# FALL MANAGEMENT AMONG FULL TIME WHEELCHAIR USERS

BY

JONG HUN SUNG

DISSERTATION

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Doctoral Committee:

Assistant Professor Laura A. Rice, Chair
Professor Jacob J. Sosnoff
Professor Laura L. Payne
Dr. Wendy D. Bartlo

## ABSTRACT

Falls are a common health issue among full-time wheelchair users, however there is a lack of evidenced-based fall prevention and management strategies for wheelchair users. The main objective of this dissertation is to develop a fall management program for full-time wheelchair users. To develop a fall management program, a sequential exploratory mixed methods research study was implemented. The first phase of the study (Chapter 4) explored the circumstances surrounding falls, aftermath of falls, and fall recovery strategies among full-time wheelchair users. In phase 1, the qualitative interview data from 38 wheelchair users was analyzed. The results of phase 1 revealed many underlying factors associated with falls and potential fall prevention and recovery strategies including exercises to enhance sitting balance, wheelchair/transfer skill training, education on management of a variety of environmental hazards, education on wheelchair set-up/maintenance and the development of comprehensive fall recovery plans.

In phase 2 (Chapter 5), a multifactorial fall management program, entitled **I**ndividualized **R**eduction **o**f Fa**LL**s (iROLL), was developed for full-time wheelchair and scooter users living with multiple sclerosis (MS) based on data obtained from phase 1 and previous literature. To examine the feasibility and preliminary efficacy of the intervention, participants underwent assessments to examine fear of falling, knowledge of fall prevention and recovery strategies, quality of transfer and wheelchair skills, and sitting balance before and after the 6-week intervention program. 13 wheelchair/scooter users living with MS (age: 59.2 ± 10.3 years, 10 female) completed the post-intervention assessment following the 6-week intervention. The results revealed that fear of falling, which was evaluated by the spinal cord injury-fall concern scale, significantly decreased ($p=0.022$). Knowledge of fall prevention and recovery strategies,

indexed by the fall management scale (p=0.008) and the fall prevention and management questionnaire (p=0.010), significantly improved. Finally, quality of transfer skills, evaluated with the transfer assessment instrument (p=0.034), improved significantly. No significant changes were found in wheelchair skills, as measured by the wheelchair skill test (p=0.551) or in sitting balance, evaluated with the function in sitting test (p=0.249). These preliminary results indicate that the iROLL program is effective in decreasing fear of falling, increasing knowledge of fall prevention and recovery, and improving quality of transfer skills. Future research is needed to examine the long-term impact of the program and the influence on fall frequency.

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## TABLE OF CONTENTS

# CHAPTER 1: INTRODUCTION

## 1.1 Background

People with disabilities, such as a Spinal Cord Injury, Multiple Sclerosis, Parkinson's disease or Cerebral Palsy, often have mobility impairments that limit their performance of daily activities such as attending school or going to work[1]. A wheelchair is a common assistive device used by those who have mobility impairments to facilitate functional mobility, daily activity, community participation, and engagement in essential social roles. According to the United States Census Bureau, it was estimated that in 2010, 3.6 million people in the United States were using wheelchairs[2]. This number is expected to consistently increase by 5% each year[3].

Although wheelchairs enhance active engagement in essential activities of daily living among those with impaired mobility[4,5], there is a high occurrence of wheelchair-related accidents and safety risks that must be taken into consideration. Among studies that have investigated the cause of wheelchair-related accidents, tips and falls have been found to be the number one cause of accidents among wheelchair users living with a variety of disabilities[6,7].

A fall can negatively influence a full-time wheelchair user's life in several ways[8-11]. Approximately 10-20% of falls result in serious injuries including fractures, dislocations, traumatic brain injuries and concussions that require medical attention [10-14]. In the worst case, falls can result in death [6]. Falling can also lead to the development of a fear of falling [9,15,16], which can have an adverse impact on quality of life, community participation, and the individual's ability to perform essential activities of daily living [17]. Due to the adverse physical, and psychosocial impact of falls on full-time wheelchair users, it is important for wheelchair users, their families, and clinicians to develop strategies to prevent and manage falls.

Despite the adverse impact of falls on wheelchair users, the number of investigations focusing on circumstances surrounding the mechanism of falls in full time wheelchair users is low compared with research in other clinical populations[18]. For example, more than 400 fall-related factors have been examined in ambulatory, frail, older adults[11,19]. Due to the differences in physical characteristics and functional mobility limitations, risk factors associated with falls for full-time wheelchair users are different from those of ambulatory individuals[18,20]. For example, poor standing balance or gait impairment are common factors associated with falls in ambulatory individuals[21]. However, among wheelchair users, previous investigations indicate that poor transfer skills (i.e., moving from a wheelchair/scooter to another surface such as a bed or toilet)[11,20,22] and impaired seated postural control are associated with falls[11,18].

Although previous investigations have provided important information regarding general fall related-factors among wheelchair users, very little in-depth research has been conducted within this population. For instance, previous research indicates that falls frequently occur during transfers, but it hasn't been investigated if/how other factors (e.g. wheelchair configurations, environments or users' characteristics) contribute to the falls during the transfer activities. Thus, a better understanding of the specific circumstances surrounding the mechanism of falls is needed to provide adequate fall prevention and psychosocial support.

To manage falls among full-time wheelchair users, interventions focusing on risk factors specific to wheelchair users (e.g. poor wheelchair transfer skill) are needed. To date, only one pilot study examined the efficacy of an intervention to manage fall risks and fear of falling in full-time wheelchairs users[22]. This intervention focused on improving seated postural control and transfer skills. The results indicated that the number of falls experience by 16 full-time wheelchair users living with multiple sclerosis significantly decreased following the intervention.

Despite limitations, such as small sample size (n=16) and the absence of a comprehensive approach to manage fall related factors, the results of this study show that there is a strong possibility that the falls among full-time wheelchair users can be effectively managed.

Despite the best efforts of wheelchair users and healthcare professionals, 100% prevention of falls is not possible to achieve. Therefore, in addition to developing effective prevention strategies, the investigation and development of fall recovery methods are necessary to comprehensively manage the adverse impact of falls. Fall recovery is the process of getting up from the surface one has fallen onto and then returning to one's wheelchair or preferred surface. When falls occur, an efficient recovery strategy that minimizes the amount of time an individual remains on the ground or the floor is important. Previous research has shown that a long lie time, defined as remaining on the floor or ground for over an hour after a fall [21], and a critical fall, defined as inability to recover from a fall independently, [23] have been associated with a decline in quality of life, serious injuries, and even death [23-25]. Therefore, it is important to pay attention to recovery strategies after falling to minimize adverse effects.

The development of fall recovery strategies has been shown to be effective in other populations. For instance, a research study examined the efficacy of a floor-rise training intervention program on the fear of falling in 63 ambulatory, independent older adults. Results indicate that it was effective in reducing fear of falling [26]. Although this previous investigation has provided important information regarding the efficacy of fall recovery training in ambulatory older adults, little is known about fall recovery strategies among full-time wheelchair users due to the limited knowledge about their post-fall experiences. To develop effective recovery strategies, it is first important to understand what occurs immediately after a fall. Therefore, examination of the of post-fall characteristics among full-time wheelchair users is critical to gain

an in-depth understanding of the typical lie periods, physical injuries sustained, complications, and fall recovery strategies.

## 1.2 Specific Aims

The purpose of this study is to develop a comprehensive multifactorial fall management program for wheelchair users through mixed methods research. The study is comprised of two phases. The first phase (chapter 4) focused on developing the foundation for an intervention program to prevent falls and develop recovery strategies among full-time wheelchair users. The goals of this project were as follows: (a) to explore wheelchair users' perceptions of falls and fear of falling (b) to gain an in-depth understanding of the circumstances surrounding falls in full-time wheelchair users, (c) to explore the aftermath of falls experienced by full-time wheelchair users, and (d) to document fall avoidance and recovery strategies among full-time wheelchair users. The second phase (chapter 5) aims (e) to develop a multifactorial fall management program based on the findings obtained from phase 1 and the previous literature, and (f) to examine the preliminary feasibility and efficacy of the program.

The first phase (chapter 4) investigated aims (a) - (d) by performing a secondary analysis of data collected as part of mixed-method research investigating the characteristics of falls and fallers among power and manual wheelchair users. The quantitative data collected by the surveys and qualitative data collected in semi-structured interviews were analyzed to answer the following research questions: 1) What are wheelchair users' perceptions of falls and fear of falling? 2) What are the circumstances surrounding falls among full time wheelchairs? 3) What occurs after a fall, including lie period, physical injuries, and recovery methods among full-time wheelchair users? and 4) How do wheelchair users think falls can be avoided and fall recovery

can be managed? Data from this phase was used to inform the development of the intervention in phase 2.

The second phase (chapter 5) examined the feasibility and preliminary efficacy of a multifactorial fall prevention program. Using information obtained from phase 1, and evidence from previous literature, a multifactorial fall prevention program was developed to provide education on a variety of topics related to the management of risk factors associated with falls in full-time wheelchair and scooter users living with multiple sclerosis (MS). Then, the feasibility and preliminary efficacy of the program was examined. To assess the feasibility of the intervention, retention rates, adherence to the intervention program, safety, and the ability to collect outcomes were examined [27]. To examine the preliminary efficacy of the intervention, wheelchair/scooter users' fear of falling, knowledge of fall prevention and recovery strategies, quality of transfer and wheelchair skills, and sitting balance were assessed before and after exposure to the intervention. Lastly, a semi-structured interview was also conducted following the intervention to gain in-depth feedback on the intervention program, changes in behavior, and perceptions of falls and fear of falling in full-time wheelchair and scooter users with MS.
In order to examine the initial efficacy of the multifactorial fall management program in phase 2, individuals living with MS, who are full-time wheelchair or scooter users, were selected. Individuals living with MS were specifically selected first to control for the inherent variation between wheelchair users due to their disabilities [28]. In addition, because MS is a progressive disease, over time symptoms associated with the disability, such as mobility impairments, get worse and more debilitating. As a result, many individuals with MS eventually need to use an assistive device such as wheelchair/scooter to facilitate their mobility [29]. However, due to the slow progression of the disease process, many individuals with MS, who use a wheelchair or

scooter, often don't receive formal rehabilitation to learn how to perform critical skills, such as transfers or wheelchair skills in acute inpatient rehabilitation setting. Finally, falls are a significant health concern among those who utilize a wheelchair/scooter as their primary means of mobility [30,31]. However, limited research has been performed to examine interventions to manage falls in this population. Thus, a significant need exists to develop effective intervention programs for this portion of the MS population. Preliminary examination of the feasibility of the program among wheelchair/scooter users with MS will provide important preliminary data on which a larger study with a more diverse population can be based.

Aim (f): To examine the preliminary efficacy of a multifactorial fall prevention program, we hypothesize that:

1) After exposure to the intervention, participants will report decreased fear of falling as measured by the Spinal Cord Injury- Fall Concern Scale and increase knowledge of fall prevention and recovery strategies as assessed via the Fall Management Scale and the Fall Prevention and Management Questionnaire.

2) After exposure to the intervention, participants will display improved transfer skills evaluated by the Transfer Assessment Instrument, sitting balance assessed by the Function in Sitting Test, and wheelchair skills indexed via the Wheelchair Skill Test.

1.3 Research needs

There is little empirical literature available on the causes, circumstances, and consequences of falls, recovery methods, and fall prevention and recovery interventions among full-time wheelchair users despite the obvious need. The benefits of fall prevention and recovery programs among ambulatory older adults have been shown to reduce fall frequency and fear of falling[26,32]. Furthermore, these fall prevention programs resulted in a positive effect on quality of

life and social engagement [33-36]. However, these benefits have not yet been examined in full-time wheelchair users. Given the lack of published research in this area, determining how to prevent falls and recover from a fall in way that minimizes injuries is challenging for full-time wheelchair users, their families, and clinicians.

Therefore, this study can help to gain an in-depth understanding of the unique circumstances surrounding falls, fear of falling, post-fall characteristics, and fall recovery strategies among wheelchair users. Further, if the proposed multifactorial fall management program is found to be feasible and effective, it will have the potential to enhance the quality of life and community participation of full-time wheelchairs users. Finally, with this knowledge, clinicians can more effectively design and utilize evidence-based fall management programs for full-time wheelchair users.

# CHAPTER 2: LITERATURE REVIEW

## 2.1 Description of Wheelchair Users in the United States

As a result of aging or of a disability, such as spinal cord injury, multiple sclerosis, or Parkinson's disease, many individuals experience mobility impairments, which may limit their walking and balance. For those who have mobility limitations, using mobility assistive devices, including wheelchairs, is necessary. The wheelchair is one of the most important mobility assistive devices and is often used to facilitate mobility, participation in community activities and performance of necessary roles and activities[37,38]. In 1999, it was estimated that there were 2.3 million wheelchair users in the United States [39]. Over time, this population of wheelchair users has increased. Based on the U.S. Census Bureau's Survey in 2010, there were 3.6 million non-institutionalized wheelchair users in the United States, and this population is expected to consistently increase by 5% every year in the foreseeable future [3].

## 2.2 Prevalence and consequences of wheelchair-related falls

According to the World Health Organization, a fall is defined as "an event which results in a person coming to rest inadvertently on the ground or floor or other lower level"[40]. Several studies investigated the prevalence and consequences of wheelchair-related falls [6,7,41,42]. In 1990, Calder and colleagues investigated the yearly incidence of serious wheelchair-related accidents in the United States and reported that 3.3% of wheelchair users had a serious wheelchair-related accident yearly, and wheelchair related tips and falls accounted for 68% of fatal wheelchair-related accidents[7]. Similarly, Ummat et al., in 1994, evaluated 2,066 non-fatal wheelchair-related accidents occurring between 1986-1990 to understand the epidemiology of wheelchair-related accidents. They reported that 73.2% of wheelchair-related accidents were the result of falls and tips [41]. More recently, in 2011, Chen et al. reported that 65 out of 74 wheelchair-related

accidents reported by 52 wheelchair users were caused by tips or falls [42]. At a national level, fall and tips are also reported to be a leading cause of wheelchair related accidents. In 2003, more than 100,000 injuries caused by wheelchair-related accidents were treated in emergency departments in the United States, and approximately 70% of these accidents were the result of tips and falls [6].

Other studies have investigated the consequences of wheelchair-related falls. For example, in 1994, Kirby et al.[11]examined wheelchair-related accidents caused by tips and falls of 577 non-institutionalized manual wheelchair users. 57.4% of the study participants reported that they had at least one fall from their wheelchairs and 47% (n=272) were injured from that fall. Importantly, 15.8% of those who sustained the injuries from a fall reported severe injuries including fractures, dislocations, traumatic brain injuries and concussions that require medical attention [11]. Similar results have been found specifically among wheelchair users living with spinal cord injury. A prospective study examining the fall prevalence and consequences of falls among Veterans with spinal cord injury who were full time wheelchair users found that 204 of 650 (31%) study participants reported 533 fall events, and 95 participants were injured as a result of these wheelchair-related falls [19]. Another investigation reported that 96 of 149 (64%) wheelchair users with spinal cord injury fell, 45 (32%) fell recurrently, 50 (34%) were injured, and 7 (5%) severely injured [9]. In the worst case, falls can result in death [6]. From 1973 to 1987, a total of 770 deaths were caused by wheelchair-related accidents [7]. Additionally, in 2005, it was reported that there was at least one wheelchair-related fall per week resulting in death in the United States [43].

In addition to physical injuries and death, falls can lead to the development of a fear of falling which can have an adverse impact on the quality of life, social enrollment, and an

individuals' ability to perform the essential activities of daily living. A recent study investigated fall and fear of falling prevalence of full-time wheelchair and scooter users living with MS by using an online survey. The results of the study indicated that 33 out of 44 (76.7%) participants experienced fear after falling and limited their involvement in some activities as a result of fear [22].

Overall, a review of the literature highlights the high prevalence and serious consequences of falls among full-time wheelchair users. Due to the adverse physical and psychosocial impact of falls on full-time wheelchair users, it is important for wheelchair users, their families, and clinicians to determine the appropriate actions to take to manage falls. Therefore, research into the factors influencing these falls as well as possible ways to mitigate them is of the utmost importance.

2.3 Factors associated with wheelchair-related falls

Although there is a limited understanding of the causes, mechanisms, and factors associated with wheelchair-related falls, previous research has provided some information about general fall-related risk factors for wheelchair users. In 1994, Kirby et al. conducted a survey study using a postal questionnaire to investigate the general fall characteristics (prevalence, causes, and consequences of falls) of full-time manual wheelchair users in Nova Scotia. Using data collected from 577 participants, Kirby, et al. reported that factors associated with an increased risk of falls and fall-related injuries were younger age, male gender, paraplegia or spina bifida as the reason for wheelchair use, wheelchair configurations (e.g. light weight), daily use of a wheelchair (e.g. use of the wheelchair for recreation), and performing a transfer without assistance [11]. Another study by Nelson et al., in 2010, similarly examined factors associated with falls in a large group (n=702) of full-time wheelchair users living with SCI using a logistic

regression analysis. Results indicated that pain in the previous two months, greater motor function, a fall incident in the past year, and lack of accessibility to home entrances were associated with wheelchair related falls. One study has looked more specifically at wheelchair configurations as a part of this problem. Gaal et al., in 1997, reported that wheelchair configurations which negatively impact the stability of the wheelchair, such as smaller casters, a short wheelbase or placing the rear axle close to the center of gravity, were associated with greater fall risk in wheelchair users [13].

Other research also examined the common actions being performed when a fall occurred. A retrospective review of 45 medical records of Veterans who sustained fractures from falling reported that the fall-related fractures occurred while performing wheelchair transfers, wheelchair propulsion, reaching for an object, and showering [12]. In line with these findings, a recent survey-based study to determine the circumstances of falls in wheelchair and scooter users living with MS reported that transferring to/from a wheelchair, and reaching for an object were the most common actions being performed during a fall [18].

Overall, a review of the literature revealed several risk factors associated with falls among full-time wheelchair users. Many of these factors can be modified through therapeutic or educational interventions. Additional work is needed to gain a better understanding of the specific circumstances surrounding the mechanism of falls in order to develop comprehensive fall prevention and management strategies among full-time wheelchair users.

2.4 Post-fall characteristics and recovery strategies

Despite the best intentions of wheelchair users and their care providers to prevent falls, fall prevention is not always possible. For example, an unexpected environmental hazard may arise, or the error of a care provider may lead to a fall. Thus, the ability of a wheelchair user to

get up safely after a fall is important. In the geriatric literature, studies have shown that a significant portion of those who fall need assistance to get up. If assistance wasn't available, they remained on the floor or ground for a prolonged period after falling.[24,44,45]. For example, in 1993, Tinetti et al. examined the prevalence of the inability to get up independently after falling in ambulatory adults over the age of 72. It was reported that 148 of 313 (47%) non-injured fallers needed some type of assistance to get up after a fall [44]. Another investigation examined the post-fall experiences of 110 older adults. Of the 110 participants, 53 reported that they needed assistance to get up after at least one fall in the previous year [24]. An investigation by Bisson et al., in 2017, examined the frequency of critical falls, defined as a fall in which the person was unable to get up [45], in 354 adults with MS who were at least 55 years old. The results showed that 54.1% (n=177) of participants reported that they required assistance to get up after their most recent fall [45].

