REQUEST FOR PROPOSALS

Preventing Bedsores and Muscle Cramps in Bedridden Patients with Multiple Sclerosis

2 March 2013

ABSTRACT

The purpose of this RFP is to deal with the issue of secondary symptoms of multiple sclerosis (MS), particularly bedsores and muscle cramps, which arise due to the patient being bedridden. Within the MS community, this RFP is focusing on the population with the most severe cases: those with progressive relapsing multiple sclerosis (PPMS) and primary progressive multiple sclerosis (PRMS) [1].

The target of this RFP is to decrease the occurrences of these preventable side effects. A technical solution is required to allow patients who have been confined to bed, generally due to fatigue and loss of muscular control [2], to reduce their dependence on a caregiver by independently managing their own care. As independence is an important factor in the measure of quality of life [3], the ability to personally aid in the prevention of one’s own bedsores and muscle cramps will mark an increase in the quality of life.

Beyond requiring a technical solution, the main necessities revolve around practicality. While more detailed guidelines are available within the document, in order for the solution to be viable it must be affordable, readily available, and reasonably easy and safe for a disabled patient to use. Though there are certain solutions to bedsores currently available, none are focused on those with MS, meaning that their specific needs were not fully met [1].

As the PRMS and PPMS populations make up 15% of the multiple sclerosis community in Toronto, the community is large enough for the solution to have an impact, yet small enough to often be overlooked.

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1. Introduction

This request for proposal is aimed at addressing a problem faced by members of the Multiple Sclerosis Community of Toronto with the final goal of generating a solution. As of 2011, there are approximately 93,535 Canadians suffering from MS, making Canada the fifth highest ranked country for prevalence of MS [1, 2]. Of this population approximately 15% of MS sufferers are categorized as progressive-relapsing MS (PRMS)¹ and primary-progressive MS (PPMS)², 10% and 5% respectively [1]. PRMS and PPMS patients face particular difficulty with symptoms of fatigue, muscle movement and muscle weakness [3, 4]. By the nature of their disease, they become bedridden to the point where bedsores and muscle cramps become common secondary symptoms [5].

Being bedridden, confined to one’s bed by sickness, with MS poses several very serious concerns [6] [Appendix 8.3]. The inability to physically move or adjust themselves in bed affects their quality of life by either forcing them to live with horrible pain caused both by bedsores and muscle cramps or forcing them to rely on caregivers. In either case, the independence of the patient is compromised; they often face challenges without any way of being able to personally deal with their situation.

This RFP outlines the community of MS patients, the problems and needs of PRMS and PPMS patients and how to frame those needs into a well-defined engineering problem. The parameters, such as the objectives, constraints and criteria for possible technical solution will then be detailed.

2. Problem Statement

This section will follow the progression of finding a problem within the Multiple Sclerosis community by first narrowing the MS community, examining the sub communities’ specific needs and finding a need that has not been met. Needs of this community stems from Maslow’s hierarchy of needs, where a need is defined as a requiring something not only from desire but also because it is essential or very important [7]. The greatest needs of people with chronic conditions are long-term care, maximized independence, and improved quality of life [8]. The problem solution must strive to address the needs of the community.

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¹ Progressive-Relapsing MS (PRMS)
A type of MS where patients experience a steadily worsening of their condition from the onset with relapses with or without recovery. There is no remission periods as the disease continues to progress even between attacks [1, 4].

² Primary-Progressive MS (PPMS)
A type of MS where patients experience gradual worsening of the disease with no remission periods or attacks. Sometimes PPMS patients experience plateaus or temporary improvements in their condition [1, 4].
Important aspects of the problem, such as safety, cost, and usability will be detailed. This problem will then be framed from an engineering design perspective within the determined design space. Finally, the need and the engineering problem will be shown to be well justified.

2.1. Chosen Community

Community can be defined as a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings [9]. The community of people addressed in this project are individuals with PPMS or PRMS who do not live in a specialized care facility and who have an EDSS\(^3\) Scale rating of >8.0, meaning that they display symptoms such that they are bedridden [10] [See Appendix 8.4]. Once the broader community of persons with MS was selected, further investigation was conducted to discover an area in which a need was still unfulfilled in the form of a technical solution. In the research process, an interview with Lynn Laccohee, Client Services Manager at the Toronto branch of the MS Society of Canada, was conducted and it was concluded that little is being done in terms of solutions for MS patients with a severe expression of the disease [11]. Patients with severe MS symptoms are no longer part of the workforce and are largely dependent on a caregiver of some form [12]. As seen in Figure 1, only 15% of the MS population is bedridden. They face specific challenges, which have not yet been addressed.

Individuals, with PRMS and PPMS, and those close to them lead lives that are severely affected by a disease that is prevalent in society. Unfortunately, those most affected by the disease are currently being overlooked in terms of specific product design. Although the need is not widespread, it is high-impact as the individuals’ conditions affect all aspects of their lives.

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\(^3\) Extended Disability Status Scale (EDSS)

A rank-order scale, which originated as the Disability Status Scale, and ranged from 0 (normal) to 10 (death due to MS). This scale was later expanded into the EDSS by halving each step 1 through 9. This bifid system is applicable to all patients with MS regardless of type or severity of neurological impairment [10].
This community’s social problems often manifest in the form of psychological distress. Patients often feel as if their situations are helpless, and as the disease has not been cured, are sometimes under the impression that nothing can be done for MS patients [13]. The issue of caregiver burnout, stress cause by continual MS patient care, impacts interactions between community members [14].

