Depression and loss are a large part of stroke, M.S. and many other conditions that result in a significant change in a person's independence, physically and cognitively.

As a caregiver they have to monitor the emotional needs of their loved one and balance that with their own needs. This seemed particularly challenging for those caregivers who are working as well as being a caregiver.

“Well his doctor has upped his dose of depression medications. Yeah it is working but I don't think we have it solved yet, I made an appointment for him to see a counselor.”

“Now all of a sudden I have to re-arrange everything I'm doing it but it's so traumatic and then the aspect of how he feels I mean it breaks my heart and then I see him crying and I am going 'oh wow' (emotion) it is just it's a lot of emotions different ones this day and different the next.”

Caregivers experience so many emotions and it is important that they address their needs - *“I was lucky too cause I had friends that kept pushing me. I had to go to the doctor to get happy pills because this was like depressing and I don't think I'm out of the woods yet.”*

Caregivers identify there is no support to address the emotional needs of their loved one or themselves - *“The system fails people that way – he should have ongoing counseling – nothing ongoing for people.”*

Theme: Transportation. Transportation was a subcomponent of the need for supportive care in the interview tool for this study. It is a theme that impacts on a person's ability to get out and integrate into their community and avoid social isolation.

“I mean I'd like to hope he will be driving sooner than later even now if he were driving even if he couldn't shoot he could at least get himself out to the range to socialize with friends and there are things that could do he's trapped because he can't drive.”

For those patients who live more rurally services such as Handi Dart are not available and a basic transportation need to go to follow-up services can limit participation in much needed therapy and ultimately can lead to medical and functional decline and risk for hospital re-admission.

“One of the physiotherapists wanted him to attend the intensive outpatient program at NRGH but it was too far that is just not reasonable. There is Wheels for Wellness but they don't guarantee when they'll pick them up so four hours of travelling for one hour of physio did not make sense.”

“We get Handi Dart too I'm capable of driving her all the time but we get Handi Dart to run he up to the hospital. The distance to see a specialist and transportation out of town is a huge issue if we are well enough to stay here....when I'm getting to the point where I can't drive.”

Summary of Caregiver Interviewer Results

Similar things were highlighted in the caregiver interviews and the patient interviews although more emphasis was placed on the challenges of an informal caregiver by the caregivers. Caregivers identified frustrations with having to hunt for information to support the recovery of their loved one. One caregiver described it as a “scavenger hunt”. Over half of the caregivers spoke of out of pocket expenses for equipment and some home modifications. The caregiver theme is a significant one as half of the caregivers identify their significant burden in roles that they fulfill. As well, there were a few caregivers who identified the need to ‘fight’ on behalf of their loved ones for services and resources. They identified the need to pay out of pocket for therapy, home supports, and the lack of services available that actually met their needs. Emotional support was again identified as a gap as it was with patients.

DISCUSSION

Understanding the perceived needs of patients and their caregivers along with the normative needs identified by clinicians is important to ensuring that our services are matching patient needs.

The purpose of this report is to explore patient needs as defined by patients, informal caregivers, and clinicians and to identify needs that are unmet. The results of this qualitative study resonate with other patient needs research, when considering the needs of patients in Island Health. Using the conceptual framework of needs, the unmet needs identified by the participants are outlined below.

Housing

The clinicians find housing to be a challenging issue to address with limited options available that directly meet a patient's needs especially when the patient is low income and/or require a renovation to their existing housing. A number of communities on the island have a high percentage of housing in need of significant repairs. A good example of this is Port Alberni community where a large number of the houses are old and a significant number of people are on income assistance or employment insurance (Island Health Planning Department-5, 2013, p. 1). Given this information many people can only afford a low rent unit, which may have issues in terms of the standard of the unit and whether it is located in a safe area of town. This can cause issues for home support if the location is deemed high risk, home support may be denied.

Housing is a complex public infrastructure issue that requires a collective approach between levels of government, community groups and the health authority to address. According to Klein and Copas (2010) the BC government has focused on "rental assistance supplements, new emergency shelter beds" (para. 2) and purchasing hotel rooms. The authors note that what is needed is newly created "low income housing units" (Ibid., para. 2). With accessible and affordable housing patients and their caregivers can focus on their recovery.

Patients and caregivers did not see their housing as an issue. This was most likely due to the fact that the patients in the study sample were generally independently mobile whether walking without an aid, using a mobility aid or in a wheelchair. All the patients in the sample with the exception of two have made minor additions of equipment and no significant renovations to the property.

