

IMPACT OF POST-STROKE MOBILITY ON ACTIVITY AND PARTICIPATION

By

ARLENE ANN SCHMID

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by

Arlene Ann Schmid

This dissertation is dedicated in the memory of my father, Albert R. Schmid.

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Abstract of Dissertation Presented to the Graduate School  
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Arlene Ann Schmid

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Post-stroke individuals often experience residual mobility impairments, reflected in decreased gait speed, increased falls, and the possible development of fear of falling. This research utilized two secondary analyses to explore the impact of post-stroke gait velocity and fear of falling on activity and participation.

The first study examined clinically meaningful changes in gait velocity in 64 post-stroke individuals. Velocity was measured at baseline and three months and was placed into a three tier ambulation classification. T-tests determined a difference in functional ability (activities of daily living (ADLs), instrumental activities of daily living (IADLs), mobility, and social participation) between those who did and did not successfully advance to the next ambulation classification. After stratifying by baseline gait velocity and controlling for age, those most severely impaired at baseline, and who advanced classifications, demonstrated significant differences in all measured functional abilities. In comparison, those moderately impaired only demonstrated significant differences in

social participation. Thus, clinically meaningful changes in gait speed were related to highly significant changes in all domains, particularly for participation.

The secondary objective was to characterize post-stroke fear of falling. Review of qualitative interviews identified those with fear of falling. T-tests compared ADLs, IADLs, and depression measures between those with and without fear. No significant differences were found for the outcome measures; however, those with detected fear exhibited slightly worse scores on all measures. Content analysis of the interviews revealed five elements used to characterize post-stroke fear of falling: (1) onset of falling with stroke event, (2) experiencing the changed body, (3) a pervasive fear of the unpredictable, (4) falls as an everyday life experience, and (5) the strategies for managing fear of falling. Such experiences and strategies became very individualized and imply the need for future research regarding assessment and intervention of post-stroke fear of falling.

Collectively, these results indicate that many post-stroke individuals live in the community, but still demonstrate residual mobility deficits. Decreased gait velocity and developed fear of falling were related to activity restriction and modification, possibly leading to further losses of independence, placing individuals at risk for decreased quality of life and life satisfaction.

## CHAPTER 1 INTRODUCTION

The American Heart Association reports stroke to be a common diagnosis occurring in 700,000 people annually. Stroke is the primary cause of disability and the third leading cause of death for those over 65 [1-4]. Stroke is also classified as the most disabling chronic disease and the cumulative consequences are often staggering for individuals, families, and society [5, 6]. Residual motor, sensory, and visual post-stroke deficits make mobility impairments common. Changes in gait velocity, falls, and fear of falling are common post-stroke mobility impairments. All may contribute to decreased performance of activities of daily living (ADLs), instrumental activities of daily living (IADLs), social participation, and overall declines in quality of life.

The purpose of this dissertation is to report findings from two studies. Both studies are secondary analyses of larger studies. The goal of the first study was to evaluate a clinically meaningful change in post-stroke gait speed and its impact on activity and participation levels post-stroke. A clinically meaningful change is important to determine as it is related to patient-valued benefits. Barrett et al. discusses the need to merge patient-oriented and evidence-based frameworks together by observing an “important difference” [7]. Such clinical significance can be seen by examining the sufficiently important difference (SID), the smallest amount of patient-valued benefit required from an intervention to justify associated costs, risks, and other harms. We observed data on post-stroke gait speed changes and the existing relationship with ADLs, IADLs, and social participation to examine a clinically meaningful change in gait velocity.

Data for this aspect of the study were derived from a prospective, randomized, controlled, single-blind, clinical intervention trial [8]. An analysis of three-month post-stroke data related to gait speed was completed. Participants were stratified by changes in gait speed. Comparisons were completed to determine significant differences in ADL, IADL, and social participation scores between those who succeeded and those who failed to increase gait speed at three months post-stroke. Literature supports an association between gait speed and mobility [9, 10]. However, limited research currently exists to support the relationship between changes in gait speed and the resultant difference in performance of ADLs, IADLs, and social participation.

The second study was completed to identify and describe the characterizations of fear of falling as reported by participants who have been discharged home following a stroke. We used qualitative and quantitative data from a longitudinal multi-site cohort study exploring stroke recovery and caregiving at one and six months post discharge following acute stroke [11]. We examined the relationship between fear of falling and demographic variables, depression, and the ability to perform ADLs and IADLs. Additionally, caregiver depression and burden associated with fear of falling was explored. Qualitative interviews were semi-structured around issues related to the post-stroke experience but did not specifically ask about fear of falling. Therefore, the interviews were examined to identify participants who discussed characteristics related to fear of falling. The data specific to those with an identified fear were re-coded in QSR N-6 (qualitative data computer software) . Content analysis was used to analyze the qualitative data and define characterizations of fear of falling across 6 months after discharge home post acute stroke. Currently, there is a paucity of information related to

the development of fear of falling after stroke. This study provides initial exploration into this complex syndrome and will supply preliminary data for future research regarding post-stroke fear of falling and the residual influence it has on activities and participation.

Cumulatively, these research projects provide researchers and clinicians with valuable information regarding performance of ADLs, IADLs, and social participation related to both gait speed and fear of falling after stroke. The impact of post-stroke gait speed on ADLs and IADLs is not well researched and this study contributes critical information. This research is the first study to examine fear of falling in a stroke population with longitudinal data that are both quantitative and qualitative. Results from the study indicates the need for development of a future index related to fear of falling in the population, and, more importantly, interventions to reduce both falls and manage fear of falling in the post-stroke population. These studies provide a foundation for future research related to post-stroke mobility and activities and participation.

### **Theoretical Models**

Two theoretical models have guided this research. The International Classification of Functioning, Disability, and Health was used to explain the fundamental relationships between post-stroke mobility and ADLs, IADLs, and participation (see Figure 1-1). An additional conceptual model was specifically proposed for these research study questions. It was developed after a review and synthesis of the literature specific to gait velocity and fear of falling (see Figure 1-2).

### **The World Health Organization Model: International Classification of Functioning, Disability, and Health**

Various models of disablement have been developed and explored over the years. Because rehabilitation strives to reverse what was previously known as the “disabling”

process, proactive alterations have occurred in the theoretical models. Therefore they are now termed “enablement models”, and represent models of health and ability. The International Classification of Functioning, Disability, and Health (ICF) is the model most frequently used in rehabilitation sciences and was proposed by the World Health Organization (WHO) [12, 13].

The ICF has recently undergone revisions to better incorporate the concepts of health and ability and to replace terms such as impairment, disability, and handicap to allow for a more positive framework and classification system [13]. The ICF provides a framework for the analysis of health conditions, body structure, body functions, activity and participation, and environmental and personal factors [12]. There are two parts of the ICF; the first deals with functioning and disability and is derived of the components of body structure, body functions, activity, and participation. The second part includes the components of contextual factors and includes environmental and personal factors. See Figure 1-1.

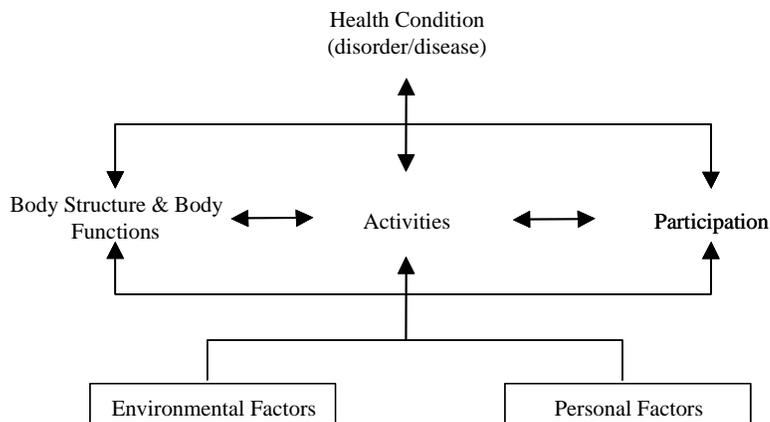


Figure 1-1. The ICIDH-2 Model of Disablement

Body structures are the anatomical parts of the body and include organs, limbs, and their components. Body functions are the physiological or psychological functions of

body systems. Body function and structure impairments are related to significant deviation or loss.

The activities and participation component collectively covers the complete range of individual and societal functioning and disability. The model captures the major actions of all people, regardless of culture or lifespan. Activity is the execution of a task or action that is completed by an individual in a uniform environment. Activity limitations are difficulties a person may have in executing activities. Activity includes self-care, mobility, learning and applying new knowledge, general tasks and demands, and communication. Participation is the involvement in a life situation in an individual's current environment. Restrictions in participation are problems a person may experience in involvement in life situations. Participation includes domestic life, interpersonal interactions and involvement in relationships, major life areas, and community, social, and civic life. Activities and participation have two qualifiers within the model. Capacity is the completion of an item in a neutral or standard environment and focuses on how an individual actually completes the task. Performance is related to completing the same item during daily life, at home and in the environment. Capacity limitations indicate the discordance between capacities of people with and without health related condition. Performance limitations indicate a need for intervention at the environmental level.

Environmental and personal factors include external features of the physical, social, and attitudinal environment in which people live and conduct their lives. Products and technology, natural environments, human-made changes to the environment, support and relationships, attitudes, and services, systems, and policies are all aspects of environmental and personal factors.

## **Theoretical Framework**

Substantive reviews of the literature were completed. The literature pertaining to post-stroke mobility, gait speed, falls, and fear of falling were incorporated into the ICF model (see Figure 1-2). It was used to guide the research questions and analyses for these studies.

In this study, the general health condition was “stroke.” The type of stroke and severity of stroke are important aspects that may impact post-stroke mobility. Stroke related body function and body structure included sensory, cognitive, and motor impairments. Environmental factors included caregiver depression, burden, and coping. Personal factors included age, race, and cognition. These stroke related impairments and personal factors might be related to activity limitations; such as difficulties completing ADLs and IADLs, including walking, stair climbing, dressing, bathing, toileting, etc. Mobility is a construct of ADLs and is therefore considered an aspect of activity. Gait speed and fear of falling are each aspects of post-stroke mobility, and are therefore considered as activity. It is thought that losses in gait speed and the development of fear of falling adversely impact ADLs, IADLs, and social participation. Body function and structure impairments and especially activity limitations may restrict participation in society, thereby limiting role fulfillment at home, work, and within the social environment. All of these post-stroke changes may also influence caregiver burden, coping, depression.

The current study was developed to specifically address the relationships between changes in gait speed and the development of fear of falling with ADLs, IADLs, participation, and depression. All aspects of the model may be affected by post-stroke mobility. Activity, participation, and environmental/personal factors must therefore be

addressed. Importantly, all are related to the greater aspect of quality of life and life satisfaction.

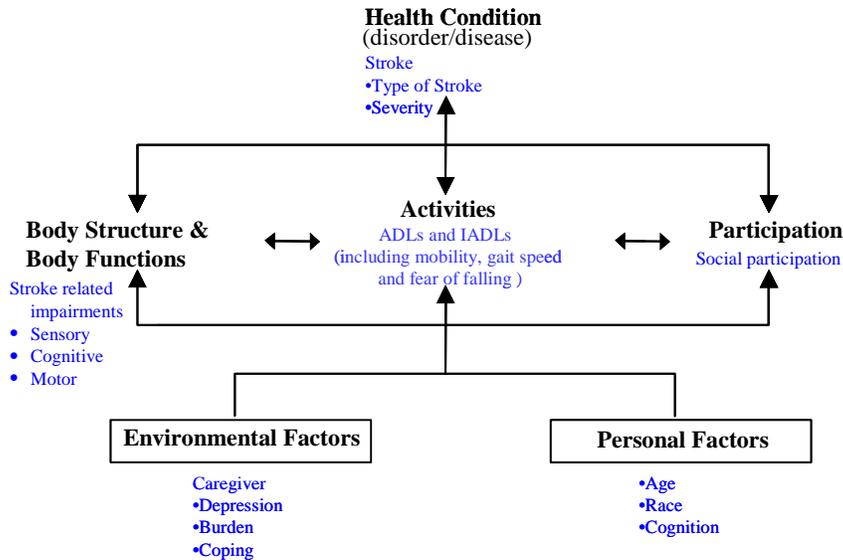


Figure 1-2. Conceptual Model

### Research Questions

The following research questions are derived from the relationships depicted in Figure 1-2. The conceptual model was the guiding focus of this study. We used both qualitative and quantitative data in this study.

We explored the post-stroke relationship between clinically meaningful changes in gait velocity and performance of ADLs, IADLs, and social participation.

1. Does a change in gait velocity classification impact the ability to perform ADLs, IADLs, functional mobility, and social participation after stroke?

We also explored post-stroke fear of falling using qualitative and quantitative data.

Our research question related to examination of the fear of falling qualitative data include:

2. How do the participants report and characterize fear of falling in the home or community environment?

To complement the study, we examined the relationship between fear of falling and quantitative data:

3. How is post-stroke fear of falling related to performance in ADLs and IADLs?
4. How does caring for an individual with post-stroke fear of falling impact caregiver burden and depression?
5. Is there a difference in the proportion of stroke survivors with fear of falling at 1 and 6 months post stroke?

## CHAPTER 2 REVIEW OF THE LITERATURE

### **Introduction**

Stroke is a common problem and the leading cause of adult disability in the United States. There are many residual motor, sensory, and visual post-stroke deficits making mobility impairments common. Common post-stroke mobility impairments include decreased gait velocity, falls, and the development of fear of falling. All may negatively impact performance of activities of daily living (ADLs), instrumental activities of daily living (IADLs), and social participation. Such restriction in activity and participation has been associated with declines in life satisfaction and quality of life.

The following review of the literature is based on the International Classification of Functioning, Disability, and Health (ICF) [12] and the conceptual framework found in Chapter 1 (Figure 1-1 and 1-2). As stated in Chapter 1, stroke related sensory, cognitive, and motor impairments negatively influence post-stroke mobility, as demonstrated in decreased gait speed and increased falls and fear of falling. These changes in post-stroke mobility may impact activity and participation. Activity and participation limitations may also negatively influence caregiver burden and depression.

In this review of the literature, there will be an overview of mobility concerns of the community dwelling elderly. Specifically, gait speed, falls, and fear of falling will be addressed. The limited existing literature specific to post-stroke gait speed, falls, and fear of falling will also be presented. Additional literature is presented on the impact of mobility on activity and participation; some is specific to the post-stroke population, but

much is generalized to the community dwelling elderly. Caregiver burden and depression are also explored in this review as care needs change for those with decreased activity and participation. Increased caregiver burden and depression are associated with a patient's history of strokes, falls, and decreased independence.

The objective of this research was to determine the impact of post-stroke mobility on activity and participation. Specifically, the relationships between changes in gait speed and the impact on activity and participation were explored. Additionally, the characterization of fear of falling by a post-stroke population was described. Performance of ADLs, IADL, and depression for those with fear was also examined. This research will provide foundational data for future studies examining the impact of post-stroke mobility on activity and participation.

### **Mobility in the Community Dwelling Elderly**

Mobility has been defined as the “ability to move from one place to another without assistance” [14]. It is a component of ADLs and is critical for the maintenance of independence and a sustained quality of life [14, 15]. Mobility disability is defined by the inability of individuals to “move effectively in their surroundings” [16]. It is a strong predictor of physical disability and often the first area in which older adults demonstrate disabilities [16-18]. The prevalence of mobility disability increases from 7.7% of those over the age of 65 to 35% for those over 80 years [19].

Disability is a risk factor for loss of independence, admission into care facilities, increased need for caregiving, and health care utilization [20-24]. Those who demonstrate mobility limitations are at risk for increased disability, dependence, morbidity, and mortality [17, 25-32]. Mobility limitations have been utilized in predicating disability outcomes [31].

Changes in gait velocity, increased number of falls, and the development of fear of falling are three important aspects of mobility. All are common issues for the community dwelling elderly population. Disability may occur due to any or all of these mobility changes.

### **Gait Velocity**

Mobility and mobility disability are commonly demonstrated by changes in gait velocities. Gait velocities often decrease with age and have been associated with severity of walking difficulties [33]. Cress et al. found that walking speed was the strongest indicator of self-perceived physical functioning [34]. Gait velocity has therefore become a frequently measured outcome and goal of rehabilitation.