The physical abilities of PRMS and PPMS patients vary; however, all are heavily impacted by their symptoms. The majority experience severe fatigue as a primary symptom of the disease [15]. Tremors are another symptom, which affect the individual’s precision of motion [16].

Along with debilitating physical symptoms affecting patients with PRMS and PPMS, most also experience some cognitive dysfunction. The impairment typically affects complex attention, information processing speed, and memory [17].

2.2. Chosen Need and Problem
A main area of interest is a way for bedridden MS Patients to combat immobility and its side effects. This is a need for MS patients due to the fact that it is often the side effects of being left unattended and unable to move that lead to hospitalization or the transfer to long-term care facilities [11]. Immobility is also directly responsible for a loss of independence which can be quantifiably measured using the Functional Independence Measure (FIM) [18] [Appendix 8.6]. A secondary effect of this is the fact that separation from one’s family can trigger purviews of social issues and social complications, which makes addressing this issue socially responsible [14].

Additionally, the chosen community of bedridden MS patients are retired and live on fixed incomes, which rarely cover the approximate $30,601 to $31,184 per year (excluding care giver) cost associated with the disease [11, 19]. This becomes an economic issue since immobile patients experience lower household income and higher medical expenses. By addressing the medical needs of the patient, social and financial issues can also be improved. As such, the side effects of immobility that will be addressed in this report are bedsores and muscle cramps [20].

2.3. Problem Specifics
In the community of MS patients in Toronto whose symptom severity has progressed to the point of confining them to a bed, bedsores are a valid concern as people are unable to shift their position unassisted [21]. Additionally, due to prolonged inactivity, muscle cramps can occur and cause severe pain.
Bedsores and Muscle Cramps in MS Patients

Bedsores are directly caused by the compression of skin and the subsequent restriction of blood flow to the area [22]. They are caused by highly progressive MS symptoms due to the fact that MS causes extreme fatigue and loss of muscular control [15]. In order to prevent bedsores, body position must be shifted approximately every two hours [5]. This is a compound problem that must be considered from both angles to create a solution that will fully address the needs of the target community.

Muscle cramps are also caused by paroxysmal symptoms and are lessened through increased motion [9]. Relief from these cramps can be obtained through regular stretching of the muscles, mechanical vibrations, and the use of a cold compress (Figure 2 provides a more detailed chart of pain relief philosophy). As the chosen MS community has a limited ability to move, carrying out the motions required to alleviate muscle cramps is difficult. Hence, any solution presented to this problem must account for these constraints. The existing solutions for this problem include both medicinal and physiological methods; however, the market is lacking products targeting the relief of symptoms rather than the root causes. The current physical solutions do not provide specific treatment plans for bedridden MS patients, meaning the needs of the chosen community remain unmet.

2.4. Engineering Problem

From the defined community, chosen problem, and problem specifics, it is possible to generate a solution to target multiple symptoms specific to PRMS and PPMS. It must be a physical device that could satisfy all of the urgent problems, while still being a technical solution, rather than a medical or social one. The problem to be solved is the occurrence of bedsores and muscle cramps in bedridden MS patients [5]. Thus, it is necessary to improve the patient’s quality of life by reducing their dependence on others and increasing their mobility. Quality of life can be defined as the burden of a disease, which can then be measured in terms of physical and mental aspects such as: physical functioning, bodily pain, mental health, and general health [23].

As the problems identified are related to secondary symptoms of MS, such as bedsores and muscle cramps, rather than primary symptoms, such as fatigue, a medical solution is not necessary to address the specified conditions [21]. Once the need for a medical solution is eliminated, it can be surmised that a technical device could be created to improve the condition of the patient. The possibility of a technical solution is further supported through...
reference designs [see Section 7]. Furthermore, as bedsores and muscle cramps are physical conditions, a social solution will have no effect on their presence.

From the outlined problems of bedsores and muscle cramps, a technical and physical solution can be generated. Based on the problem specifics it is possible to employ physical concepts to create a device that will meet the needs of the chosen community. From that, it follows that a solution can also be found in this instance through the process of engineering design.

3. Stakeholders
Acknowledging the prominent parties affected by the outlined problem and understanding their positions and biases can aid in developing a solution more catered to their needs. The following stakeholders have varying influence on the solution. To rank their importance they will be divided into three groups, primary (I), secondary (II), and tertiary (III).

I. Primary stakeholders have the most direct relationship with the problem and are most affected by its solution. They are the obvious stakeholders.