Equipment

Like housing, equipment is another significant unmet need from the clinician perspective. The clinicians report spending much of their work day assessing and recommending equipment, sourcing funding for the equipment and identifying the most appropriate pieces to meet their patients' needs. "Many will fall through the eligibility cracks" (Provincial Equipment & Assistive Devices Committee (PEADC), 2004, p. 1) as patients try to navigate through the myriad of funding organizations and support groups who are trying to provide assistance to patients in need.

The patient needs assessment literature supports equipment as an unmet need for a variety of populations. Turner Stokes et al. (2013) showed major gaps related to a variety of needs including equipment. Their study also examined the cost of meeting the need as opposed to providing the services of home support and they identify that ensuring access to equipment is less costly than providing the human resources in terms of home support (Turner Stokes op. cit., p. 7). The clinicians in this study believe that if home and community care therapy staff were able to provide therapy, they would be able to increase independence and decrease reliance on home support.

Allen & Mor (1997) support the need for therapy to improve independence with ADL's (p. 1141). The authors note that unmet needs for ADL resulted in patients accessing the primary care and acute care systems more often than they saw in the cohort where ADL needs were met (p. 1141).

The patients and caregivers in this study identified significant out of pocket expenses while others had few issues obtaining equipment especially through short-term loan through Red Cross. This may also have been due to the fact that half of the patient group was only mildly impaired for their mobility. The lack sample diversity is a limitation for this study as the sample failed to reflect a full spectrum of disability.

Clinicians and patients alike experience challenges in accessing equipment that can be mixed with "confusion, complexity and a lack of resources" (PEADC, op. cit., p.1).

With these challenges, patients with disabilities are constrained in achieving independence and being able to remain in their home. As well, the clinicians note that without equipment and therapy patients are at risk of falling, the care workers at more risk of injury and the caregiver is at risk of burning out.

Therapy

It is clear from the focus groups and interviews that patients experience service deprivation as noted by Heinemann op.cit., p. 1052. Intensive outpatient therapy programs involving three to four disciplines are only located in the larger centres of Nanaimo and Victoria leaving patients in the other communities with a decision to make about their ability to participate. Many are unable or unwilling to get themselves to the larger centres.

From a clinician perspective newly diagnosed and/or discharged patients are offered upwards of three months of post-acute therapy. Once they have used this resource the patients are expected to be able to meet their ongoing needs through non-Island Health services such as an adapted exercise program through the recreation centre.

Patients and caregivers identified needs for follow up therapy for cognition and speech therapy. In the study by Vincent et al their findings support therapy as an unmet need. Of the 20 patients in the Island Health study almost half of them had needs for speech therapy and none were receiving this service. Patients identified that they were searching for private services, another out of pocket expense, however had not been successful in locating any in their communities. There is an expressed need for SLP; we see evidence of that through significant wait lists in all three of our outpatient SLP sites.

As well, patients express a need for ongoing support around adjustment to their disease and disability. This type of support can be sought through a counselor or may be provided through a non-profit support groups such as the M.S. Society or the Paraplegic Association.

Clinicians describe the impact of the unmet need in terms of the moral distress that they experience in trying to meet the obvious needs of patients. Vincent et al. (2004) highlighted this distress for their health professional participants, as clinicians are constrained by the environment in which they work and must prioritize their efforts to those most in need (p. 10).

Supportive Care

Clearly clinicians are attempting to ‘work the system’ in order to get the services that the patients need. Therapists were reluctant to admit that they would modify their assessment of independence to allow for some home support services so patients would get some additional support of meals and lite house cleaning activities as examples.

Transportation

There was unanimous agreement that transportation was a significant barrier to accessing available services by clinicians, patients, and caregivers. The prescribed accessible public transportation system – Handi Dart is described as unreliable and yet it provides basic community access for many disabled individuals (Denison, n.d. p. 1).

In this study more than half of the participants were unable to drive post stroke or due to changes in M.S. Seven out of the thirteen patients not driving, had spouses who were driving. Transportation options are limited in most communities and those available have restrictive criteria as to where they travel and what for. Inadequate accessible transport was identified as an issue in a user satisfaction survey in the United States where they recognize the need to understand the customer’s expectations for a transit service for special needs populations (Denson, n.d., p. 1).