The inability to get up from the floor or ground after falling is critical [23,24]. If the faller remains on the floor or the ground alone and does not receive assistance for over an hour after the fall (defined as a long lie period) [21], serious physical injuries including pressure sores, dehydration, hypothermia and even death can result [23]. It is reported that a long lie period after a fall nearly doubles the risk of death [46]. In addition to the physical impairments, critical falls were found to be associated with a decline in the performance of essential daily activities and cognitive impairment as well as the development of a fear of falling in older adults [44,47]. Therefore, scholars in the geriatric fall prevention field recommend that older adults at risk of falling be taught how to get up independently from the floor after falling. Cox, et al., in 2016 examined the effect of a floor-rise training program on fear of falling in 63 independent, older adults and reported that the training intervention was beneficial in reducing fear of falling. These

studies highlight the serious consequences, and the importance of developing recovery strategies to minimize the adverse impacts of falls[26].

A major limitation of the research on post-fall characteristics and fall recovery strategy is its nearly exclusive focus on ambulatory individuals. To date, little is known about post-fall characteristics including lie period, physical injuries, fear of falling, complications, and recovery strategies among full-time wheelchair users. However, this matter is critical to full-time wheelchair users. Due to the mobility impairment associated with their disabilities, wheelchair users may experience long lie periods and require more assistance to recover from a fall compared to other clinical populations. Due to longer lie periods, the consequences of fall can be more significant for wheelchair users.

## 2.5 Theoretical Models for research design

A theoretical framework plays an important role in guiding the research process from designing a research question to interpreting observed phenomena. In addition, a theoretical framework would be the lens through which a researcher evaluates his/her research problem and questions. In this research study, two theoretical frameworks were used: The International Classification of Functioning, Disability and Health (ICF) and, the Health Belief Model (HBM).

### 2.5.1. International Classification of Function, Disability and Health

The ICF is a classification system that documents the complex interactions of a person's social and psychological environments and how this interaction affects a person's health status [48](Figure 2.1). The ICF provides a framework for understanding and describing the factors that healthcare professionals should consider when managing a health condition. The ICF divides overall health condition into five key components: body functions and structures, activities, participation, environmental and personal factors [48].

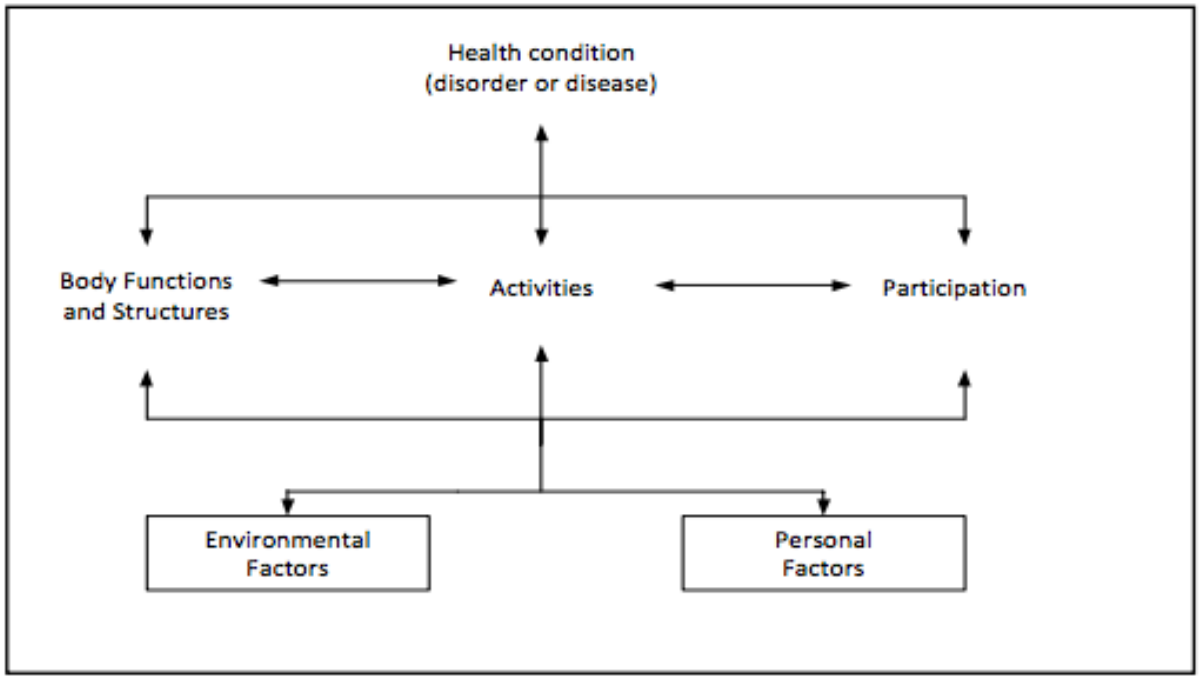


Figure 2.1. The international classification of function, disability and health

The ICF provides the following definitions for the components mentioned above [48].

1. Body functions are defined as “the physiological functions of body systems” (including psychological functions).
2. Body structures are defined as the anatomical parts of the body, such as organs, limbs and their components, and impairments as problems in body function and structure, such as significant deviation from normal body function or a loss of function.
3. Activity is defined as “the execution of a task or action by an individual.”
4. Participation is defined as “involvement in a life situation.”
5. Environmental factors are defined as “the physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person’s functioning.”

6. Personal factors include gender, age, race lifestyles, habits, education and profession. Personal factors are not described in their entirety under the ICF framework due to their cultural and social variance.

In this study, the ICF was used to identify the risk factors associated with falls experienced wheelchair users, and to characterize the participants who underwent the intervention program using the five components in the framework. The ICF model is useful as a guideline for understanding falls sustained by wheelchair users. First, identifying risk factors associated with falls is a complex task because falls are generally caused by a variety of factors [21]. Thus, the ICF model allows researchers to systematically investigate falls and to characterize fallers. For example, Beninato et al., in 2009, examined the associations between falls and several clinical outcome measures to determine if those outcome measures could detect fall risk for 27 post stroke survivors[49]. Another investigation by Yen et al. applied the ICF model to identify and categorize a variety of risk factors for patients in acute rehabilitation settings[50]. In this investigation, the various domains of the ICF model served as a guideline to select the clinical outcome measures. Second, qualitative data analysis can be influenced by researchers' bias. For example, physical therapists may focus more on the physical condition of the individual (e.g. body function and structure, personal factors) related to fall circumstances and consequences, such as poor strength or balance, while occupational therapists may focus more on environmental factors, such as a cluttered environment or poor street conditions. Therefore, the ICF framework can help to avoid personal bias and to create a well-balanced guideline for data analysis based on the five components of health. Given these reasons, the ICF model is helpful as a guideline for understanding falls and identifying the risk factors associated with falls experienced wheelchair users.

### 2.5.2 Health Belief Model

The Health Belief Model (HBM) is a widely used framework for predicting preventative health behavior, and for developing interventions to facilitate behavior changes [51]. The HBM is based on the idea that people will only change their health behavior if given a good reason to change it. The HBM theorizes that the extent to which an individual takes action to change their health behavior is determined by personal beliefs or perceptions about a disease and the strategies available to decrease its occurrence [52]. There are four key concepts of the personal beliefs or perceptions in the HBM: perceived seriousness, perceived susceptibility, perceived benefits and perceived barriers [52]. These 4 perceptions are influenced by other variables such as culture, education level, etc. In addition to the 4 perceptions and variables, the HBM suggests that behavior is also influenced by cues to action, which are events, people, or things that move people to change their behavior. Lastly, the concept of self-efficacy was added to the HBM as a separate construct. Figure 2.2 illustrates the relationships among the components.

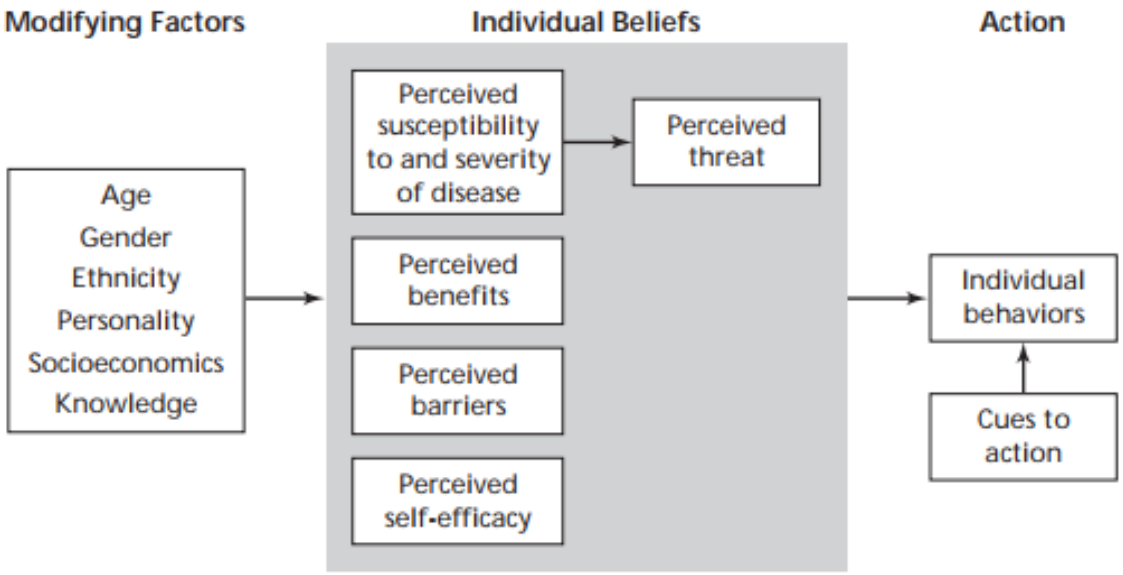


Figure 2.2. The health belief model

The HBM provides the following definitions for the components mentioned above[51]

1. Perceived Susceptibility is defined as "belief about the chances of experiencing a risk or getting a condition or disease."
2. Perceived Severity is defined as "belief about how serious a condition and its sequelae are."
3. Perceived Benefits are defined as "belief in efficacy of the advised action to reduce risk or seriousness of impact."
4. Perceived Barriers are defined as "belief about the tangible and psychological costs of the advised action."
5. Cues to action are defined as "strategies to activate readiness"
6. Self-efficacy is defined as "confidence in one's ability to take action"

The use of HBM in development of a multifactorial fall management program has great potential to assist participants with development of their own fall prevention and recovery

strategies. The previous research has shown that the HBM has successfully been implemented in the development a variety of intervention programs to facilitate behavior changes including fall prevention in older adults [53-59]. For example, in 2009, Hill et al. conducted a randomized control trial with 222 elderly hospital inpatients to evaluate a video-based fall prevention education program developed based on the HBM. The results indicated that the intervention successfully increased the study participants' knowledge of fall prevention strategies [57].

In this project, the multifactorial fall management program is designed based on the constructs of the HBM and aims to facilitate behavior change in full-time wheelchair users by targeting the key perceptions mentioned above. For example, the program educates participants on a variety of risk factors and the adverse consequences associated with falls in order to increase their awareness of their own susceptibility to falls and the severity of fall consequences. Also, various prevention strategies and their benefits are emphasized in order to increase participants' perceived benefits of using those strategies to manage falls. Collectively, the intervention serves as a cue to action (strategies to activate readiness) by assisting the participants with the development of fall prevention and fall recovery strategies that they can implement in their real lives.

2.6 Fall intervention program in wheelchair users.

A number of fall prevention interventions have been developed and their efficacy for ambulatory populations has been examined [60-62]. Consequently, there is an abundance of literature demonstrating the success of fall prevention programs in reducing falls and fall risk in ambulatory people. However, there is limited evidence demonstrating the benefits of fall prevention programs for full-time wheelchair users. In 2006, Martorello et al. examined the efficacy of an automatic manual wheelchair braking system in the reduction of falls during

transfers among 18 individuals living in nursing homes. They found that the number of falls sustained by these individuals was significantly reduced in the one year following the installation of the automatic braking system[63]. Other research on fall prevention for wheelchair users was conducted by Dyer, et al., in 2008. In this study, researchers examined the impact of a participant specific program to decrease fall frequency among individuals receiving treatment in acute inpatient rehabilitation with new lower extremity amputations who primarily used wheelchairs for mobility [64]. Results indicated that after completion of the program, fall incidence decreased by 5%. More recently, in 2017, Rice et al. investigated the efficacy and feasibility of an intervention put in place to reduce the number of falls and fear of falling in full-time wheelchair users living with MS[65]. The intervention attempted to decrease the number of falls by improving transfer skills and seated balance abilities. These two items have previously been recognized as factors associated with falls among full time wheelchair users [18]. The intervention consisted of educational materials to improve the quality of transfer skills and a home-based exercise program to improve core strength and seated balance. The results indicated the number of falls significantly decreased in 16 full-time wheelchair users with MS after exposure to the intervention. It is noteworthy that this was the first research study to examine methods to manage falls and fear of falling among community-dwelling full-time wheelchair users.

Although previous investigations have provided relevant information on fall prevention in full-time wheelchair users, these interventions only targeted one or two fall related risk factors and may not be comprehensive.

2.7. Benefits of multifactorial fall prevention programs in wheelchair users.

Given that falls in full-time wheelchair users are complex and multifactorial in nature [20], interventions that cover a wide range of risk factors associated with falls may potentially help to reduce falls and fear of falling among full-time wheelchair users. To date, no study has examined the efficacy of multifactorial fall prevention programs in preventing falls in full-time wheelchair users. However, a number of interventions have been developed, and their efficacy in preventing falls has been examined in ambulatory individuals [60-62]. For example, Sosnoff et al., in 2015, examined the feasibility of a multifactorial fall prevention program (combined exercise and education program) delivered over 12-weeks among 34 individuals with MS, who were able to walk either with or without an assistive device (e.g. cane or walker). The results indicated that the program was found to be feasible, and after the intervention, the number of falls experienced by the individuals and their fall risk measured by the Physiological Profile Assessment both decreased [66]. Another investigation by Lee et al., in 2012, examined the efficacy of a multifactorial fall prevention program on fall incidence and fall risk as measured by the Physiological Profile Assessment among 616 community-dwelling older adults who had at least one self-reported fall and were at high risk of falling. The multifactorial prevention program consisted of a small group exercise program, health education classes focusing on management of risk factors associated with falls, fall prevention strategies and home hazards evaluation/modification. Of the 616 participants, 313 received the intervention, and it was found that the multifactorial fall prevention program helped reduce the number of falls and decrease fall risk as measured by the Physiological Profile Assessment[67].

Several studies have systematically reviewed the effectiveness of different kinds of intervention programs, and multifactorial intervention programs have generally proven to be

some of the most effective programs to prevent a fall. A meta-analysis study performed in 2004 systematically reviewed 40 randomized control trials in older adults to evaluate the effects of fall prevention interventions, indicated that the most effective intervention was a multifactorial fall management program [68]. Other studies have shown similar results. In 2009, Gillespie et al. systematically reviewed 62 fall intervention programs to seek the best predictors for the effectiveness of programs designed to reduce the incidence of falls in older people [61]. They found that several multifactorial fall prevention strategies effectively reduced falls. More recently, an investigation performed by Stubbs et al., in 2015, reviewed 47 fall prevention intervention randomized control trials in older adults and found that exercise and individually customized multifactorial interventions were effective in reducing falls in older adults [62]. A review of the fall prevention intervention literature reveals that effective intervention programs to reduce falls were 1) a multifactorial fall management programs and 2) exercise-based interventions targeting balance improvement. Collectively, the results highlighted that a multifactorial approach including exercise programs is beneficial for improved management of falls. Thus, the multifactorial approach should be applied to the fall management strategies for full-time wheelchair users.

# CHAPTER 3: THEORETICAL FOUNDATION OF THE RESEARCH METHODOLOGY

## 3.1. Research paradigm

A research paradigm is defined as "the set of common beliefs and agreements shared between scientists about how problems should be understood and addressed" [69]. Research paradigms are important because they influence the practice of research at many different levels from the attitude of the researcher to the selection of research tools and methods [70]. Research paradigms affect researchers understanding of their research on three different levels: ontological, epistemological, and methodological. Briefly, ontology deals with the nature of reality, which is concerned with "what kind of world we are investigating, with the nature of existence, with the structure of reality as such"[71]. The ontological assumptions of a research paradigm provide answers to questions such as "what is there that can be known?" or "what is the nature of reality?"[72]. Next, the epistemological assumptions of a research paradigm pertain to "a way of understanding and explaining how we know and what we know" [71]. In other words, epistemological assumptions focus on the relationships between the researcher and reality. Lastly, methodological assumptions deal with the methods and procedures that are allowable within the paradigm.

## 3.2. Mixed method Research paradigm

The research paradigms underpinning mixed methods are extensive and the debate of suitability have been ongoing about what philosophical assumptions researchers bring to mixed method research paradigms. Greene et al., in 2006, summarized three different stances that are taken by researchers doing mixed method research: 1) The Purist Stance, 2) The Pragmatism Stance, and 3) The Dialectic Stance[73].

First, the researchers, who take a purist stance argue that different research paradigms should not be mixed within the same study because each research paradigm is fundamentally different. Each research paradigm has different sets of philosophical assumptions, which guide and direct the research methodology and should be respected and preserved.

Second, the pragmatists argue that the differences in paradigms do not really matter as long as a suitable solution to the problem in question is found. Pragmatists only focus on applications, what works, as well as solutions to problems [74]. At the ontological level, pragmatists view reality in terms of what is useful and practical, and do not consider the possibility of multiple realities [75]. From the pragmatic perspective, how the problem is approached is not important; the important issue is to how to solve the problem. Instead of focusing on methods, researchers emphasize the research problem and use all approaches available to understand the problem. In other words, 'Reality is known through using many tools of research that reflect both deductive and indicative evidence' [75]. At the level of methodological assumption, pragmatism is associated with mixed-methods research, which embraces features associated with both positivism/post-positivism and constructivism assumptions [76].

Lastly, researchers who support the dialectic stance argue that each research paradigm is fundamentally important and should be respected but is not absolute. Jennifer Greene, who is a lead researcher of the mixed method approach from a dialectic stance, represented the dialectic stance well in her statement: "The assumptive sets of different paradigms are different in important ways but paradigms themselves are historical and social constructions and so are not inviolate or sacrosanct."[77]. Moreover, the differences should be used together within and across studies toward a dialectical discovery of enhanced, reframed, or new understanding.

The research paradigm chosen for this mixed-methods research is the dialectic stance. The dialectic stance allows the researcher to combine deductive and inductive approaches by mixing both qualitative and quantitative research methods. Because human behaviors are complicated and unpredictable, both of these methods are needed to best understand the complex problems presented by fall prevention research.