### **Gait velocity as an outcome measure**

Numerous elderly specific research studies have utilized gait velocity as a primary outcome measure to assess mobility impairment [35]. Velocity has been deemed useful in rehabilitation medicine and research as it correlates well to many gait parameters [36]. It has been related to discharge placement following hospitalization in the elderly population [37, 38].

Gait speed is an important measure of stroke recovery as it is simple to measure and has been demonstrated as reliable and sensitive to the stage of recovery post stroke [9, 35, 39]. Gait speed has been associated with discrimination of stroke effects and is related to rehabilitation prognosis [40]. Studenski and colleagues demonstrated gait speed measures of less than 0.6 meters/second (m/s) as a predictor of future health care utilization and declines in health status [41]. In their study, 69% of the elderly with a walking velocity of less than 0.6 m/s developed new personal care difficulty as compared to 12% of those walking faster than 1.0 m/s.

**Gait velocity and other aspects of mobility**

Decreased gait speed has been related to falls and fear of falling [42-44]. Hausdorff et al. reported a relationship between falls and factors such as gait speed and functional status [45]. Maki demonstrated a relationship between decreased gait speed and increased falls and fear of falling in the community dwelling elderly population [42].

**Falls**

A fall has been defined as “an event which results in a person coming to rest unintentionally on the ground or other lower level, not as a result of a major intrinsic event (such as stroke) or overwhelming hazard” [46, 47] or as “falling all the way down to the floor or ground, or falling and hitting an object like a chair or stair” [48]. Falls are significant mobility issues addressed in the literature for the community dwelling elderly.

**Incidence and consequences of falls in the community dwelling elderly**

Falls are the leading cause of injurious death for those over 65 in the United States [49]. At least 30% of those over 65 and residing in the community fall annually; 10-20% fall two or more times [50]. After age 80, annual fall rates increase to 50% [46, 51]. The elderly who fall are likely to sustain more fall related trauma and serious injury and demonstrated increased health care utilization compared to young fallers [52]. Fall related trauma is more likely to be the cause of death in older fallers [53]

In 2001, more than 1.6 million emergency room visits and 15,000 deaths were attributable to falls [54]. Severe consequences related to falls include hip fractures and head trauma, increased health care utilization, declines in ADLs and IADLs, decreased socialization, increased admissions to long-term care facilities, premature disability, and death [53, 55]. Additionally, King and Tinetti determined that morbidity, physical injury,

restriction of mobility, reduction of activity and participation, and generalized decreases in independence were fall related consequences [56].

**Long-term care admissions.** Donald and Bulpitt completed a longitudinal prospective cohort study to assess fall related deaths and long-term care admissions [57]. Risk of death increased at both one and three years for recurrent fallers. However, all who fell demonstrated loss of function and independence, consequently increasing long-term care facility admissions. Tinetti et al. reported 40% of all nursing home admissions as being fall related [46].

**Fractures as a consequence of falls.** Approximately 360,000 adults suffer a fall related hip fracture each year [49]. Half of those who suffer a hip fracture will never regain their prior level of functioning. Hip fractures are a significant concern as they are related to more deaths, disability, and medical costs than all other osteoporotic fractures combined [58].

Falls are an independent risk factor and contribute to 90% of all hip fractures [59, 60]. Minor injuries such as bruises and abrasions occur after 30%-55% of falls [48, 51, 61] and about 4%-6% of falls end in a fracture, often of the hip [46, 48, 61, 62]. Death is uncommon following a fall; however, fall related hip fractures are the leading cause of death for those over the age of 65 [63, 64].

### **Multifactorial risk factors**

A review of the literature indicates fall risks are considered multi-factorial [46, 51, 52, 65-75]. Meta-analyses and predictive models have been used to determine many of the evidence based risk factors. An epidemiological study determined that over 400 fall risk factors exist [76]. Factors may differ between community dwelling individuals and those residing in long term care facilities [66]. Table 2-1 provides a list of common falls

risk factors. Each factor is supported in the literature and by recent meta-analyses [46, 49, 51, 52, 66, 68-71, 77].

Table 2-1. Multifactorial risk factors for falls

<b>Risk Factor</b>	<b>Supporting Evidence</b>
<b>Disease &amp; Disability</b>	
Stroke	[52, 78-86]
Parkinson's Disease	[49, 61, 77, 87-89]
Cardiovascular function/ disease/blood pressure issues	[49, 66, 77, 90, 91]
Arthritis	[49, 52, 77, 92-94]
Neuromuscular disease	[49, 77]
Depression	[49, 52, 66, 77]
<b>Mobility Impairments</b>	
Previous falls	[52, 56, 95, 96]
Balance and gait deficit	[46, 52, 66, 97-100]
Decreased gait speed/gait impairments/mobility impairments	[42-46, 66, 69, 78, 90, 95, 97, 101]
Foot problems	[46]
Decreased strength	[46, 52, 61, 66, 71, 74, 90, 95, 97, 99, 102-109]
<b>Other</b>	
Environmental factors	[46, 66, 110, 111]
Fear of falling	[96, 112-115]
Medications and polypharmacy	[46, 66, 90, 116, 117]
Cognition	[46, 52, 66, 90, 118-122]
Vision and hearing	[48, 52, 66, 90, 97, 123]
ADL participation	[52, 66, 90, 107, 124]
Use of assistive device	[52]
Female gender	[46, 100, 125-130]
Age	[46, 74, 126, 131-133]
Urinary incontinence	[66, 69, 74, 134, 135]

### **Number of risk factors**

The risk of falling is exacerbated when the actual number of existing risk factors is increased [46, 70]. Tinetti and colleagues completed a community based study examining those with and without fall risk factors [46]. At one year, 27% of individuals with one or no risk factors fell compared to 78% of those with four or more factors. Nevitt and colleagues indicated falls increased from 10% to 69% as the number of risk factors increased from one to four or more [61]. Robbins et al. compared one-year fall rates for

those with and without three identified risk factors: hip weakness, unstable balance, more than four medications [100]. One hundred percent of those with all three risk factors fell compared to 12% who had none of the risk factors. Furthermore, Tinetti et al. ascertained that falls increased from 0% in those with 0-3 risk factors to 100% for those with seven or more factors [90].

### **Fear of falling as a risk factor and consequence of falls**

Fear of falling has been established as both a risk factor and consequence of falls [96, 112, 113]. Fear of falling may develop post-fall, or a fall may occur due to severe issues related to fear of falling [96]. Psychological trauma related to a fall may be related to concern of suffering another fall or a result of changes in function and pain related to a previous fall. Additionally, being stranded on the ground after a fall is a common fear.

Friedman et al. determined fear of falling as a significant risk factor for future falls, and also demonstrated falls as a risk factor for the development of fear of falling [96]. Delbaere and colleagues examined the “vicious” cycle that exists between falls and fear of falling [114]. The authors concluded fear of falling is both a risk factor and serious consequence of falls.

### **Fear of Falling**

Fear of falling was first identified and termed “postfall syndrome” [136] or ptophobia in 1982 [137], and then simply “fear of falling” in the later 1980’s [138, 139]. Fear of falling has been defined as a “disabling symptom of impaired mobility among frail older people that is significantly associated with depression, diminished performance in gait, and restricted IADL” [113] and “as a lasting concern about falling that leads to an individual’s avoiding activities that he/she remains capable of performing” [140]. Others have considered fear of falling as a loss of confidence balance abilities [141, 142]. It has

also been defined as a general concept that describes low confidence (efficacy) for avoiding falls and simply being afraid to fall [143].

### **Incidence of fear of falling in the community dwelling elderly**

Fear of falling is a common difficulty faced by the elderly and is one of the greatest fears experience by the elderly [115]. Walker and Howland compared fear of falling to the fear of robbery, fear of forgetting an important appointment, fear of financial difficulties, and fear of losing a cherished item. Twenty-five percent of the 115 community based participants determined fear of falling as their greatest fear.

Great variability exists surrounding the incidence of fear of falling and incidence may or may not be related to a previous fall. Researchers have indicated fear of falling in 29%-92% of those recently sustaining a fall and 12%-65% of those without a recent fall [46, 70, 113, 115, 144-152]. Fear may develop simply due to knowing someone who had sustained a serious fall or fall related injury [153].

Myers et al. examined fear of falling in community dwelling elders [150]. Fear of falling was assessed by asking “are you afraid of falling?”; 56% of those with a previous fall and 58% without a fall reported being fearful. Further analysis with the Falls Efficacy Scale determined similar results. The authors expressed that fear of falling may be underestimated in the elderly due to a fear of institutionalization and a resultant refusal to participate in such research.

Arfken completed a study to better determine the prevalence and the correlates of fear of falling [43]. Fear of falling was determined to be more prevalent among the older participants. Dependent on age, 10%-16% of men reported to be moderately fearful and 0%-5% were very fearful. Comparatively, 15%-34% of women were moderately fearful and 6%-12% were very fearful. More recently, Stolze et al. completed a prospective

study to investigate the prevalence of falls in differing neurological diseases [154]. Prior falls were significantly correlated with fear of falling; 57% of the fallers reported fear of falling compared to 24% of the nonfallers.

### **Fear of falling risk factors**

Like falls, fear of falling is considered to have multifactorial risk factors. Other than a previous fall, risk factors correlated to the development of fear of falling include: increased age [43, 144, 148], female gender [43, 144, 148, 155, 156], hospitalization [143], and dizziness [157]. Murphy et al. completed a study to identify predisposing risk factors for the development of fear of falling in an all female community dwelling population [158]. Predisposing factors for fear development included: age over 80, visual impairments, sedentary lifestyle, and lack of available emotional support.

Mobility [42, 155] and prior falls [96, 112, 113] are significant risk factors for the development of future fear of falling. Maki and colleagues completed a cross-sectional study to investigate the relationship between fear of falling and postural balance and control [155]. The researchers discussed significantly decreased scoring on balance assessments for those with fear of falling. Additionally, Maki et al. demonstrated an association between fear of falling and changes in mobility, such as decreased stride length, decreased speed, increased double stance time, decreased clinical gait scores, and increased stride [42]. Vellas et al. demonstrated those with a reported fear of falling experienced greater balance and gait disorders compared to those without fear of falling [144]. Ultimately, participants with fear of falling endured decreases in mobility.

Friedman et al. examined the temporal relationship and the shared predictors of falls and fear of falling [96]. Falls and fear of falling data were collected at both baseline and 20 months. If participants were assessed as fearful of falling, they were asked about

fear related activity restriction. During the initial assessment, 27.8% participants reported a fall, 20.8% expressed fear of falling, and 46.2% of those with fear of falling had curtailed activities. At follow-up, nonfallers with fear were more likely to report falls than those without fear (32.6% vs 17.9%). Fallers with no fear of falling at baseline were twice as likely than nonfallers to report fear at follow-up (20.6% vs. 11.6%). Regardless of fall status, all who expressed fear of falling at baseline were very likely to express fear again at 20 months.

Researchers have discussed “evidence of a spiraling effect of increasing falls, fear, and functional decline” [114]. They stated fear of falling is not only an acute outcome secondary to falls, but “more likely recognition of being at risk, both of falling and of the adverse outcomes that can result from falls”. Additionally it was concluded that once fear develops, it is likely to persist and influence activities and future fall rates.

### **Mobility in the Post-Stroke Population**

#### **Stroke and Mobility Impairment**

Post-stroke residual deficits may exacerbate the mobility issues of the community dwelling elderly population. Such mobility impairments may negatively gait speed, falls, and fear of falling after a stroke.

#### **Stroke**

Stroke is the primary cause of disability and is the third leading cause of death for those over the age of 65 [1-4]. The American Heart Association reports stroke as a common neurological event occurring in 700,000 people annually; over 4 million are living with residual deficits [159]. O’Sullivan has defined a stroke, or cerebrovascular accident (CVA), as “an acute onset of neurological dysfunction due to an abnormality in cerebral circulation with resultant signs and symptoms that correspond to involvement of

focal areas of the brain” [160]. It has been classified as the most disabling chronic disease with deleterious consequences for individuals, families, and society [5, 6].

Because age is a known risk factor for stroke, stroke incidence is expected to increase as the population ages. Stroke prevalence is expected to increase as stroke survival rates continue to increase [161, 162]. The majority of stroke survivors will be discharged from the acute care setting and will return home with mild or moderate physical, cognitive, or emotional deficits [78]. For example, in the Department of Veterans’ Affairs, 72% of all stroke survivors were discharged home into the community in 1999 [163].

### **Gait Velocity After Stroke**

Mobility impairment, such as decreased gait velocity has been related to stroke related outcomes. Perry and colleagues assessed the relationship between gait speed and mobility in participants 3 months post-stroke [9]. Six ambulation categories were developed, each was related to post-stroke mobility and ambulation in and out of the home (borrowed from Hoffer et al. who utilized a four step walking handicap scale for children [164]). See Table 2-2 for the six ambulation categories.

Perry et al. used five clinical measures to place post-stroke participants into one of the six categories. The measures included: a walking ability questionnaire, stride characteristics including gait speed, upright motor control testing, and proprioception. Many analyses were completed, and the difference in gait velocity demonstrated the greatest statistical significance between categories. Discriminate analyses were completed and identified gait velocity as the only clinical measure to significantly predict placement into the categories. Those considered as physiological walkers had a mean

velocity of  $0.1 \pm .03$  m/s compared to community walkers with a gait velocity of  $0.8 \pm 0.18$  m/s.

Table 2-2. Six ambulation categories

<b>Ambulation level</b>	<b>Ambulation ability</b>
Physiological walker	Walks only for exercise or in therapy
Limited household walker	Requires assist for some walking activities, does walk during some home activities
Unlimited household walker	Able to walk for all household activities, has difficulty with stairs and uneven terrain, not able to enter and leave the house independently
Most-limited community walker	Able to enter and leave their home independently, is able to ascend and descend curbs, able to manage stairs but with assistance, independent in at least one community activity, but needs assistance with others
Least-limited community walker	Independent in stairs, all moderate community activities, and in local stores and uncrowded shopping centers
Community walker	Independent in all home and community activities, can walk with crowds and on uneven terrain, and able to be independent in shopping centers

The classification system was condensed to depict three distinct gait velocity based classifications (see Table 2-3). This was necessary due to the similarities in gait speed between the household walkers. A walking speed of less than 0.4 m/s was determined equivalent to severe gait impairments and the *household ambulation* category. *Limited community ambulation* equals moderate gait impairments and speeds between 0.4 m/s and 0.8 m/s. Those in the *community ambulation* category walk over 0.8 m/s and are considered to have mild or limited post-stroke gait impairment. The normal healthy older population has been documented to walk at a gait velocity of 1.33 m/s [165].

Table 2-3. Gait Speed Classification

<b>Speed, m/s</b>	<b>Impairment</b>	<b>Ambulation Ability</b>
< 0.4	Severe	Household ambulation
0.4-0.8	Moderate	Limited Community Ambulation
> 0.8	Mild	Community Ambulation
1.33	None	Normal, Healthy Elderly Population

Lord and colleagues extended this work and evaluated the relationships between post-stroke gait speed and community ambulation [10]. Community ambulation was defined as “locomotion outdoors to encompass activities such as visits to the supermarket, shopping malls, and back; social outings; vacations; and pursuit of leisure activities”. All 130 post-stroke participants lived at home, 115 participants received physical therapy for mobility impairments and 15 did not require therapy. Mobility outcome measures assessed gait velocity, indoor and outdoor walking ability, functional mobility, and gait endurance. An additional self-report questionnaire assessed community ambulation according to unsupervised mobility. Participants were placed into one of four ambulation categories (see Table 2-4.), 1) not ambulating outside of the home, 2) ambulating as far as the letterbox, 3) ambulating within the immediate environment, 4) ambulating in a shopping center and/or other places of interest.

Those not requiring physical therapy post-stroke demonstrated the fastest gait velocity. Gait speed was within normal limits for this group and significantly higher than the overall mean, 1.36 m/s compared to .94 m/s. Gait speed differed between the four categories and increased as community ambulation increased (Table 2-4). The self-report questionnaire indicated 14.6% of the participants were unable to leave their home unsupervised, 16.9% were able to walk to the letterbox, 7.6% were limited to ambulating in their immediate environment, and 60.7% were able to ambulate within a shopping center and/or other place of interest. The authors concluded gait velocity was important to community ambulation and demonstrated that nearly one third of the sample was not able to ambulate independently within the community after a stroke.