For those reliant on others to drive in Island Health, most had modified their activities because they had limited support and did not want to burden the support they had. Transportation can be a barrier for different reasons based on issues specific to the individual (Rimmer, Wang, and Smith, 2008, p. 320). For some patients the cost of the transportation may be the issue whereas for others, they may live in an area or community that does not receive Handi Dart services. Although not specifically addressed in this study return to driving or the opposite – driving retirement appears to be a source of concern and frustration for clinicians when it comes to understanding the process for reporting concerns regarding a person’s ability to drive post illness.

Caregiver

In reviewing the literature there seems to be a growing interest in the caregiver role. Interestingly, the clinician group did not make any significant comment about caregivers in their focus groups. From the patient perspective concern about the caregivers was a key theme. The patients clearly were concerned about the impact that their illness and/or disability had on the caregiver. The caregivers, particularly the ones who were also working during the day identified significant concerns about burden. A number of them felt unsupported by inpatient rehabilitation because they had wanted their loved ones to be kept

in the hospital until they were more independent. Although it could be argued that if the appropriate supports were available during the period post discharge they may not feel that way.

Island Health caregivers identified feeling isolated, they felt they were on their own and carrying the burden of the house and caregiving and doing their job. Periard & Ames (1993) identified that changes to a caregiver's lifestyle and the amount of stress varies based on the age of the caregivers (p. 255). The Island Health caregiver group had a small subset of younger caregivers and they identified greater stress given the number of responsibilities they had as compared to the older subset (Ibid., p. 255). Periard and Ames (1993) also identified "time and confinement" (p. 255) as an important aspect when considering lifestyle changes due to caregiver stress. A few caregivers in the Island Health study identified a lack of time for themselves in their own home to pursue basic self care and leisure activities that would address their own emotional well-being (Ibid., p. 255). Hodgson, Wood and Langton-Hewer (1996) explored a tool to identify the caregivers at risk (p. 343). One of the key predictors they found was a caregiver's contentment with the "formal services" (p. 343) that their loved one was receiving.

This was particularly evident in the Island Health study in most caregivers. Several identified that the formal supports such as home support and transportation were not meeting 'their needs'. Hodgson et al. (1996) identify the importance of taking into account the caregiver's needs for supports and services for their loved one as part of service delivery (p. 343).

To address concerns similar to the ones identified here, van Heugten, Visser – Meily, Post, and Lindeman (2006) developed a guideline meant to address "the expressed need" (p. 155) to provide more formal support to caregivers. The guidelines provide information on a number of topics including "information provision, supporting the carer through education, family workers and counseling, active involvement of family members and sexuality" (Ibid., p. 153).

A few patients and caregivers identified that they had to 'fight' to get services for themselves or their spouses. This experience was supported in a study that identified the caregiver participants felt that they were not being provided with the information they needed and that the "information they did obtain was highly dependent on chance" (Edmonds, Vivat, Burman, Cilber, & Higginson, 2007, p. 664).

Patients and caregivers identified the need for information as a gap, which was particularly apparent at transition points as between inpatient services and outpatient programs. A number of patients and caregivers said that they felt left to their own devices to determine what follow up services were available to them. Clinicians did not identify information as an issue. This could represent their assumption that the information they do provide is consistent with what patients and caregivers' need although, they do not directly evaluated this.

Information gaps were relevant in a study by Garratt and Cowdell (2005) that identified that information should be customized for the individual context and needs to be reiterated throughout the engagement to ensure recall (p. 3).

Social/Recreational

Clinicians identified variable involvement with recreation centres around providing a continuum of therapy services to patients. Patients struggle to be able to participate in a variety of community-based activities. In some cases this is because the recreation centre does not have accessible equipment and/or they do not provide adaptive programming. In other cases patients are unable to access transportation. In a study conducted by Rimmer et al (2008) that looked at access to physical activities by stroke patients, the authors identified barriers to participation that were described as “the cost of fitness programs, transportation, and lack of awareness and understanding of where and how to exercise” (Rimmer, op. cit., p. 321). Patient participants identified a lack of awareness and limited information provided by the clinicians to support them in identifying appropriate follow-up services.

Vocational Need

There were a few patients who were working prior to their stroke or prior to the exacerbation of MS. The clinicians were unaware of any types of services for supporting someone to return to work. As a matter of fact many commented that most of their patients were seniors and retired so this area did not apply to them.

Teasell, McRae, and Finestone (2000) describe the needs that can remain unmet for younger stroke patients (p. 205). The authors note that younger patients have a poor rate of return to work after stroke especially within the first year. Patient participants in the Island Health study expressed concern as to the lack of support for them in returning to work and felt they were on their own to figure it out.