3.3 Mixed method research design

Mixed methods research has been defined as the type of research in which a researcher or team of researchers combine elements of qualitative and quantitative approaches for the purpose of depth of understanding and corroboration [78]. In this project, mixed methods research underpinning the dialectic stance was performed using a sequential exploratory (qualitative→ quantitative) design. This design typically begins with a qualitative study, which allows researchers to gain in-depth understanding of problems where the research is new or lacking. Then, these findings assist in developing an intervention program. The sequential exploratory design is particularly useful when a researcher needs to develop and evaluate an intervention program when there are limited instruments available [75,77]. For example, although the multifactorial fall prevention strategies are the most effective strategy to reduce falls in ambulatory individuals, no study has implemented the multifactorial strategy for wheelchair users due to the lack of an in-depth understanding of the circumstances surrounding falls experienced by wheelchair users.

3.3.1. Phase 1: Qualitative research based on constructivist assumptions

To gain in-depth understating of the causes, circumstances, and consequences of falls, and recovery strategies among full-time wheelchair users, phase 1 used a qualitative research method based on constructivist assumptions. Constructivism is typically associated with the

qualitative research method [76,79]. In general, constructivism states that reality is constructed through individuals' lived experiences and interactions with others[75]. The reality is multiple, complex, and not easily quantifiable. The knowledge/reality is created through interaction between the researcher and participants using inductive methods[80].

Qualitative research is appropriate for this stage of the research because it is useful for the exploration of an area of study where research is new or lacking [81]. Using the inductive method, researchers begin with a completely open mind without any preconceived ideas of what will be found. In a similar vein, the author explored new insights on the causes, circumstances, and consequences of falls, and recovery strategy among full-time wheelchair users, using the inductive method.

Additionally, qualitative research is useful for describing complex issues, which cannot be measured by numeric or statistical methods [70]. Under the assumptions of constructivism, the researcher must be sensitive to the context of the research and immerse themselves in the natural setting of the people whose situation, behavior and thoughts they are studying if they wish to explore complex issues. As a fall is multifactorial in nature [20,21], the investigation of wheelchair users' stories about detailed experiences of their falls allows the author to gain a better understanding of the falls among fulltime wheelchair users.

Finally, qualitative research is useful for providing specific insights into the research topic. Under constructivism, qualitative research involves a naturalistic approach to the world, which includes individuals' specific contexts as a part of the research problem[80]. The researcher should value each subject's experiences within their individual contexts because knowledge/reality is created through interaction between the researcher and participants[80]. Using this assumption, the contents of the intervention, which were specifically designed for the

wheelchair users, were created by combining wheelchair users' insights into falls and the researcher's knowledge of fall prevention.

3.3.2. Phase 2: Quantitative research based on post-positivist assumptions

The findings obtained from phase 1 of the study assisted in developing the content of the intervention program. Then, quantitative research based on post-positivist assumptions was conducted to evaluate the feasibility and the preliminary efficacy of the multifactorial fall management intervention program developed after phase 1. In general, post-positivist assumptions are the foundations of quantitative research and the scientific method. post-positivism emphasizes the existence of a probabilistic reality which is apprehensible[70]. Under post-positivism, researchers begin with a theory and test the theory using deductive methods and numerical variables[79].

The quantitative research method is appropriate for this stage of the research because it is useful when a researcher wants to test and validate already constructed theories about how a phenomenon occurs. In a similar vein, this phase proposed several hypotheses about the influence of the multifactorial fall management program on full-time wheelchair users. Then, these hypotheses were tested through statistical analysis of the data collected.

3.3.3. Limitation of mixed method research

There are some limitations of using mixed methods in the project. First, data collection and analysis are often time consuming. One of the key features of mixed method research suggested by Creswell [75] is that researchers need to use rigorous qualitative and quantitative methods. Conducting two rigorous research studies may take more time than conducting only one study.

Second, information gathered from the first phase of the project may not be generalizable to other people or other settings. However, the intent of qualitative research is not to generalize the data or findings. The intent is to gain an in-depth understating or insights of the topics within each subject's specific context.

Third, the researcher must learn about multiple methods and approaches in order to understand how to mix them appropriately. The mixed method design can be effective, but only if the researcher is well versed in both quantitative and qualitative research paradigms and methodologies.

# CHAPTER 4: PHASE 1

## 4.1 Introduction

Approximately 3.6 million people in the United States utilize a wheeled mobility device to facilitate functional mobility and to perform the activities of daily living[2]. This number is expected to grow consistently by 5% each year [3]. As the use of wheelchairs is increasing, the high occurrence of wheelchair-related accidents needs to be taken into consideration. Falls are the number one cause of wheelchair-related accidents among wheelchair users living with a variety of disabilities [42]. For example, Kirby et al., in 1994 examined wheelchair-related accidents caused by tips and falls among 577 non-institutionalized manual wheelchair users. According to their research, 57.4% of participants had completely tipped over or fallen from their wheelchairs at least once [11]. Likewise, Berg et al. found that 38% of 525 wheelchair users had fallen at least once in the year prior to their study [8].

Falls can lead to severe consequences among full-time wheelchair users. Approximately 100,000 wheelchair accidents, many of which are caused by or result in falls, occur every year. A significant portion of these falls result in injuries, such as fractures and/or concussions, that are serious enough to require medical attention[6,11,12]. In addition to physical injuries, falls can result in the development of a fear of falling [15,16] which can have an adverse impact on wheelchair users' quality of life [19], community participation [16], and ability to perform the essential activities of daily living [17]. Such observations highlight the high frequency and serious consequences of falls and the importance of developing strategies to reduce the occurrence of falls.

To manage fall risk effectively, it is important to understand the unique circumstances surrounding falls among full-time wheelchair users. Although limited, previous research has shown that falls often occur during performance of certain actions including transfers,

pushing/driving a wheelchair, and reaching for objects[12]. The locations in which falls most commonly occur are in bathroom and bedroom and on the street. Additionally, wheelchair-related falls are associated with impaired seated postural control, equipment failure, muscles spasms, excessive speed, and environmental hazards (e.g. uneven surface, crack on the street)[12,18]. Although previous investigations have provided important information about situations in which falls occur, more research is needed to further investigate if/how these factors interact. For example, a fall often occurs while propelling a wheelchair; however, it is unclear if other factors, such as surface conditions and user's wheelchair skills influence falls. Therefore, examining the specific circumstances surrounding the mechanism of falls among full-time wheelchair users is needed to develop effective fall prevention strategies.

In addition to an in-depth understanding of fall circumstances, understanding challenges wheelchair users face when recovering (i.e. getting off the floor/ground and returning to a desired sitting position) from a fall is important to providing comprehensive fall management education. Due to the functional limitations experienced by wheelchair users, getting off the ground is likely to be challenging for a wheelchair user. If the individual is unable to recover independently, he/she may experience a long lie period after a fall. A long lie period is defined as remaining on the floor or the ground alone for over an hour after a fall occurs[21]. Previous studies have shown that among ambulatory populations, a significant number of fallers needed assistance to get up after falling. Without assistance, they remained on the floor or ground for a prolonged period after falling[24,44,45]. For example, an investigation by Bisson et al., in 2017 examined the frequency of critical falls, defined as a fall in which the person was unable to get up independently[45], in 354 adults with multiple sclerosis who were at least 55 years old. The

results showed that 54.1% (n=177) of participants reported that they required assistance to get up after their most recent fall[45].

The consequence of a long lie period can be significant. It can lead to serious physical injuries including pressure sores, dehydration, hypothermia and even death [23]. In addition to the physical impairments, critical falls were found to be associated with the development of fear of falling in older adults [44,47]. Such observations highlight the serious consequences and the importance of developing recovery strategies to minimize the adverse impacts of falls. Currently, there is limited information about the aftermath of falls including lie periods, physical injuries, and recovery strategies among full-time wheelchair users.

Therefore, in-depth knowledge of the circumstances associated with falls, the aftermath of falls, and fall recovery techniques used by wheelchair users is essential for the development of a fall prevention and recovery education program for full-time wheelchair users. The purpose of this study is (a) to explore wheelchair users' perceptions of falls, and fear of falling, (b) to gain an in-depth understanding of the circumstances surrounding falls in full-time wheelchair users, (c) to explore the aftermath of falls experienced by full-time wheelchair users, and (d) to document fall avoidance and recovery strategies among full-time wheelchair users.

## 4.2. Methods

### 4.2.1. Study design

This is a secondary data analysis of data collected as a part of two concurrent triangulation mixed-method research studies that investigated the comprehensive characteristics of falls and fallers among power and manual wheelchair users. The participants were: 1) over 18 years of age, 2) using a wheelchair as their main form of mobility (>40 hours per week), 3) self-

reported inability to ambulate outside of the home, 4) able to comprehend spoken and written English and 5) had fallen at least once in the past 12 months.

The sample size was determined based on previous literature in qualitative research. In accordance with Glaser and Strauss [82], there are no specific rules when determining an appropriate sample size in qualitative research, but qualitative sample sizes typically rely on the concept of saturation. Saturation occurs when adding more participants to the study does not result in additional information. Qualitative sample size is often determined by the time allotted, resources available, and the study objectives [83].

4.2.2. Data collection

Basic demographic information including age, gender, type of disability, type of wheelchair used, duration of wheelchair use, duration of disability, and self-reported number of falls experienced in the past 12 months were extracted from the data collected in the original studies.

During the data collection of the original studies, participants underwent a semi-structured interview lasting approximately 40-50 minutes. This interview aimed to comprehensively investigate the characteristic of falls in full-time wheelchair users (see appendix A). All interviews were conducted as face-to-face interviews and were audio recorded using a digital recorder. In addition to audio recording, a research assistant took written notes.

4.2.3. Data Analysis

All quantitative data retrieved from the demographic survey were entered into IBM SPSS version 23 (SPSS, Inc, Chicago, IL), and descriptive statistics were performed to characterize the sample.

The qualitative data were analyzed using a thematic analysis [84] . An inductive process was employed [84]to unveil patterns, themes, and categories in the data set[43]. Initially, all interviews that had been audio recorded were transcribed verbatim using Microsoft Word. Transcription creation focused on capturing both the interviewer's and interviewee's whole statements. Then, the transcribed data were prepared for analysis by the lead investigator using Microsoft Excel.

Corbin and Strauss [85] suggested that researchers use line-by-line, open coding strategies on the first five interview transcriptions to develop the themes of most importance based on the data. Using this strategy, two researchers J.S. and J.P., PhD students studying Kinesiology, carefully read and re-read all the transcriptions, and they individually coded the transcriptions to analyze common themes found in the data. After initial coding, researchers met to compare and discuss the key themes and patterns relating to the original research questions. After a consensus on coding was reached, a codebook was developed to aid in analysis. All final themes and codes were reviewed by the auditor L.R. (PhD, MPT, ATP) who did not take part in the data collection or coding. L.R. is a licensed physical therapist and has a PhD in Rehabilitation Science and Technology. The purpose of this audit process was to examine the final codes for bias or discrepancies and to address any outstanding concerns about the data. Finally, all the researchers discussed any discrepancies and made changes to the codebook until a consensus on the most appropriate coding was reached.

## 4.3. Results

### 4.3.1 Participant Characteristics

Data from a total of 38 community-dwelling full-time wheelchair users (19 power and 19 manual wheelchair) living with a variety of disabilities including cerebral palsy (CP), spinal cord

injury (SCI), multiple sclerosis (MS), spina bifida and stroke were analyzed. The participants' ages ranged from 19 to 70, with an average age of 43.1±15.6 years. The duration of their disabilities ranged from 3 to 47 years, with an average of 21.2± 11.1 years, and their years of wheelchair use ranged from 2 to 43 years, with an average of 18.1 ± 12.3years. The sample included 20 men and 18 women. All participants in this study had at least one fall experience in the past 12 months. The median number of self-reported falls in the previous 12 months was 3 (interquartile range: 1–6). The basic demographic characteristics and self-reported falls are summarized in Table 4.1.

Table 4.1. Participants Characteristics(n=38)

| Variable | Value |
|---|---|
| Age (years) [mean ± SD] (range) | 43.1 ±15.6 (19-70) |
| Gender [n (%)] | Male= 20 (54), Female = 18 (46) |
| Disability Duration (years) [mean ± SD] (range) | 21.2 ± 11.1 (3- 47) |
| Type of disability [n (%)] | CP= 10 (26)<br>MS= 7 (18)<br>SCI =13 (34)<br>Spina Bifida =1 (3)<br>Post-stroke= 1 (3)<br>Degenerative Disk Disease=2 (5)<br>Neuropathy =3 (8)<br>Severe Arthritis =1 (3) |
| Type of wheelchair [n (%)] | Manual = 19 (50)<br>Power= 19 (50) |
| Years of wheelchair use (years) [mean ± SD] (range) | 18.1 ± 12.3(2-43) |
| Number of falls in the past 12 months, Median (Interquartile range) | 3 (1-6) |
| Note: PWC=Power Wheelchair Users; MWC= Manual Wheelchair Users; CP= Cerebral Palsy; MS= Multiple Sclerosis; SCI= Spinal Cord Injury | |

4.3.2 Aim (a): Wheelchair users' perceptions about falling and fear of falling.

Analysis of the interview transcriptions resulted in 2 themes related to aim (a) wheelchair users' perceptions about falling and fear of falling: 1) perceptions about fall experiences and 2) sources of fear of falling. Table 4.2 illustrates the themes and codes that were developed.

Table 4.2. Themes and codes relating to the participants' perceptions to falling and fear of falling.

| **Main Themes** | **Codes** |
|---|---|
| Perceptions about fall experiences | Development of fear of falling |
| | Impact on confidence and independence |
| | Apathy toward falls |
| Sources of fear of falling | Fall-related injuries |
| | Being aware of limitations |

*Perceptions about fall experiences*

Participant's perceptions of their fall experiences were separated into three codes. The first code, "development of fear of falling", was used to indicate that the participants considered their fall experiences to be a cause of their development of a fear of falling. For instance, a participant who is a manual wheelchair user living with SCI reported,

> *I have scary times that I think I'm going to fall just from falling before. So, I worry about falling again. (Participant #24).*

The second code "impact on confidence and independence," was used to indicate in what ways falls and fear of falling impacted the participant's confidence and independence in the performance of daily activities. For example, a participant, who was a power wheelchair user living with MS reported a reduction in confidence caused by a fall experience.

> *I just have less and less – what's the word I want? Confidence in myself to do things because I'm afraid to fall (Participant #14).*

The last code, "apathy toward falls", was used to indicate a participant's apathy toward falls. Some participants described falling as simply a part of their lives and stated that falling did not affect their participation in activities. For example, a power wheelchair user living with SCI reported:

> ***A fall really hasn't impacted my daily living.*** *It's just mostly looking to the ground a little more, and I just feel I guess more scared every time I hit a bigger bump****. But nothing that hinders me*** *(Participant #8).*

Similarly, a manual wheelchair user with SCI stated:

> *I fall kind of regularly, as you know a little bit, but* ***I don't really have a fear of it. It doesn't stop me from doing anything*** *(Participant #36).*

*Source of fear of falling*

The sources of fear of falling included 1) fall-related injuries and 2) being aware of limitations. Many participants reported that they had developed a fear of falling as a result of experiencing an injury from a fall. For example, a participant who is a manual wheelchair user living with SCI stated:

> *I do have a fear of falling just because* ***I do not want to break my hip again and go back to a nursing home*** *(Participant #23).*

The other source of fear of falling reported by the study participants was being aware of their limitations. For example, many participants expressed that they were afraid of falling because they did not have the ability to get back up to a preferred surface without assistance when a fall occurred. A participant who is a manual wheelchair user living with SCI reported:

> ***I do have a fear of falling just because I can't independently get back up into my chair.*** *So, falling****,*** *hurting myself, not being able to get up back into my chair, or nobody being there to help me. (Participant #37)*

Similarly, a participant who is a manual wheelchair user living with MS stated that getting back up after a fall occurred was more of a problem than falling:

> ***Falling for me, I can say that I don't usually worry about the falling as much as I worry about the having to get back up.*** *Because, falling is easy to do, getting back up is really hard. The getting back up and the worrying about who's gonna get me back up. (Participant #27).*

Additionally, some participants reported that they were afraid of falling because of their physical limitations. For example, a participant with CP who is a power wheelchair user reported,

> ***I'm very afraid of falling because I don't have the same power*** *that I had before. So, I'm kind of leery. I mean, I try to get it to where I don't fall off the wheelchair. I mean,*

*I'm not like the same as I was before the accident…I got hit by a car last year crossing the street over there by the terminal (Participant #17).*

4.3.3 Aim (b) circumstances surrounding the most recent fall experienced in the past 12 months in full-time wheelchair users.

During the original study, participants were asked to describe the circumstances surrounding their most recent fall. A total of 38 circumstances describing the most recent fall reported by participants were reviewed. Three main themes emerged during the analysis: 1) action-related fall contributors, 2) location of falls, and 3) fall attributions. Table 4.3 illustrates themes, subthemes, and corresponding codes that were developed.