The relationship between gait speed and mobility has been supported in the literature. However the relationship between changes in post-stroke gait velocity and the ability to perform ADLs, IADLs, and social participation has never been explored.

Table 2-4. Community ambulation

<b>Group</b>	<b>Community Ambulation Level</b>	<b>% of Sample</b>	<b>Speed (m/s)</b>
1	Unable to leave home	14.6%	0.515 m/s
2	Able to walk to letter box	16.9%	0.66 m/s
3	Limited to immediate environment	7.6%	0.82 m/s
4	Ambulate in shopping center	60.7%	1.14 m/s

### **Falls After Stroke**

Falls are considered the most common medical complication after stroke [166]. Fall rates increase significantly post-stroke due to motor and sensory impairments and residual functional, cognitive, and emotional deficits. These deficits are often related to mobility impairments and losses in ADLs, IADLs, social participation, and overall quality of life. Falls may contribute to post-stroke residual impairments and further decreased abilities to complete ADLs and IADLs.

Researchers have shown 22-39% of the acute stroke population falling before hospital discharge [166-168]. Those who fall while in the hospital are twice as likely to fall after discharge. Existing research indicates falls remain an issue at discharge [78, 79] and still at 10 years post-stroke [82, 169]. Forster and Young examined falls incidence and consequence and reported 73% of the participants fell in the first six-months post-stroke [79]. Importantly, only 21% of those who fell during the study had fallen prior to their stroke. The “fallers”, those with two or more falls, walked with a slower gait speed, were engaged in less social activity, and were more likely to be depressed.

**Stroke as a risk factor for falls**

Stroke is one of the most commonly cited risk factor for falls [82]. Hyndman et al. determined stroke as a risk factor for falls in a cross-sectional, observational study [170]. Half of the 41 community dwelling stroke survivors sustained a post-stroke fall and 10 had fallen more than once. Additional risk factors for those deemed “repeated fallers” included: post-stroke mobility deficits, upper extremity ability, and declines in ADLs and IADLs. Byers and colleagues studied acute stroke survivors and concluded post-stroke fall risk factors included a history of falls, impaired decision making ability, restlessness, generalized weakness, and abnormal hematocrit levels [81]. Jorgensen et al. determined the risk of falling was at least twice as high for those post-stroke in a case-control study [82]. Forster and Young found those post-stroke who fell in the hospital were twice as likely to fall after being discharged home [79].

Yates and colleagues indicated that those post-stroke are at increased risk for falling [78]. They investigated the effect of accumulated impairments on the risk of falling in community-dwelling stroke survivors. Of 280 participants, 51% sustained a fall between 1 and 6 months post-stroke. Accumulated post-stroke impairments were characterized as motor, motor and sensory, or motor and sensory and visual. Fall rates for those with accumulated deficits were compared to those without any of the impairments. Results from a multiple logistic regression indicated that the risk of falling increased with motor impairment and motor and sensory impairments. Interestingly, those with motor and sensory and visual impairments had decreased falls risk. This was most likely due to increased severity of the stroke, decreased balance, and therefore overall decreased mobility. The authors concluded that the community-dwelling post-stroke population demonstrate a higher risk of falling.

### **Post-stroke hip fractures**

Those post-stroke are at risk for both falls and the development of osteoporosis of the hemiparetic limb, consequently, increasing risk for hip fractures [58]. Ramnemark and colleagues observed hip fracture incidence in 1139 post-stroke individuals [171]. One hundred and twenty participants sustained 154 fractures, 84% of all fractures were secondary to an accidental fall. Hip fractures accounted for 70 (45%) of all recorded fractures and most affected the paretic side. A four-fold increase of hip fracture was demonstrated in this post-stroke population.

Ramnemark, et al. completed an additional study examining those sustaining a femoral neck fracture [172]. Short-term outcomes and mortality were compared for those with and without a history of stroke. In total, 27.4% participants had sustained a stroke prior to the hip fracture. Additionally, the majority of hip fractures occurred to the hemiparetic limb and survival rates were reduced for these patients.

### **Fear of Falling After Stroke**

#### **Post-stroke balance confidence**

Currently, there is little research regarding the prevalence of fear of falling development in the post-stroke population. At this time, the only work related to post-stroke fear of falling has been completed to validate fear of falling assessments for the post-stroke population [173-175]. The researchers have indicated that those who have sustained a stroke are likely to exhibit lower falls confidence while performing activities, thus demonstrated increased fear of falling.

Decreased falls confidence, or falls efficacy, is based on Bandura's theory of self-efficacy [176]. Those with low self-efficacy for a particular activity will tend to avoid that activity. In contrast, those with high self-efficacy will initiate the activity with

enhanced confidence. The self-efficacy theory suggests a reciprocal relationship between efficacy and function; efficacy may influence function, but the ability to complete functional activities also influences efficacy. Fear of falling assessments are often based on self-efficacy and assess whether a person feels confident in their ability to complete activities with out sustaining a fall [112, 147, 174].

### **Post-stroke fear of falling assessments**

Hellström and Lindmark completed a test-retest reliability study of the expanded Falls Efficacy Scale (Swedish Version) (FES(S)) and compared group differences in scores on the assessment [173]. The FES was developed by Tinetti et al. and measures self-perceived fear of falling during the performance of 10 common activities [112]. The FES(S) includes an additional three items, getting in and out of bed, grooming, and toileting. These three items were added due to the reduced independence often sustained by the post-stroke population. Thirty post-stroke participants were included, overall-test-retest-reliability was high and the FES(S) was indicated as a reliable assessment of falls efficacy in the post-stroke population. Hellström and colleagues completed additional reliability assessments to determine the ability of the of the FES(S) to assess clinically meaningful changes over time in the post-stroke population [174]. The changes as measured by the FES were compared to changes evident using the Berg Balance Scale and the Fugl-Meyer balance and motor function subscale. The assessments were completed at admission and discharge from rehabilitation and 10 months later. The analyses of responsiveness determined individuals post-stroke demonstrated decreased fall related self-efficacy compared to elderly participants in other fall studies.

A very recent study examined the reliability and validity of the Activities-specific Balance Confidence (ABC) Scale for those post-stroke [175]. The ABC is a previously

validated and reliable measure of balance confidence that measures confidence in performing various tasks without falling [150, 177, 178]. All participants were community dwelling ambulatory older adults who had sustained a stroke at least one year prior to the study. Significant correlation existed between the ABC and gait speed and balance assessments (Berg Balance). The authors concluded the ABC reliable and valid for the post-stroke population.

### **Post-stroke fear of falling**

While there is profuse research related to fear of falling in the community dwelling elderly, there is a paucity of information specific to the development of fear of falling after stroke. It can be construed that as fall rates increase [79] and mobility decreases after stroke, an increase of fear of falling will be demonstrated. Motor function, balance, mobility, emotional well-being, and attention may all be diminished following a stroke. All may influence falls incidence and the development of fear of falling [78, 79]. Increased fear of falling may too be related to a realization of physical and cognitive declines developed post-stroke.

Fear of falling has been demonstrated as both a risk factor for falls and as a serious consequence resulting from falls [96, 112, 113]. With post-stroke falls incidence as high as 73% [79], it is likely that the rate of fear of falling is equally exacerbated after a stroke. However, there is little evidence-based literature to support this relationship.

## **Activity and Participation**

### **Restriction of Activity and Participation**

Restriction of activity has been related to the development of disability in the elderly population. Health and functional status, health care utilization, decreased independence, increased social isolation, and overall quality of life and life satisfaction

are all impacted by activity curtailment [179, 180]. It is related to decreased independence and increases in caregiver burden. Restriction of activity has been used as an outcome measure in geriatric intervention trials attempting to reduce disability [181-183]. Thus activity restriction is an important consideration for the community dwelling post-stroke population.

Gill et al. attempted to identify health and non-health related problems associated with activity restriction [179]. Within the 15-month study period, 76.6% of the elderly sample restricted activity during at least one month and 39.3% for two consecutive months. Health care utilization was elevated during months of activity restriction. Gill and colleagues also evaluated the relationship between restricted activity and disability development [180]. The authors concluded that activity restriction was significantly related to disability development for the community dwelling older population.

Guralnik et al. explored mobility disability and found that limitations in mobility can lead to decreased performance of ADLs [17]. Such limitations in ADLs and IADLs have been related to disability and increased health care utilization. It therefore is essential to explore the impact of mobility, such as gait speed, falls, and fear of falling, on activity and participation.

### **Gait Speed, Activity, and Participation**

Gait speed has been associated with community mobility [9, 10]. Those with declines in gait speed may demonstrate decreases in activity and participation and experience decreased opportunities to return to societal and personal roles [184]. Consequently, perceived quality of life and life satisfaction are at risk.

Potter and colleagues completed a study to determine a relationship between gait speed and ADL performance in the elderly population [184]. All participants were older

than 65 and independently mobile. Participants were all admitted to inpatient or outpatient care, but not hospitalized due to a specific diagnosis. All participants had nonsurgical hospitalizations, were medically stable, and were appropriate for rehabilitation. Participants with differing diagnoses and a range of functional abilities were eligible for inclusion, therefore, those with acute infectious illnesses, strokes, acute relapses of chronic neurological disease (Parkinson's disease, multiple sclerosis), falls, and cardiovascular pathologies were included. Gait speed, ADLs, and mental status were assessed. Gait speed ranged from 0.05 m/s to greater than 0.55 m/s and was placed into one of six categories.

The authors concluded that an association between decreased gait speed and ADL ability levels was evident. Those with a gait speed of less than 0.25 m/s were more likely dependent in one or more ADL; only 36% of those with gait speed less than 0.25 m/s were considered independent in all ADL functioning. In contrast, 72.1% of those with gait speed between 0.35 m/s and 0.55 m/s were independent in all ADLs.

Studenski et al. completed a prospective cohort study to determine whether gait speed could be used as a "clinical vital sign" in a community dwelling elderly population [41]. Outcome measures included demographics, health and functional status, and physical performance. Those with a gait speed of less than 0.6 m/s were categorized as slow walkers and demonstrated a 69% incidence of new personal care difficulty. Comparatively, 28% of those with a gait speed of 0.6 to 1.0 m/s and 12% with gait speed greater than 1.0 m/s demonstrated new care needs. The researchers concluded that a slowing of gait speed has negative effects on overall mobility and the ability to complete ADLs and IADLs.

### **Falls, Activity, and Participation**

Restriction of mobility and declines in ability to complete ADLs and IADLs are severe consequences associated with falls [56, 138, 170]. All are negatively related to decreased independence and quality of life. Stel and colleagues examined fall related declines in functional status and physical activity [185]. Functional status was measured with stair climbing, dressing, standing from a chair, cutting toenails, walking outside and transportation. Physical activity changes were measured with walking, bicycling, gardening, sport activities, and light and heavy household activities. Post-fall declines in functional status were reported by 35.3% of their sample and 15.2% reported declines in physical activity. Vellas et al. determined that those who fell in a prospective study demonstrated restricted activity and decreased independence at 6 months [138].

Tinetti and Williams completed a study to determine the impact of falls and fall related injuries on ADLs, IADLs, social activity, and advanced physical activities in a community dwelling elderly population [141]. At one and three years, falling was associated with declines in ADLs, IADLs, and social participation. Those with multiple falls experienced greater declines in activity and participation and those with injurious falls also demonstrated declines in advanced physical activity. An association between declines in activity and falls incidence and/or severity of injury was demonstrated, thus indicating a “dose response” relationship between falls and functional losses.

Yardley and Smith examined the most commonly held beliefs regarding falls and activity curtailment [186]. The Consequences of Falling (CoF) Scale was developed and validated by the authors. It assessed types of fear related to falls, such as fear of physical injury, fear of long-term functional incapacity, fear of subjective anxiety, and fear of social discomfort. Demographics, mobility level, use of a walking aide, falls history and

incidence, falls related safety, and fear of falling were also assessed. Nearly half of the participations reported a fall in the previous year. Long term functional disability and loss of independence were cited as the most common fears. Social discomfort and a loss of confidence and personal identity were also indicated as common fears. Activity restriction was correlated with anticipated damage to personal identity and loss of independence. Social participation was avoided to decrease the risk of social embarrassment secondary to a fall. The CoF was correlated to activity avoidance, but importantly, it also predicted increased avoidance of activity performance at follow up.

### **Fear of Falling, Activity, and Participation**

Activity restriction has been demonstrated in 20% to 55% of those reporting fear of falling [46, 93, 148, 187]. Activity limitations and decreased social participation may be due to fear of falling or due to the injury or pain experienced from a previous fall [46, 48, 188]. Overall decreased independence, quality of life, and life satisfaction are at risk due to fear of falling related changes in activity and participation.

Fear of falling has been related to declined performance of ADLs and IADLs, social participation, and community integration [43, 137, 143, 149, 151, 152, 189-192]. Additionally fear of falling is related to decreased mobility, stair climbing, vision, general health, depressed mood, decreased social and physical activities, and poor life satisfaction [10, 56, 113, 140, 147, 186]. Fear of falling is associated with deteriorated health status [143, 144, 148, 149, 152] and therefore negatively influences physical and functional well-being [193]. All lead to further functional declines, decreased quality of life, and increased caregiver burden [113].

Li et al. summarized a relationship regarding fear of falling and concluded that fear negatively influences falls related self-efficacy [194]. This subsequently impacts balance,

physical ability, and mobility impairments. This cycle accelerates declines of physical health, activity, and participation; possibly increasing the incidence of falls. Delbaere et al. emphasized the “vicious cycle” of frailty regarding fear related avoidance of activity. They concluded an association between fear of falling with new physical declines such as increased frailty, decreased postural control, and decreased muscle strength, and an overall increase of falls risk, thus leading to increased fear of falling [114].

The literature regarding the impact of fear of falling on activity and participation is profuse. It has been identified, reviewed, and synthesized into an evidenced based table found in Appendix a. It is evident from this review of the literature that those with developed fear of falling are at great risk for decreased performance in ADLs, IADLs, and social participation, and are therefore at significant risk for declines in quality of life and life satisfaction.

## **Caregivers**

### **Stroke and Caregiving**

As demonstrated in the conceptual model, post-stroke mobility disability may negatively impact activity, participation, and depression, thereby increasing dependence and possibly increasing caregiver depression and burden. A review of the literature reveals abundant caregiving research, however, there is a paucity of research specifically related to caregiving after a stroke or specifically regarding the burden and stress experienced by informal caregivers [4].

Those participating in post-stroke caregiving may provide assistance in many life domains including mobility, self-care, and communication. However, stroke related complications such as cognitive impairment, depression, and personality changes may require increased provision of caregiving and assistance [4, 195]. A post-stroke reduction

in ADL and IADL performance frequently results in reduced levels of functional independence and subsequently increases the necessity of additional care in the home. Often, those post-stroke are dependent on caregivers to maintain community living and stave off facility or institution admission. The review of the literature indicated more research is necessary, specifically in the areas of caregiver physical health, ethnicity, and caregiver interventions.

### **Mobility Disability and Caregiving**

Researchers have demonstrated relationships between mobility disability and limitations in activity and participation and consequential losses of independence, and increased need for care, health utilization, and admission into care facilities [14, 15, 20-24]. Specifically, caregiving after falls has been explored. The resulting complications of a fall can be severe and include death, fractures, and further losses of independence. It is therefore expected that falls are negatively associated with caregiver burden and depression. Forster and Young demonstrated negative effects for the caregiver when post-fall declines in ADL performance were evident [79]. The caregivers taking care of “fallers” were more stressed, and one-third of all caregivers stated that concern for a fall limited their own social activity. Stolze et al. also indicated increased burden for those caring for the post-fall population [154]. Howland and colleagues also demonstrated a relationship between caregiver support and fear of falling related activity curtailment [148].

There has been no research completed specifically examining caregiving after fear of falling development or changes in gait speed. However it is expected that caregiving needs will increase due to mobility related declines in performance of activities.

### **Caregiver Depression**

Researchers have indicated high levels of depression associated with stroke survivor caregivers compared to non-caregivers [4]. The prevalence of depression in the caregiving population ranges from 34% to as high as 52% [196-199]. Spousal and female caregivers have demonstrated increased depression which tends to persist over long periods of time [200].