II. Secondary stakeholders are still involved in the problem but emerge as much more subtle parties effected.

III. Tertiary stakeholders include parties that are most unanticipated in the problem area and solution development.

3.1. Stakeholder Identification Table

<table>
<thead>
<tr>
<th>Rank</th>
<th>Stakeholder</th>
<th>Context to RFP</th>
<th>Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Patients of PRMS and PPMS</td>
<td>As this RFP is targeted specifically at PRMS and PPMS patients, they would receive the most direct and obvious benefits. The potential improvements for PPMS and PRMS patients are more fully covered in sections 3.3 and 6.1.</td>
<td>Patients may be sceptical of solutions given the history of the disease and the often pervasive attitude that their situation is helpless [13].</td>
</tr>
<tr>
<td>I</td>
<td>Caregivers and Family members</td>
<td>Caregivers and family are an integral part of the solution as they are directly connected to the patients. The important considerations from the perspectives of care givers and family members are care giver burnout and care giver burden (see section 2.1) [14]</td>
<td>Family members and caregivers can often feel overly responsible for the patient. As such, they may not trust the care to anything but themselves. [12].</td>
</tr>
<tr>
<td>II</td>
<td>MS institutes (including the MS society of Canada Toronto Chapter, Toronto Rehab Centre, etc.)</td>
<td>MS institutes must be taken into consideration as they are often critical in helping patients with MS. Most institutes strive to provide resources, rehabilitation and continual support to their patients to ensure their well-being [24]. For this reason, any possible solution stemming from this RFP would be of interest to any MS institute.</td>
<td>MS institutes often feel responsible for connecting people to resources and providing them with information, but they do not feel responsible for the development of the solutions themselves.</td>
</tr>
<tr>
<td>II</td>
<td>Physical Therapist</td>
<td>Physical therapists (in the context of MS) aim specifically to reduce the extent of physical debilitation for MS patients (known as secondary symptoms). As such, they are affected by the inception of any aid/device targeted at the MS community, specifically those targeting secondary symptom relief [25].</td>
<td>Physical therapists are financially involved in the care of the patients, creating a conflict of interest.</td>
</tr>
<tr>
<td>III</td>
<td>Government run Health Care Facilities in the City of Toronto (such as Hospitals)</td>
<td>The Health Care facilities provide the social services to patients with PRMS and PPMS. As the government is responsible for the basic health care of the patients, any device that would further aid the patient would be of interest. As stated by the Disability Tax Fairness report in 2004, “the most important action that the government can take to assist persons with disabilities is to invest in the supply of disability supports.” [26] As the role of government assistance has not changed since 2004, disability supports are still in demand for disabled communities.</td>
<td>The population of PRMS and PPMS not significant enough to allocate the appropriate research and funding into disability supports [1, 4].</td>
</tr>
<tr>
<td>III</td>
<td>Interested Groups in Solution Generation (Design Teams)</td>
<td>As the design team is given the challenge to develop and create a feasible solution to the framed problem, fully comprehending their limitations can aid in framing and parameterizing the solution.</td>
<td>The design team begins their development with the least amount of knowledge of the community, making them the most factual in terms of the science, yet the least experienced in terms of practicality.</td>
</tr>
<tr>
<td>III</td>
<td>Manufacturers</td>
<td>Responsible for developing the methods of efficiently constructing and mass producing the final product.</td>
<td>Very disconnected from the users</td>
</tr>
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</table>
3.2. Interrelationships Between Stakeholders

The various stakeholders all have some investment in the solution; however they often have differing opinions on the design. The chart below will express the relationships between the different stakeholders on common expectations or what they expect from each other.

![Diagram](image)

**Figure 3.** Detailing the interconnectedness of the stakeholders, and the nature of those connections.

4. Methodology

The approach when beginning to develop a solution should remain focused on the human aspects of the design. The product is being created for patients with a severe set of symptoms and as such their comfort should be at the forefront of the design decisions. Safety and ease of use are crucial factors and consumer satisfaction should be weighted above all technical prowess. The following sections outline the major concerns to be addressed and discuss their impacts on solution generation.

5. Solution Requirements

The main objective is to solve the problem in a manner accessible to all members of the target community. As such, certain specific factors must be taken into consideration. Potential solutions
might want to consider the specific locations where patients would be using the device. Since patients are bedridden, solutions may include, but are not limited to: additions to the existing bed, a redesigned mattress, a redesigned bedframe, surrounding room modifications, or a completely new bed unit. Options for the operation of the device include, but are not limited to: manual and automatic, but the device operation must be independent for the user (unassisted).

5.1. Objectives
The ultimate goal is to improve the quality of life for MS patients suffering from PPMS and PRMS through addressing the following objectives.

5.1.1. High Order Objectives
The high ordered objectives are solely based off of the needs of the patients and no other stakeholder has been considered thus far.

- A reduction in the severity and prevalence of secondary symptoms (i.e. bedsores and muscle cramps) of MS such that their effect on independence and mobility is lessened
- Improve the relationship between patients and caregivers
- Develop a solution that takes into account the needs of the specific community
- Increase economic feasibility for both fixed income and low income MS patients

5.1.2. Objective Justification
The detailed objectives fall within the scope of the following higher order objectives and can be justified though consideration of the primary and secondary stakeholders.

- A reduction in the severity and prevalence of secondary symptoms (i.e. bedsores and muscle cramps) of MS such that their effect on independence and mobility is lessened
  - All stakeholders are interested in this outcome as it will positively impact the lives of many individuals in the chosen community [21].
  - As this is an engineering problem, it will require a technical solution. Multiple solutions should be offered to reach the broadest group of PPMS and PRMS patients.
  - Lacking in this community are affordable products that will minimize suffering. Many methods seek to cure the root cause, however fail to provide general primary and secondary symptom relief.
• Improve the relationship between patients and caregivers
  - The caregiver feels over encumbered and doubts their ability to fully care for the patient [12].
  - Caregiver burnout results in irritability, depression and anxiety [14]. Burnout is especially common among the families of patients with MS [27].