Table 4.3. Themes, sub-themes and codes related to aspects of the most recent fall circumstances

| Themes | Sub themes | Codes |
|---|---|---|
| Action-related fall contributor | In wheelchair | Transfers<br>Wheelchair driving/propulsion<br>Reaching for an object |
| | Out of wheelchair | Walking short distances |
| Location of falls | Indoors | Bathroom<br>Bedroom<br>Living room<br>Office<br>Kitchen,<br>Hall way |
| | Outdoors | Street/Side walk |
| Fall attributions | Intrinsic factors | Loss of balance<br>Fatigue<br>Muscle weakness/spasms<br>Distraction<br>Spatial misjudgments<br>Pushing/Driving at a high speed |
| | Extrinsic factors | Inaccessible environment<br>Unfamiliar environment<br>Surface condition<br>Assistive technology failure |

*Action-related fall contributors*

The results revealed that four actions occurred during 38 fall incidents: 1) transferring, 2) wheelchair driving/propulsion, 3) reaching for an object and 4) walking short distances. The first action being performed at the time of the fall was a transfer. Participants described transferring from various surfaces when their fall occurred, including a bed, a car, an office chair, a shower chair, and a couch. For example, one manual wheelchair user living with MS fell while performing a transfer to a recliner:

> *The most recent fall was trying to transfer from the wheelchair to my recliner, just a regular recliner. And, basically my knees, I just didn't have a very good base and they just kind of swiveled and I fell (Participant #27).*

Another action performed which resulted in a fall was wheelchair driving (power) or propulsion (manual). This action was closely related to the location of the fall (street/side walk). For instance, a participant with SCI who is a power wheelchair user reported:

> *I was going along the sidewalk, I was going full speed, and then I was just looking around and seeing because I rarely ever looked around.* ***So, I didn't notice that there was a difference between sidewalk*** *and, I guess kind of like a brick layout. And, there was also a big dip with it, which I didn't notice until last minute… And, I was on the seat, teeter-tottering for a little bit, and then I fell into the grass (Participant #7).*

Falls also occurred when participants tried to reach for an object. For example, a participant with MS who is a power wheelchair user stated:

> *One time I fell into the bushes, and I know the reason behind that.* ***That's overreaching Reaching too far forward with my feet on the ground and yeah, just trying to get that extra inch of reach to get the tool*** *and the buttocks lifts up a little bit and center of gravity gets too far forward and out you go. Those are probably the ones I refer to in the six times in the last year that I've done. Those are, to me, the scary falls, even though nothing happens (Participant #11).*

Two falls occurred when participants tried to walk for a short distance. Both of the reported falls occurred in the participant's bedroom. These participants reported that they walk sometimes

because their wheelchairs cannot be used in their bedrooms due to limited space. For example, a power wheelchair user living with CP stated:

> *I was in my bed and my wheelchair was in the living room, and my PA was helping me pack.* ***I was walking in the narrow*** *– how to describe my room? So, there's the door, and I would say that the door and then my bed is right in front – there's not a lot of distance. And then there's a little room to walk to the rest of the room which is one of the reasons I can't have my chair in there. And I kind of wanted to see and move and see what he was packing. And I was in that narrow area and I fell just –* ***I don't know if my leg spasmed and I fell right flat on the ground*** *(Participant #4).*

*Locations of falls*

Another important theme emerging from the data was the location of the fall. Upon analysis of the data, location of fall occurrence was broken down into two sub-themes: indoors and outdoors. Study participants reported falls in six different indoor locations: bathroom, bedroom, living room, office, kitchen, and hall way, and one outdoor location: street/side walk. The most commonly reported locations in which falls occurred were the bedroom and on the street/sidewalk. The study participants reported that falls often occurred in the bedroom while transferring (action related fall contributor). For example, a manual wheelchair user living with SCI reported:

> *When this fall occurred****, I was transferring into bed****… That time was because I forgot to lock the one side of the chair. (Participant #37)*

Also, the falls which occurred on the street/sidewalk were frequently reported in conjunction with wheelchair propulsion/driving. For instance, a manual wheelchair user living with CP stated:

> *I tried to get somewhere fast, and oftentimes,* ***when I'm pushing my wheelchair fast on the street,*** *I'm not always aware of the situation on the pavement of where bumps are and where I need to kind of pop a little wheelie at. So, I fell because I hit a bump in the road and just dumped out forward (Participant #28).*

*Fall attributions*

A total of 10 distinct fall attributions were noted. All attributions were further evaluated by examining extrinsic and intrinsic factors that were attributed to the fall. An intrinsic factor was defined as a factor that was of a physiological or cognitive origin, such as muscle weakness or being distracted. Intrinsic factors include loss of balance, fatigue, muscle weakness/spasms, distraction, spatial misjudgments, and pushing/driving at a high speed. For example, a power wheelchair user living with CP reported that she fell because she and her personal assistant misjudged the distance between her wheelchair and the bed while transferring:

> *I was transferring from my bed back into my chair**. My chair was too close to the bed, but neither I nor my PA realized that.** Basically, my shoe got stuck under the foot plate, if that makes sense, and she went to lift me off…… The chair was doing everything right; it was just a **spatial misjudgment** (Participant #1).*

An extrinsic factor was defined as a factor that was related to the environment or other hazards. Extrinsic factors include inaccessible environments, poor surface conditions, unfamiliar environments, and assistive technology failure. For example, a manual wheelchair user who is diabetic with a bone infection in his feet reported that his chair moved while transferring because the floor was slippery:

> *I was transferring to a shower chair in my bathtub at my house and when I put my hand on the chair and the side of the tub, the chair went like that [The participant described that the wheelchair had flipped backwards] when I got out of it. See how easy it flips…..The wheelchair just took off **because there was water on the floor** and the chair just went flying and I hit the ground (Participant #30).*

Importantly, all the falls described by the study participants in this investigation included more than one factor which contributed to their fall. For example, a participant living with SCI, who is a manual wheelchair user, reported that a fall occurred while transferring because of the absence of wheel-locks, being in hurry and not paying attention.

*I was transferring out of the toilet onto the wheelchair and just the wheelchair I didn't grab it strong enough and, when I transferred into it, I went right down onto the floor.* ***I don't have the brakes on my wheelchair*** *so it was just one of those where* ***I was in a hurry and not really too cautious.*** *(Participant #36)*

4.3.4 Aim (c): Aftermath of falls in full-time wheelchair users

During the original study, after describing the circumstances associated the most recent falls, the participants were asked to describe the aftermath of the fall including: 1) if the participant sustained a physical injury or developed a fear of falling, 2) how they recovered from the fall and 3) the length of time they were lying on the ground. Table 4.4 illustrated a full description of the themes, subthemes and codes generated.

Table 4.4. Themes, sub-themes and codes related to aspects of the most recent fall aftermath

| Themes | Sub themes | Codes |
|---|---|---|
| Recent fall injury | Physical | Fracture<br>Sprain<br>Pain<br>Contusion<br>Skin abrasion<br>Bruise |
| | Psychological | Fear of falling |
| Recent fall recovery | Method | Independent<br>1-person assistance<br>2 or more people assistance |
| | Fall lie time | 1-5 minutes<br>6-10 minutes<br>>10 minutes |

Among the 38 fall incidents analyzed, a total of 18 falls resulted in physical injuries, and 8 of those injuries required medical attention. The physical injuries ranged from bruises to more significant problems, such as hip or neck fractures. Furthermore, when participants were asked a question "Have any concerns or feelings towards a fear of falling developed since this most recent fall occurred?", 53% of participants (n=20) reported that a fear of falling was developed as a result of their most recent fall. For example, a participant living with CP who is a manual wheelchair user reported:

*I'm always fearful since I fell. That's like I said, I have to pay attention to what I'm doing because I'll fall (Participant #29).*

The majority of the participants reported that they needed assistance to get up from their fall, and 20 participants reported that they were assisted by two or more people in order to get up from their falls. A power wheelchair user living with CP reported that he was assisted by the paramedics and immediately taken to the emergency room:

*When I went to go to the bed, I fell. So, I had to call. I called 911 and then Carle [local hospital] came and got me to the ER (Participant #17).*

Finally, many participants reported that they were lying on the ground or the floor for 10 minutes or less after their most recent falls had occurred. Five participants reported lying on the ground for over 10 minutes. The reasons given by these five participants for the delayed recovery time was that they were alone, and they were not able to recover independently when the fall had occurred. Therefore, they had to wait for someone to come help them. For example, a manual wheelchair user living with SCI reported:

*Well, I can't independently get up from the floor, so I had to – I always keep my phone with me, so I had to call my mom. She lives – I don't know – 15, 20 minutes away, so she came over. And with assistance, I can get up back into my chair (Participant #37).*

4.3.5 Aim (d): Fall avoidance and fall recovery ideas

Upon examination of the participants' descriptions of how they would avoid falls and recover from falls, three main themes emerged during the analysis: 1) current fall prevention strategies 2) future fall avoidance ideas, and 3) fall recovery ideas. Table 4.5 illustrates the themes, subthemes and codes that were developed.

Table 4.5. Themes, sub-themes and codes related to fall avoidance and recovery idea

| Theme | Subtheme | Codes |
|---|---|---|
| Current fall prevention strategy | | Heightened awareness<br>Seeking assistance<br>Engaging wheel-locks |

Table 4.5 (cont.)

| Theme | Subtheme | Codes |
|---|---|---|
| Future fall avoidance idea | Assistive Technology | Wheelchair improvements<br>Hazard Sensor<br>Assistive device |
| | Intrinsic strategy | Enhanced focus<br>Wheelchair maintenance |
| | Skill education | Wheelchair skill education program<br>Transfer education program |
| | Environmental modification | Indoor modifications<br>Outdoor modifications |
| Fall Recovery Ideas | Technology Assisted Fall Recovery | Grab bars<br>Emergency buttons<br>Retrieval system<br>Auto lock system |
| | Human Assisted Fall Recovery | Gaining upper body strength<br>Floor transfer training program |

*Current fall prevention strategies*

Three different fall prevention strategies were in use by the study participants. The first strategy was "heightened awareness". Participants described paying increased attention during performance of activities in which they had previously experienced a fall. For example, a power wheelchair user living with neuropathy stated that she was very cautious when performing a transfer because she had a pervious fall experience during a transfer.

> *Yeah. So, I'm now very cautious. So, from now on, what I do is I make sure before I even take a step that my pants – I go like this [The participant lifted her leg from the footplate using her arms and moved it onto the floor, thus avoiding catching the end of her pants on the wheelchair's foot plate]. Make sure that my leg is moving and not caught anywhere. I've learned my lesson. Yeah, I'll say learned my lesson. Learning your lesson is when you've done something stupid. It wasn't me doing something stupid. It was an accident that happened. But I've learned how to be cautious, so it won't happen again. (Participant #15)*

Another fall prevention strategy reported by the participants was "seeking assistance". For instance, a participant with MS who is a manual wheelchair user living in an assistance living facility reported that she did not hesitate to call the certified nursing assistants when she needed:

> *I don't have a big fear of falling now, because I've taken steps to prevent them. A lot of the people who live here [the assistive living facility], they won't call the CNAs [Certified*

> *Nursing Assistants] for something like opening a window or the temperature. And, I'm like, I'm paying $XXX per month to live here,* ***I'll pull the cord and let them come open a window for me,*** *rather than fall. (Participant #31)*

The last current fall prevention strategy reported by participants was engaging wheel-locks. Many wheelchair users emphasized the importance of the use of wheel-locks during transferring. For instance, a participant living with SCI who is a manual wheelchair user stated:

> *Last time, I forgot to lock the one side of the chair, so when I went to kind of push off on my armrest, the chair kind of slipped out from under me and I just kind of fell right between my chair and the bed. Since then, I always lock the both sides of the chair (Participant #34)*

*Future fall avoidance idea*

The fall avoidance ideas suggested by study participants were categorized into four different subthemes: Assistive Technology, Intrinsic Strategy, Skill Education and Environmental Modification.

*Assistive Technology*

The first important subtheme emerging from the data was the use of assistive technology. The study participants suggested many ways to improvements their wheelchairs that would help them to avoid a fall. Such improvements included: better suspensions, durable wheel-lock systems, better footplate designs and bigger casters. Many participants who use manual wheelchairs reported that their wheelchairs were not stable during transfers even though they engaged their wheel-locks while transferring. Therefore, the need for a durable wheel-lock system to avoid falls was emphasized by manual wheelchair users. For instance, a manual wheelchair user living with SCI stated:

> *Because sometimes, even though you have your brakes locked, I don't know if it's possible, but put some, like, what am I trying to say, the grippy stuff – – is it possible to maybe put grippy stuff on the wheel? Even though the wheelchair would be locked, sometimes you do stuff and it still moves. If it had, like, the grippy stuff, like, on the wheel, it would help it from moving more (Participant #22).*

Some power wheelchair users suggested that having a better suspension system on their chair could help avoid a fall when driving on uneven surfaces. For example, a power wheelchair user living with SCI stated,

*Maybe better suspension will be helpful, so I could handle bumps better (participant 8).*

In addition to wheelchair improvements, some participants suggested a hazard sensor that could detect uneven surface, blind spots or irregular road conditions to help avoid falls:

> *You know how some cars have that blind-spot sensor? If they could install some sort of a wheelchair fall/uneven sensor. If they could do that for cars, maybe they could do that for wheelchairs too. (Participant #32)*

*Intrinsic strategy*

Participants suggested two different intrinsic strategies to help avoid falls in the future: enhanced focus and wheelchair maintenance.

Enhanced focus on their environment while transferring or maneuvering their wheelchairs was suggested as a future fall avoidance strategy by participants. For instance, a manual wheelchair user living with SCI suggested paying more attention to his environment to avoid a fall:

> *The fall can easily have been avoided if I was just paying more attention to where I was rolling and also it was by my house, so I knew that that crack was there. I just need to pay more attention to my environment to avoid a fall (Participant #36)*

The other intrinsic strategy to avoid future falls suggested by study participants was regular wheelchair maintenance to make sure wheelchair components work properly. For instance, a power wheelchair user living with arthrogryposis reported:

> *As far as the wheelchair one, just the seatbelt getting fixed. If that hadn't been broken, I probably wouldn't have fallen out…I suggest just making sure to maintain the chair on a regular basis (Participant #2).*

*Skill Education*

Another subtheme related to future fall avoidance that emerged from the analysis was skill education. Some participants reported they would have avoided falls if they had better wheelchair driving skills or transfer skills. For example, a power wheelchair user living with MS reported:

> *The falls are when you get out of the wheelchair. Yeah, if one-wheel hangs over a curb, you're in trouble. But, for the most part, I can't blame the wheelchair for my falls. Should you take a class in driving when you get into a wheelchair? Yes [The participant asked himself and answered his own question] (Participant #11).*

*Environmental modifications*

Lastly, environmental modifications were suggested as useful methods of avoiding falls. First, in the outdoor environment, street or sidewalk modifications were discussed as a strategy that would help wheelchair users avoid falls. A participant living with CP who is a power wheelchair user reported:

> *Honestly, had they painted the edge of that sidewalk, and/or had a different colored street next to it that wasn't the exact same color as the edge of the sidewalk, that would have never happened. Pretty easy fix, why I was so mad at them for not doing anything. (Participant #1)*

Similarly, a power wheelchair user reported that their fall would have been prevented if the city had maintained better street conditions (e.g. fixing cracks on street):

> *Sure, when the city would fix their stuff. I mean, that's all it was, 100 percent. And those two – that was the last time. It was three falls before that I'd called on the city and wrote a letter to the city and a letter to the editor. The same thing was the fall after that, just a month – or actually a few weeks was –or before that. I'm going backwards, was the same thing. It was the same sidewalk to street difference in the asphalt to the – the ramp was good, but the asphalt was eaten away. (Participant #13)*

The second environmental modifications suggested by study participants were indoor (e.g. home) modifications. For example, a study participant reported that he fell while walking into his room because his room did not have enough space to maneuver his wheelchair.

> *If I was able to – if my apartment were large enough – if my room were large enough so I could have my wheelchair in there, and if I could move my wheelchair instead of just walking, I probably – even though it's a short distance and I can technically walk, yeah that would have helped (Participant #4).*

*Fall recovery ideas*

In addition to the "current fall prevention strategies" and "future fall avoidance ideas", the fall recovery ideas suggested by study participants were also documented (see Table 4.5). Two subthemes emerged in the findings: Technology Assisted Fall Recovery and Human Assisted Fall Recovery

The study participants shared a variety of technology-related fall recovery ideas that would help them recover from a fall including a grab bar attached to their wheelchairs, an auto lock system, emergency buttons, and a retrieval system. The majority of participants reported that a grab bar attached to the lower level of their wheelchairs would help when they recover from a fall. For example,

> *I think maybe a device on the chair, some kind of handle on the wheelchair where they can if they were fallen, that they can get grab yourself up – anything that can help them to get up (Participant #16).*

An auto-lock system was suggested by the study participants, which would be activated automatically and lock their wheelchairs when a fall occurred. As a result, their wheelchairs would not move and would be stable when they recovered from a fall. Another technology described by the study participants was an emergency button or a smartphone application that could simply and quickly be used to make a call for help in an emergency. For example, a manual wheelchair user living with SCI reported:

> *Emergency button. Like a panic button on a watch or something, or something you can call in an emergency right away. I guess iPhones have that, or smart watches have that (Participant #40).*

Lastly, some participants described a wheelchair retrieval system that could automatically or remotely position a power wheelchair close enough to a faller for his/her fall recovery. This technology was described below:

> *A device could like scoot your chair over towards you if your chair rolled away after you flipped out of it and automatically flip itself back upright so that you don't have to deal with that. That would help out (Participant #28).*

Two different human assisted recovery ideas were suggested by the study participants including floor to chair transfer training programs and gaining upper body strength. For instance, a manual wheelchair user living with SCI stated

> ***For me it's keeping a great upper body strength*** *because I can't use my legs. I think it's important that people with disabilities work out, exercise regularly if they can, do those stretches and all that kind of stuff or do whatever they can. Then I also think that – in some instances –* ***I think it would be beneficial for people with disabilities to practice how they get up from a fall*** *(participant #39).*

## 4.4 Discussion

Our examination of wheelchair-related falls revealed the complex nature of falls as described by full-time wheelchair users living with a variety of disabilities. The results of the study provide an in-depth understanding of 1) the wheelchair users' perceptions about falling and fear of falling, 2) the circumstances surrounding falls, 3) the aftermath of falls, and 4) fall avoidance behavior and recovery ideas. The findings will provide insight into in the development of a comprehensive fall management intervention program (chapter 5).

All participants in this study had personally experienced falls, and several participants stated that they had developed a fear of falling after experiencing a fall. Furthermore, some participants reported a loss of confidence and stated that they needed more assistance to do the activities that they used to do as a result of the falls they had experienced. These results support the preliminary data from a quantitative study by Rice et al. indicating that fear of falling and

activity restriction associated with fear of falling was common among full-time wheelchair or scooter users living with MS who had had a fall experience[22].

Most of our understanding of fear of falling comes from the geriatric fall prevention literature. It is important to note that previous evidence in this literature indicates that elevated fear of falling is associated with negative outcomes including increased fall risk, loss of confidence and independence, and physical decline[17]. Furthermore, fear of falling can negatively influence community participation and quality of life among older ambulatory adults[86-88]. Although, these studies provide important information about fear of falling and its consequences, limited research has been done with populations of full-time wheelchair users. Our findings provide a preliminary understanding of fear of falling in fulltime wheelchair users that can be used to inform the design of a prospective study to examine the influence of fear of falling on confidence, community participation, quality of life and other important aspects of living well with a disability among wheelchair users.

Sources of fear of falling among full-time wheelchair users were also examine. First, several participants reported that their fear of falling had developed due to their experience of fall-related physical injuries. For example, a participant who experienced a hip fracture caused by a fall, reported that she had a fear of falling because she did not want to break her hip again. This finding is similar to previous reports that indicate that an injurious fall is closely associated with a fear of falling in older adults[89,90]. In addition to physical injuries, we found that study participants developed a fear of falling because they were made aware of their limitations, such as the inability to get up by themselves after a fall occurs. In the current study, a majority of participants stated that they needed assistance to get up after a fall had occurred due to their mobility limitations or lack of upper body strength. Among the participants who needed

assistance to recover from a fall, some of them reported that they were afraid of falling because they were uncertain if assistance would be available to help them recover. This unique finding emphasizes that building a fall recovery strategy is an important component of a comprehensive fall management program for full-time wheelchair users to manage fear of falling.

The most important finding from the examination of the circumstances surrounding falls is that falls are multifactorial. This finding is consistent with the previous research[20]. The three themes which emerged regarding the circumstances of the most recent fall were action-related contributors, locations in which falls occur and fall attributions (see Table 4.3). It is important to note that the reports of all the falls in this study included a combination of these themes. Thus, a multifaceted approach must be taken when developing a comprehensive fall management program for full-time wheelchair users.

We found that falls most often occurred while performing a transfer, during wheelchair driving/propulsion, or when reaching for an object. These findings support previous evidence that wheelchair transfers, and wheelchair driving/propulsion are common actions being performed while falls occurred among full-time wheelchair users[12,18]. Ambulatory individuals do not share the same action-related fall contributors as wheelchair users, thus these findings highlight the need for a population-specific fall management program[21].

The findings revealed that the falls reported by study participants frequently occurred in seven different locations (see Table 4.3), and some of these locations were closely related to the action-related fall contributors. For example, falls often occurred in the bathroom and bedroom while performing a transfer. Additionally, the results of the examination of future fall avoidance strategies highlighted the importance of environmental modifications, including home modifications. Home modifications (e.g. ramp, grab bars in the bathroom) were suggested as fall

prevention strategies that would help make the home environment more accessible and safer for wheelchair users [8,20].