Cognitive/Emotional Needs

According to the clinician participants, cognition and emotional issues are minimally addressed through therapy and what support is provided is short-term in nature. Within the patient participant group, 75% of the group identified issues with depression. Other than medications there seems to be little support through the health authority for ongoing therapy for either cognition or emotional issues.

Participants in the Island Health study, particularly the younger M.S. patients, had made some attempts at participating in local support groups. Those who had attended a group stopped attending as they felt they did not fit. They described having nothing in common with the age group attending (often seniors) and did not want to be in a group with people with the same diagnosis. In reviewing the small amount of literature on support groups, Finlayson and Cho identify that age is an important element that prescribes use of these services by younger people (p. 488). These authors also supported the idea that some persons with fewer impairments would avoid homogenous support groups due to fear of seeing those who are more impaired (Ibid., p. 389).

One Island Health study participant noted ‘that is a mirror I just don’t want to look into right now’. Of interest though is that the Island Health patient participants expressed

interest in a heterogeneous support group, like the paraplegic support group, which has people with a variety of diagnoses, and are generally a younger crowd. This finding varied from the literature.

CONCLUSIONS

Patient needs assessment can play an important role in planning and evaluating services. Building a program based on the experiences of the end users will create a program that supports patient and caregiver focused care and is responsive to their needs.

There are several important findings to be highlighted from this study.

The patients and caregivers identified several themes including information, out of pocket expenses, caregiver issues, accessibility and availability, emotional support and transportation.

The next most significant finding is related to the availability and accessibility of services within Island Health. The accessibility and availability of services for patients is significantly impacted by the distribution of full time equivalent positions across the island with the central and north part of the island having significantly lower numbers of FTE expected to cover larger geographies. As well, the operationalization of roles has been more generalized in home and community care and clinicians identify that they do not have the chance to do rehabilitation with patients and they provide more of a crisis response through the provision of equipment and home safety assessments with no time for actually hands on practice of skills.

There was agreement across the three participant groups that there is a significant lack of psychosocial supports provided across the continuum of care. Patients do not receive adequate supports to assist in their adjustment to their physical and cognitive changes. Patients identified significant gaps in services that provide both short-term therapies for follow up and more ongoing supports post the typical three months allotment.

Another significant and unexpected finding is related to the experiences of the caregivers. They articulated a strong sense of being isolated and several of them identified significant levels of stress especially among the younger participants as they were working to maintain an income as well as managing the household and providing various levels of personal care to their family member.

There was an interesting difference experienced by a younger subset of the sample. These younger patients and caregivers shared that they felt there was not a fit between themselves and the services that are available. This seemed especially true when trying to access support groups through the Stroke Recovery Association. Younger patients identified that they didn't feel that the older patients in these groups shared the same needs as they did. As well, the younger patients were employed prior to their illness and express the desire to return to paid employment. The clinicians are not aware of resources and services for vocational supports and so this need remains unmet.

Through this study it has become apparent that we do measure the risk that caregivers are experiencing based on the context of their caregiving situation. There was a strong sense amongst several caregivers that they have to fight for all the services and resources that they have found.

The clinicians identified housing and equipment as significant needs on the island. Housing options for patients with low income are limited and this issue causes problems in acquiring

other services. Equipment drains therapist time in securing equipment and funding for patients to support their independence.

As well, there is room for improvement in the information that we provide patients and caregivers and the literature suggests that we need to provide them with regular education to assist them with caring for their family member

Based on these findings there are several recommendations for the health authority to consider and these are addressed here.

1. In order to provide services that meet the needs of patients beyond the typical three-month period allotted for outpatient therapy, partnerships need to be explored with community programs such as those provided through the community recreation centres as well as non-profit support groups. This could provide for distribution of information to patients and caregivers, providing physical and cognitive follow up activities as well we provide some supportive or adjustment type services through a peer-to-peer type service. As well, community partnerships can be explored to improve transportation opportunities in smaller communities.
2. For clinical services we need to examine the roles of the different provider groups and determine the opportunities to look at the work that each discipline is doing and look at the addition of support roles to improve accessibility and availability. As well, the expansion of the use of tele health to provide access to those in rural settings.
3. We need to do a better job with informal caregivers as they provide a significant amount of support to patients that the health authority relies on. It is time to look at patients and caregiver focused care through the provision of services that support both the patient and caregiver such as care pathways and education on how to manage the needs of their loved one. Some of the work can be leveraged though the BC Stroke Rehabilitation Collaborative that is about to get underway as this was a gap identified at a recent Stroke collaborative meeting in Vancouver on March 23rd and 24th, 2015.
4. Develop a standard guideline following the best practice guidelines for Stroke care for patient education. See Appendix C
5. Explore the CONNECT model currently in operation in the Interior Health Authority as a public provide partnership. This model can address gaps in care for brain injured clients. There is a need to create a coalition or partnership with community agencies to provide more low income type residences as well a program that would support the needs of those with behavioural issues.
6. Explore opportunities for a comprehensive provincial look at equipment provision. At this point equipment is fragmented in terms of how it is funded and/or provided. A solution to this issue would be to look at what other provinces are doing such as in Alberta where there is the Alberta Aids to Daily Living program. This program has been operational since 1980 and provides for the equipment needs for patients with short term and long-term equipment needs in a coordinated fashion through a recycling program (Alberta Aids to Daily Living, 2014, p. 7).