• Develop a solution that takes into account the needs of the specific community
  - Device operation should require minimal physical labour. Debilitating fatigue and muscle weakness are some of the original symptoms causing patients to be bed-ridden, and as such, a device requiring muscle strength undermines the overall goal [28].
  - Fatigue and other symptoms of advanced MS, as mentioned above, cause severe motion limitations [15]. For the device to remain accessible to all users, minimal motion should be required for operation.

• Increase economic feasibility for both fixed income and low income MS patients
  - The fixed income of such patients is often an obstacle when it comes to the practicality of owning assistive technology [29, 30].
  - For the product to be a success, it will have to be available to the vast majority of the PRMS and PPMS patients.
  - The most significant hindrance for investing into in-home care is the cost, therefore an affordable installation is essential [30].

5.2. Table of Corresponding, Objectives, Constraints, and Criteria

<table>
<thead>
<tr>
<th>OBJECTIVES</th>
<th>CONSTRAINTS</th>
<th>CRITERIA</th>
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<tbody>
<tr>
<td>A reduction in the severity and prevalence of secondary symptoms (i.e. bedsores and muscle cramps) of MS such that their effect on independence and mobility is lessened</td>
<td>Must decrease occurrences of both symptoms, though equal decrease is not required</td>
<td>Fewer bedsores and muscle cramps are better. None is ideal.</td>
</tr>
<tr>
<td>Reduction in number of bedsores and muscle cramps.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve patient’s ability to obtain muscle cramp relief.</td>
<td>Must not cause movement that would harm the patient.</td>
<td>Number of muscles that can be treated with the assistance of the device. More is preferred.</td>
</tr>
<tr>
<td>Offer non-medical (non-pharmaceutical and non-</td>
<td>Solution to combat bedsores and muscle cramps must not (yes/no)</td>
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therapeutic) pain relief or the possibility of preventing the discomfort. Include medication of any kind.

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<tr>
<th>Improve the relationship between patients and caregivers</th>
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</thead>
<tbody>
<tr>
<td>Eliminate the caregivers’ roll in moving the patient or providing them physical aid.</td>
</tr>
<tr>
<td>Reduce caregiver burnout.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Develop a solution that takes into account the needs of the specific community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compensate for cognitive issues of the patients [31].</td>
</tr>
<tr>
<td>Account for muscle weakness and delayed reaction/response time of patients [31].</td>
</tr>
<tr>
<td>Allow accessibility of the device to all possible users.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Increase economic feasibility for both fixed income and low income MS patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>More financial feasibility of current solutions (see section 7 for cost limits).</td>
</tr>
<tr>
<td>Minimal additional effort, time, and/or money involved in the installation process.</td>
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<td></td>
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6. Available Solutions and Reference Designs
There are some solutions that are currently in place, however, they fail to either meet the exact situation and needs of PPMS and PRMS patients or fail to satisfy constraints. This stems from both the cost and the lack of research being done in the specific area (see section 3.5). Some of the following solutions are not need-specific to MS but do offer insight on how to deal with bedridden patients.
6.1. Electrical Beds

Electric beds are one branch of solutions to relieve pressure sores. Electric beds come in many types, each with different functions. The main function necessary to aid with the prevention of bedsores is axial rotation, because it can change the distribution of pressure on the patients’ body. Additionally, the patient can change the bed position for various tasks. These beds are also useful for transferring a patient to a wheelchair or other transportation. However, beds with this particular function are mostly used in hospitals and are outside of the typical price range for patients, as they normally cost approximately $5000 [33]. The economical affordability of the device is a concern and given the prices outlined below, electric beds fail to meet the solution in terms of feasibility. Additionally, electric beds fail to offer any solutions regarding muscle cramps.

![Figure 4. A functional electric turning bed [33].](image1)

6.2. Bedsore Prevention Device

Filed as a United States Patent [34] in 1985, this device is specially designed to prevent bedsores. It can be categorized as an electric bed, but is not as sophisticated or powerful. As shown in Figure 5, changing the orientation of the side of the bed helps to move patients from side to side, therefore changing the pressure distribution on their body. While this device provides a solution to bedsores, it does not address the need of physically moving and stretching the body of the user, which is a specific function that the device must perform to deal with muscle cramps (see Section 5.1).

![Figure 5. Functional drawing of the bedsore prevention device [34].](image2)
6.3. Hired Caregiver

The most basic solution to bed immobility is hiring a caregiver in order to facilitate movement of the person bed. According to [5, 11, 34], a person needs to be moved at least every two hours and due to the short time difference, a caregiver must be constantly or almost constantly present.

Although a caregiver can be useful in many situations, such as companionship, this solution is not feasible for several reasons. Firstly, the salary of a qualified caregiver ranges from $20 to $30 per hour [11, 35] and the accumulated cost can be very high over a long period of time. This price range was confirmed by Audrey Miller, who has been certified in the areas of geriatric care, rehabilitation counseling and life care planning for 25 years, as she stated that the average rate for a for-profit agency is about $23/hour [35].