We identified a total of eleven fall attributions. Importantly, most of these attributions have the potential to be effectively managed through therapeutic and educational interventions or changes in environment. For example, several participants fell because they lost their balance while performing an activity such as transferring and reaching for an object. This finding is consistent with previous research that a loss of balance was a factor associated with falls among full-time wheelchair users [12,20,42]. Furthermore, previous research demonstrates that sitting balance can be improved through therapeutic interventions. Betker et al. reported that dynamic sitting balance in individuals living with SCI and traumatic brain injuries can be improved by game-based balance exercise training [91]. In addition, these attributions were often closely associated with action-related fall contributors and fall locations. This finding highlights the need for a multifaceted approach to fall prevention. For example, it would be beneficial to provide exercises to improve sitting balance while also providing instructions on how to reach an object safely, such as using a reacher.

In the examination of the aftermath of falls among full-time wheelchair users, a variety of injuries were reported that ranged from mild injury (e.g. bruise) to severe injuries (e.g. neck fracture). Some of the participants reported that they received medical attention because of their injuries. These injury reports are consistent with those found in previous studies [6,8,11,12,22] and further highlight the significant influence falls can have on the health of wheelchair users.

In addition to the injury reports, the majority of participants reported the need for assistance to recover from their falls whether they were injured or not. Some participants who lived alone or were alone at the time when a fall had occurred were involved in a dangerous

situation because immediate assistance was not available to help them recover after the fall had occurred. For instance, a manual wheelchair user who was at home alone when a fall occurred had to wait for his wife for over 30 minutes on the floor after an injurious fall occurred. This finding emphasizes the importance of an effective fall recovery plan.

In the evaluation of fall prevention methods currently being used by study participants, three fall prevention strategies were noted: heightened awareness, seeking assistance, and engaging wheel-locks. For example, several participants reported that they now pay more attention while performing a transfer because they had experienced a fall while performing this action in the past. Also, participants reported that they had asked for assistance to do challenging activities instead of taking a risk.

*Components of a fall management program*

The study findings provide evidenced-based information that can aid in the development of a multifactorial fall management program. The current results indicated that falls among full-time wheelchair users involved many underlying factors, including, but not limited to poor transfer/wheelchair skills, poor sitting balance, intrinsic factors (e.g. loss of balance, fatigue, muscle weakness/spasms, distraction, and spatial misjudgments), and extrinsic factors (e.g. include inaccessible environments, poor surface conditions, unfamiliar environments, and assistive technology failure)(see Table 4.3). Many different potential strategies for fall prevention were suggested such as enhanced focus, wheelchair maintenance, and skill education programs (see Table 4.5); these were also taken into consideration in the development of a fall prevention program. Based on these findings, the five important components for a comprehensive fall management program for full-time wheelchair users are suggested: 1) exercises to enhance sitting balance, 2) transfer/wheelchair skill training, 3) education on

wheelchair set-up and maintenance, 4) education on management of a variety of environmental hazards, and 5) education on fall recovery strategies.

*Exercise*

Exercise to enhance sitting balance is an important component to include in fall management programs intended for full time wheelchair and scooter users. Findings indicated that poor seated balance was involved in many of the reported falls. For instance, several participants reported that their falls were caused by loss of balance while performing a transfer or reaching for an object. Fortunately, previous research indicates that sitting balance can be improved through therapeutic interventions[91]. Rice et al. developed a structured intervention that included an exercise program to improve sitting balance and tested it in a pilot study with 16 wheeled mobility device users living with MS. [65]. The result of this investigation indicates that sitting balance, which was indexed by virtual time to contact[92], significantly improved after exposure to 3-month home-based exercise program. Additionally, an exercise program can also positively influence other health-related outcomes, such as fear of falling. Headley et al. reported that a structured, 6 week fall prevention program, including a balance exercise program, reduced fear of falling and increased self-efficacy among older ambulatory adults. [32] Given the positive effects of exercise on fall prevention, we suggest that an exercise program should be included as a part of a multifactorial fall management program.

*Transfer/wheelchair skill training*

Education on transfer and wheelchair skills are an important component of a multifactorial fall management program. Previous research indicates that up to 50% of wheelchair users have never been educated on vital mobility skills, like transferring[93].Moreover, in the current investigation, many study participants reported that if they had known the proper

way to transfer and/or to maneuver their wheelchairs, their falls could have been avoided. These observations highlight the need for transfer/wheelchair skill trainings.

Previous research demonstrates that transfer skills can be effectively improved through therapeutic and educational interventions [65,94]. Previous transfer training programs have focused on teaching fundamental transfer skills such as: how to position a wheelchair properly, ideal hand and foot placement and body position related to the transfer surface. Because falls during transfer activities are common and often occur due to a lack of knowledge of how to correctly perform the activity, particularly in areas such as the bedroom or the bathroom, further transfer training is necessary. In addition to the fundamental transfer skills training, future transfer training programs should include the teaching of more complex transfer skills, such as how to transfer to and from a variety of surfaces, such as a toilet, a vehicle, and a bed.

The implementation of a comprehensive wheelchair skills training program developed by MacPhee et al., in 2004, was shown to improve the quality and safety of wheelchair skills in wheelchair users.[95-97]. However, further improvement can still be made to this program. Information about the identified attributions, such as paying more attention and not being in a hurry while driving in unfamiliar settings should be integrated into wheelchair skills training programs to manage the risk of falls effectively. Several participants reported that they fell while driving or propelling their wheelchairs because they had failed to detect environmental hazards such as a crack or pothole on the street. Thus, education on the methods to manage various environmental hazards should be emphasized in wheelchair training programs.

Exercise and wheelchair transfer/skill training programs should be individualized to each wheelchair user's specific needs and functional abilities. Given that falls in full-time wheelchair users are multifactorial [20] and there is variability in wheelchair users' physical abilities, ages, or

fall management skills, individualized strategies will allow wheelchair users to effectively tailor their fall prevention and recovery strategies based on their fall risks, their needs, and their skills. For example, when exercise instructions are provided, the trainer should provide the participants with additional individualized instructions on the frequency or intensity of the exercises based on their current level of fitness and ability. For example, if a participant is already comfortable with one of the developed exercises, the trainer might advise the participant to complete the activity while holding light weight objects, such as a dumbbell or water bottle.

*Education on wheelchair set up and maintenance*

Another important component of a fall management program is education on how to properly set up or maintain a wheelchair. Regarding wheelchair set-up, several manual wheelchair users reported that they had fallen because their wheelchair did not have proper weight distribution. On some manual wheelchairs, the center of gravity can be adjusted by moving the axle associated with the large rear wheels forwards or backwards. If the wheelchair's center of gravity is not positioned appropriately, the wheelchair can easily tip over. For example, the chair is more likely to tip over backwards if the axle is moved too far forward. Additionally, a participant suggested that a bigger caster would be beneficial to avoid a fall because he often falls due to his small caster catching on uneven surfaces. Thus, education on the benefits and drawbacks of various wheelchair components should be emphasized in a wheelchair set-up program.

In addition to the wheelchair set-up program, the current findings highlighted the need for a wheelchair maintenance program. Several participants reported they often did not use the wheel-locks because they did not work properly. For instance, a participant reported that although his wheelchair was only a year old, he has needed adjustments made on his wheel-locks

several times due to malfunction. Also, some participants reported that they did not use their wheelchair seatbelt because it was broken. A participant, who is a power wheelchair user, stated that he would not have had a fall after his chair had hit an obstacle, if the seatbelt had not been broken on his wheelchair. These wheelchair components are critical for wheelchair users' safety while transferring, reaching or maneuvering wheelchairs. These observations highlight the importance of an education program on how to perform wheelchair maintenance activities independently or when to contact a wheelchair vendor to assure that the wheelchair is safe and in good working condition. Therefore, education on wheelchair set-up and maintenance should be included in a comprehensive fall management program.

*Education on management of a variety of environmental hazards*

The management of environmental hazards is another important component of a fall management program. Some identified fall attributions were related to environmental hazards, such as poor surface conditions (e.g. slippery floor). Additionally, some participants reported that their falls could have been avoided if they had been able to detect the environmental hazards such as curb or crack on the street that caused their falls. For example, one participant said that she fell because she failed to detect a curb on the sidewalk while maneuvering her power wheelchair. Another participant reported that he sent multiple request letters to his city's public works department to repair the cracks on the streets around his living area. These observations highlight the importance of an education program on management of environmental hazards.

*Fall recovery strategy*

Finally, the findings from the examination of the aftermath of falls and the participants' fall recovery strategies highlight two important elements of the fall recovery education. The first element is floor to chair transfer skills. In the ambulatory fall prevention literature, it has been

recommended that older adults at risk of falling should be taught how to get up independently from the floor[26]. Participants in the current study also suggested that a floor to chair transfer training program should be implemented. These techniques might be feasible for some wheelchair users, who have sufficient upper and lower body strength; however, the majority of participants interviewed reported they were unable to perform an independent floor to chair transfer. For those individuals, other recovery strategies such as developing plans to perform an assisted floor to chair transfer with a care partner or use of assistive technology, such as a transfer lift, should be considered to reduce long-lie times and to minimize the risk of injury.

The second element is the development of a fall recovery plan prior to a fall event. For example, a frequent "check-in" system with a close friend or family member would be beneficial to help prevent an individual from lying on the floor for an extended period of time after a fall occurs. Additionally, many participants suggested the use of a wearable medical alert device would also be beneficial for fall recovery (see Table 4.5). A medical alert device is a device that can either be automatically or manually triggered to call for assistance when a fall occurs. Many modern smartphones have similar emergency features that can help notify family or friends when assistance is needed. All of these options could be presented to patients as ways that they could recover from a fall more quickly.

These two elements of fall recovery education, including the information about floor to chair transfers, and a fall recovery plan is integrated into a comprehensive fall management program for full-time wheelchair users (Chapter 5). Importantly, introducing these ideas will assist wheelchair users, who have different functional statuses due to different disabilities, or physical capabilities, to develop an efficient fall recovery plan.

## 4.5 Limitations

The study participants were recruited from the Midwest region of the United States. The experiences of falls may be different among wheelchair users in different regions or settings, and results cannot be generalized to a larger population. However, the intent of this qualitative study was to gain an in-depth understanding of the perceptions of falls, circumstances surrounding falls, the events occurring immediately after the fall, and participants' ideas about fall avoidance and recovery. Therefore, the findings can be used as a preliminary foundation for the development of a comprehensive fall management program.

## 4.6 Research Challenges

Gaining an in-depth understanding of the circumstances surrounding falls was at times challenging to obtain. During the interviews, participants may have omitted details that they thought were not important or may have forgotten about. After asking probing questions, additional details often emerged that were not provided during the participant's initial descriptions. In addition, participants may have limited their discussion about circumstances that they felt embarrassed to discuss. For example, consumption of alcohol was at times associated with the fall circumstances. Participants may have been hesitant to report they were consuming alcohol at the time their fall occurred.

## 4.7 Conclusion

This research highlights the complexity of the falls experienced by full-time wheelchair users. Given the complex set of circumstances surrounding each fall, a multifactorial approach to fall prevention and risk management should be taken. First, a multifactorial, evidenced-based program is needed to educate wheelchair users on risk factors associated with falls, methods to prevent falls and fall recovery strategies. Based on our findings, exercises to enhance sitting

balance, wheelchair skill/transfer training, education on the management of a variety of environmental hazards and education on the wheelchair set-up/maintenance are necessary components of a multifactorial fall management program. The findings have facilitated the development of a multifactorial fall management program for wheelchair users that will be discussed in the upcoming chapter.

# CHAPTER 5: PHASE 2

## 5.1 Introduction

Multiple Sclerosis (MS) is a progressive disease, and symptoms associated with the disability, such as mobility impairments, get worse and more debilitating over time[98]. As a result, many individuals with MS eventually need to use an assistive device such as wheelchair or scooter to facilitate their mobility [29]. Approximately 25% of the MS population uses a wheelchair or scooter as their primary means of mobility [99]. Since MS symptoms are slowly progressive, many wheelchair or scooter users living with MS often don't receive formal rehabilitation to learn how to perform critical skills, such as transfers or wheelchair skills in acute rehab settings. The lack of this wheelchair-related rehabilitation may increase the risk of falling in this population.

Previous research indicates that falls are prevalent among wheelchair and scooter users living with MS and the consequences of falls can be significant[20,22]. A recent investigation examined fall prevalence among 44 full-time wheelchair/scooter users living with MS, and reported that 75% of study participants experienced at least one fall in a period of 6 months and 48% of those who fell sustained an injury[22]. Another investigation examining the prevalence of fear of falling among 18 full-time wheelchair users with MS found that 83% of wheelchair users living with MS reported a fear of falling and 78% limit their activities due to these fears [20]. The development of fear of falling can have an adverse impact on quality of life and community participation, loss of confidence and independence [19].

Despite the significant consequence associated with falls, limited research has been performed to examine the interventions to manage falls and risk factors associated with falls among wheelchair users living with MS[100]. A recent investigation by Rice et al. examined the

efficacy and feasibility of a one-time therapeutic intervention to manage fall risk and fear of falling among 16 full-time wheelchair users living with MS[65]. The intervention targeted transfer skills and sitting balance, two items that have previously been recognized as factors associated with falls among full time wheelchair users [18]. The intervention consisted of educational materials to improve the quality of transfer skills and a home-based exercise program to improve core strength and seated postural control. Results indicated that the number of falls significantly decreased and transfer quality and seated postural control significantly improved after exposure to the intervention. However, no significant changes were among fear of falling, quality of life and community participation. Along with this result, there are several limitations to be considered in this investigation such as small sample size (n=16). Importantly, fall recovery education, which may have an impact on fear of falling among full-time wheelchair users, was not included in this intervention. Additionally, this intervention only targeted two fall risk factors (transfer skills and seated postural control) and did not provide comprehensive fall management.

A multifactorial fall prevention intervention that targets a variety of fall risk factors may have great potential in the management of fall incidence among full-time wheelchair users living with MS. First, falls are complex and multifactorial in nature. In 2017, Sung et al. examined the circumstances surrounding falls among full-time wheelchair users living with MS[20], and reported that falls result from diverse and interacting circumstances. Second, multifactorial fall prevention and management interventions have demonstrated great success in the management of fall incidence in individuals with MS who were ambulatory. For example, an investigation in 2015 by Sosnoff et al. examined the feasibility of a multifactorial fall prevention program (combined exercise and education program) delivered over 12-weeks among 34 individuals with MS, who

were able to walk either with or without an assistive device (e.g. cane or walker). The results indicated that the number of falls experienced and fall risk, measured by Physiological Profile Assessment, decreased after exposure to the intervention[66].

Based on the previous literature with similar populations, interventions that cover a wide range of risk factors associated with falls have great potential to reduce fall incidence and fear of falling among full time wheelchair users. Therefore, the purpose of this paper is to describe 1) the development of a multifactorial fall prevention program designed for full-time wheelchair users living with MS based on the findings from phase 1(chapter 4) and previous literature, and 2) to examine the preliminary feasibility and efficacy of a multifactorial fall management program.

## 5.2 Methods

### 5.2.1 Design

To examine the preliminary feasibility and efficacy of a multifactorial fall prevention program, a single-group interventional study was performed. All procedures for the study were approved by the University of Illinois at Urbana-Champaign's institutional review board.

### 5.2.2 Participants

Participants were recruited through the use of informational flyers, online advertisements, and word of mouth. In addition, study recruitment materials were sent to 136 individuals with MS who met the inclusion criteria living within 100 miles of the study locations via the North American Research Committee on Multiple Sclerosis Patient Registry (NARCOMS). Materials were sent to the participant's home address that was provided in the NARCOMS registry. While the registry requests that participants update their contact information frequently, we were unable to verify the number of individuals who received the NARCOMS mailing.

Inclusion criteria for participants was to 1) have a diagnosis of Multiple Sclerosis (MS) 2) be over 18 years of age, 3) Patient Determined Disease Steps (PDDS) level of 7 (i.e., main form of mobility is via a wheelchair), 4) receive a score of 10 or above to the Short Blessed Test, 5) use a wheelchair (power or manual) or scooter as their main form of mobility 6) self-report an inability to ambulate outside of the home, 7) have a history of at least one fall in the past 12 months, 8) be able to comprehend spoken and written English.

5.2.3 Procedures

The study procedures consisted of 2 assessment visits and 6 education sessions, as described in Figure 5.1.

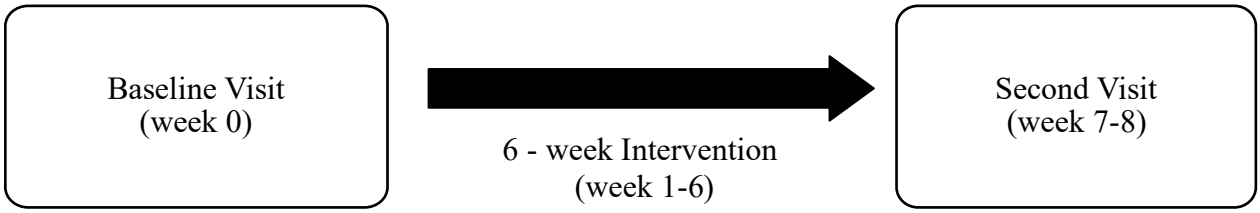


Figure 5.1. Study procedures

Upon initial arrival to the laboratory for the baseline assessment, all study participants had the opportunity to review an informed consent document and ask questions to a research assistant about the study details. Once all inquiries regarding the investigation were addressed, participants signed an IRB approved informed consent document. After providing consent, the study participants provided demographic information. Then, participants underwent a baseline assessment using the outcome measures described below in the section "5.2.4 Measures".

After completion of the baseline assessment participants were invited to participate in a 6-week educational program focused on management of fall risk. The details of the program are described below in the section "5.2.5 interventions". After completion of a 6-week intervention, all participants returned for a second study visit and were reevaluated using the same protocol

performed during the baseline assessment. Each visit for the assessment lasted approximately 2 hours. Participants received a $30 amount amazon gift card for each study assessment.

5.2.4 Measures

a) *Feasibility*

To assess the feasibility of the intervention program, retention rates, ability to collect outcomes, safety, intervention completion rate and the number of participants that missed each intervention session were evaluated [27]. The retention rate was calculated as a percentage of the number of participants who complete all aspects of the study from the number of participants who completed the baseline assessment. Ability to collect outcomes was examined by evaluating the amount of missing data. Lastly, to evaluate safety of the program, the number of adverse events (e.g. injury) occurred during the intervention period was collected.

*b) Fall prevention and recovery strategies*

To evaluate the participant's ability to understand ways to manage fall risk and avoid dangerous environmental situations associated with falls, participants were asked to complete the Fall Management Scale (FMS)[101], and the Fall Prevention and Management Questionnaire (FPMQ).