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APPENDIX

Appendix A Needs Based Approach

Descriptor	Community Dwelling Elderly	MS population	NPCS Article	TBI Needs
Basic needs	Basic maintenance (main heading) = required by all persons -food, living quarters, transportation	Basic (main heading) – food, clothing, electricity, water	Accommodation (main heading) Adapted housing Sheltered/residential care	Basic Improving my Health Increasing my independence in walking, lifting, balancing Accommodation Finding housing that is affordable and accessible Travelling in my community
Equipment	Rehabilitative (main heading) =improve functional capacity Supportive devises and prosthetics	Equipment (main heading) – similar types of equipment grouped together	Environment (main heading) Equipment – basic, specialist, high specialist	Equipment Obtaining equipment such as wheelchairs and computers
Therapies	Rehabilitative (main Heading) = improve functional capacity Physical Therapy and Speech Therapy	Service needs (main heading) Therapy Advice/Education Complementary therapies	Rehabilitation (main heading) Therapy Needs(sub heading) Therapy disciplines Therapy intensity	Service Needs Increasing my independence in walking, lifting, balancing Increasing independence in housekeeping, cooking and shopping Increasing my independence in eating, dressing, bathing and toileting Communication Expressing my needs Understanding others
	Treatment (main heading) = cure or alleviate Consultation Medication Medical services, nursing care, mental health services	Service needs (main heading) Medical care	Healthcare (main heading) Medical needs Skilled/specialist nursing	Healthcare Improving my Health
Social/Recreational	Rehabilitative (main heading) = improve functional capacity Social/recreational activities	Self-actualization needs (main heading) Ability to be intellectually and socially fulfilled Employment Education Social activities Hobbies	Rehabilitation (main heading) Vocational/educational support/ rehabilitation needs (sub heading)	Employment Improving job skills Finding paid employment Social Finding places and opportunities to socialize with others Participating in sports and recreation Feeling part of my community Education Increasing my education qualifications
Supportive Care	Supportive Needs (main heading) = maintains function Personal care, Homemaking, Meal preparation, Supervision, Transportation, protection/legal		Personal Care (main heading) Care in and around the home (sub heading) # of carers, frequency of care Personal Assistant/enabler for community activities (sub heading)	Supportive Care Handling a legal problem Travelling in my community Obtaining personal care attendant/personal care assistant service

Descriptor	Community Dwelling Elderly	MS population	NPCS Article	TBI Needs
	services		heading)	
Supportive Care		Service Needs (main heading) Support for children and carers	Social and Family support (main heading) <i>Social work and case management (sub heading)</i> <i>Family carer support needs (sub heading)</i> Respite Care (sub heading) Residential Day care <i>Advocacy needs (sub heading)</i>	Service Needs Caring for my children
		Information Needs (main heading) About disease/prognosis/services		
		Financial Needs (main heading) To enable patients to pay for treatment, rehabilitation, equipment and unspecified finances		Finances Increasing my income Managing my money Paying bill
	Preventive (main heading) = reducing prevalence of risks/increase behaviours to reduce risk Examples include immunization, risk factor reduction, early detection, proper nutrition			
	Promotive (main heading) = promote physical and mental well-being Examples include physical activity and stress management			
Cognitive/ Emotional				Cognitive Improving memory Problem solving
Cognitive / Emotional				Emotional Managing stress, emotional upset Improving my moods Controlling my temper Fulfilling my need for intimacy Participating in religious services or spiritual programs Controlling my alcohol and/or drug use

Appendix B

Interview Script for Patients

The purpose for this study is to develop an understanding of your needs as a patient having had some involvement with rehabilitation or therapy. As a patient you may have had an admission to an acute rehabilitation unit, in an outpatient department or may have been seen in your home by therapy.