A Japanese study demonstrated depression in 52% of 100 stroke caregivers, this was double the depression rate for the control group (23%) [201]. Hartke and King found that depressed caregivers were more likely to have difficulty with caregiving, report more problems with the care recipient, experience financial concerns, and report a decrease in social involvement [202]. Researchers have found a relationship between increased stroke caregiver depression and increased stroke severity [203, 204]. Kotila et al compared the incidence and severity of depression at 3 and 12 months post-stroke [205]. Both stroke survivors and their caregivers demonstrated increased levels of depression which were maintained at the one-year follow up.

### **Caregiver Burden**

Morimoto and colleagues found that the strongest predictor of declining quality of life for stroke caregivers was a high level of caregiver burden [201]. Burden is caused by feelings of large responsibility, uncertainty about the care needs of the stroke survivor, decreased social interaction, and being the sole provider of care [206]. Bugge and colleagues (1999) studied caregivers at 1, 3, and 6 months post-stroke. The amount of time spent helping a patient, the amount of time spent with the patient, and the caregiver's health were determined as the most influential factors of caregiver strain

[207]. Caregivers providing greater levels of care (e.g. toileting, bathing) experienced greater emotional distress and greater caregiver burden [208, 209].

### **Summary of the Literature Review**

This review of literature demonstrates that post-stroke motor, sensory, and cognitive impairments influence mobility. Falls, fear of falling, and gait speed are all impacted aspects of post-stroke mobility and all may be related to restriction of activity and participation. Activity curtailment has been related to decreases in quality of life and life satisfaction.

There is no research specific to the development of fear of falling post-stroke. This research was completed as an initial exploration of fear of falling in the post-stroke population. Fear of falling was characterized for the post-stroke population, and activity restriction was explored. Similarly, the relationship between post-stroke gait speed changes and its impact on activity and participation were evaluated. This research will provide a foundation for exploring the impact of post-stroke mobility on activity and participation.

CHAPTER 3  
THE IMPACT OF POST-STROKE GAIT VELOCITY CHANGES ON  
ACTIVITY AND PARTICIATION

**Introduction**

The American Heart Association reports that 700,000 people sustain a stroke annually [159]; it is the primary cause of adult disability [2-4]. Stroke related deficits include motor, sensory, and cognitive impairments that negatively influence mobility. Losses in mobility are often reflected by declines in gait velocity [40, 210]. Mobility impairments and changes in gait velocity are related to losses of independence and decreased ability to reengage in the community [9].

Gait speed is an important clinical and research outcome measure. It is a common measure of mobility and a reliable, valid, and sensitive measure of post-stroke locomotor recovery [9, 39]. It discriminates the effects of stroke and is related to the potential for rehabilitation recovery [40]. Gait velocity is a predictor of health status and health care utilization in the elderly [41]. It is associated with performance of activities of daily living (ADLs) and community ambulation [9, 10, 184].

Potter et al. determined a relationship between gait speed and ADL performance in the community dwelling elderly [184]. Participants with multiple diagnoses were included and those with decreased gait speed demonstrated decreased independence. A gait speed less than 0.25 meters per second (m/s) was associated with dependence in one or more ADL; only 36% of those with gait speed less than 0.25 m/s were considered

independent in all ADLs. In contrast, 72.1% of those with gait speed between 0.35 m/s and 0.55 m/s were independent in all ADLs.

Perry et al. examined the association between post-stroke gait velocity and ambulation [9]. The authors developed an ambulation classification related to necessary gait speed for home and community ambulation. *Household ambulation* was equal to severe gait impairment and velocity less than 0.4 m/s. *Limited community ambulation* was equivalent to moderate gait impairments and walking between 0.4 m/s and 0.8 m/s. *Community ambulation* indicated mild impairment and speed over 0.8 m/s. Increases in gait velocity were related to improved home and community ambulation.

The relationship between post-stroke gait speed and community ambulation was further explored by Lord and colleagues [10]. Participants included 115 individuals who received physical therapy for mobility impairments and 15 not requiring such therapy. Mobility outcome measures assessed gait speed, indoor and outdoor walking ability, and gait endurance. An additional self-report questionnaire assessed unsupervised mobility. Participants were categorized by community ambulation levels as seen in Table 3-1. Gait velocity differed between the categories and increased from 0.52 m/s for those unable to leave home to 1.14 m/s for those able to ambulate in a shopping center. One third of the sample was not able to ambulate independently within the community after a stroke.

Table 3-1. Community ambulation and gait speed

<b>Group</b>	<b>Community Ambulation Level</b>	<b>% of Sample</b>	<b>Speed (m/s)</b>
1	Unable to leave home	14.6%	0.52
2	Able to walk to letter box	16.9%	0.66
3	Limited to immediate environment	7.6%	0.82
4	Ambulate in shopping center	60.7%	1.14

In summary, the relationships between gait speed and ADL performance in the community dwelling elderly and between gait speed and post-stroke ambulation are well

established [9, 10, 184]. However, it is not known whether a change in post-stroke gait velocity is “clinically meaningful”, as reflected by improved functional abilities such as activity and participation. A clinically meaningful change is important to determine as it is related to patient-valued benefits. Barrett et al. discussed the need to observe a clinically “important difference” by merging patient-oriented and evidence-based frameworks together [7]. Such clinical meaningfulness can be seen by examining the sufficiently important difference (SID), the smallest amount of patient-valued benefit required from an intervention to justify associated costs, risks, and other harms. Lord and Rochester recently stated a need for a conceptual framework related to post-stroke mobility and that there is “no guarantee that increases in gait velocity will denote a meaningful improvement in performance” [211]. The objective of this study was to determine whether a change in gait speed over three months was clinically meaningful as reflected by the impact on ADLs (including mobility), instrumental activities of daily living (IADLs), and social participation after stroke.

## **Methods**

### **Design**

Data in this study are derived from a parent study; a prospective, randomized, controlled, single-blind, clinical intervention trial [8]. The trial was completed to determine the effects of a therapist-supervised 12-14 week home-based, structured, and progressive exercise intervention on participants post-stroke. The intervention focused on upper and lower-limb strength, balance, endurance, and increased use of the affected extremities. The intervention group was compared to a usual care group who received rehabilitation as prescribed by their physician and bi-weekly visits from research staff. Informed consent was received from all participants through methods approved by the

Institutional Review Board of the university and each participating facility. All participants were recruited from an ongoing stroke registry. This secondary analysis was approved by the University of Florida Health Science Center Institutional Review Board.

This analysis did not examine differences between intervention and usual care groups. Rather we examined the differences in ADLs, IADLs, and social participation between those who did and did not successfully advance to the next ambulation classification as portrayed by Perry et al. [9]. For example, the participants considered successful, transitioned from an initial gait velocity of less than 0.4 m/s to 0.4 to 0.8 m/s or faster or they advanced from an initial gait velocity between 0.4 to 0.8 m/s to greater than 0.8 m/s. Gait velocity was measured at baseline and repeated at 3 months.

### **Participants**

All participants were selected from one of 17 medical facilities, all of which were partaking in an ongoing Kansas City Stroke Registry. All those registered gave informed consent and permission to be screened for eligibility for future research studies. Those eligible for the registry had a confirmed diagnosis of a stroke within 3-28 days, were over age 50, and lived within a 50-mile radius. Registry exclusion criteria included the following: subarachnoid hemorrhage, being lethargic, obtunded, or comatose, uncontrolled blood pressure, hepatic or renal failure, NYHA III/IV heart failure, known limited life expectancy, or pre-stroke disability in self care; or previously lived in a nursing home prior to the stroke.

Those in the registry were eligible to be screened for this randomized clinical trial. Inclusion for the parent clinical trial included: (1) stroke within 30-150 days, (2) ability to ambulate 25 feet independently, (3) mild to moderate stroke deficits defined by a Fugl-Meyer score of 29 to 90 for upper and lower extremities, an Orpington Prognostic Scale

score of 2.0 to 5.2, and palpable wrist extension on the involved side; and (4) Folstein Mini-Mental Status examination score greater than 16. Exclusion criterion included: (1) serious cardiac conditions (hospitalization for heart disease within 3 months, active angina, serious cardiac arrhythmias, hypertrophic cardiomyopathy, severe aortic stenosis, pulmonary embolus, or infarction), (2) oxygen dependence, (3) severe weight-bearing pain, (4) other serious organ system disease, and (5) life expectancy of < 1 year. All participants signed an informed consent to partake in the trial and all had approval from a primary care physician [8]. Ninety-two individuals completed the clinical trial, 44 in the intervention arm and 48 in the usual care arm. Specifically, only 64 of the 92 participants were included in this three-month analysis because those walking > 0.8 m/s at baseline were excluded. This report does not compare the intervention to the usual care groups, but combines all participants walking < 0.8 m/s at baseline to allow for examination of clinically meaningful changes in post-stroke gait speed.

### **Outcome Measures**

The parent clinical trial included the Orpington Prognostic Scale to measure stroke severity [212]. Disability outcomes measures included the Functional Independence Measure (FIM) [213], the Barthel [214], the Lawton and Brody IADLs assessment [215], and gait speed thresholds for community ambulation [10]. Quality of life measures included subscales of the Stroke Impact Scale [216] and the Medical Outcomes Study SF 36 [217]. Results for outcome measures are found elsewhere [8]. Gait speed, activity, and participation were the specific outcome measures used for this secondary analysis.

### **Gait velocity**

Gait velocity was measured by the 10-Meter Walk, a valid and reliable measure for gait velocity assessment in the elderly post-stroke population [218]. The 10-Meter Walk

consisted of two completed walks without rests in between and collected in meters/second.

Specifically, the main outcome for this analysis was the proportion of participants who demonstrated “success” by transitioning from one ambulation classification to the next. Both baseline and final outcome measures were placed into the ambulation classification previously developed by Perry et al.:  $< 0.4 = \textit{household ambulation}$ ,  $0.4 - 0.8 = \textit{limited community ambulation}$ , and  $> 0.8 = \textit{community ambulation}$  [9]. Changes in gait velocity were considered as successful walking recovery when participants shifted from  $< 0.4 \text{ m/s}$  to  $0.4 - 0.8 \text{ m/s}$  (*household to limited community ambulation*) or  $0.4 - 0.8 \text{ m/s}$  to  $> 0.8 \text{ m/s}$  (*limited community to community ambulation*) [9]. A dichotomous variable of “success” or “fail” was utilized for the analysis.

### **Activity and participation**

Activity and participation were assessed with the Stroke Impact Scale (SIS), a comprehensive and psychometrically robust stroke-specific outcome measure [216, 219]. The SIS was developed from the perspective of patients, caregivers, and health professionals with stroke expertise. It has been demonstrated to be reliable, valid, and sensitive to change related to stroke recovery. There are eight domains and 59 items in version 3.0, specifically, the SIS ADL/IADL, mobility, participation, and SIS-16 physical functioning components were used for this analysis [220]. Items such as food preparation, bathing, toileting, shopping, and household tasks were assessed with the ADL/IADL component. Mobility was assessed with items regarding loss of balance, transferring, walking, and stair climbing. Participation items included work, social activities, quiet recreation, family and friend roles, religious and spiritual activities, and helping others.

The SIS-16 is a validated short instrument used to assess physical functioning with ADL and mobility items [221].

### **Statistical Analysis**

All analyses were completed using SAS statistical software. Simple descriptive statistics were used to describe demographics and outcomes scores for the entire sample. Additional descriptive data delineated by success or failure of increasing to the next walking classification was examined. Baseline characteristics of the 64 people who completed the study with initial gait speed of  $< 0.8$  m/s included demographics, stroke characteristics, and baseline outcome measures. T-tests were utilized to determine significant differences in activity and participation (SIS) between those who succeeded and who failed to increase to the next walking classification at three months post-stroke.

### **Results**

Baseline demographics for the 64 participants are presented in Table 3-2. The average age of the sample was 71.03 (10.64). Those successful in increasing to the next ambulation classification were significantly younger than those who failed ( $p = .0023$ ). The entire sample included 54.69% males and 78.13% were white. All other demographic characteristics and data related to participation and retention of participants specific to the Kansas City Stroke Registry are reported elsewhere [8].

Mean baseline gait speed was 0.50 (0.16) m/s for the entire sample, 0.51 (0.17) m/s for those who succeeded and 0.49 (0.16) m/s for those who failed to increase to the next ambulation classification ( $p = 0.689$ ). At three-months, gait speed for the entire group was 0.68 (0.24) m/s. As anticipated, a significant difference was detected for three month gait velocity scores between those who succeeded (0.82 (0.25) m/s) and failed (0.56 (0.16) m/s) to proceed to the next ambulation classification ( $p < 0.0001$ ).

Table 3-2. Baseline characteristics for participations with initial gait speed < 0.8 m/s  
(success = advancing to a higher ambulation classification)

	All	Success	Fail	p value
<b>Demographics</b>				
Sample Size	64	29	35	
Age, Year	71.0 (10.64)	66.72 (9.29)	74.6 (10.48)	0.0023
Male Sex, n (%)	35 (55%)	16 (46%)	19 (54%)	0.9434
Race (White), n (%)	50 (78%)	22 (44%)	28 (56%)	0.6902
<b>Stroke Characteristics</b>				
Orpington Prognostic Score	3.51 (0.84)	3.67 (0.89)	3.38 (0.78)	0.176
NIH Stroke Score	6.62 (3.33)	6.76 (3.46)	6.50 (3.27)	0.763
Right Hemisphere (%)	34 (53%)	15 (44%)	19 (56%)	
Left Hemisphere (%)	24 (38%)	9 (38%)	15 (63%)	0.1530
Brain Stem/Other (%)	4 (9%)	3 (83%)	1 (17%)	
Stroke Type, Ischemic (%)	57 (89%)	25 (44%)	32 (56%)	0.6920
<b>Baseline Measures</b>				
Barthel Index	40.16 (20.1)	40.17 (19.5)	40.16 (21)	0.998
Folstein MMSE	26.45 (4.23)	26.31 (3.72)	26.57 (4.67)	0.804
Geriatric Depression Scale	4.61 (3.29)	4.59 (3.61)	4.63 (3.06)	0.960
10 Meter-Walk, m/s at Baseline	0.50 (0.16)	0.51 (0.17)	0.49 (0.16)	0.689

Values are mean (SD) when appropriate

The proportion of participants who succeeded or failed to transition from one ambulation classification to the next is documented in Table 3-3. The highest proportion of participants who transitioned to the next classification had initial gait speed of less than 0.4 m/s; 63% of the *household ambulators* increased to the *limited community ambulator* classification. In contrast, only 38% of those initially considered a *limited community ambulator* (0.4 – 0.8 m/s) advanced to the *community ambulation* classification. In all, 45% of the sample was successful and 55% failed to increase to the next ambulation classification at three months.

Three-month outcomes associated with gait velocity are presented for the entire sample in Table 3-4. Age was significantly different between those who were successful and who failed to transition to the next ambulation classification. Therefore age was controlled for at the < 0.100 level, as it is common that adjustment variables are retained

in the model at a lower significance level than that of the main factors. Equal variance was established for all values except for the SIS-16 measure for the entire group.

Therefore t-tests were deemed appropriate and equal (pooled) p-values were used except for the SIS-16 with the Satterthwaite unequal variance p-value used. After controlling for age, there were significant differences in SIS measured mobility and participation between those who succeeded and failed to advance to the next ambulation classification ( $p \leq 0.05$ ). SIS ADL/IADL approached significance at 0.0524. When controlling for age and stratifying by baseline gait speed, those with initial gait velocity of  $< 0.4$  m/s demonstrated significant differences in SIS ADL/IADL, mobility, social participation, and SIS-16 measures between those who succeeded and failed ( $p \leq 0.05$ ) (Table 3-5). In contrast, when age was controlled for and initial gait speed was between 0.4 m/s and 0.8 m/s, only participation scores were significantly different between those who succeeded and those who failed to progress to the next ambulation classification.