The FMS was originally developed to measure ambulatory older adults' perceived ability to manage fall risk. The FMS assesses whether the participant feels sure of his/her ability to: 1) recover after a fall, 2) to reduce falls, 3) to protect him/herself in case of a fall, 4) to increase physical strength, and 5) to get more steady on your feet. Ratings range from 1, which indicates "not sure at all", to 4, which indicates "very sure". Items scores were summed (range = 5–20). Internal consistency of the FMS among ambulatory older adults have ranged from 0.76 to 0.87[102]. The FMS has been previously used to examine the knowledge of fall prevention and

recovery strategies among ambulatory individuals living with MS [103] but has not previously been utilized among wheelchair users.

The FPMQ was designed to evaluate 12 areas of knowledge related to fall prevention and fall recovery strategies particularly for individuals living with MS.[103] Examples items include "I know how to safely get up after a fall" and "I can identify hazards in my home that influence my fall risk". Items are scored from 0 ("strongly disagree") to 4 ("strongly agree"). Response were summed (range =0-48). Although, the FPMQ has not been validated, the FPMQ has been successfully utilized in previous studies evaluating knowledge related to fall prevention and fall recovery strategies among ambulatory individuals with MS[66,103].

*c)Fear of falling*

Participants were asked to complete the Spinal Cord Injury-Fall Concerns Scale (SCI-FCS)[15]. The SCI-FCS was originally developed to assess concern about falling during common activities of daily living performed by fulltime wheelchair users with SCI. The SCI-FCS has been shown as a valid and reliable tool for assessing concern about falling in wheelchair users with SCI [15,104,105]. The SCI-FCS has not been validated in other clinical populations, but it assesses activities frequently performed by fulltime wheelchair users and no other validated outcome measure assessing concerns about falling exists. The SCI-FCS has been previously used to examine concerns about falling among wheelchair and scooter users living with MS [22,65]. The SCI-FCS consists of 16 items on a 4-point scale (1=not all concerned to 4=very concerned). Participants were asked to mark how concerned they were about falling for common activities of daily living such as getting dressed or undressed, washing or showering self, transferring in/out of car, etc.

*d) Sitting balance*

Sitting balance was measured with the function in sitting test (FIST). The FIST is designed to capture the complex interaction between seated postural control and functional performance. The test evaluates an individual's static and dynamic seated balance abilities when performing 14 functional sitting tasks: quiet sitting with eyes open and closed for 30 seconds, turning head, lifting foot, picking up an object from behind, forward reach, picking up an object from floor, lateral reach, reactive nudges, and scooting. The FIST requires minimal training in administration, is low cost, and requires less then 10 minutes to be completed. The FIST was found to be a reliable and valid measure in individuals with acute stroke, MS and spinal cord injury who utilize a wheelchair as their primary means of mobility [106-108]. Each item is scored on a scale from 0 to 4, with 0 indicating that the individual is incapable of performing the task and 4 indicating that the individual is able to perform the seated task successfully without any assistance or arm support to maintain balance. Individual item scores are summed, yielding a total score ranging from 0 to 56, where 0 equates to inability to perform any of the sitting tasks and 56 equates to full ability to perform all of the tasks. Minimal clinically important difference in FIST during inpatient rehab was change greater than 6.5 points [109].

*e) Transfer Skills*

Participants were then asked to perform 4 transfers to/from a height adjustable mat to evaluate the quality of their transfers using the Transfer Assessment Instrument 3.0 (TAI)[110] . Participants were instructed to perform the transfer in their typical manner and were allowed to utilize assistive devices (such as transfer board) or human assistance, as needed. Items such as hand placement or the distance from the target surface are assessed. A final score between 0 -10 is given, in which 0 indicates very poor transfer quality and 10 indicates excellent quality. The

TAI has been found to be valid and reliable in full time wheelchair users, including those living with a variety of disabilities [111].

f) *Wheelchair skills*

Participant's ability to control their wheelchair or scooter was evaluated using the Wheelchair Skills Test (WST)[112]. The WST is a well-established measure validated among individuals living with various neurological impairments, including MS[113]. Separate versions of the tool are available for manual, power and scooter users. The assessment is made up of 32 individual skills commonly performed by wheelchair and scooters users, such as rolling forward and backward, ascending and descending curbs, etc. Possible scores were "Pass" (score of 2), "Pass with difficulty" (score of 1), "Fail" (score of 0), and "Not possible" (the wheelchair does not have the parts to allow this skill). A final score between 0 - 100 is given, in which 0 indicates very poor wheelchair skills quality and 100 indicates excellent quality.

*g) Cognition*

To characterize a participant's cognitive function, the brief international cognitive assessment for MS (BICAMS) was utilized in the first assessment visit [114]. The BICAMS is composed of the symbol digit modalities test (SDMT), California verbal learning test-II (CVLT-II) and the revised brief visuospatial memory test (BVMT). The SDMT, which quantifies cognitive processing speed, involves a paper based matching test in which participants match as many numbers to their corresponding symbols within 90 seconds. The CVLT-II evaluates verbal memory. During the CVLT-II test, an audio recording of a 16 words list is played aloud to the participant for a total of 5 trials. Participants are asked to recall the words in any order after each trial. The number of words recalled is the outcome score. The list was pre-recorded to ensure consistent word spacing and intonation. The BVMT indexes visual memory. It requires

participants to inspect a 2 X 3 array of abstract shapes. Participants were shown the array 3 times for 10 seconds each. Each time that the array was removed, participant was asked to draw the shapes in the correct location for a total of 3 trials. If a participant has difficulty drawing the shapes due to limitations in hand function, the exam was not conducted. The collected BICAMS scores were converted to regression- based norms, z-score, based on their performances using the BICAMS website (www.bicams.net). Participants were defined as impaired if their z score was below -1.5.

*h) Post intervention interview*

After completion of the intervention, a semi-structured interview was conducted to gain in-depth feedback on the intervention program, changes in behavior, and perceptions of falls and fear of falling in full-time wheelchair/scooter users living with MS. The interviews were performed face-to-face or over the phone by a trained investigator. Participants were asked direct questions about the content and perception of the intervention program. The following questions were asked within the interview.

1) Please tell me why you chose to participate in this program?
2) Please describe your overall experiences with the program. Can you think of a specific story or incident that characterizes the overall experience?
3) Was this program helpful to you in your everyday life, why or why not?
4) Do you feel the frequency of your falls increased, decreased or stayed the same? Why do you feel this way?
5) Do you feel that your transfer and/or wheelchair/scooter skills improved or became more refined as a result of the education program? Why do you feel this way?
6) Were there any challenges or barriers to your participation in this program?
7) What are your feelings about fear of falling and fall management after completing this program?
8) Have you made any changes in your life to prevent or manage falls after completing this program?
9) Is there anything else that you would like to tell me about this program that I have not asked you about?

Additional probing questions were made during the interview, as necessary. All interviews were audio recorded using a digital recorder. In addition to audio recording, a research assistant took written notes during the interview to fill in any inaudible sections of the interview recording.

5.2.5 Interventions (iROLL)

After completion of the baseline assessment, participants engaged in a comprehensive intervention, named iROLL (***I***ndividualized ***R***eduction of Fa***ll***s). In order to effectively develop and implement the iROLL program, the Health Belief Model, as discussed in chapter 2, was adopted (Figure 5.2).

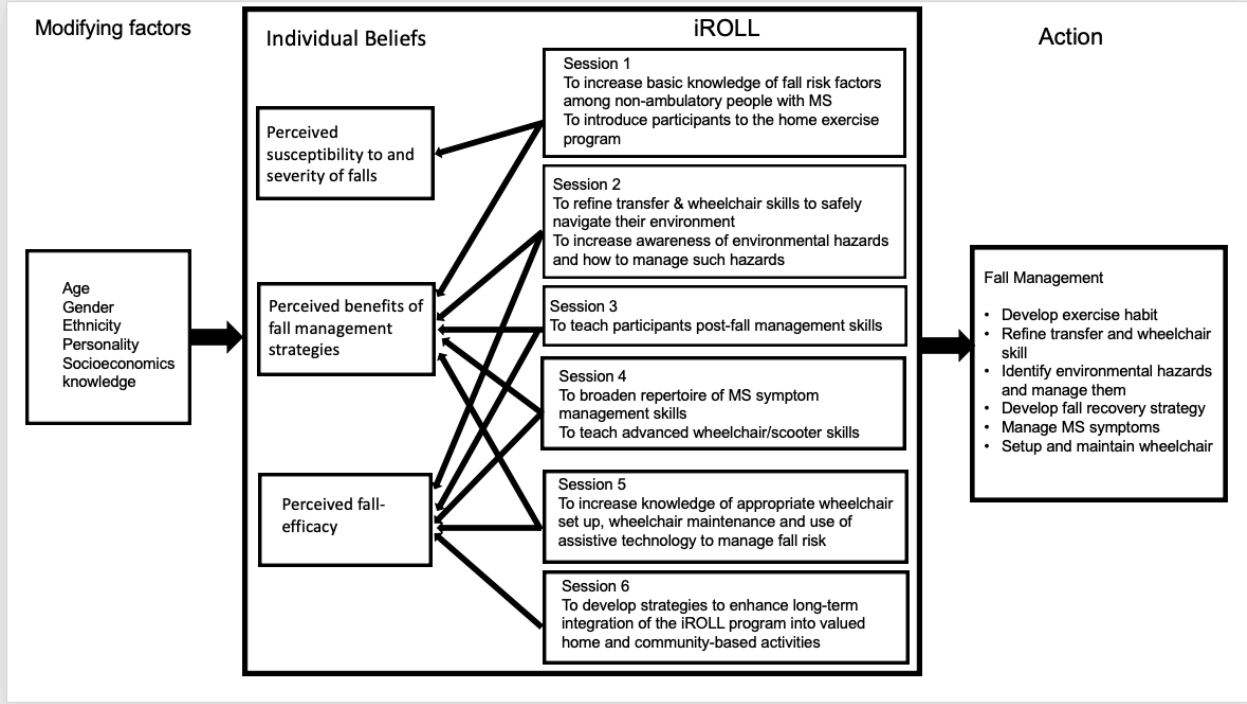


Figure 5.2. Adopted HBM for iROLL program

The circumstances surrounding falls, and various fall prevention and management strategies found in phase 1 were integrated into the iROLL program. Then, the iROLL program was implemented to target participants' perceptions about falls and strategies to manage falls. Finally, it was expected that using this strategy would make participant's behavior change as it related to

fall management. Details of the program structure and contents of the iROLL program are described below.

*Program Structure*

The intervention consisted of 6 sessions held over 6 consecutive weeks. The sessions were led by licensed physical and occupational therapists. The information was delivered to a small group of 2-5 participants for a period of two hours each. The intervention education was provided to study participant utilizing a variety of strategies including presentation-based lecture, interactive group discussions and practice opportunities utilizing a variety of learning styles (visual, auditory, and kinesthetic) [115,116]. To deliver the information effectively, a variety of educational materials were used including a paper-based instructional manual, video demonstrations, and power point slide-based lectures. Utilizing multiple forms of education materials has been shown to be more effective than reliance on one method of education. Use of only paper based, printed materials, has not been found to be successful [117].

Although the format of each session varied based on the information presented, often the trainer introduced the topic using a presentation-based lecture that incorporated visual materials, such as pictures and videos. After the initial information was presented, a group discussion was held which provided wheelchair users a chance to share their experiences, ask individual questions and problem solve through difficult situations. Finally, practice periods were provided to give participants a chance to apply what they had learned. The active participation in training sessions provided participants the chance to demonstrate their skills and understanding of the material. Trainers also had the opportunity to provide individualized feedback to participants. Additionally, each session, except the first, began with a review, which included a simple quiz and a discussion so participants could share their experiences based on the materials they had

learned and practiced throughout the previous week. Overall, these strategies helped to enhance initial understanding and long-term retention on knowledge of fall prevention and management strategies.

*Program Content*

The content of the program was based on findings from in-depth interviews of full-time wheelchair users describing the circumstances of their most recent fall, fall management strategies and recovery techniques (Phase 1) and previous literature examining fall circumstances of wheelchair and scooter users and management strategies. In each week of the course, participants were provided instruction on a variety of topics related to the management of fall risk including general knowledge of fall risk, exercises to improve sitting balance, transfer and wheelchair skills, management of environmental factors associated with falls, equipment management, and fall recovery strategies. Table 5.1 provides a description of the topics covered during each session. The main content of each session is described below.

Table 5.1. Intervention goals and session objectives

| Key Session Goals | Session Objectives |
|---|---|
| Session 1:<br>• To introduce participants to the iROLL program<br>• To introduce the GET WISE framework<br>• To increase basic knowledge of fall risk factors among non-ambulatory people with MS<br>• To introduce participants to the home exercise program | • Introduce participants to program with emphasis on program goals and the importance of group members sharing expertise/supporting each other during the 6 sessions. The success of the program depends heavily upon thoughtful conversations and active involvement of program participants.<br>• Highlight that the program builds upon participants' strengths and expertise. The program activities were developed with the understanding that participants have experience with transfers, W/C management, etc., and the activities are designed to help refine those skills to improve safety, save energy and use the body in a way that is efficient and prevents overuse injuries.<br>• Discussion regarding "ground rules." |

Table 5.1 (cont.)

| Key Sessions Goals | Session Objectives |
|---|---|
| Session 1 | • Identify participants' motivation for joining iROLL and key outcomes sought.<br>• Introduce GET WISE<br>• Provide a brief introduction to the problem of falls and fall risk factors specific to non-ambulatory people with MS, including fear of falling.<br>  o Highlight the multifactorial nature of most falls and the importance of a multifactorial approach to managing fall risk (i.e., the GET WISE motto)<br>• Justify the importance of developing fall prevention strategies that a) meet unique needs; b) address risk factors operating within and outside the individual; and c) support participation in valued home and community-based activities.<br>• Introduce therapeutic exercise program focused on enhancement of postural control and practice exercises.<br>• Discuss exercise expectations associated with the program (i.e. participants will go through exercises 3x/week, during the weeks that they are participating in the program) |
| Session 2:<br>• Revisit & refine transfer & wheelchair skills to safely navigate their environment<br>• Refine exercise skills<br>• To increase awareness of environmental hazards and how to manage such hazards | • Participants will learn how to perform transfers in a manner that reduces the potential for falls and conserves energy<br>• Participants will learn how to perform basic wheelchair skills to enhance safety<br>• Draw from participants' experiences to review common environmental hazards in the home and community<br>• Problem solve management of common environmental hazards<br>• Provide practice opportunities to review the therapeutic exercise program, transfer and wheelchair skills |
| Session 3:<br>• To teach participants post-fall management skills<br>• To teach complex transfer skills<br>• To teach intermediate wheelchair/scooter skills | • Introduce post-fall management skills & assess skills currently being used<br>• Support development or refinement of individualized fall management plans<br>• Participants will learn how to perform complex transfer skills to enhance safety<br>• Participants will learn how to perform intermediate wheelchair skills to enhance safety<br>• Provide practice opportunities to perform and receive feedback on transfer and wheelchair skill techniques and the therapeutic exercise program |

Table 5.1 (cont.)

| Key Sessions Goals | Session Objectives |
|---|---|
| Session 4:<br>• To broaden repertoire of MS symptom management skills<br>• To teach advanced wheelchair/scooter skills<br>Develop individualized goals | • Discuss key strategies to manage common MS symptoms than can increase fall risk: Example: fatigue and spasticity management.<br>• Provide practice opportunities to perform and receive feedback on transfer and wheelchair skill techniques and the therapeutic exercise program<br>• Assess the impact of skills learned through the iROLL program on confidence, quality of life and community participation & set-realistic individualized goals for safe participation in home or community-based activities<br>• Participants will learn how to perform intermediate wheelchair skills to enhance safety |
| Session 5:<br>• To increase knowledge of appropriate wheelchair set up, wheelchair maintenance and use of assistive technology to manage fall risk | • Discuss use of different types of assistive technology to manage fall risk and how to access & maintain equipment<br>• Provide practice opportunities to perform and receive feedback on transfer and wheelchair skill techniques and the therapeutic exercise program<br>• Revisit impact of skills learned through the MFPP on confidence, quality of life and community participation: Evaluate progress on goals for individualized activity |
| Session 6:<br>To develop strategies to enhance long-term integration of the iROLL program into valued home and community-based activities | • Examine strategies to manage threats to sustained use of MFPP skills: findings from participants' journals.<br>• Provide practice opportunities to perform and self-evaluate transfer and wheelchair skill techniques, exercise skills and future needs.<br>• Compare strategies participants plan to use to sustain transfer, wheelchair and exercise skills in order to prevent future falls. |

Session 1

The main focus of session 1 was to 1) increase basic knowledge of falls, risk factors associated with falls and consequence of falls among wheelchair/scooter users with MS, and 2) introduce participants to the home exercise program. To enhance the understanding of falls, trainers provided an overview of circumstances surrounding falls. Lecture based teaching was conducted to deliver this information including the presentation of relevant research and concrete examples extracted from the findings from aim (b) in phase 1 (see Table 4.3). The three main

themes: action-related fall contributors, location of falls and fall attributions, were introduced to increase participants' knowledge of falls and risk factors associated with falls. Then, a group discussion was conducted in which participants had an opportunity to share their personal fall experiences.

After they completed their discussion, participants learned a standardized series of exercises designed to enhance one's sitting balance. The exercise program was included based on the findings from phase 1 in which participants reported that their fall was caused by loss of balance while performing a transfer or reaching for an object. For example, a power wheelchair user with MS reported

> *The fan is above my chair, and I'm short. So, I would have to reach up above me to get the pulls. There is a load in front. So, I probably had to lean too far, and lost my balance and fell over (Participant #05).*

The exercise program was delivered using a video demonstration. After the initial demonstration was provided, participants practiced the exercises, and trainers provided feedback based on their performance. Participants were provided written and video-based versions of the exercise instructions and were assigned individualized programs to do at home based on their functional level and physical fitness. Participants were asked to keep a log of their at-home exercise sessions as well as their experiences of performing the exercises, so they could be discussed with the group and trainers during their next sessions.

Session 2

The main focus of session 2 was 1) the refinement of transfer and wheelchair skills and 2) examining the influence of the environment on falls. To educate wheelchair/scooter users on transfer and wheelchair skills, the trainers described an overview of transfer/wheelchair skills and provided video demonstrations of each skill. After the completion of the lecture and video

demonstrations, participants had an opportunity to practice the skills. During the practice periods, the trainers provided individualized feedback on the participants' performance of the wheelchair skills.

As the findings from phase 1 indicated, many wheelchair users reported that they fell while performing a transfer. For example, a manual wheelchair user reported:

> *The most recent fall was trying to transfer from the wheelchair to my recliner, just a regular recliner. And, basically my knees, I just didn't have a very good base and they just kind of swiveled and I fell (Participant #27).*

In this study a transfer training program that was successfully used in previous research [65] was adopted and utilized to enhance participant's transfer skills. Wheelchair users learned fundamental transfer skills such as: how to position a wheelchair properly, ideal hand and foot placement and body position related to the transfer surface. This information was delivered through verbal discussion and video demonstration. After initial demonstrations were provided, wheelchair users practiced individually with trainers, and receive feedback based on their performance. After this session was over, wheelchair users were given access to a demonstration video for use at home and encouraged to practice these skills over the next week.