Secondly, the caregiver, whether paid or unpaid (such as a family member), must be present for most of the day and the constant responsibility and demand could develop into care giver burnout, which would only add stress, anger and frustration to an already difficult situation [14].

6.4. Pneumatic Mattresses

Similar to other technical solutions, this type of mattress changes the pressure distribution under the patient’s body, using pressured air. For instance, this example mattress (APM-Rotational Mattress System) circulates air along pressured air containers parallel to the patient’s body in order to change the pressure under the mattress [32]. This type of mattresses is effective in preventing bedsores; however, its function is limited to that. These mattresses do not help with the issue of muscle cramp, since they do not move the patient or provide any relieving effects discussed in section 2.3. Additionally, pneumatic mattresses are very expensive, starting usually from $2000 - $15000 [32]. This is outside the typical price range of MS patients.

Figure 6. Cross section of a pneumatic mattress [32].
6.5. Massage Chairs

Despite the fact that a massage chair is not a direct solution to the problem of this RFP, they do provide insight on treating muscle cramps. According to section 2.3, cramps can be relieved by mechanical vibrations of the muscle. A massage chair provides these vibrations through physical oscillations of the device surrounding the body parts [36].

![Massage Chair Image]

Figure 7: Mechanical massage therapy chair [40].

7. Conclusion

The above sections have defined every aspect for a possible physical solution to the problem of bedsores and muscle cramp in PRMS/PPMS community. The engineering problem requires solving all urgent problems safely with a consistent focus on patient’s perspective and needs. Solving this problem not only benefits the patients, but also their families, caregivers and MS institution.
8. Appendix

8.1. Interview with MS Society Client Services Manager Lynn Lacchione [11]

- What is your position and how long have you held it?
  - Manager of client services, providing Counseling, social advocacy and etc.
  - I have been holding it for 28 years

- What percentage of the MS community do you have contact with?
  - We are connected to a third of the community.
  - We also have connections beyond the MS community, such as ethnic groups or other social groups

- What have been the most important breakthroughs in this field recently?
  - A lot has changed, recently 8 disease modifying drugs
  - Understanding of the disease has changed
  - More research per capita than cancer

- What are the most debilitating symptoms of MS are?
  - No two patients are the same, the progression of the disease is different for everyone
  - The uncertainty is the most difficult thing to live with; people do not know how to plan their lives regarding marriage, children, career and etc..
  - However, even for the people who are not very disabled, fatigue is pervasive and overwhelming (90% of people with MS experience it)
  - Also, the lack of judgment in weight and heat is a problem; this is caused by the element of weakness and the loss of dexterity
  - People with MS, find heat very debilitating and their symptoms progress much faster (Inside houses A/C might be available, but there is no widely distributed solution available for going outside)
  - Blurred vision is also a symptom of MS. It can be combatted by wearing a patch over the eye whose cornea is inflamed

- What kinds of solutions are available in the market for assistive technology for daily life?
  - The computer technology exists in some cases, like voice activated computers. Although, some of the patients cannot afford a computer, never mind the additional software.
  - Regarding fatigue, there are solutions like wheelchairs and scooters. However, they are very expensive, and might cause other problems (such as incompatibility in terms of size and accessibility with the houses of patients). For instance, bathrooms are not always wheelchair compatible.

- Do healthcare plans help patients financially?
  - They rarely cover the main costs, and the coverage is limited to a narrow range of products
  - Much of the income of the families with MS goes towards medication, as it can range from $15k-$40k
  - It is extremely expensive to afford the basic requirements, like wheelchairs or ..., and due to the nature of the disease the basics change rapidly over the years
  - Unfortunately most of the problems go back to money

- What things do MS patients have to give up, as their disease progresses?
Mainly exercise, which also causes the symptoms to get worse

- What problem do you personally think would be the most suitable for our purpose?
  - There are some people who can’t move and need to be turned or assisted in movement in order to maintain their health. Even just moving or shifting their legs can be impossible
  - Hiring a caregiver is out of the question for the majority of the patients, as it is very expensive and not generally possible on the fixed income, when combined with the cost of medication. The costs for a caregiver can range from $20-$30/hour
  - There is no mass production of devices, meaning that all solutions remain rather expensive
  - A product that would help move someone would address the needs of about 10% of the MS population, as that is approximately the number of people who suffer from this severity of symptoms

- What are the current solutions to this problem of reduced health due to immobility?
  - There are pressure mattresses on the market to assist with limiting bed-sores, but not a lot of solutions to address muscle cramping
  - Also, these mattresses ranges generally from $2k-$15k, making them too expensive for many to consider
Multiple sclerosis and rehabilitation

Through its Neuro Rehabilitation Program, Toronto Rehab offers a Multiple Sclerosis Service that provides specialized interprofessional treatment and education for adults living with the many challenges of multiple sclerosis.

What is multiple sclerosis?

- Multiple sclerosis (MS) is a disease of the central nervous system. It attacks the protective myelin covering the arms (axons) of nerve cells, causing inflammation and destruction. This short circuits the nerve signals sent from the brain and to other body parts, which causes a variety of symptoms, depending upon which part(s) of the nervous system are affected.
- MS symptoms may include problems with vision, balance and/or coordination, muscle stiffness, fatigue, speech or memory, and even paralysis. The cause of MS is not known and there is no cure. Medications and therapies can help control symptoms.
- MS can range from being relatively mild to totally disabling. At its most extreme, MS can cause the loss of self-care, speaking and walking abilities, and drastically reduce independence and quality of life.