Table 3-3. Proportions of success/fail for transitioning to next ambulation classification between baseline and 3 months

	Initial Gait Velocity in m/s	All	
		Success	Fail
Total n (%)	< 0.4 (Household)	12 (63%)	7 (37%)
	0.4–0.8 (Limited Community)	17 (38%)	28 (62%)
	Total	29 (45%)	35 (55%)

Table 3-4. Three month outcomes for entire sample

	Success	Failure	p value	p value <sup>^</sup>
Sample Size	29	35		
SIS ADL/IADL	77.8 (14.1)	69.6 (19.0)	0.0589	N/A
SIS Mobility	77.6 (2.2)	65.5 (16.1)	0.0015	0.0359 <sup>^</sup>
SIS Participation	68.2 (8.6)	52.9 (20.6)	0.0031	N/A
SIS – 16	81.3 (11.2)	71.6 (16.5)	0.0076	0.0844 <sup>^</sup>

<sup>^</sup>p-value after adjusting for age when age is significantly different at the  $< 0.100$  level

Table 3-5. Three month outcomes stratified by gait speed

	Success	Failure	p value	p value <sup>^</sup>
<b>&lt; 0.4 m/s at Baseline</b>				
Sample Size	12	7		
SIS ADL/IADL	75.5 (15.2)	51.4 (12.5)	.0026	N/A
SIS Mobility	77.1 (11.4)	50.5 (10.9)	<.0001	N/A
SIS Participation	66.1 (15.2)	42.9 (19.6)	.0100	N/A
SIS – 16	67.2 (12.5)	46.7 (9.8)	<.0001	N/A
<b>0.4 – 0.8 m/s at Baseline</b>				
Sample Size	17	28		
SIS ADL/IADL	79.6 (13.5)	74.2 (17.7)	.2891	N/A
SIS Mobility	77.9 (13.1)	69.3 (14.9)	0.0565	.2215 <sup>^</sup>
SIS Participation	69.7 (21.0)	55.5 (20.5)	.0308	N/A
SIS – 16	81.8 (12.7)	67.6 (13.7)	.1756	.0718 <sup>^</sup>

<sup>^</sup>p-value after adjusting for age when age is significantly different at the < 0.100 level

### Discussion

Gait speed is a valid and reliable assessment used frequently in elderly and post-stroke research [9, 39, 40]. In the hopes of determining what is a clinically meaningful change in gait speed, researchers have attempted to determine relationships between gait speed and functional abilities [9, 10, 184]. Perry et al. and Lord et al. have previously examined gait velocity classifications dependent on home and community ambulation in the post-stroke population [9, 10]. Potter and colleagues demonstrated a relationship between ADL performance and gait speed in an elderly population with various diagnoses [184].

This secondary analysis is the first study to examine the association between actual changes in post-stroke gait velocity and the reciprocal impact on performance of ADLs and IADLs and social participation as measured by the SIS. Our results validate ambulation classification in both research and clinical rehabilitation settings, and specifically validates the prior classification developed by Perry et al. [9]. Additionally, our results show that a clinically meaningful change in gait speed, as represented by an

increase to the next ambulation classification, was significantly associated with increased activity and participation scoring, particularly for those with the slowest baseline gait velocity.

Those who successfully transitioned to the next ambulation classification were significantly younger than those who did not ( $p = 0.0023$ ). When age was controlled for, those with baseline gait speeds of  $< 0.4$  m/s demonstrated the greatest gains in activity and participation. Among those who walked less than 0.4 m/s, there were significant differences in SIS ADL/IADL, mobility, participation, and SIS-16 scores found between those who were successful and who failed to advance to the next ambulation classification. This may be attributable to the fact that those with greater deficits had more opportunity for improvement and there were less ceiling effects in the measures.

After age was controlled for in the less impaired walking group, there was significant difference in participation, between those who did and did not successfully progress to the next classification. SIS participation items include higher level home and community activities. Increased gait velocity was clearly attributable to increased abilities to complete higher level tasks at home and in the community. A significant difference in age contributed to mobility and SIS-16 scores. After controlling for age, the SIS-16 approached significance, but likely was related to the assessment of higher level ADLs and mobility. The lack of other significant findings is probably due to the participants' high degree of independence at baseline and subsequent ceiling effects of the measures.

Stratifying by gait speed decreased the sample size, possibly decreasing the detected differences between groups. Other post-stroke changes may have also impacted

ability to complete ADLs, IADLs, mobility, and social participation. The severity of residual deficits is an additional component of post-stroke gait speed and activity and participation; side of the lesion, medical complications, rehabilitation days, assistive devices, caregiving, and overall support all play a role in performance of post-stroke ADLs (including mobility) and IADLs and social participation.

Research completed by Potter et al. may provide some rationale for our specific findings [184]. The authors noted that some participants demonstrated greater gait speed but not greater ADL performance. They concluded that some had difficulties specific to upper extremity ADL and IADL activities that were not reliant on gait. Therefore no relationship between ADLs and gait speed existed. Additionally, all of their study participants walking between 0.35 m/s and 0.55 m/s were independent in all ADLs. Our average baseline gait velocity was 0.50 (0.16) m/s for the entire sample, therefore, independence in ADLs would be expected for our participants, particularly for those walking initially walking greater than 0.4 m/s.

An important strength of this study is that the included participants are derived from a large parent study of community living stroke survivors. This is a clinically significant group because even though they have returned home, they still have limited ambulation and other stroke related deficits. Additionally, the assessors were blinded regarding intervention or control placement and all assessments were standardized. There are also limitations. Duncan et al. reports study limitations related to the intervention and possible bias in self-report because the control group participants knew their treatment assignment [8]. In future studies, we will assess the impact of post-stroke gait speed changes using a continuous measure rather than ambulation classification.

Clinically meaningful changes in gait speed are important in rehabilitation clinics and research. Rehabilitation goals often include increases in gait speed and endurance. The results of this study indicate a significant impact of gait velocity on performance of ADLs, IADLs, mobility, social participation, and SIS-16 scores making increased gait speed an appropriate goal. These results are very relevant as they validate the ambulation classification previously portrayed by Perry et al. [9] and represent a clinically meaningful change in gait speed; encouraging the use of ambulation classification for goal setting as it is related to overall increases in activity and participation. We have demonstrated that a clinically meaningful change in gait speed is related to highly significant improvement in all domains, particularly for social participation. Such clinically meaningful gait speed changes may have a profound impact on overall quality of life and life satisfaction as both have been negatively associated to restriction of activity and participation [179, 180].

## CHAPTER 4 FEAR OF FALLING AFTER STROKE

### **Introduction**

Stroke is the primary cause of disability in the United States and is the third leading cause of death in the country for those over 65 [2-4]. The American Heart Association reports that stroke is a common neurological event occurring in 700,000 people a year [159]. Those surviving a stroke are often left with sensory, cognitive, motor, and balance impairments which negatively influence mobility and other activities of daily living (ADLs) and instrumental activities of daily living (IADLs) [222-224]. Fall rates increase due to post-stroke mobility deficits [78] and are considered the most common medical complication after stroke [166]. The annual 30% [49] incidence of falls in the community dwelling elderly population rises to 73% within the first six months post-stroke [79]. Those who fall post-stroke may be prone to developing fear of falling. The development of fear of falling, with the cascading consequences of further mobility disability and declines in activity and participation may be related to an overall decrease of independence and quality of life [56, 170].

There is currently an abundance of research regarding falls after stroke and fear of falling in the community dwelling elderly, but there is little specific to how people describe the experience of fear of falling after stroke or how fear of falling develops among this population. Fear of falling has been operationally defined for this study as “a developed and lasting concern about falling related to a loss of confidence in balance abilities and mobility and is often related to an avoidance of activities that he/she remains

capable of performing” [113, 140-143]. The incidence of fear of falling is still unclear with researchers reporting fear of falling in the community dwelling elderly ranging from 29%-92% for those recently sustaining a fall and 12%-65% for those without a recent fall [46, 70, 113, 115, 144-152]. Fear of falling incidence may rise after stroke due to increased fall rates and declines in physical ability and mobility.

Fear of falling has been associated with declines in performance of ADLs and IADLs, decreased participation, and community integration [43, 137, 143, 149, 151, 152, 189-192]. It has also been related to declines in mobility, stair climbing, vision, general health status, depression, and poor life satisfaction, [10, 56, 113, 140, 147, 186], all negatively influencing general well-being and life satisfaction [193]. In addition, 20% to 55% of those with fear of falling have reported activity restriction [42, 43, 113, 114, 143, 148, 186, 187, 225-230]. Activity restriction has been independently related to increased health care utilization, social isolation, depression, and caregiver burden and decreases in health, functional status, and independence; resulting in overall decline in quality of life and life satisfaction [10, 43, 56, 113, 140, 143, 147, 149, 151, 152, 179, 180, 186, 189]. Activity restrictions related to functional deficits, falls, and fear of falling may result in reduced levels of independence and increasing need for additional care in the home [4]. Such decreases in abilities may be associated with increased caregiver burden, strain, and depression [4, 79, 154]. Informal caregivers of people who have fallen report decreased social activity, increased stress, and increased burden [79, 154].

This study is a secondary analysis of existing qualitative and quantitative data obtained from a larger study [11]. The objectives of this study were (1) characterize post-stroke fear of falling as described by participants during the first six months following

discharge home; (2) explore the relationships between fear of falling and performance of ADLs, IADLs, and depression; and (3) examine the relationship between fear of falling and caregiver depression, burden, and coping.

## **Methods**

### **Design**

This study used both qualitative and quantitative methods to evaluate fear of falling in a population of veterans discharged home post-stroke. Participants who discussed fear of falling were identified in the sample enrolled in the larger study. Content analysis was used to identify descriptors that characterize fear of falling across six months after discharge home post acute stroke. Patton describes content analysis as the process of identification, coding, and categorization of the primary patterns in qualitative data [231]. Quantitative data were obtained from standardized outcome measures collected from stroke survivors and their caregivers at one and six months.

### **Sample**

All veterans and caregivers included in this study met the inclusion criteria to participate in the larger study. The larger study included a total of 132 participants, 42 (32%) of these participants were identified with fear of falling at one or six months and were included in the sub-study. The inclusion criteria for veterans to be involved in the larger study were: (1) member of one of three ethnic groups (Caucasian, African American, or Puerto Rican Hispanic), (2) discharged directly home from an acute care unit following a stroke, (3) a Mini Mental Status Exam (MMSE) of 18 or higher and able to verbally communicate at discharge, (4) have a caregiver willing to participate, and (5) sign a consent form or have the consent form signed by a proxy. Inclusion criteria for the informal caregivers were: (1) family or friend who the stroke survivor identified as a

primary caregiver, (2) able to communicate verbally, (3) willing to participate and sign a consent form. Exclusion criteria for both veterans and caregivers was the inability to communicate or unwillingness to participate. Inclusion criteria for this sub study were: (1) male; (2) described some aspect of fear of falling during the interviews at one or six months after discharge home. Each participant gave informed consent prior to participation in the larger study through methods approved by the University of Florida (UF) Health Science Center Institutional Review Board (IRB) and the Veterans' Affairs Subcommittee on Clinical Investigations (VA SCI). This secondary analysis was approved by the UF IRB and VA SCI as an exempt study using existing data.

### **Data Collection**

Data for the larger study were obtained to develop stroke recovery trajectories for stroke survivors and their caregivers after discharge home following acute stroke for three ethnic groups: African American, White, and Puerto Rican Hispanic. The larger study is a longitudinal multi-site cohort study that includes qualitative and quantitative data derived from participant interviews and responses to questionnaires. Demographics were collected and baseline assessments were completed at the time of discharge. The study was designed so that each stroke survivor was interviewed for approximately 50 minutes. Qualitative data were obtained during at home, in-depth, semi-structured interviews with the stroke survivors at one and six months. Interviews were completed with the stroke survivor first; probing questions were presented to capture stroke related disability and recovery. Interviews were tape recorded, transcribed verbatim, verified, and entered into QSR N6, a software application designed to assist with qualitative data analysis [232].

Fear of falling was not part of the formal assessments. Participants instead spontaneously talked about fear of falling as an important part of managing their daily lives and their experiences post stroke. Transcriptions of all interviews at one and six months for all 132 participants in the larger study were transferred into a word processing document to enable identification of those who discussed fear of falling and concerns about falls, balance, and stability.

Identification of participants with a fear of falling was conducted via a semantic content analysis of the qualitative interviews. During reviews of interviews, the following word list was developed from the text. These words were then used to search all word documents: fall, fell, balance, trip, stumble, wobble, wobbly, slip, dizzy, dizziness, walk, walking, walker, cane, crutches, crutch, fear, fearful, afraid, scared, worry, worried.

Participants were identified for inclusion in this sub study when they specifically stated they were fearful or used statements/words regarding concern, confidence, or fear related to falling, balance, or mobility. A qualitative research specialist validated this review of qualitative data and selection of participants with fear of falling. A second dataset was created that included all one and six-month interviews for participants identified as fearful. This dataset of interviews was coded to identify themes related to the experience of fear of falling.

The interviews for those identified as fearful of falling were coded in N-6 to identify themes derived from the interviews. All coding was validated by a rehabilitation health care professional. Characterizations, quotes from participants, and recorded observations were used to identify three main recurrent themes that were refined during analyses. The three initial coding themes were “physical”, “psychosocial”, and

“strategies for managing fear of falling”. Each code included sub-codes that have been listed in the coding structure found in Table 4-1. Content analysis was completed to identify phrases and sentences under this coding structure. A phrase or sentence could be coded under more than one primary or secondary theme.

Table 4-1. Coding structure for qualitative interviews

<b>Primary Theme</b>	<b>Secondary Themes</b>
Falls as a Physical Event	Paralysis/hemiplegia Fell at time of stroke Balance/stability Dizziness Decreased participation Injury (such as hip fracture or head injury) Talk about falls (stumble, trip, wobble, etc)
Fearing Falls	Fear, afraid, concern Caregiver afraid will fall Afraid of injury
Strategies for Managing Fear of Falling	Walker/cane/WC/wall/other Relies on others Being careful

In addition to the qualitative interviews, stroke survivors completed standardized measures to assess activity performance of ADLs and IADLs and depression. Caregivers also completed standardized measures of depression and caregiver burden. Most often, caregivers and stroke survivors were not interviewed with each other in the room.

### **Outcome Measures**

Demographic data were collected at baseline for each stroke survivor and caregiver included in the qualitative and quantitative analyses. Stroke survivor demographic data included age, gender, race/ethnicity, employment status, income, and comorbidities recorded in their medical records. Baseline standardized assessments included the Functional Independence Measure (FIM) to assess functional status and the Mini Mental Status Exam (MMSE) [233, 234] to measure cognitive status.

**Functional status**

The FIM was utilized to measure functional status at baseline and was repeated at one and six months. The FIM is the most widely used method of assessing functional ability in persons with disability. Reliability and validity of the FIM have been established [235, 236]. The FIM consists of 18-items and responses are scored on a 7-level ordinal scale with six subscales: self-care, sphincter control, transfer capability, locomotion, communication, and social cognition [235]. The FIM was utilized as a measure of severity of disability and functional status change over time.

The Frenchay Activities Index (FAI) was used to measure IADLs. The FAI is a valid and reliable measure used to better assess normal living activities that occur among community dwelling adults [237]. The FAI is composed of 15 items and three major subscales: domestic chores, leisure/work, and outdoor activities. Scores range from 0 (inactive) to 45 (very active). Wilkinson et al. [224] defined intact IADL function with an FAI score of over 15.

**Cognitive status**

The MMSE, a standardized test used to evaluate basic cognitive abilities, assessed mild to moderate cognitive impairment for the stroke survivors [233, 234].

**Depression**

Stroke survivor and caregiver depression was assessed using the Geriatric Depression Scale (GDS). The GDS has been used with the elderly population and those who are cognitively impaired. It is a 30-item scale with dichotomous variables (yes, no). Reliability, internal consistency, test-retest validity, and concurrent validity have all been established for the GDS [238]. Higher scores indicate increased levels of depression.

### **Caregiver demographics, burden, and coping**

Demographic data on caregivers included age, gender, race/ethnicity, education, and relationship to patient. Caregiver burden was measured using the Sense of Competence Questionnaire (SCQ). The SCQ contains 27 items with three different subscales: satisfaction with the care recipient, satisfaction with one's own performance as a caregiver, and consequences of involvement in care for the personal life of the caregiver. Each item is scored using a four point Likert type scale; burden is determined by summing the three scales. Higher scoring indicates higher levels of burden experienced by the caregiver. The three subscales and the aggregate burden score have all been demonstrated to be both valid and reliable for use with stroke survivors.