In addition to the transfer skill, the findings from phase 1 indicate that several participants reported that they fell while driving or propelling their wheelchairs. For example, a power wheelchair user reported:

> *I was going along the sidewalk, I was going full speed, and then I was just looking around and seeing because I rarely ever looked around. So, I didn't notice that there was a difference between sidewalk and, I guess kind of like a brick layout. And, there was also a big dip with it, which I didn't notice until last minute… And, I was on the seat, teeter-tottering for a little bit, and then I fell into the grass (Participant #7).*

As a result, the Wheelchair Skills Training Program developed by MacPhee et al [95] was adopted and utilized to enhance participant's wheelchair skills. This program is freely available for general use and permission was obtained from the developer for use in this study. Particularly,

this program focuses on how to drive/propel one's wheelchair on the street and navigate complex environments. Additionally, information obtained from phase I regarding attributions associated with a fall while driving/pushing a wheelchair, such as paying more attention and not being in a hurry while driving in unfamiliar settings were integrated into the iROLL program.

Next, the influence of the environment on falls was addressed. As the main theme "Fall attribution- extrinsic factors" of circumstance surrounding falls revealed, the influence of the environment was commonly associated with falls occurring while driving the wheelchair or transferring. For example,

> *I'm not always aware of the situation on the pavement of where bumps are and where I need to kind of pop a little wheelie at. So, I fell because I hit a bump in the road and just dumped out forward (Participant #28).*

Participants learned strategies to manage a variety of environmental hazards with an emphasis placed on strategies that can be employed during transfers and during wheelchair/ scooter use in the home and community. Participants were asked to discuss environmental hazards that contributed to a recent fall they had experienced. Trainers then provided a variety of photo examples of environmental hazards and instructed participants on strategies to manage those hazards. After completion of the discussion, participants were given an opportunity to develop an action plan to make environmental modifications, where possible, within their home and community. Participants made use of a structured worksheet to help them develop a plan to modify their environment to make it safer and more accessible. Participants had an opportunity to discuss their plans with the trainer and were also encouraged to discuss the plan with their care partners and report back to the group during session 3.

Session 3

The main goal of session 3, was to discuss fall recovery strategies. As the theme "source of fear of falling" found in phase 1 indicated, participants reported that fear of falling developed due to an inability to recover from a fall or a long lie time. For example, a manual wheelchair user living with MS reported:

> *Falling for me, I can say that I don't usually worry about the falling as much as I worry about the having to get back up (Participant #27).*

Thus, education on the fall recovery strategies was an important component. The detail contents of the fall recovery education program, which was discussed in phase 1 (page 56; *Fall recovery strategy*), were adopted and implemented. First, trainers asked participants to consider key aspects associated with fall recovery, such as if they could get back into their wheelchair/scooter themselves, how long it takes them to get back into their wheelchair/scooter and what other factors (such as fatigue or injury) influences their ability to recover. Based on participant's responses, the trainer provided information on why it is important to develop a fall recovery plan and various strategies to take to develop a recovery plan, such as creating a check-in plan with friends and/or family members. Next, participants were educated through verbal discussion and video demonstration on how to get off the floor, both independently and with assistance. Finally, various pieces of assistive technology that can facilitate fall recovery were discussed. After completion of the lecture and video demonstrations, participants were given an opportunity to develop their own fall recovery plans. Participants made use of a structured worksheet to help them develop a check in system, section a communication device and determine how they would practice fall recovery with their primary care partner. Participants had an opportunity to discuss their plans with the trainer and were also encouraged to discuss the plan with their care partners and report back to the group during session 4.

After delivering the instruction on fall recovery strategies, additional wheelchair/scooter and transfer skills were discussed using the same strategies outlined in session 2. As the main theme "location" of fall circumstance surrounding falls indicates, falls occurred in many different locations while performing a transfer. For example, a manual wheelchair user reported:

> *I was transferring out of the toilet onto the wheelchair and just the wheelchair I didn't grab it strong enough and, when I transferred into it, I went right down onto the floor (Participant #36).*

Additionally, another manual wheelchair user reported:

> "*when this fall occurred, I was transferring into bed… That time was because I forgot to lock the one side of the chair. (Participant #37)."*

Thus, participants learned more complex transfer skills, such as how to transfer to/from their wheelchair and to/from various surfaces including a bed, car, couch, toilet and shower bench.

Session 4

Session 4 was designed 1) to increase participants' ability to identify and manage MS symptoms that can increase their fall risk during transfers, exercise, wheelchair use and other activities, and 2) engagement in home and community participation. As the theme "fall attribution-intrinsic factors- assistive technology failure" from phase 1 indicated, MS symptoms such as fatigue, spasticity and muscle weakness impacted wheelchair users' falls. For example, a power wheelchair user living with MS reported that she fell because she had spasticity in her lower extremity musculature when a fall occurred:

> *Thinking back about it now, another reason that I fell is that I have spasticity in my knees and I think if I remember it seems that they locked up on me, that caused me also to – think about you're walking along and all of a sudden you try to stop, but you've got a rollator in front of you. And, you stop suddenly, but then you kinda slide too, so everything kind of went (Participant #27).*

Thus, participants learned how to manage some of MS symptoms associated with falls. First, the trainers delivered information about the unique symptoms associated with MS, which could

increase the potential for falls. The symptoms discussed included fatigue, muscle spasticity, muscle weakness and impaired vision, all of which have an impact on fall risk[103]. Then, the trainers instructed participants on ways to manage those symptoms. For example, participants learned how to conserve their energy and utilize assistive technology whenever possible to prevent extreme fatigue. After the education on MS symptom management, additional wheelchair/scooter skills were discussed using the same strategies outlined in session 2.

Next, participants were educated through verbal discussion on the importance of active participation in their home and community. Trainers asked participants to discuss any activities that they would like to be involved in and any barriers which hold them back from engaging in those activities. Then, participants made use of a structured worksheet to help them develop weekly goals and a plan to pursue their desired activity. Participants had an opportunity to discuss their goals and plans with the trainer and report back to the group during session #5.

Session 5

The main goal of session 5 was to increase knowledge of appropriate wheelchair/scooter set up and wheelchair/scooter maintenance. As the theme "fall attribution-extrinsic factors-assistive technology failure" from phase 1 indicated, improper set up and a lack of appropriate maintenance of assistive technology impacted wheelchair users' falls. Some manual wheelchair users reported that they had fallen because their wheelchair did not have proper weight distribution. For example, a manual wheelchair user reported:

> *I was moving down the hall, and my chair tipped over backwards, I think because of the way the wheelchair was weighted (Participant #32).*

Another participant reported the need for regular maintenance to prevent a fall:

*Just making sure I'm maintaining the chair on a regular basis to prevent a fall (Participant #2).*

Utilizing verbal discussion and video demonstration, participants learned about the most common wheelchair components that can influence the occurrence of a fall, such as appropriate caster size, and correct wheelchair rear axle position. Participants also learned how to appropriately set-up their wheelchair, how to access the assistive technology (including funding options), and how to maintain the technology correctly in order to prevent falls associated with improper equipment [11]. Finally, participants were asked to set a goal to investigate the information about their wheelchair/scooter vendor, including the name of the company and contact information so that they could reach their vendor in case any repairs need to be done to their wheelchair/scooter in the future.

Session 6

The main focus of session 6 was to develop strategies to enhance long-term integration of the intervention program into valued home and community-based activities. Utilizing verbal discussion, the trainer emphasized the importance of sustaining the skills learned throughout the intervention and discussed tips to maintain exercise habits. Finally, the participants were provided with additional practice opportunities to perform a variety of wheelchair skills including transfer and exercise that they desired additional feedback on.

### 5.2.6 Data analysis

All the survey and physical assessments data were analyzed using SPSS version 23 (IBM, Chicago, IL). Descriptive statistics were calculated for all variables. To examine the differences pre and post exposure to the intervention, Wilcoxon Signed-rank test (non-parametric test) was utilized due to the small sample size[118]. Effect sizes *(d)* were calculated using Cohen's $d_z$ and interpreted as small ($d \leq 0.2$), moderate ($d \sim 0.5$), large ($d \geq 0.8$) [119]. P values equal or less than

0.05 were considered statically significant. The qualitative data was analyzed using a thematic analysis [84] in the same manner as described in the data analysis section of the study phase 1.

## 5.3 Results

### 5.3.1 Study participants

Between May 1, 2018 and December 31, 2018, a total of 13 participants received the intervention and completed both the baseline and post assessment. The participants' age ranged from 46 to 72, with an average age of 59.2 years. The sample included 3 men and 10 women. The duration of diagnosis of MS ranged from 8 to 34 years, with an average of 21.4 years, and the years of wheelchair use ranged from 4 to 18 years, with an average of 9.5 years.

The median number of self-reported falls in the previous 6 months was 2 (interquartile range: 1–3). For the BICAMS scores, 7 participants had z-scores below -1.5 in information processing speed as indexed by the SDMT. Additionally, 1 participant's z score was below -1.5 in the verbal memory task, evaluated by CVLT-II. Lastly, 3 participants received z scores below -1.5 in the visual memory task, assessed by BVMT. The basic demographic characteristics, self-reported falls in the past six months, and cognition data measured by the BICAMS are summarized in Table 5.2.

Table 5.2. Characteristics of the participants of the study phase 2 (n=13)

| Variable | Value |
|---|---|
| Age (years)<br>[mean ± SD], (range) | 59.2 ± 10.3, (46 – 72) |
| Gender [n (%)] | Male = 3 (23)<br>Female =10 (77) |
| Types of MS [n (%)] | Relapsing-Remitting = 7 (55)<br>Primary- Progressive = 1 (8)<br>Secondary Progressive = 4 (31)<br>Unknown = 1 (8) |
| Time with MS (years)<br>[mean ± SD] (range) | 21.4 ± 8.6, (8 – 34) |

Table 5.2(cont.)

| Variable | Value |
|---|---|
| Years of wheelchair use, (years) [mean ± SD] (range) | 9.5 ± 4.1, (4 – 18) |
| Type of wheeled mobility device [n (%)] | Power wheelchair = 10 (77)<br>Manual wheelchair = 2 (15)<br>Scooter =1 (8) |
| Number of falls in the past 6 months, Median (Interquartile range) | 2 (1-3) |
| BICAMS (z score) [mean ± SD, n= the number of participants whose z score was below -1.5, which is suggestive of cognitive impairment (%)] | SDMT = -1.47± 1.31, 7 (54)<br>CVLT-II= -0.21± 0.95, 1 (7)<br>BVMT = -0.75± 1.27, 3 (23) |
| Note: MS= Multiple Sclerosis, BICAMS= Brief International Cognitive Assessment for Multiple Sclerosis, SDMT= Symbol Digit Modalities Test, CVLT-II= California verbal learning test-II, BVMT = Brief Visuospatial Memory Test (BVMT) | |

5.3.2 Feasibility

After screening, a total of 15 individuals were enrolled in the study and underwent the baseline assessment. The retention rate was 86.7 percent. Of the 15 participants who underwent the baseline assessment, 13 received the intervention and completed the post assessment. After baseline assessment, two participants discontinued the study protocol. Regarding data collection, one participant declined to participate in the post intervention interview. No missing data occurred for other outcomes of interest.

All 13 participants of 4 groups completed the intervention. Table 5.3 indicates the number of participants that missed each session. In group 1, one participant missed session 2. No absence was reported in group 2. One absence was reported during session 4 for both group 3 and 4.

Table 5.3. The number of participants the missed each session by groups

| Session | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| Group 1 (n=3) | 0 | 1 | 0 | 0 | 0 | 0 |
| Group 2 (n=2) | 0 | 0 | 0 | 0 | 0 | 0 |
| Group 3 (n=4) | 0 | 0 | 0 | 1 | 0 | 0 |
| Group 4 (n=4) | 0 | 0 | 0 | 1 | 0 | 0 |

Finally, no adverse events were reported by the participants or the trainers during the intervention period.

5.3.3 Outcomes

Table 5.4 summarized the changes in all outcome measures before and after intervention.

Table 5.4. Differences in outcomes pre-intervention to post-intervention (N=13)

| | Pre-intervention Mean (SD) | Post- intervention Mean (SD) | Wilcoxon Signed rank Test (P-value) | Effect size (Cohen's $d_z$) |
|---|---|---|---|---|
| SCI-FCS | 34.39 ± 8.08 | 29.38 ± 8.32 | 0.022* | 0.61 |
| FPMQ | 33.00 ± 5.82 | 37.54 ± 4.89 | 0.010* | 0.84 |
| FMS | 12.84 ± 4.71 | 9.41 ± 2.43 | 0.008* | 0.91 |
| TAI | 7.75 ± 1.49 | 8.70 ± 0.78 | 0.034* | 0.79 |
| FIST | 47.31 ± 7.95 | 45.77 ± 9.98 | 0.551 | 0.17 |
| WST | 78.98 ± 18.36 | 80.75 ± 21.23 | 0.249 | 0.08 |
| Note: FPMQ - Fall prevention and management questionnaire, FMS- Fall management Scale, SCI-FCS- Spinal Cord Injury- Fall Concern Scale, TAI-Transfer Assessment Instrument, FIST-Function in Sitting Test, WST-Wheelchair Skill Test | | | | |

*Spinal Cord Injury- Fall Concern Scale*

The fear of falling was indexed by the SCI-FCS. After exposure to the intervention, a significant decrease was found in the SCI-FCS scores, indicating a reduction in fear of falling. A moderate effect size was observed (baseline: 34.39 ± 8.08, post-intervention: 29.38 ± 8.32, $p=0.022$, $d_z=0.61$).

*Fall prevention and management questionnaire*

After exposure to the intervention, a significant increase was observed in the FPMQ scores, indicating an improvement in knowledge of fall prevention and recovery strategies. A large effect size was found (baseline: 33.00 ± 5.82, post-intervention: 37.54 ± 4.89, $p=0.010$, $d_z=0.84$).

*Fall management Scale*

After exposure to the intervention, a significant decrease was found in the FMS score, which indicated that the participants' knowledge of fall prevention and recovery strategies improved. A large effect size was noted (baseline: 12.84 ± 4.71, post-intervention: 9.41 ± 2.43, p= 0.008, $d_z$ =0.91). The differences in each item of the FMS between pre and post exposure to the intervention were further examined. There were significant changes in the items 'I am sure that I can find ways to reduce falls' (baseline: 2.41 ± 0.99, post-intervention: 1.50 ± 0.91, p= 0.031, $d_z$ =1.02), and 'I am sure that I can increase the physical strength' (baseline: 2.00 ± 1.03, post-intervention: 1.33 ± 0.49, p= 0.033, $d_z$ =0.82). No significant changes were found in the follow items, however moderate effect sizes were noted among several of the items evaluated: 'I am sure that I can find a way to get up if I fall' (baseline: 3.17 ± 2.25, post-intervention: 2.25 ± 1.05, p= 0.176, $d_z$ =0.52, 'I am sure that I can protect myself if I fall' (baseline: 2.66 ± 0.78, post-intervention: 2.08 ± 0.79, p= 0.107, $d_z$ =0.74), and 'I am sure that I can get more steady on my feet' (baseline: 2.58 ± 1.16, post-intervention: 2.25 ± 1.05, p= 0.336, $d_z$ =0.29).

*Transfer Assessment Instrument*

There was significant increase in the TAI scores after exposure to the intervention indicating an improvement in the transfer quality. A moderate effect size was observed (baseline: 7.75 ± 1.49, post-intervention: 8.70 ± 0.78, p=0.034, $d_z$ =0.79).

*Function in Sitting Test*

After exposure to the intervention, no significant change was found in the FIST scores and a small effect size was observed. (baseline: 47.31 ± 7.95, post-intervention: 45.77 ± 9.98, p=0.551, $d_z$ =0.17).

*Wheelchair Skill Test*

The WST was used to evaluate the study participant's wheelchair skills. No significant changes were found in the WST scores after exposure to the intervention and a small effect size was observed (baseline: 78.98 ± 18.36, post-intervention: 80.75 ± 21.23, $p=0.249$, $d_z=0.08$).

5.3.4 Post- intervention interview

Analysis of the interview transcriptions resulted in 6 themes: 1) Reason for participation, 2) Barrier to program participation, 3) Program experience, 4) Application of program content to daily life 5) Program Outcomes, and 6) Future Directions. Table 5.5 illustrates the themes, subthemes, and corresponding codes that were developed.

Table 5.5. Themes, sub-themes and codes related to the iROLL feedback

| Theme | Sub-theme | Codes |
|---|---|---|
| Reason for participation | | Gain information/skills<br>MS Research support |
| Barrier to program participation | | Intervention Time<br>No Barrier |
| Program experience | Helpful program components | Experienced trainers<br>Small group<br>Action planning<br>Video materials<br>Fall recovery plan<br>Environmental safety<br>Transfer training<br>Exercise<br>Awareness and knowledge about available resources<br>Multiple sessions<br>Wheelchair set up/maintenance |
| | Improvement opportunities | Clear instruction for the video materials<br>Bigger font<br>exercise program modifications |

Table 5.5 (cont.)

| Theme | Sub-theme | Codes |
|---|---|---|
| Application of Program Content to Daily Life | | Heightening awareness<br>Refined transfer skills<br>Wheelchair maintenance<br>Use of assistive device<br>Environmental modifications<br>MS symptom management |
| Program Outcomes | Perception of fall frequency | Decreased<br>No changes |
| | Perception of fear of falling | Decreased<br>No change |
| Future Directions | | Early timing of intervention<br>Continuing education throughout disease process |

*Reason for participation*

In response to the question, "Please tell me why you chose to participate in this program?", most participants reported that they participated in the study in order to learn new skills or to gain information regarding fall management.

> *I thought that it would help me to protect myself if I was to fall. I felt like I could gain some new insight and hopefully develop some new skills (Participant #9).*

One participant stated that she participated in the study to support MS research moving forward.

> *I have experienced falls and I believed that physical therapy has helped me to maintain my independence and; therefore, exercise, but there isn't enough data to support it. So, I think that it's very important for us to collect the data to prove that this is important so we can get insurance companies to reimburse for physical therapy. Plus, I think that professionals, and health care professionals, could use more education in multiple sclerosis because it is a little bit different than other mobility disabilities. So, um, I think it's wonderful that there's more research in that. So, I think that, and I knew that I would benefit from participating in the class myself (Participant #3).*

*Barrier to program participation*

Participants were asked "Were there any challenges or barriers to your participation in this program?" A majority of participants reported there was no barrier. However, two participants reported that the time at which the intervention took place was a challenge.

Participants stated that having the intervention in the late afternoon limited the activities they could complete that day or caused fatigue. For example,

> *The only thing was the time 4:30 to 6:30, I couldn't do many activities during the day. My activities on that day was limited so I had enough energy to come down here [intervention location]" (Participant #5).*

> *Have the class a little bit earlier, like even today I got up at 5:30 in the morning I'm kind of really tired, so I'm not doing as well as I could (Participant #1).*

*Program experience*

During the interview, participants were asked to describe their experiences with the iROLL program. Upon analysis of the data, program experience was broken down into two sub-themes: (a) helpful program components and (b) improvement opportunities.

a. Helpful program components

Study participants stated that small group size, experienced trainers, use of video materials and multiple sessions were the most helpful features during the intervention. Many participants reported that small group setting was helpful because participants had opportunities to share information regarding fall management and learn fall management strategies from other participants. For example,

> *I like the fact that the week was sectioned and **that the classes were small and kind of felt like a one-on-one almost**...We get to practice and kind of watch, observe each other in the class, how each person transfers. I thought that was interesting because it's not just you, now you're looking at other people what you changed what you thought was the best possible ways based on the information received and how other people processed it. So, I thought that was a big part of it because now I'm not just looking at how I transfer, but I can actually sit there and observe the others in the class and learn also from how they did theirs as opposed to just mine. So, I thought that was a big part of it and part of the course as well (Participant #10).*

Also, participants expressed that the multiple sessions (a total of 6 sessions) was another helpful feature because they had opportunities to review the materials repeatedly and to follow up with questions.

