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THE IMPACT OF ENVIRONMENTAL FACTORS ON CAREGIVER PERCEPTION FOR
CAREGIVING DYADS

by

ASHLEY HARRILL

Under the Direction of Candace Kemp

ABSTRACT

Data from the CG ASSIST program were evaluated to investigate whether modifying shared environmental factors within caregiving dyads influences caregiver perceptions. Revisions to the International Classification of Functioning, Disability, and Health (ICF) framework for cohabitating care-partners are proposed to emphasize the entwined connections between caregivers and care recipients. Eleven older Veteran care-recipients and their informal caregivers participated in a randomized controlled trial to evaluate whether an in-home training intervention with assistive technology influenced how caregivers perceived the level of assistance they provided and the level of care needed by their care-recipients. Caregivers who received the training (Training Group, n=6) perceived their assistance as more appropriate and more accurately assessed their care-recipient's needs than caregivers who were not trained (Novice Group, n=5). Though more research is needed, the proposed ICF revisions appear to be a viable framework to illustrate complex interactions within cohabitating caregiving dyads.

INDEX WORDS: Perception, Disability, Assistive technology, Caregiving dyads, Older adults, Level of assistance, Veterans

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by

ASHLEY HARRILL

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

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Georgia State University

2014

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Ashley Harrill
2014

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DEDICATION

I dedicate my thesis to Christopher Langston, John Baxter Harrill, and Olivia Ruth Harrill-Shaw. My fiancé, Chris, is a constant source of support and is the most patient person I know. Over the past two years he has weathered an impressive number of panicked moments, cooked countless dinners, brewed unending cups of coffee, and even coordinated appointments with our wedding vendors. It would be an understatement to say I am grateful to have him in my life, and I am elated to know we will share the rest of our lives together.

The first Veteran I ever loved, Grandpa J.B., lied about his age to enlist in the Navy during World War II. He became one of the first Navy Divers, and though he rarely spoke about the war, I remember having strangers from his town walk up to me when I was little to tell me my grandfather was a hero. At the time I thought this was because he could always find the best costume jewelry for his granddaughters, but now I know that is merely the tip of the iceberg. I am honored by the opportunity to work with the brave service men who served before, with and after my grandfather, and I am humbled by their dedication to this country and by their sacrifices.

Finally, during the process of writing this thesis my gorgeous niece, Olivia Ruth, came into this world and stole my heart. I knew I loved her before she was born, but I was not aware how powerful and limitless my love for her would be until six months ago when I first heard her voice. She has already taught me that unimaginable delights can always be just around the corner. I cannot wait to see what other lessons she has in store.

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LIST OF ABBREVIATIONS

ADL	Activity of Daily Living
AoA	Administration on Aging
AT	Assistive Technology
CG	Caregiver
CG ASSIST	Caregiving Assessment of Skill Sets & Individualized Support thru Training
CR	Care Receiver
FIM	Functional Independence Measure
HIPAA	Health Information Privacy and Authorization Act
IADL	Instrumental Activity of Daily Living
ICF	International Classification of Functioning, Disability and Health
IRB	Institutional Review Board—ethics board
LoA	Level of Assistance
NAC	National Alliance for Caregiving
NG	Novice Group
RR&D	Rehabilitation Research and Development
TG	Training Group
VAMC	Veterans Affairs Medical Center
VHA	Veterans Health Administration
WHO	World Health Organization

CHAPTER 1 : INTRODUCTION AND OVERVIEW

As US citizens live longer, there are higher rates of morbidity and higher numbers of older adults who require assistance to perform activities of daily living (ADLs). This assistance may be provided from a caregiver, an assistive device, or both (Agree & Freedman, 2003). Yet the majority of these caregivers are unpaid, informal caregivers who do not have adequate training in how to best provide assistance for their care recipients (National Alliance for Caregiving, 2009; Silva, Teixeira, Teixeira, & Freitas, 2013). As a result, many caregivers inadvertently provide inappropriate support or are unsure how to provide the support their care recipient needs.

Inadequate levels of assistance are reported most frequently with transfer tasks such as transferring in and out of bed, transferring on and off the toilet, and transferring in and out of the tub or shower (Desai, Lentzner, & Weeks, 2001). Care recipients have been found to have negative emotional reactions to assistance when too much or too little assistance is provided, which may result in increased burden for both care-partners (Newsom & Schulz, 1998). On the other hand, when caregivers provide an appropriate level of assistance, care recipients report encouraging outcomes such as a positive affect and good attitude towards their caregiver (DePaulo, Brittingham, & Kaiser, 1983). In turn, these outcomes may lead to an improved quality of life for the care recipient *and* the caregiver. An intervention is needed that will help caregivers to adequately assist care recipients with transfer impairments.