The Sense of Coherence (SOC) questionnaire is a global measure of the ability to mobilize adaptive coping resources and is used as a measure of coping ability. The SOC is a 13-item, self-report scale which has been utilized in over 20 countries [239, 240]. The items on the scale are on a Likert-type scale, and possible scores on the SOC range from 13-91, with higher scores indicating better ability to cope. This scale has demonstrated strong internal validity, reliability, and test-retest correlations. Specifically, Cronbach's alpha (internal consistency) has ranged from 0.74 to 0.91 and the test-retest correlations for 12-month follow-ups ranged between 0.54 and 0.78.

### **Analysis of Quantitative Data**

Quantitative data were used to describe the sample and to explore outcome measures. Descriptive statistics were used to describe participant demographic characteristics and performance of ADLs and IADLs, depression, and cognition for those who did and did not discuss fear of falling. A chi-square was completed to examine the proportions of participants who reported fear of falling at one month and six months post-

stroke. Additional descriptive statistics for caregivers delineated by stroke survivor fear of falling status are included.

## Results

### Description of Sample

The larger study enrolled 132 participants. Overall, 42 (32%) participants discussed fear of falling at either one or six months and 90 (68%) did not. See Table 4-2 for demographics of those with and without fear of falling.

Table 4-2. Baseline data for those with and without fear of falling (FoF)

Measures	No FoF During 6 Months	FoF During 6 Months
n	90	42
Age	65.62 (9.68)	67.50 (11.93)
White	29 (32%)	19 (45%)
AA	34 (38%)	16 (38%)
PR Hispanic	27 (30%)	7 (17%)

Values are mean (SD) when appropriate

A total of 33 (25%) participants were identified as fearful at one month. Nine additional individuals described fear of falling at month six (7%). Thirteen participants (10%) discussed fear of falling at both one and six months. Therefore, 20 participants (61%) who reported fear of falling at one month did not discuss fearful at six months. In total, 22 participants (17%) described fear of falling at month six (13 were fearful at one and six months plus 9 new participants discussed fear at six months). See Table 4-3 for demographics and baseline data for participants with fear at one and six months.

### Relationships Between Fear of falling, Functional Status, and Depression

To explore the relationship between fear of falling, functional status, and depression, we used descriptive statistics to provide a profile for stroke survivors with fear of falling using data on ADLs, IADLs, depression, and cognition. See Table 4-4 for the mean scores and standard deviations of the FIM, FAI, MMSE, and GDS scores for

the 42 unique individuals with fear of falling and the 90 who did not discuss fear.

Participants demonstrated consistent increases in FIM and FAI scores from baseline and one month to six months scores regardless of fear of falling status. T-tests were completed to assess differences between those with and without fear of falling. There were no statistical differences for any assessment scores between those who did and did not discuss fear of falling. The participants with fear of falling are slightly older and demonstrate a somewhat lower functional status. Depression and cognition scores for those who did and did not discuss fear of falling did not appear to differ.

Table 4-3. Baseline/discharge data for those discussing fear of falling at one and six months

	<b>Month 1 FoF</b>	<b>Month 6 FoF</b>		
	33 FoF at Month 1	9 New FoF at 6 Months	13 FoF at 1 and 6 Months	22 Total FoF at 6 Months ( <b>9 + 13</b> )
n	33 (25%)	9 (7%)	13 (10%)	22 (17%)
Age	64.58 (10.42)	78.22 (11.45)	68.08 (8.34)	72.23 (10.76)
White	15 (45%)	4 (44%)	6 (46%)	10 (45%)
AA	11 (33%)	5 (56%)	3 (23%)	8 (36%)
PR Hispanic	7 (21%)	0 (0%)	4 (31%)	4 (18%)
MMSE	26.52 (2.40)	25.44 (3.97)	26.92 (2.90)	26.65 (3.20)
FIM Motor	73.10 (11.89)	74.56 (11.26)	74.69 (12.04)	74.63 (11.45)
FIM Cog	31.18 (3.25)	31.22 (3.47)	31.84 (3.34)	31.59 (3.32)
FIM Total	104.27 (14.20)	105.78 (11.64)	106.54 (2.9)	106.23 (13.17)

(AA = African American, PR = Puerto Rican)

In addition, we examined scoring of individual FAI and FIM items specific to activities that may be directly affected by fear of falling. Specifically we reported scoring for “social occasions” and “walking outside for > 15 minutes” on the FAI and the “walk/wheelchair” and “stairs” items from the FIM. See Table 4-5 for specific FAI and FIM items for those who did and did not discuss fear of falling. Findings indicate that those with fear of falling scored somewhat lower on all FIM and FAI individual items at all assessment times. T-tests compared differences and only the FIM “stairs” item was

statistically significant different between those with and without fear of falling. Such a result would not be uncommon in an elderly population, and those post-stroke would be assumed to have increased difficulty with stair climbing. Changes in IADLs were reflected in the qualitative interviews. Some participants talked about falls at home, often in the bathroom, while performing basic ADLs. However, more often participants commented on falls and fear of falling during higher-level activities, such as walking around a store, community outings such as church or social gatherings, and physical activities such as stair climbing. Thus IADLs and stair climbing were more likely impacted by fear of falling in this higher functioning post-stroke group of participants. These patterns of decreased performance in ADLs and IADLs for those with post-stroke fear of falling warrant future research to better understand the impact on activity, participation, and general quality of life.

Table 4-4. Baseline/discharge data and outcome measures for those with and without fear of falling

<b>Measures</b>	<b>No FoF</b>	<b>FoF During 6 months</b>
n	90	42
Age	65.62 (9.68)	67.50 (11.93)
<b>Baseline</b>		
FIM motor	75.71 (17.40)	73.40 (11.64)
FIM cognition	31.14 (4.18)	31.19 (3.26)
FIM total	106.86 (20.47)	104.60 (13.57)
MMSE	26.76 (3.35)	26.29 (2.79)
<b>Month 1</b>		
FIM motor	80.46 (15.59)	78.86 (11.75)
FIM cognition	32.27 (3.47)	31.19 (3.85)
FIM total	112.73 (17.66)	110.05 (13.54)
FAI	30.54 (10.44)	27.26 (10.58)
MMSE	26.60 (3.05)	26.76 (2.54)
GDS	8.84 (6.59)	9.33 (6.76)
<b>Month 6</b>		
FIM motor	82.84 (13.54)	82.69 (8.31)
FIM cognition	32.45 (3.72)	32.33 (2.95)
FIM total	115.30 (15.59)	115.03 (9.83)
FAI	33.13 (11.29)	31.50 (11.40)

Table 4-4. Continued table

	<b>No FoF</b>	<b>FoF During 6 months</b>
MMSE	27.17 (3.82)	26.53 (3.18)
GDS	8.76 (6.92)	9.03 (5.98)

Of the 33 participants who discussed fear of falling at month one, 13 (39%)

continued to demonstrate fear of falling at month six. See Table 4-6 for frequency counts.

A chi-square test was calculated examining the proportions of participants who were identified as fearful of falling at month 1 and who continued to be fearful at month 6. A significant interaction was found ( $X^2$ ,  $p < .05$ ), and those with fear of falling at month one were likely to demonstrate fear of falling at month six, see Table 4-7.

Table 4-5. Scoring of FAI and FIM items for those with and without fear of falling

<b>Measures</b>	<b>No FoF</b>	<b>FoF During 6 months</b>
n	90	42
<b>Baseline</b>		
FIM, walk/wheelchair	5.78 (1.44)	5.48 (1.40)
FIM, stairs	4.41 (2.34)	3.74 (2.30)
<b>Month 1</b>		
FAI, social occasions	2.50 (1.32)	2.26 (1.27)
FAI, walking outside	2.90 (1.38)	2.60 (1.38)
FIM, walk/wheelchair	6.17 (1.30)	5.76 (1.19)
FIM, stairs	5.50 (1.87)	4.64 (2.08) *
<b>Month 6</b>		
FAI, social occasions	2.84 (1.28)	2.78 (1.20)
FAI, walking outside	2.97 (1.31)	2.61 (1.44)
FIM, walk/wheelchair	6.39 (1.16)	6.08 (1.16)
FIM, stairs	5.88 (1.75)	4.97 (1.95) *

\* Statistically significant at the  $\leq 0.05$  level

Table 4-6. Frequency counts of fear of falling at one and six months

		FoF at 6 Months			Total
		No FoF	FoF	Missing	
FoF at Month 1	No FoF	90	9		99
	FoF	16	13	4	33
Total		106	22	4	132

Table 4-7. Proportions of those with and without fear of falling and chi square

	Month 1	Month 6	$X^2$
Fear of Falling	25%	17%	.000
No Fear of Falling	75%	83%	

We also examined the relationship between fear of falling and caregiver depression, burden, and coping, see Table 4-8. Caregiver results are delineated by stroke survivor fear of falling status. There were no significant differences in caregiver scoring in depression, burden or coping skills between those providing care for those with and without fear of falling ( $p \geq 0.05$ ). However, in the interviews, it was common for caregivers to comment on fears related to stroke survivor falls and injury. Additionally, many stroke survivors indicated dependence on caregivers as a strategy to prevent falls.

Table 4-8. Comparison of caregivers for participants with and without fear of falling

<b>Measures</b>	<b>No FoF</b>	<b>FoF During 6 months</b>
n	90	42
Caregiver Age	59.80 (14.10)	59.38 (11.83)
<b>Month 1</b>		
GDS	6.62 (6.17)	6.97 (5.65)
SCQ	51.64 (10.02)	50.08 (12.57)
SOC	71.42 (13.37)	71.13 (16.65)
<b>Month 6</b>		
GDS	5.99 (5.57)	6.38 (5.63)
SCQ	51.89 (11.76)	52.44 (11.99)
SOC	70.54 (13.40)	71.53 (13.69)

### **The Experience of Fear of Falling Post-Stroke**

Qualitative findings are described in this section. Initially, three major theme headings of “physical”, “psychosocial”, and “strategy” were used for the coding of the qualitative interviews. However, after a review of the qualitative interview data and content analysis, it became evident that the development of fear of falling is a process, one that often impacts everyday life. Therefore, we present the characterization of fear of falling as the process that reflects the way stroke survivors experience fear of falling in their everyday lives. Data indicated that the beginning of the process was often the first sustained fall that usually occurred at the time of the stroke. Participants discussed themes related to: bodily changes that influenced falls and fear of falling, experiences

related to a pervasive fear of fall and injury, and the impact of fear of falling on activity and everyday life. The unpredictability of falls and the resultant general acceptance of fear became evident, making strategies to manage falls and fear of falling necessary. Each of these themes are described below. See Table 4-9 for original content analysis frequencies derived from 33 month one interviews and 22 from month 6 interviews.

Table 4-9. Content analysis frequencies (derived from 55 qualitative interviews)

<b>Primary theme</b>	<b>Secondary Themes</b>	<b>Frequency</b>	
Falls as a Physical Event	Paralysis/hemiplegia	15	27%
	Fell at time of stroke	22	40%
	Balance/stability	21	38%
	Dizziness	17	31%
	Decreased participation	14	25%
	Injury (such as hip fracture or head injury)	6	11%
	Talk about falls (stumble, trip, wobble, etc)	45	82%
	<b>Total from 55 interviews</b>	<b>140 occurrences</b>	
Fearing Falls	Fear, afraid, concern	32	58%
	Caregiver afraid will fall	16	29%
	Afraid of injury	6	11%
	<b>Total from 55 interviews</b>	<b>108 occurrences</b>	
Strategies for Managing Fear of Falling	Walker/cane/WC/wall/other	35	63%
	Relies on others	9	17%
	Being careful	27	49%
	<b>Total from 55 interviews</b>	<b>152 occurrences</b>	

### **Onset of falling with the stroke event**

Falling at the time of a stroke is a common experience and maybe a harbinger of development of fear of falling. For some, having a fall signaled a possible second stroke, thus fear of falling and fear of another stroke became intertwined. Others discussed the fall at the time of the stroke and the experience of laying on the floor without someone to help them. Fear associated with a possible fall continued as individuals were concerned about falling in the future and being left on the floor for substantial periods of time. One participant stated “Yes, I fell. It was horrible; I lost control of my left arm, and my hand,

my left foot. They failed me and that's why I fell." Others said "When I had the stroke, I was, I couldn't walk. I had to crawl and if I tried to stand up at all my legs and things, just like that (unintelligible), sit down quick or you would fall over" and "Well, when I fell, I knew I had a stroke and I was in such a bad shape. I was sweatin', the worst kind of sweat and I asked the Lord."

Some stroke survivors who fell at the time of their stroke were living with the fear of another stroke and of future falls. One participant commented, "I was scared of falling, you know, uh it's sorta like it was the other stroke, you know?" These participants equated the two and feared both. They realized a future stroke may further limit their abilities and independence. However, the fear they live with daily may limit activity performance and in itself cause increased dependence. These early experiences of falling with stroke onset represent the early stages of development of fear of falling.

### **Experiencing the changed body**

Another part of the process of developing fear of falling is related to experiencing the changed body. The residual motor deficits related to mobility were of great concern to many participants. Changes in movement and ability of the lower extremities were frequently described. Individuals discussed not being able to move the same as before the stroke, and how this negatively impacts mobility, adding to the fear of falling. For example, participants made several statements about fearing their legs would no longer function properly. Some said, "My legs give out real fast", "I fear, I fear a little that my legs don't fail me", and "No, that's what I, I mean, well, as I told you before, you always worry about a leg failure or that, right?" Others stated, "Oh, am I tired. I'm tired. Legs just bow, buckle underneath me", "I'll be walking and all of a sudden I'm making love to the pavement", and "Let's see, after I walk so long (long pause) the feeling that any time

now, the hip and leg are gonna give out and I'm gonna fall, so I watch where I walk so that if I would fall, I wouldn't fall into something too expensive (laughs)."

Bodily changes were also related to the loss of balance, stability, and strength. For example, one man stated, "Uh, the only problems I can think of I'm having now is balance...around me I have to hold onto things, so it's a balance problem and I'm, sometime I'm tipping and leaning and, prone to fall down." Many talked freely about paralysis and hemiplegia, or general changes to their body, most often impacting balance and strength. Another commented, "Well, weak in the knees still weak, have to walk more slowly and seems like sometimes I get a little wobbly cause I'm so weak and I haven't got all my strength back yet." Interestingly, some participants discussed concerns related to their balance, but did not specifically discuss falls or fear of falling. For instance, one man stated, "The only thing that concerns me is my balance, sometimes I lose my balance a little bit, that's about it, nothing else . . . because the balance, it isn't all right." This may be important when utilizing fear of falling assessments, as participants may worry about balance, but not connect the concern to fear of future falls.

Participants also discussed dizziness as a common aspect of the changed body. For many, dizziness became a part of everyday life, making falls and fear of falling very common. When feeling dizzy, participants would discuss the need to curb walking or other activities and their need for assistance to maintain their balance and prevent a fall. As an example, one man stated "I get dizzy and I start falling down", and others stated "I am insecure when I walk around the house, because I get dizzy, and I start falling face down. My nervous system doesn't help me . . . and it's not the same" or "Helped my wife

in a lot of things . . . but now I can't, because now . . . now I get dizzy and I start falling face down, I can't I'm not stable, I don't feel self-secured."

The participants who experienced post-stroke bodily changes often developed unpredictable episodes of imbalance, instability, and dizziness. These changes were often related to hemiplegia, paralysis, and other post-stroke bodily changes and were reflected in their discussions of insecurity in mobility and subsequent falls and fear of falling.

### **A pervasive fear of the unpredictable**

Participants often described a pervasive sense of fear of falling. Some specifically talked about being afraid of a fall in the future. When the interviewer asked "What are your greatest concerns about your body now?" a participant stated "Fear of falling . . . I think that's most concern of everybody is falls." Others commented that "My greatest concern, that I don't fall, that I don't have another stroke" and "That is my fear, well, that I could fall. That is what, what they look for, that I don't fall. Because in order to get up afterwards is hell." Another stated "I fear a little that my legs . . . that my legs don't fail me" and a different man said "One feels afraid of falling and even dying because I can get hit by something. I fell and almost hit my head, and thank God, I hit my butt instead."

Some participants avoided the use the words 'afraid' or 'fearful' in relation to falls. Instead, individuals often talked about having a concern about falls, balance, or safety. One standard interview question asked participants about their concerns post-stroke, many discussed issues related to balance, stability, dizziness, falls, safety, and walking. Some stated, "Trouble with balance, but I'm not about to fall" or "The only . . . thing that concerns me is the balance, sometimes I lose my balance a little bit but that's about it, nothing else."