Facts about multiple sclerosis

- An estimated 55,000-75,000 Canadians have multiple sclerosis.
- Canada has one of the world’s highest rates of MS; the disease occurs more often in countries with temperate climates farther from the equator.
- MS can occur at any age. It is usually diagnosed between the ages of 15 to 40, but can make its first appearance in young children or older adults.
- Women are more than three times as likely to develop MS as men.
- MS is seen most commonly in people of northern European background.
- Every day, three more people in Canada are diagnosed with MS, making it the most common neurological disease affecting younger adults. Approximately 1,000 new Canadian cases of MS are diagnosed each year.
- The economic impact of MS in Canada totals more than $1 billion annually.
- As the incidence rate of MS continues to rise, so will the cost to the health care system. Rehabilitation is a vital part of Canada’s solution to this challenge.

Toronto Rehab’s expert multiple sclerosis rehabilitation

- At Toronto Rehab, rehabilitation is the interprofessional process of helping people who experience disabling injury, illness and conditions associated with aging to regain the skills, abilities, confidence and independence they need to live their lives to the fullest.

www.torontorehab.com
Rehabilitation can improve quality of life for people with MS by helping them improve their balance and mobility, communication skills, cognitive functioning and ability to perform daily activities, especially dressing, eating and other activities involving their hands and arms.

Rehabilitation for people with multiple sclerosis includes an individualized program of therapy that may involve, for example, cognitive retraining, mobility and daily living skills training, adaptive aids, fatigue management and counselling for mood and adjustment.

In order to ensure our patients and others around the world can benefit from the newest therapies, methods and equipment, leading-edge research is at the centre of the care Toronto Rehab provides. Through close collaboration between Toronto Rehab researchers and clinicians, innovations in research are rapidly translated to the clinical setting.

**Pushing the frontiers of multiple sclerosis rehabilitation research**

Toronto Rehab conducts high-impact research that leads to advances in knowledge, treatment and technology and has a valuable impact on people affected by disability and their caregivers. Our rehabilitation research program is one of the largest and most diverse in North America. Current MS-related research projects include:

- **TIME to address the gap** – Jo-Anne Howe, clinical educator in physiotherapy, played a key role in launching Together In Movement & Exercise (TIME), an evidence-based community fitness and wellness program designed for adults with MS, acquired brain injury and stroke. The program was created to address a service gap that exists after people complete their rehabilitation. Developed in partnership by Toronto Rehab and Toronto Parks, Forestry and Recreation, the program includes exercises adapted from research by Toronto Rehab physiotherapists and is taught by city fitness instructors who have attended education sessions conducted by hospital physiotherapists.

- **Improving attention and memory** – Nadine Richard, a Toronto Rehabilitation Institute Scholarship in Rehabilitation-related Research for Graduate Students with Disabilities recipient, is testing treatments for attention and memory problems in people living with MS. She uses a combination of cognitive testing and neuroimaging to understand how MS affects communication between different parts of the brain, and how the brain's attention networks recover and adapt over the course of rehabilitation. Her latest study places people with a progressive form of MS in a clinical rehabilitation setting that mimics the challenges of the real world and requires them to manage multiple tasks on a timed schedule.

- **Exercise DVD for people with MS** – Physiotherapists in the Neuro Rehab Program developed a DVD that provides an in-home option for ongoing exercise after discharge from therapy. Adjunct scientist Dr. William Gage and physiotherapist Jo-Anne Howe explored the effects of the DVD after 12 weeks of use and found improvements in strength, balance and some aspects of walking. These findings suggest that people with MS can attain benefits from exercising independently within their own home after discharge.

For more information
Marketing and Communications, 416-597-3422, ext. 3837, communications@torontorehab.on.ca

Sources beyond Toronto Rehab: Multiple Sclerosis Society of Canada
8.3. Extended Definition Information

Definition for Independence

Not depending on another for livelihood or subsistence; capable of thinking or acting for oneself. [37]. Quantifiably, independence can be measured using the Functional Independence Measure (FIM). FIM assesses areas of function that fall within two dimensions, motor and cognitive, and has been previously tested for patients with multiple sclerosis. In this case, our measure of independence will fall within the motor category, specifically self-care and transfers. Independence can be scored based on how much assistance is required for the individual to carry out activities of daily living [38].

Definition for Bedridden

A study striving to define bedridden as a medical versus colloquial term has decided that the most appropriate definition is a model of the process. It was determined that the condition of being bedridden developed gradually, progressing through the following five phases: instability, incident, immobility in the room, local confinement and, ultimately, in the final phase of being bedridden. [39] The final stage involves confinement to bed by one’s sickness or old age [6].
8.4. Extended Disability Status Scale (EDSS)

This is a rank-order scale, which originated as the Disability Status Scale, and ranged from 0 (normal) to 10 (death due to MS). This scale was later expanded into the EDSS by halving each step 1 through 9. This bifid system is applicable to all patients with MS regardless of type or severity of neurological impairment [10].