> *What was nice, instead of just coming to one class and that was it, when I could come back then. Maybe the first week, I didn't realize that when I did the exercise, but then the second week I thought, am I really doing this properly. So, then I could come and ask the OTs if I was doing it properly and then I could go home and try it and then, even then, I wasn't getting it. So, it's, I really like the ability over a 6-week period (Participant #3).*

In addition to the general program features, participants reported benefits from various programs including physical skill trainings (exercise and transfer training), information on insurance and technology options, education on fall recovery, environmental hazards management, and wheelchair set-up/maintenance. The most frequently reported helpful program content was transfer training. For example, a participant reported that he had learned a safer way to transfer to his bed:

> *Well, I have lately, when I get in my bed I learn to come in at an angle. Come in kind of like a 25-degree angle, and you can actually move a lot better. They show us how to sit on the seat, and be able to push yourself up, and twist around, and boom you got on the bed (Participant #12).*

Education on fall recovery was also reported as beneficial by participants. For example, a participant stated that he had less fear of falling because he learned how to recover when a fall occurs:

> *I really realized that my fear was not so much falling as it is, kind of recovering once I fall. I realized that most during this time and if I hadn't had that process I guess in my mind. So that is what stands out to me. that now I am not as fearful. If certain things happen and I will fall, um to not just be afraid of falling, but to kind of know how to better control the environment or modifications around me, kind of being more conscious of that, but then being able to recover from it (Participant #9).*

b. Improvement opportunities

Participants suggested three areas of the iROLL program that could help improve future interventions: clear instruction for the video material, bigger font, and exercise program modifications. First, one participant expressed a need for clear instruction on how to access the video materials or program website:

> *Actually a couple of days ago I sent in the evaluation for the last day of the class and I had gone through the book, and one of the things that I noted in the form that I sent in is that at least one of the other students was very savvy with online things, and so she would look at the video tapes online and I kind of forgot that there was a video tape. There was a website that was listed. And my suggestion is that, if you list the link, put it frequently, larger letters, or circle it so that it's easy for me to find, because it was just kind of buried in a lot of language. And so, that's my suggestion… Maybe a little bit more training about how to use the website would be helpful in the class. (Participant #1).*

Another area suggested by participants was the use of a bigger font size in the training manual. Some participants reported that the font size was too small to read as they had visual problems:

> *Increase the font size…the size of the typing. Because most of us with MS have visual problems (Participant #2)*

Finally, participants suggested some modifications related to the exercise program. One participant reported that having a supervised exercise program would be beneficial:

> *A few years back I participated in a, from May through November, an exercise program here. I think it might've been Dr. Rice who had it, it's about maybe six years ago, and we met either twice or three times a week here and we did exercises together. I really liked that program. Also, I'm hoping that they have another program like that (Participant #5).*

Another participant expressed a desire for the iROLL program to provide an instructional video in which the trainer went through the entire workout with the participants, rather than only demonstrating one repetition of the motion.

> *Now what I would like the exercise program, just an idea, is that initially it's good to just show you how to do it, but for an ongoing thing if you could access a video for ongoing reps. If you could do it with them… what would be nice, let's say, to go to one of the exercises and she [a trainer who demonstrated the exercises in the exercise video] did the whole set. So that you could sort of turn it on and do it along (Participant #3).*

*Application of program content to daily life*

Participants described how they have applied the program contents to their personal life in order to manage falls. Upon analysis of the data, the following strategies from the program contents were used by participants to manage falls: heightening awareness, refined transfer skills, use of assistive device, environmental modifications, and MS symptom management. One

participant expressed that she altered the way in which she positioned her scooter when she transferred and paid more attention during transfers than she did prior to the intervention:

> *I'm always driving, inside my home, my scooter so it's always willy nilly where I was going to park it**. But after I started this course, I always park it 20 to 45 degrees**. **I pay attention** to where I'm going to, and I make the transfer (Participant #1).*

Another participant discussed how he used assistive devices after exposure to the intervention. He installed a wireless alarm system and uses an Apple watch to seek assistance as needed.

> *We changed the alarm system, the door lock system and that was a nice change… [Interviewer: What kind of alarm system?] ADT. We have had one since we moved in this house, but now you can control your door locks and it is all wireless. So, if you fall out of your wheelchair, I can use my watch. I can call 911 on my Apple watch (Participant #2).*

Some participants also interpreted how the program helped them with MS symptom management. For example, one participant reported how she managed her fatigue to prevent falls.

> *I do get fatigued in the afternoon so now I make sure that if I have activities early in the morning or in the afternoon, I do make sure that I take a rest break around 3:00 for a good 45 minutes or hour. Either sitting in a chair, resting or taking a short nap. So, I don't wear myself out. I think those are times when I used to have a fall, when I was just completely exhausted (Participant #5).*

*Program Outcomes*

a. *Perception of fall frequency*

Participants were asked "Do you feel the frequency of your falls increased, decreased or stayed the same? Why do you feel this way?" Most participants answered that they felt the frequency of their falls decreased. One participant reported that she felt her falls decreased as a result of several educational components in the iROLL program that they had not receive elsewhere:

> ***I would say they decreased**… you know, outpatient physical therapy can help you, but you don't get the big class like this on how to use a wheelchair and transfer which focuses on that all. So, I think that people with MS especially, we don't get any formal*

*training like this to address this area of our life. So, this program has helped me to focus more, to think about where my feet are, to make sure my wheelchair is off. All of those things you kind of knew, but this formally taught me, you have to do this because it's safer. And then these exercises, you get so many exercises at physical therapy, but to know that these are going to really improve your strength and ability to transfer really helps. (Participant #3)*

b. *Perception of fear of falling*

Participants were asked, "What are your feelings about fear of falling and fall management after completing this program?" Most participants reported that their fear of falling decreased. One participant stated that his fear of falling was reduced as a result of heightened awareness of risk factors associated with falls in his environment:

*You know what, I think this program should increase your feel of falling. Not a paralyzing fear, but just to make you more attentive to your transfers to minimize your falls. Maybe we don't want to use the word fear, we want to use the word concern Um, yes, you know what, maybe I'd say this program decreased my fear and increased my caution (Participant #2)*

*Future Directions*

Some participants provided insights on the future directions of the iROLL intervention. Participants stated that some of the components of the intervention, such as wheelchair/scooter skills training, would be most beneficial if targeted at newer wheelchair/scooter users.

*I thought that it was very beneficial and that it was something that I probably needed earlier on in my 60s because the things that I learned; I think I could have used before I got to this point (Participant #9).*

Additionally, one participant described that the intervention might be more beneficial if split into multiple interventions as MS is a progressive disease. Each of these interventions would target subpopulations within the MS community in different stages of the disease process.

*I think this is a program anyone with MS should take…**maybe it should be divided into beginning MS, cane users, walker users...maybe it needs to be divided into 4 to 5 courses...different stages** (Participant #2)*

## 5.4 Discussion

This investigation (phase 2) examined the feasibility and preliminary efficacy of the iROLL program developed using information obtained from phase 1 (chapter 4), and evidence from previous literature. The iROLL program provided education on a variety of topics related to the management of risk factors associated with falls for full-time wheelchair/scooter users living with MS. Overall, the preliminary results indicate that the iROLL program was feasible to implement, and it was effective in 1) reducing fear of falling, 2) enhancing the participant's knowledge about fall prevention and recovery strategies, and 3) improving transfer quality. No adverse events related the intervention were reported.

After exposure to the iROLL program, preliminary results indicate that fear of falling, which was indexed by the SCI-FCS, significantly decreased and a moderate effect size was found. This results also supported by the qualitative data analysis indicating that most participants reported that their fear of falling decreased. This is the first documented instance of a significant decrease in fear of falling among full-time wheelchair/scooter users living with MS[100]. A previous study in older ambulatory adults with MS by Finlayson et al.[103] found similar results that indicate that a structured fall management education program can reduce fear of falling. As there is growing evidence that fear of falling is common among full-time wheelchair users living with MS [20,22,120], this preliminary result is noteworthy. Therefore, the iROLL program, which utilized a multifactorial approach to fall management and fall recovery, has a great potential to manage the fear of falling for this population.

In addition to the reduction of fear of falling, the findings indicate that the knowledge to manage fall risk factors and to recover from a fall safely evaluated by the FMS and FPMQ improved. Especially, the areas of knowledge to reduce falls, to increase physical strength, to

manage MS symptoms, and to identify environmental hazards at home and community were improved. This finding is similar to a previous investigation performed by Finlayson el al., in an examination of a pilot study of a fall risk management program for ambulatory middle aged and older adults with MS[103]. In this investigation, 30 individuals living with MS received a 6-week MS specific fall management education program delivered by an occupational therapist. After exposure to the intervention, the study participants' knowledge of fall risk factors and knowledge to manage fall risks were significantly improved. Along with the result from the previous investigation, our finding highlights that the iROLL program, which specifically targeted wheelchair/scooter users living with MS, enabled the study participants to develop or enhance knowledge and skills to reduce their fall risk and to improve their fall recovery strategies.

Several program features may have contributed to the findings. It is important to note that the iROLL program was developed using the Health Belief Model (HBM) as a theoretical framework [51]. A previous fall prevention education program developed based on the HBM for 222 older adults who were hospital inpatients successfully increased the study participants' knowledge of prevention strategies [57]. Therefore, providing education programs designed based on the HBM has great potential to allow the wheelchair users to develop fall prevention and recovery strategies.

In addition to the HBM framework, the qualitative analysis revealed several helpful program components including experienced trainers, multiple sessions, small group setting, and various educational programs (e.g. physical skill training, education on fall recovery, environmental hazards management, and wheelchair set-up/maintenance). The combination of these strategies might positively influence the reduction of fear of falling and increase knowledge how to effectively manage fall risks among full-time wheelchair users. For example,

one participant reported that the education on how to better manage environmental hazards, or the recovery strategy were beneficial to decrease his fear of falling.

For the physical assessments, the preliminary results revealed that transfer quality, indexed by the TAI 3.0, significantly improved and a moderate effect size was noted. Furthermore, qualitative data analysis revealed that many participants reported that they changed the way they performed their transfers after exposure to the intervention. Additionally, the transfer training is the most frequently reported helpful program component by participants. The significant improvements observed in transfer quality potentially had an influence on the positive findings. In addition, this finding highlights that transfer training is an important component of fall management programs for wheelchair and scooter users living with MS.

Unlike the transfer quality, sitting balance evaluated by the FIST was not significantly improved and a small effect size was observed. The exercise program in the current study was a home-based exercise program for 6 weeks. Although the efficacy of targeted exercise training programs to improve balance are well known in individuals with MS, many of these programs had either longer period than 6 weeks or were supervised programs[121]. A 6-week training period for a home-based exercise training program might not be long enough to show significant improvement in sitting balance among full-time wheelchair/scooter users living with MS. Further research is needed to investigate the long-term effect of the current intervention program on sitting balance.

In addition to sitting balance, the wheelchair skill scores evaluated by the WST did not significantly change and a small effect size was noted. This result was observed in both power wheelchair/scooter and manual wheelchair users. One of the potential explanations for this result is that our sample had a greater portion of power wheelchair and scooter users (n=11). According

to a current systematic review investigating the effectiveness of wheelchair skills training programs, the effect of the power wheelchair skills training still remains questionable [122]. Additionally, the result of the qualitative data analysis revelated that some participants reported that the wheelchair skill training was redundant because they were already familiar with the skills instructed in the training. For example, one participant reported her perception on the wheelchair skill training: "*A lot of people already know how to drive their wheelchairs because they've been in them for quite a few years*" *(participant #4).* This observation might lead to our findings that the training failed to induce an effect on the participant's wheelchair skills.

5.5. Limitations

It should be noted that this study has limitations. The sample size in this study was small (n=13). As a result, this limits the ability to generalize the study findings. Another limitation is the limited follow- up period. Participants were only evaluated pre- and immediately post-intervention. It limited the ability to investigate the long-term impact of the iROLL program. Further research is needed to examine the long-term effect of the intervention program on the outcomes used in the current study. Additionally, fall frequency was not included as a main outcome due to the limited follow-up period. However, the perception of participants' fall frequency during the intervention was evaluated qualitatively and most participants reported that they felt their fall frequency decreased. This observation indicated that iROLL program has a good potential to positively influence fall frequency. Further testing is needed to examine the efficacy of iROLL on fall frequency objectively. Another limitation is that the program was delivered to a total of 4 small groups. Each group had a different number of members and was conducted by different trainers. As a result, there might be differences in the group experience for participants dependent on trainers and the number of group members. Since the knowledge of

fall prevention and recovery strategies were measured with self-reported surveys (FMS and FPMQ), the findings may be impacted by expectancy effects because participants might feel that they were supposed to improve their knowledge of fall prevention and recovery strategies by attending the iROLL program. Also, the validation of some outcome measures (SCI-FCS, FMS, and FPMQ) has not been established among full-time wheelchair users living with MS. Finally, a control group was not included in the study. As a result, it is not clear if or how other variables such as demographic characteristics affected the findings.

## 5.6 Research Challenge

The author encountered some challenges to complete this study. One challenge was establishing effective communication between the testing locations. Monthly meetings were held to discuss the study, however communication problems occurred related to exchange of data and participant status. Another challenge was scheduling the assessment and intervention sessions. Transportation to and from the assessments sessions was difficult, despite efforts to locate the sessions in central locations and provide participants stipends for transportation. In addition, many participants needed the assistance of a care partner to come to the assessment or intervention sessions which resulted in additional scheduling conflicts. Finally, secondary disability related symptoms or exacerbations would at times require participants to cancel assessments and limit attendance in the intervention. Challenges were also faced related to the recruitment of participants due to many of the same challenges noted above.

## 5.7 Conclusion

This is the first study to describe the development and implementation of an intervention program using a multifactorial approach to manage falls among full-time wheelchair/scooter users living with MS. Findings indicate that the iROLL program was found to be beneficial in

the reduction of fear of falling and in increasing the knowledge of fall prevention and recovery strategies. In addition, the preliminary assessment indicates that transfer quality significantly improved. The results of the study indicate that use of the iROLL program has the potential to assist full-time wheelchair/scooter users in fall management. Future studies need to add a fall frequency outcome as well as a longer follow-up period to evaluate whether the intervention has an effect on fall frequency reduction.

# CHAPTER 6: CONCLUSION

This study is the first effort to develop a multifactorial fall management program for wheelchair users through mixed methods research. Overall, this study fills a void in the research of fall management among populations of full-time wheelchair users. Phase 1 of the study provides insight into the circumstances of falls and the aftermath experienced by full-time wheelchair users. Several potential fall prevention and recovery strategies to manage falls were found including exercises to enhance sitting balance, wheelchair skill/transfer training, education on the management of a variety of environmental hazards, education on wheelchair set-up/maintenance and education on fall recovery strategies. The findings formed the foundation for the development of a multifactorial fall management program (iROLL) targeting full time wheelchair users.

The second phase of this study describes the development and implementation of the iROLL program and its preliminary efficacy. The content of the iROLL program was developed based on the themes and codes that emerged from in-depth interviews of full-time wheelchair users describing the circumstances of their most recent fall, fall management strategies and recovery techniques (Phase 1). In addition, the information from previous literature examining fall circumstances of wheelchair and scooter users and management strategies were integrated into the program. Preliminary results indicate that the intervention reduces fear of falling and positively influences knowledge of fall prevention and recovery strategies and quality of transfer skills among wheelchair and scooter users living with MS. Thus, the iROLL program shows good potential to be an effective fall management program for full-time wheelchair/scooter users living with MS. The results of this study can inform the design and develop of other multifactorial fall management programs for different clinical populations who use wheelchairs

or scooters. Future research is needed to examine the influence of the iROLL program on fall frequency and the long-term influence of the program. Also, the efficacy of the iROLL program should be further evaluated with larger and more diverse populations of wheelchair users who are at risk of falling.

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## APPENDIX A: INTERVIEW QUESTIONS (CHAPTER 4)

Assessment of Fall Characteristics Among Wheelchair User

Interview questions

1) Could you tell me a little bit about yourself?
    a. What type of activities do you like to do for fun?
    b. Do you prefer to stay in your home or get out and about in the community?

2) We are now going to ask you a series of questions about falling.
    a. How many times did you fall in the past 12 months?
    b. Please describe the circumstances surrounding your most recent fall.

*Note to investigator: Allow the participant to describe their most recent fall without prompts. After they have completed their description, make sure the following items have been answered. Please ask the below directed questions to gather this information.*

i. Where did the fall occur?
ii. What were you doing just prior to the fall occurring?
*iii.* What were you doing when then the fall occurred? *(Note: make sure to get a very specific answer to this question)*
iv. Did any type of distraction contribute to your fall?
    1. If so, please describe the distraction.
v. Were there any unstable surfaces involved?
vi. Was the PWC/MWC moving or stationary during fall?
vii. Was the PWC/MWC hit by another object?
viii. Was the fall due to a malfunction of the PWC/MWC?
    1. *If yes:* Please describe what type of malfunction occurred.
ix. *If the person has power seat functions:* Where you using any of your power seat function(s) during the fall?
    1. *If yes,* can you describe how you were using your power seat function?
x. Where any other people involved with the fall?
xi. Please describe any injuries that occurred.
xii. Have any concerns or feelings towards a fear of falling developed since this most recent fall occurred?
xiii. How did you recover (get up) from the fall?
    1. Did someone help you get up or were you able to do it yourself?
*xiv.* Approximately how long were you lying on the floor or ground before you were able to get up?

3) We are now going to ask you some questions about how your worst/most injurious fall that you describe above could have been avoided. (We will refer to this fall as your worst fall moving forward.)
    a. Do you think your worst fall could have been avoided?
    *If yes:* How do you think the fall could have been avoided?
    *If no:* Why do you think this fall could not have been avoided?

b. Do you think that anything could be changed about your wheelchair to help you avoid falls in the future?
c. What do wheelchair manufactures need to know to help wheelchair users prevent falls?

4) Finally, we are going to talk about ways that a PWC/MWC user can recover from a fall. Recovering from a fall means to get up from the floor or whatever surface you fell onto and return to your PWC/MWC or preferred surface.
    a. When you fell, what type of thoughts came into your mind when you ended up on the floor
    b. What type of technology do you think should be developed to help you recover from a fall?
    c. If a device was developed to help you recover from a fall, would you be willing to pay for it out of pocket or would you only use the device if your insurance cover it?
        i. *If yes:* How much would you be willing to pay for a fall recovery device?
        ii. *If no:* Why would you not be willing to pay for the fall recovery device?