Still others talked about fear of falling and not feeling safe. Safety therefore became an issue for participants while at home and in the community. One man said, “I don’t feel safe because the people there run around. And I don’t feel safe because I sit in a corner, and I tell you, they can trip you over.” and another stated “I didn’t feel safe ‘cause I didn’t know if I was goin’ to fall or what.”

Participants characterizing fear of falling often talked about the fear of sustaining future fall related injuries. Some made the following comments: “Ummm . . . I worry because there have been times where I have tripped and nailed myself” and “I’m afraid to. I’ll lose my balance. That’s a long ways down. The fall wouldn’t hurt you, it’s just the sudden stop (laughs) . . . That ground’s hard. Like I say that fall ain’t gonna hurt ya.”

Of most concern were hip fractures and head injuries. For example, some stated, “Cause once you fall, could break a hip” and “I think it’s falling like it it’s it’s falling, all the time that’s your worst fear, it’s falling and you might hurt or break a leg, or or or or you might uhh break a hip or something, I think you’re more conscious of it yeah.”

Participants described genuine concern about being hurt after sustaining a fall and the subsequent impact on function, one commented, “Uh huh, it worries me; I can fall and hurt myself bad, or hit my head and make it worse than it is.”

Those who discussed a fear of falling tended to discuss fears and concerns related to falls, future falls, and safety issues. While many participants specifically and openly discussed fear of falling, many others only admitted to concerns about balance and stability, not addressing actual fear. Those who communicated fears about future falls were also likely to discuss fear of future injuries. For these individuals, the fear of falling, and the prevention of falls often became a part of everyday life.

### **Falls as an everyday life experience**

Participants discussed how falls became a frequent event and a common concern, often part of every day life. For example, one man said, “Sometimes I fall down, but I’m used to that now” For some, it seems that falls and fear of falling became all consuming. Regardless of the frequency of falls, fear of falling became a constant worry for some. Falls as a common occurrence were expressed in the following statements: “I always fall on the stairs” and “I’d make about four steps and I fall down” or “I worried about those steps out there . . . every time I fall it’s been on those steps”

Some participants were concerned they would fall while out in the community and they addressed the embarrassment of a public fall. One individual commented, “Yeah. Uh huh. Do something that I find difficult to do, is not be embarrassed when you stumble and watch when you’re going somewhere.” They were also concerned about how they looked while walking around and seemed to be worried about the stigma related to falls and decreased mobility. One man discussed the following situation: “What worries me is that I had the experience that I fell down, I fell down on a street, someone called 911 and they picked me up because when I fell I had lost my conscience, because I have unbalance in my legs, I fall down.”

### **Strategies for managing fear of falling**

Because fear of falling became an all consuming issue for some participants, talk about strategies for the prevention of future falls and management of fear of falling was common. Many participants discussed limiting everyday life activities, such as ADLs and IADLs at home and out in the community. One participant said, “You know, I was, I, I’m generally, well, no I wasn’t a real religious fella or anything like that but I did go to church occasionally with my wife on Sunday, y’know. But uh, I, in fact the last time I

went to church with her I lost my complete balance as we were walkin' out o' church, because of the fall problem I have, and I almost knocked an old lady down. So that was a concern for me and I wouldn't go back to church. Y'know, since the stroke I've lost confidence" Another man commented, "Well, well, like I tell you, I stutter, I stutter more, I wobble and uh that's why I don't, I don't get out in the streets to much, I could, I have enough energy to go walk and more but I don't" Others discussed limiting higher level skills, for example, "Well, now I can't (laughing), now it's impossible for me to climb a ladder. Now I can't do it because I can't get up the ladder (unintelligible), I fall."

Participants also discussed the use of assistive devices such as walkers, canes, and wheel chairs to reduce falls and feel secure in their environment. As an example, one man said, "Yeah, I use a cane . . . ahhh . . . just to . . . for protection like in, so I don't fall. Because, you know, somewhere along the line there was times when my leg felt like it was going to give out, but it didn't." and another stated, "I keep my cane . . . because I never know whether one of my legs is gonna decide to give out, so I keep my cane with me." Other individuals expressed their use of assistive devices with the following quotations, "Like that cane. Once I, I got it set right by the door over there, 'cause I go out that door, I'll grab that cane, keep my balance . . . And when I get out the door I got things I can hang onto but once I get away from it I can't. I gotta have that cane. So I gotta have that cane handy" or "Mainly the only reason I use the walker is for balance." Interestingly, some even used the furniture or walls as an alternative to assistive devices. One participant stated, "I feel safe, like I say, the only thing that I am, ah, really concerned about in here is after I walk so long that my hip starts giving away and then I might fall into somebody of up against something and break something, so I watch that.

If I have a banister, I feel, great, hold on to the banister,” and an interviewer commented, “At times, it was noted that he was unsteady on his feet and often used the furniture for balance.”

Participants also discussed where they used assistive device. Some commented on using a device at the store or out in the community, but not at home. For example, “Yeah, when I go in stores I carry my cane, and if I didn’t I’d probably fall” and another, “I got a walker in there that I use whenever I go up the hospital. Here in the house I really don’t, I use a cane occasionally, but you have the wall here, everything’s close, see, y’know.”

Others indicated reliance on others as an additional strategy utilized to reduce falls and manage fear of falling. One man stated, “I was settin’ there goin’ to the left like that, kept slidin’ to the left, cause the left side’s gone. It was in these here foldin’ chairs. She pulls hers right up side of me, leans up there before so I can lean against her, instead of fallin’ out of the chair . . . Yeah, she’s sittin’ on the left and she slid her chair right up against mine, put her shoulder there where I can lean against her, keep me a slidin’ out, fallin’ out of this chair.” Many discussed dependence on their caregivers or others for the maintenance of balance and the prevention of falls. A participant referred to his caregiver and said, “Oh, sure, grabbin’ my hand, helpin’ me help straight up and down, keepin’ me from fallin’, she’ll walk along side of me every now and then, and, when I need her, you can tell you know why I’m a little more off balance.” Others commented, “Well my beliefs are that I never will walk alone, I can’t be alone at any time”, “I’m afraid of falling when she’s not here. I may hurt myself . . . Yeah, it makes a difference when she is here, I walk around and all that.” and “Well, yes, he helps me get ready to go to the

bathroom, because sometimes I fall.” One stated, “. . . I want someone beside me to tell me things and . . . At least to prevent me from falling because the last time I fell.”

Some caregivers were in the room during the interview and interjected information about falls and their fear of the stroke survivor falling in the future. Caregivers made the following comments, “I’m afraid he’s going to fall again”, “We don’t want him to fall”, and “Cause I’m afraid he’ll fall and wouldn’t be able to get up.” Stroke survivors were aware of their caregiver’s surveillance of possible falls and attempts to decrease falls incidence. For instance, one stroke survivor commented, “My wife keeps attention when I walk, if I fall or something”, and another said, “She was watching me, to see if I was gonna fall.” Still others stated, “Well, they help me to stand up and walk, right? And they fear that I might fall, right?” Another said, “During the day my wife is here with me in the house, here . . . paying attention to everything I do, too. If go walk over there she’s paying attention that I don’t fall or anything.”

A general tool for the management of fear of falling and a reduction of future falls was simply to “be careful” or “cautious”. For example, one man said, “I don’t know how to describe it but I think that you, uhh, are more cautious and more careful like, uhh, umm, in you, when you in bathrooms, if you’re in the shower and, uhh, you have to use, sit down in the chair so that you won’t fall.” Being “careful” while performing specific mobility and other everyday activities was commonly addressed. Being cautious was expressed in the following excerpts: “It’s about the same, only thing you do is um, make sure you don’t trip over nothin’ an’ try your best to sit some place where you don’t fall off of nothin’” and “I walk slower. I take my time now . . . but I, uh, try my best to avoid tripping. I just slow down.” Another said, “Yeah, I, uh, had to be very careful ‘cause, uh,

I first come home, home from the hospital, I'd try to get outta' my chair and I fell a couple a' times." One man said, "I have to be careful when I walk. I might fall."

Many different strategies were utilized for the prevention of falls and the management of the complexity of fear of falling. Participants discussed use of assistive devices, reliance on others, and simply being cognizant of their own personal fall risks.

To summarize, quantitative and qualitative data were analyzed to explore the characterization of fear of falling post-stroke. The main themes derived from the data conceptualize the process of developing fear of falling, often beginning at the time of the stroke or initial fall and continuing as individuals live with fear of falling as part of their daily lives and learn to manage their new bodies and strategize against future falls and fear of falling.

### **Discussion**

To our knowledge, this is the first study examining the development of fear of falling in the post-stroke population. It is also the first qualitative studies on fear of falling in the elderly. Characterization of post-stroke fear of falling has been derived from analyses of the qualitative interviews and descriptions of participants using standardized assessment scores. It is evident that falls and fear of falling are difficulties faced by many of those who have sustained a stroke, often on a daily basis. Our findings are based on secondary analyses and indicate that further study of the development of post-stroke fear of falling and its management at home and in the community is warranted.

Many of the participants discussed falls and fear of falling during the first one to six months post stroke. The experience of falls is supported by research completed by Forster and Young who reported a 73% incidence of falls in the first six months post-stroke [79]. Our reports of fear of falling were less than expected when compared to the

community elderly population. Researchers have indicated fear of falling in 29%-92% of those recently sustaining a fall and 12%-65% of those without a recent fall [46, 70, 113, 115, 144-152]. In our study, 25% of participants (33 of 133) in month one and 32% (42/132) of all participants described fear during the first six months post stroke.

The lower fear of falling incidence may be related to the high functioning of our participants. At discharge, the mean FIM motor score for all participants, regardless of fear of falling, was 74.98 (15.79) with a range of 13 to 91, and 46% of all participants scored over 80 (maximum score is 91). This increased to 69% at month one and 74% at month six, indicating a high functioning group of post-stroke participants.

Incidence may have been impacted by an all male veteran sample. Women are more likely to report a fear of falling [43, 144, 148, 155, 156] and men may underreport fear due to a perceived negative stigma related to their fears. Fear of falling may be underreported because those with the greatest fear may not partake in research [155, 241] and others may fear institutionalization [143, 150].

### **Characterization of Fear of Falling**

Participants discussed the characterization of fear of falling. Through review and analysis of the interviews and exploration of post-stroke fear of falling functional status, we have determined five important factors to include in the characterization:

(1) The time of the initial fall: participants often discussed a first fall coinciding with their stroke. Participants realized they were at risk for both future falls and strokes and indicated fear of decreased abilities and subsequent dependence on others. This provides a preliminary exploration of the timing and development of fear of falling after stroke. Timing may be related to the impact fear has on everyday life and important when evaluating assessments and the efficacy of interventions to reduce future falls and

management of fear of falling. In preparation for discharge, clinicians need to talk with patients about fear of falling and how they will manage safely at home.

(2) Post-stroke related changes in the body: resultant declines in balance, stability, strength, and dizziness due to hemiplegia and paralysis were commonly discussed. Yates and colleagues previously determined increased fall risks related to post-stroke motor impairments [78]. This sample of post-stroke participants discussed decreased mobility due to the stroke and how it related to increased risk of future falls and fear of falling. Rehabilitation clinicians and researchers need to develop interventions to support mobility and safety among those patients with post-stroke fear of falling.

(3) Pervasive fear of future falls: many naturally discussed fear of falling, falls, and balance issues when discussing post-stroke concerns and barriers. In contrast, others discussed concern or trouble regarding balance, stability, strength, or their “legs giving out” but did not admit to actual fear. Perhaps the stigma of “being afraid” was overwhelming, especially for an all male veteran population. Researchers have demonstrated increased likelihood of female fear of falling, perhaps our all male veteran population were embarrassed to admit such fears [43, 144, 148, 155, 156]. The difference in levels of fear may impact future research when assessing fear of falling evaluations and preventative interventions. Participants not admitting to being fearful may require different interventions to manage issues related to fear of falling and future falls.

(4) Every day fear of falling: it became evident that different levels of fear of falling existed within this population. There is an apparent continuum of fear of falling in this post-stroke population. It ranges from a healthy sense of fear to an overwhelming, all encompassing, everyday, obtrusive fear that is reflected in a “constant awareness” of falls

risks and reported changes in activity and participation. The development of fear of falling may have great impact on every day life, for some, it becomes all-consuming. Assessing fear of falling and openly discussing it with patients and their caregivers may help them manage more efficiently after discharge.

(5) Strategies for the management of fear of falling: participants discussed individual techniques to manage falls and fear of falling. Many discussed restricting or modifying performance of ADLs, IADLs, and social participation due to fear. Activity restriction is common in those with fear of falling in the community dwelling elderly [43, 113, 114, 143, 148, 186, 187, 225-230]. Those with fear of falling related activity restrictions may become increasingly dependent on caregivers. This may impact stroke caregiver burden and depression. The use of assistive devices such as walkers, canes, and wheel chairs was also common. Others discussed being careful or cautious to manage falls and fear of falling. Overall, the development of strategies indicate that a certain, normal, healthy fear may reduce future falls. Because fall risks are multidimensional [52, 65-67], the independent use of multiple strategies represents the need for multidimensional and individualized interventions.

In summary, the process of fear of falling may begin at the time of the fall, often coinciding with the stroke, possibly making the time of the development of fear an important issue. We found that mobility issues related to changes in the body greatly impact falls and fear of falling, and that the actual fear or concern may differ dependent on individuals, ability levels, and possible fear of stigma or embarrassment. Interestingly, participants naturally developed strategies to manage fear of falling and their fall risks.

Perhaps this was necessary because for some, fear of falling became an all consuming aspect of life, impacting activity and participation.

### **Limitations**

There are several limitations to this study. Our study primarily used qualitative data derived from a larger study. We were restricted to a convenience sample. Common to all qualitative studies, generalization is not possible, although findings may be informative across similar populations.

This study was a secondary analysis of naturally occurring data. There was not a specific interview question related to falls, fear of falling, or post-stroke mobility, and we did not include a standardized fear of falling or falls incidence assessment. We were dependent on the use of natural conversation elicited from questions regarding changes since stroke, concerns about bodily changes, and barriers to everyday life to determine those who would be considered fearful of falling. Although this naturalistic approach derives significant amounts of information, all of those with fear of falling may have not been considered in the qualitative and quantitative analyses, thus possibly reducing detection of fear of falling incidence.

### **Future Research**

Because falls and fear of falling are unpredictable, it is of great concern to those managing life post-stroke. This preliminary research provides insight into the development of fear of falling after discharge home post-stroke and the impact it has on activity and participation. It is evident that some people develop a fear that promotes safe completion of activities. However, others are likely to engage in a cycle of restricted activities and then experience further functional losses. This plays into the “vicious circle” portrayed by Delbaere and colleagues who suggested a pattern between reduced

activities and decreased muscle strength and balance, leading to further declines in ADLs, increased falls incidence and fear of falling, and completing the circle with additional declines in activities [114]. Li et al. discussed the existing relationship between fear of falling and falls efficacy, the effect on balance and physical disability, continuations in deteriorated health, and future falls and development of fear of falling [194].

Clearly, more interventions are needed to assist stroke survivors and their caregivers to effectively manage this cycle. It is important to acknowledge the number of individuals who return home with significant residual mobility losses. This was a relatively high functioning post-stroke population, and still many discussed fear of falling and the necessity to manage it with assistive devices, activity restriction, and decreased functioning.

Future studies are needed to better define the natural history and experience of the development of post-stroke fear of falling in the home and community. The utilization of standardized fear of falling assessments, such as the Falls Efficacy Scale or the Activities-Specific Balance Confidence Scale, both recently found valid and reliable for the post-stroke population, [173-175] combined with qualitative data will provide more complete explanations to better understand fear of falling development. This dual qualitative and quantitative research study provided preliminary information to justify future research. Addressing the impact of fear on quality of life and life satisfaction will be an important step in determining the impact of fear on post-stroke management. Important future research will include the advent of a fear of falling intervention specific for the post-stroke population. Likely, interventions to manage fear of falling and reduce

fall rates will require individual treatment plans and will need to address the very issues described by these participants.