The following details the level of the EDSS scale [40].

**Kurtzke Expanded Disability Status Scale (EDSS)**

**Note 1:** EDSS steps 1.0 to 4.5 refer to patients who are fully ambulatory, and the precise step number is defined by the Functional System (FS) score(s). EDSS steps 5.0 to 9.5 are defined by the impairment to ambulation, and usual equivalents in Functional System scores are provided.

**Note 2:** EDSS should not change by 1.0 step unless there is a change in the same direction of at least one step in at least one FS. Each step (e.g., 3.0 to 3.5) is still part of the DSS scale equivalent (i.e., 3). Progression from 3.0 to 3.5 should be equivalent to the DSS score of 3.

0 - Normal neurological exam (all grade 0 in FS).

1.0 - No disability, minimal signs in one FS (i.e., grade 1).

1.5 - No disability, minimal signs in more than one FS (more than on FS grade 1).

2.0 - Minimal disability in one FS (one FS grade 2, others 0 or 1).

2.5 - Minimal disability in two FS (two FS grade 2, others 0 or 1).

3.0 - Moderate disability in one FS (one FS grade 3, others 0 or 1) or mild disability in three or four FS (three or four FS grade 2, others 0 or 1) though fully ambulatory.

3.5 - Fully ambulatory but with moderate disability in one FS (one grade 3) and one or two FS grade 2; or two FS grade 3; or five FS grade 2 (others 0 or 1).

4.0 - Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability consisting of one FS grade 4 (others 0 or 1) or combinations of lesser grades exceeding limits of previous steps; able to walk without aid or rest 500 meters.

4.5 - Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance: characterized by relatively severe disability usually consisting of one FS grade 4 (others 0 or 1) or combinations of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 300 meters.
5.0 - Ambulatory without aid or rest for about 200 meters; disability severe enough to impair full daily activities (e.g., to work a full day without special provisions): (usual FS equivalents are one grade 5 alone, others 0 or 1: or combinations of lesser grades usually exceeding specifications for step 4.0).

5.5 - Ambulatory without aid or rest for about 100 meters; disability severe enough to preclude full daily activities: (usual FS equivalents are one grade 5 alone, others 0 or 1: or combination of lesser grades usually exceeding those for step 4.0).

6.0 - Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100 meters with or without resting: (usual FS equivalents are combinations with more than two FS grade 3+).

6.5 - Constant bilateral assistance (canes, crutches, braces) required to walk about 20 meters without resting (usual FS equivalents are combinations with more than two FS grade 3+).

7.0 - Unable to walk beyond approximately 5 meters even with aid, essentially restricted to a wheelchair; wheels self in standard wheelchair and transfers alone; up and about in wheelchair some 12 hours a day; (usual FS equivalents are combinations with more than one FS grad 4 +; very rarely pyramidal grade 5 alone).

7.5 - Unable to take more than a few steps; restricted to wheelchair, may need aid in transfer; wheels self but cannot carry on in standard wheelchair a full day; may require motorized wheelchair; (usual FS equivalents are combinations with more than one FS grade 4 +).

8.0 - Essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself much of the day, retains many self-care functions; generally has effective use of arms; (usual FS equivalents are combinations, generally grade 4 + in several systems).

8.5 - Essentially restricted to bed much of the day; has some effective use of arm(s); retains some self-care functions; (usual FS equivalents are combinations generally 4 + in several systems).

9.0 - Helpless bed patient: can communicate and eat; (usual FS equivalents are combinations, mostly grade 4 +).

9.5 - Totally helpless bed patient; unable to communicate effectively or eat/swallow; (usual FS equivalents are combinations, almost all grade 4 +).

10.0 - Death due to MS.
8.5. **The Zarit Burden Interview** [41]

### THE ZARIT BURDEN INTERVIEW

Please circle the response that best describes how you feel.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative's behaviour?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>7. Are you afraid what the future holds for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8. Do you feel your relative is dependent on you?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>9. Do you feel strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>11. Do you feel that you don't have as much privacy as you would like because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>13. Do you feel uncomfortable about having friends over because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Do you feel that your relative seems to expect you to take care of</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>him/her as if you were the only one he/she could depend on?</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Do you feel that you don’t have enough money to take care of your</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>relative in addition to the rest of your expenses?</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Do you feel that you will be unable to take care of your relative</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>much longer?</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Do you feel you have lost control of your life since your relative’s</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>illness?</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Do you wish you could leave the care of your relative to someone</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>else?</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Do you feel uncertain about what to do about your relative?</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Do you feel you should be doing more for your relative?</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Do you feel you could do a better job in caring for your relative?</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Overall, how burdened do you feel in caring for your relative?</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Total Score (out of 88)**

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**Interpretation of Score:**
- 0 – 21: little or no burden
- 21 – 40: mild to moderate burden
- 41 – 60: moderate to severe burden
- 61 – 88: severe burden

Score values and interpretation are guidelines only, as discussed in:
8.6. **Functional Independence Measure** [18]

**FUNCTIONAL INDEPENDENCE MEASURE AND FUNCTIONAL ASSESSMENT MEASURE**

**Functional Independence Measure**
The Functional Independence Measure (FIM) scale assesses physical and cognitive disability.