I would like to understand what needs you have, what needs are being met and which remain unmet and why.

The questions that I will be asking are open ended and are looking for your experiences post illness/injury and involvement with therapy or SW clinicians. In particular I am interested in what needs you are experiencing in your home community and how you are or are not addressing these. I will ask you to provide an example to illustrate the need you are describing.

Warm Up Questions:

How old are you?

What was the nature of your illness or injury?

How many months since the onset of illness/injury?

Where were you located when you were involved with therapy?

What supports do you currently receive both formal and informal?

What was your functional ability prior to your illness/injury?

Needs Based Interview Questions:

1. Housing/Accommodation

Describe an example of how your current living situation impacts your ability to live in your home community.

Probes: a) This was due to needing an alternate method to access their house

b) Need to look at an alternate living arrangement

2. Equipment/Devices/Splints

Describe an example where you needed to get equipment specific to your current disability.

What went well?

What didn't go well?

Probes: a) Equipment may be basic i.e. RTS or tub seat or specialty power wheelchair – prosthetic devices

b) Accessibility of equipment for loan, rental or purchase

c) Splinting for hands either custom made or over the counter

d) Cost implication

3. Therapy

Describe an example of what services you have accessed within your home community related to your illness/disability.

What went well?

What didn't go well?

Probes: a) Which disciplines?

b) Referrals from rehab and availability of services closer to home

c) Intensity of service

d) Any cost impacts

4. Supportive Care

What types of services do you rely on living in your home community?

Please indicate which of the following apply?

- Personal Care
- Homemaking
- Meal Preparation
- Supervision
- Transportation
- Other:

Describe an example of supportive care you received upon living in your home community.

What went well?

What didn't go well?

5. Social/Recreational

Describe an example of programs/services you have considered in your home community for participation in following your involvement with therapy.

What works well?

What didn't work well?

Probes: a) Recreation programs/seniors centres/societies

b) Financial impact

c) Motivation to participate

6. Vocational

Is your illness/disability impacting your ability to return to work?

Yes No

If yes:

Describe an example of the impact your illness/disability is having on your ability to participate in employment.

What went well?

What didn't go well?

Probes: a) supports to return to work

- b) Barriers
- c) Financial Issues

7. Cognitive and emotional needs

Please describe an example of concerns you have related to memory, reasoning, problem solving, etc. and what services have you accessed to meet these needs?

What went well?

What didn't go well?

Describe an example of emotional issues that you have expressed such as anxiety, depression, emotional outbursts, etc. What services have you accessed to meet these needs?

What went well?

What didn't work well?

8. Summary

What do you see as the three (3) most important needs in order of priority for rehabilitation patients living in their home community? Please indicate if these needs are met or unmet by Island Health services? By any community based services (non-Island Health)?

Probes: a) May include any of the needs list above or may be other needs not yet identified.

b) Clarify what the interviewee means by the needs they identify to ensure that I understand their references.

Note:

The tool used for the caregivers and clinicians followed the same format of questions as for the patient population with minor wording changes to reflect the differing roles.

Appendix C

Stroke Services BC

A program of the Provincial Health Services Authority

Patient Education Best Practice Handout

From Canadian Best Practice Recommendations for Stroke Care (www.strokebestpractices.ca)
Section 6.2.2vi:

Depending on the needs and phase of care of the patient, education topics may include:

- a description of the roles of all members of the healthcare team, and how and when they will be involved in the individual patient's recovery;
- the role of the patient, family and informal caregivers as members of the team, and the need for them to be active participants in decision-making and planning;
- stroke symptom awareness and risk of recurrent stroke;
- treatment goals within each care setting and environment;
- information regarding discharge planning options and settings available following acute care to help support decision-making for care setting selection based on individual needs and functional status following stroke (e.g., benefits and costs of long-term care);
- medical information and information regarding type and cause of stroke, physical, psychological, functional and emotional impact of stroke and expectations for recovery;
- change in social and family roles and relationships;
- prevention of recurring stroke including risk factor modification and medication non-compliance;
- availability of and access to community services;
- information about community resources that should be broadly encompassing (e.g., the broad range of therapy and treatment resources available, home renovation resources, financial/tax consultants);
- on-going practical information and how to seek help if problems develop;
- information about the availability and potential benefits of local stroke groups;
- information on stroke patient advocacy within the healthcare system and within the community.