## CHAPTER 5 CONCLUSION

The objective of this dissertation was to utilize secondary data from two larger studies to examine the impact of post-stroke gait velocity and fear of falling on activity and participation [8, 11]. In Chapter One, we presented a conceptual framework as the foundation for this research (Figure 1-2). The framework indicates that those who sustain a stroke are likely to demonstrate sensory, cognitive, and motor impairments. These impairments are reflected by mobility disability, specifically changes in gait speed and fear of falling. Through reviews of the literature, we speculated that change in gait speed or the development of fear of falling would be associated with change in stroke survivor performance of activities of daily living (ADLs) (including mobility), instrumental activities of daily living (IADLs), social participation. Additionally we believed that such changes in activity and participation, and therefore independence, would impact caregiver depression, burden, and coping.

Our findings indicate that mobility disability was demonstrated in both of our post-stroke populations. The first study examined clinically meaningful changes in gait speed and the second study explored fear of falling. In support of our model, we observed that those who portrayed a clinically meaningful increase in gait speed demonstrated improved performance in ADLs, IADLs, mobility, and social participation. We also described how a post-stroke veteran population characterizes fear of falling in the first six months after discharge. In addition we examined post-stroke activity, participation, and depression in those discussing fear of falling.

In the first study, we measured the proportions of participants who successfully advanced to a higher ambulation classification, demonstrating a clinically meaningful change in gait velocity. Forty-five percent of our total sample transitioned to a higher classification; however, after baseline gait speed stratification, 63% of those walking slower than 0.4 meters/second (m/s) and 38% walking between 0.4 and 0.8 m/s advanced to the next ambulation classification. This indicates that those with the slowest speed, and possibly the most severe mobility deficits, have the greatest potential for gains in gait velocity.

We also compared the differences in Stroke Impact Scale (SIS) measured ADLs/IADLs, mobility, social participation, and physical functioning (SIS-16) dependent on success or failure of advancement to a higher ambulation classification. After controlling for a significant difference in age, all SIS scores for those with baseline gait velocity less than 0.4 m/s were statistically different. In contrast, only the participation score was significantly different for those with baseline gait velocity between 0.4 and 0.8 m/s. This suggests that a transition to the next ambulation classification is a clinically meaningful change because it is related to increased function, particularly for the initially more impaired stroke survivors. This is important as it validates the previous ambulation classification developed by Perry and colleagues [9]. More importantly, it confirms the use of ambulation classification in clinical and rehabilitation research settings. It indicates that using ambulation classification is appropriate for goal setting and that increased gait velocity is associated with highly significant increases in performance of activity and participation.

In the second study, we used qualitative and quantitative data to examine how post-stroke veteran populations characterize fear of falling and the relationship between fear and ADLs, IADLs, and depression. Additional exploration of caregiver burden, coping, and depression for those caring for post-stroke individuals with fear of falling was completed. It is evident that those with fear demonstrated slightly lower scores for almost all Functional Independence Measure (FIM), Frenchay Activity Index (FAI), and depression scores. This trend was also established for individual FIM and FAI items and caregiver burden, depression, and coping.

Content analysis and review of the qualitative interviews verified that many participants naturally discussed post-stroke falls and fear of falling. We discovered that participants characterize post-stroke fear of falling with five main factors, including: (1) the importance of the time of the initial fall, (2) how post-stroke related changes in the body were associated with falls and fear of falling, (3) the pervasive fear and concern of future falls, (4) a continuum of everyday and unpredictable fear of falling, and (5) the natural strategies utilized and discussed by participants for the management of fear of falling and the prevention of falls.

These qualitative findings can be related to the examination of data retrieved from the standardized assessments. Participants discussed concern regarding falls during performance of both ADLs and IADLs, but it seems that participants were more likely to discuss fear of falling in regard to the performance of higher level activity at home and in the community. A small difference in FAI scores between those with and without fear of falling is apparent. This implies that fear of falling had a bigger impact on higher level IADLs in this relatively high functioning post-stroke population. Of additional

importance, participants naturally developed strategies to prevent falls and manage fear of falling. This may impact future interventions to decrease falls and fear of falling in this population. Programs may need to be individualized dependent on the need and abilities of the post-stroke individual. This exploration warrants future research of post-stroke fear of falling.

In conclusion, we studied two post-stroke community dwelling populations, and although all participants lived at home, we established that many continued to demonstrate mobility impairments. The present studies provide support of the negative impact of post-stroke mobility changes on activity and participation. Further study of gait speed change and its influence on activity and participation is warranted. Natural recovery may play an important role in improvement, but further evidence is needed to determine appropriate interventions and timing of intervention to best enhance gait velocity and consequently improve activity, participation, and quality of life. Future research is necessary to better understand the true trajectory of the development of fear of falling after stroke. It is evident that fear of falling development was very individualized and our results provide preliminary data demonstrating that prevention strategies also need to be individualized. This preliminary research provides foundational data to continue investigation into post-stroke gait velocity and fear of falling, its impact on everyday life, and future interventions. Collectively, this research will promote our understanding of post-stroke mobility and its impact on functional independence.

APPENDIX  
EVIDENCE BASED TABLE FOR FEAR OF FALLING AND ACTIVITY  
RESTRICTION

Table A-1. Fear of falling and activity restriction

Article	Design	Sample	Fear of falling assessment	Functional Activity Measures	Results
Arfken, et al., 1994) [43]	Cross-sectional analysis of data from a prospective study 1 year follow up	890	“At the present time, are you very fearful, somewhat fearful, or not fearful that you may fall (again)?”	<ul style="list-style-type: none"> <li>• Mobility activities</li> <li>• Social activities</li> <li>• Depression</li> <li>• Life satisfaction</li> <li>• Frailty measure</li> </ul>	<ul style="list-style-type: none"> <li>• 29% reported some FoF</li> <li>• Of those very FoF <ul style="list-style-type: none"> <li>○ 48% not satisfied with life</li> <li>○ 25% depression</li> <li>○ decreased mobility and social activities</li> <li>○ 91% reported at least one characteristic of frailty</li> <li>○ 85% exhibited diminished balance</li> <li>○ 22% were delayed in getting up after sustaining a fall</li> <li>○ 85% impaired balance</li> </ul> </li> </ul>
Brouwer, et al., 2004 [225]	Cross-sectional study	50 25 with FoF and activity curtailment and 25 without FoF	Activity-specific Balance Confidence	Human Activity Profile	<ul style="list-style-type: none"> <li>• Those with FoF had lower ABC scores, decreased balance, slower gait speed, lower limb weakness, and decreased physical health.</li> <li>• Similar activity profiles</li> </ul>
Bruce, et al., 2002 [230]	Cross-sectional analysis of baseline data from a longitudinal study	1500 females	<ul style="list-style-type: none"> <li>• “Are you afraid to fall?”</li> <li>• “Do you limit any household activities because you are frightened you may fall?”</li> <li>• Do you limit any outside activities because you are frightened you may fall?”</li> </ul>	<ul style="list-style-type: none"> <li>• “Do you participate in any sports recreation or regular physical exercise?”</li> <li>• “Please list any sports recreation or regular physical activity, including walking, that you undertook in the last 3 months” (duration / frequency)</li> </ul>	<ul style="list-style-type: none"> <li>• 34% afraid of falls</li> <li>• More FoF in sedentary woman (45.2%)</li> <li>• FoF was independent risk factor for nonparticipation in physical activity</li> <li>• Analysis suggests FoF affected activity levels at a predisability stage in those with mildly impaired mobility</li> </ul>
Chandler, et al., 1996 [113]	Secondary analysis of data from a prospective observational study of falls risk	149 male veterans	“Would you say that you are somewhat afraid, not afraid, or very afraid of falling?”	<ul style="list-style-type: none"> <li>• Mobility performance</li> <li>• PADL and IADL</li> <li>• Change in inside and outside activity</li> </ul>	<ul style="list-style-type: none"> <li>• 43% of the high risk participants were very afraid of falling</li> <li>• 55% had prior fall</li> <li>• Walk time and life space reduced in nonfallers who were very afraid of falling</li> <li>• Increased depression in those very afraid of falling</li> <li>• Decreased functional reach and activity for those very afraid of falling</li> <li>• Decreased walk time, mobility skills, functional reach, IADL, PADL, lifespan, and activity levels if a faller AND very afraid to fall</li> <li>• Walk time and IADL were independent contributors to FoF</li> </ul>

Table A-1. Continued

Article	Design	Sample	Fear of falling assessment	Functional Activity Measures	Results
Cumming, et al., 2000 [143]	Secondary data form a prospectivel OT home visit falls prevention study	418 at baseline and 307 at 12 months	<ul style="list-style-type: none"> <li>Falls Efficacy Scale</li> <li>“Are you afraid of falling?”</li> </ul>	<ul style="list-style-type: none"> <li>ADLs</li> <li>Use of community services</li> </ul>	<ul style="list-style-type: none"> <li>Those with lowest confidence in balance had increased risk of falls, poorer health, significant declines in ADLs, lowest QoL</li> </ul>
Delbaere, et al., 2004 [114]	Cross-sectional study and longitudinal study	225 (and 221 for longitudinal portion)	Survey of Activities and Fear of Falling in the Elderly (SAFFE) Scale	<ul style="list-style-type: none"> <li>Survey of Activities and Fear of Falling in the Elderly (SAFFE) Scale</li> <li>Physical Performance Test (physical frailty)</li> </ul>	<ul style="list-style-type: none"> <li>Frequent fallers more likely to avoid FoF related activities</li> <li>Mobility tasks avoided the most by those with FoF</li> <li>FoF activity restriction was correlated with physical performance, forward excursion of the center of pressure and muscle strength</li> <li>FoF and activity restriction predicted falls at the one year follow up</li> <li>Stated FoF is a “vicious circle of frailty” where individuals cease activities, but become more fearful and continue to reduce activity, decreasing mobility levels, and becoming more fearful</li> </ul>
Fletcher and Hirdes, 2004 [229]	Cross-sectional study	2,304, all receiving home care services	“Limited going outdoors due to fear of falling (e.g., stopped using bus, goes out only with others)	<ul style="list-style-type: none"> <li>Minimum Data Set for Home Care</li> <li>Clinical Assessment Protocols</li> <li>IADLs</li> </ul>	<ul style="list-style-type: none"> <li>41.2% restricted activity de to FoF</li> <li>27% sustained previous fall</li> <li>Predictive factors of activity limitation                             <ul style="list-style-type: none"> <li>Female</li> <li>Older</li> <li>Need for informal support for IADLs and ADLs</li> <li>Being alone for long periods of the day</li> <li>Impaired gait</li> </ul> </li> </ul>
Howland, et al., 1998 [148]	Sample survey	266	<ul style="list-style-type: none"> <li>“Are you afraid of falling?”</li> </ul>	<ul style="list-style-type: none"> <li>Falls history</li> <li>Social support</li> </ul>	<ul style="list-style-type: none"> <li>55% with FoF</li> <li>56% of those with FoF restricted activity</li> <li>Fear related to function and social support</li> <li>Those with restricted activity:                             <ul style="list-style-type: none"> <li>Did not communicate about falls</li> <li>Less social support</li> <li>Knew someone who had fallen</li> </ul> </li> </ul>
Kressign, et al., 2001 [228]	Base-line cross-sectional study	287	<ul style="list-style-type: none"> <li>Falls Efficacy Scale</li> <li>Activity-specific Balance Confidence</li> </ul>	<ul style="list-style-type: none"> <li>CESD</li> <li>360 turn</li> <li>Functional reach</li> <li>10-meter walk</li> <li>Single limb stands</li> <li>Picking up and object</li> <li>Chair stands</li> </ul>	<ul style="list-style-type: none"> <li>About ½ of participants demonstrated fear of falling</li> <li>Those fearful were more depressed and used a walking aid</li> <li>FoF was correlated to all functional measures</li> <li>Depression, walking-aid, slow gait speed, being African American related to being more fearful</li> </ul>

Table A-1. Continued

Li, et al., 2003 [227]	Cross-sectional study	256	Assessed with the Survey of Activities and Fear of Falling in the Elderly (SAFFE) Scale	<ul style="list-style-type: none"> <li>• Assessed with the Survey of Activities and Fear of Falling in the Elderly (SAFFE) Scale</li> <li>• Berg Balance</li> <li>• Functional Reach Test</li> <li>• Dynamic Gait Index for functional mobility</li> <li>• IADLs</li> <li>• Quality of Life via SF-12</li> </ul>	<ul style="list-style-type: none"> <li>• FoF varied across differing activities of the SAFFE</li> <li>• 18% reported “high fear”</li> <li>• Those with high fear more likely to report fear with activities of the SAFFE</li> <li>• Fallers had a higher SAFFE score</li> <li>• Difference in balance, functional mobility, IADLs, and QoL between those with high and low fear</li> <li>• Those with higher fear engaged in fewer activities</li> </ul>
Murphy, et al., 2002 [187]	Cross-sectional study	1064	<ul style="list-style-type: none"> <li>• “Afraid of falling?”</li> <li>• Those with FoF were asked “did the fear cause them to cut down on activities?”</li> </ul>	<ul style="list-style-type: none"> <li>• ADLs</li> <li>• IADLs</li> <li>• CESD</li> </ul>	<ul style="list-style-type: none"> <li>• 24% reported FoF</li> <li>• 19% reported FoF and activity restriction</li> <li>• Highest activity restriction seen in those over 80, female, white, poor health status, dizziness, 5 or more medications, visual impairment, two or more diseases</li> <li>• Those with FoF and activity restriction were more likely to be 80 and over, female, 2 or more disease, slow timed physical performance, ADL disability, prior injurious fall, anxiety, and depressive symptoms</li> </ul>
Suzuki, et al., 2002 [226]	Cross-sectional study	135	“At the present time are you very fearful, somewhat fearful, or not fearful that you may fall?”	<ul style="list-style-type: none"> <li>• Short Form 36 Health Survey measured health related quality of life and perceived changes in health status</li> </ul>	<ul style="list-style-type: none"> <li>• Females more likely to express FoF</li> <li>• Older participants more likely to express FoF</li> <li>• 63.7% were moderately or very fearful of falling</li> <li>• Females: walking and bathing had significant relationship with FoF</li> <li>• Majority of those who required assist with ADLs answered “moderately” or “very fearful”</li> <li>• Those with increased FoF demonstrated decreased scoring on SF-36 subscales <ul style="list-style-type: none"> <li>○ Physical problems</li> <li>○ Social functions</li> <li>○ Physical function</li> <li>○ General health perceptions</li> </ul> </li> </ul>
Yardley and Smith, 2002 [186]	Convenience sample form a pragmatic double-blind randomized controlled trial	224 at baseline and 166 at 6 months	“In general, are you afraid of falling over?” Answered: not at all, a little, quite a bit, very much	<ul style="list-style-type: none"> <li>• Consequence of Falling Scale (CoF) (validated by authors) <ul style="list-style-type: none"> <li>○ Assesses fall related fears of physical injury, long term functional incapacity, subjective anxiety, and social discomfort.</li> </ul> </li> <li>• Modified Survey of Activities and Fear of Falling in the Elderly (SAFFE) Scale</li> </ul>	<ul style="list-style-type: none"> <li>• Nearly half had fallen in previous year</li> <li>• 57% reported FoF <ul style="list-style-type: none"> <li>○ 46% a little afraid</li> <li>○ 11% more severe fear</li> </ul> </li> <li>• FoF related activity avoidance increased with age, female gender, and number of falls in the last year.</li> <li>• Each increase of reported FoF was associated with an increased in activity avoidance and perceived negative falls consequences</li> </ul>

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## BIOGRAPHICAL SKETCH

Arlene Ann Schmid was born in Buffalo, New York, in December 1974. She was raised in the Buffalo area and completed a dual bachelor's and master's degree in occupational therapy from D'Youville College in 1997. Arlene worked for five years on the island of Oahu in Hawaii as a therapist in a variety of clinical settings. She entered the University of Florida rehabilitation science doctoral program in January 2002. During her doctoral career, she was awarded a prestigious VA Pre-doctoral Health Rehabilitation Research Fellowship to fund her dissertation research. Arlene plans to continue her research at the Indiana University Occupational Therapy Department and the Indianapolis Richard L. Roudebush VA Medical Center. She plans to complete research within the aging population, particularly looking at mobility issues and health promotion. Arlene enjoys artwork, reading, exercise, being outside, spending time with her family and friends, and playing with her two dogs.