**Scoring**
Items are scored on the level of assistance required for an individual to perform activities of daily living. The scale includes 18 items, of which 13 items are physical domains based on the Barthel Index and 5 items are cognition items. Each item is scored from 1 to 7 based on level of independence, where 1 represents total dependence and 7 indicates complete independence. The scale can be administered by a physician, nurse, therapist or layperson. Possible scores range from 18 to 126, with higher scores indicating more independence. Alternatively, 13 physical items could be scored separately from 5 cognitive items.

**Time**
It takes 1 hour to train a rater to use the FIM scale, and 30 minutes to score the scale for each patient.

**Clinical application**
The FIM scale is used to measure the patient’s progress and assess rehabilitation outcomes. This scale is useful in clinical settings of rehabilitation. The FIM was carefully designed and developed with the consensus of the US National Advisory Committee, with close attention to definitions, administration and reliability. Manuals, training and videos are provided (further information can be found at [www.udmnr.org](http://www.udmnr.org)). The FIM has been used in a number of countries, including the USA, Canada, Australia, France, Japan, Sweden and Germany. Studies of large samples have been published, including a study of 93,829 subjects. The FIM has been used extensively in rehabilitation, including that for stroke and multiple sclerosis. Scores are responsive to change and also reflect the patient's discharge destination.

**FIM and FAM**
The Functional Assessment Measure (FAM) includes FIM items but also adds 12 new items, mainly covering cognition, such as community integration, emotional
MEASUREMENT SCALES USED IN ELDERLY CARE

status, orientation, attention, reading and writing skills, and employability. The FIM scale on its own had ceiling effects, so the FAM was proposed, which extends the coverage of the FIM. This scale was originally intended for patients with brain injury, but is in fact useful in all rehabilitation settings.

FIM + FAM is completed by a healthcare professional for the patient.

UK FIM + FAM

This scale was developed in the UK, and was last modified by the UK FIM+FAM Group in 1999. Some of the items used in the original FAM from the US Developmental Group in California were considered to be too vague. For this reason the UK version was developed after modification of the original FAM. The UK FIM + FAM Group was coordinated by the Regional Rehabilitation Unit at Northwick Park Hospital, Middlesex, UK. This group has improved the consistency of scoring. The original 30 items and 7 levels remain the same as in the original version.

<table>
<thead>
<tr>
<th>UK FIM + FAM SCALE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-care</strong></td>
</tr>
<tr>
<td>1. Eating</td>
</tr>
<tr>
<td>2. Grooming</td>
</tr>
<tr>
<td>3. Bathing/showering</td>
</tr>
<tr>
<td>4. Dressing upper body</td>
</tr>
<tr>
<td>5. Dressing lower body</td>
</tr>
<tr>
<td>6. Toileting</td>
</tr>
<tr>
<td>7. Swallowing’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sphincters</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bladder management</td>
</tr>
<tr>
<td>2. Bowel management</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mobility</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Transfers: bed/chair/wheelchair</td>
</tr>
<tr>
<td>2. Transfers: toilet</td>
</tr>
<tr>
<td>3. Transfers: bathtub/shower</td>
</tr>
<tr>
<td>4. Transfers: car’</td>
</tr>
<tr>
<td>5. Locomotion: walking/wheelchair</td>
</tr>
<tr>
<td>6. Locomotion: stairs</td>
</tr>
<tr>
<td>7. Community mobility’</td>
</tr>
</tbody>
</table>
MEASUREMENT SCALES USED IN ELDERLY CARE

Communication
1. Expression
2. Comprehension
3. Reading
4. Writing
5. Speech intelligibility

Psychosocial
6. Social interaction
7. Emotional status
8. Adjustment to limitations
9. Use of leisure time (replaces employability in original version)

Cognition
10. Problem solving
11. Memory
12. Orientation
13. Concentration (replaces attention in original version)
14. Safety awareness (replaces safety judgement in original version)

"FAM items

**Seven levels for each item**

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Complete independence</td>
</tr>
<tr>
<td>6</td>
<td>Modified independence</td>
</tr>
<tr>
<td>5</td>
<td>Supervision</td>
</tr>
<tr>
<td>4</td>
<td>Minimal assistance</td>
</tr>
<tr>
<td>3</td>
<td>Moderate assistance</td>
</tr>
<tr>
<td>2</td>
<td>Maximal assistance</td>
</tr>
<tr>
<td>1</td>
<td>Total assistance</td>
</tr>
</tbody>
</table>

- Fully independent
- Requiring the use of a device but no physical help
- Requiring only standby assistance or verbal prompting or help with set-up
- Requiring incidental hands-on help only (subject performs > 75% of the task)
- Subject still performs 50–75% of the task
- Subject provides less than half of the effort (25–49%)
- Subject contributes < 25% of the effort or is unable to do the task
MEASUREMENT SCALES USED IN ELDERLY CARE

Scoring principles

- Function is assessed on the basis of direct observation.
- Admission scoring is done within 10 days of admission.
- Discharge scoring is done during the last week before discharge.
- Scoring is done by a multi-disciplinary team member.
- The subject is scored on what they actually do on a day-to-day basis, not on what they could do.
- Do not leave any score blank.
- Score 1 if the subject does not perform the activity at all, or if no information is available.
- If function is variable, use the lower score.


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