Some researchers propose that the best way to assist older adults who are not receiving the appropriate assistance from an informal caregiver is to introduce training

at the dyadic level—train both the caregiver and the care recipient simultaneously (Gitlin et al., 2003; Zarit, Femia, Kim, & Whitlatch, 2010). The terms *dyad* and *care-partners* are used interchangeably in this thesis, though there are slight differences in their etymology. *Dyad* refers to a social group composed of two people while *care-partners* specifically refer to the care recipient, in this sample a Veteran, and caregiver who rely on each other to perform the respective social roles. These terms are used to emphasize that the individuals often function as a social unit that is affected by various factors in tandem. Considering both care-partners in training is crucial because there is no way to provide training to a care recipient without impacting the caregiver—training both care-partners at the same time is more efficient.

Dyadic training should involve the proper use of assistive technology (AT) or devices and home modifications that may help the care recipient meet the demands of the environment when performing different tasks. When AT is used appropriately, care recipients report an increased sense of independence and task–efficacy, caregivers have reported reduced caregiver burden, and both care-partners have reported reduced physical strain and incidents of injury (Darragh et al., 2013; The Lewin Group, 2011; Sanford et al., 2006; [Scherer & Gleukauf, 2005). Unfortunately, AT is not always used, resulting in a high frequency of abandonment. For instance, Schere and Gleukauf (2005) found that 30% of AT is abandoned within a year of being acquired. The main ways to increase the appropriate use of AT are to: recommend the devices to the care-partners after observing them perform activities in their home, elicit feedback from both the caregiver and care recipient about the recommended devices, and obtain both care-partners' consent to install or provide the AT devices (Verza, Carvalho, Battaglia &

Uccelli, 2006). The CG ASSIST study, the parent study for this thesis, delivers an intervention that implements all of these considerations as described below.

CG ASSIST Project

This thesis examines a subset of data from the Caregiving Assessment of Skill Sets and Individual Support thru Training (CG ASSIST) project at the Atlanta VA Medical Center (VAMC). CG ASSIST employs an intervention involving in-home training on safely performing ADLs for older adult Veterans with transfer impairments and their informal caregivers. This training is implemented through either an in-person training or a remote tele-rehabilitation training mechanism. Informal caregivers provide un-paid assistance to Veterans who are care receivers. The study's training intervention focuses on training the care-partners to use assistive technology (AT), home modifications, and transfer techniques to safely, skillfully, and—when appropriate— independently perform three ADLs: getting in and out of bed, getting on and off the toilet, and getting in and out of the tub/shower. This training is provided by AT Experts who are proficient in recommending and training older adults in the appropriate use of AT and home modifications. Proficiency is established with either an Occupational Therapy license or more than 25 years of experience recommending AT and supervising transfers in older adults.

Thesis Project

CG ASSIST pilot data demonstrated that caregivers and AT Experts who implement the intervention, report different levels of assistance. This discordance is worrisome because care recipients may experience premature loss of functioning or increased risk of injury from undue strain when caregivers do not provide appropriate

assistance (Beck et al., 1997; Desai, Lentzner & Weeks, 2001; Newsom & Schulz, 1998; Rogers et al., 2000).

This study is unique from the larger CG ASSIST project because it compares the level of assistance caregivers report providing and the level of assistance caregivers report their care recipients need to perform transfer tasks. These reports are then compared to AT Expert observations of the assistance provided by the caregiver and needed by the Veteran. Furthermore, both informal caregivers and AT Experts are asked to answer open ended questions to gain a more comprehensive understanding of how the training intervention impacts caregivers' perceptions of care recipients' limitations. In turn, an influence on perception may provide further insight into how this training intervention is effective for caregiving dyads.

Purpose

This thesis investigates whether a dyadic intervention involving the provision of assistive technology and in-home training on how to safely perform transfer tasks influences caregivers' beliefs and perceptions about Veteran care recipients' needs.

This thesis contains five chapters. Following this introductory chapter, Chapter Two presents the theoretical framework and the literature review and concludes with a detailed statement of research aims and questions. Chapter Three presents the methods outlining the research design, measures, instruments, participant characteristics, sampling, procedures and analysis. It concludes with a statement of research aims and questions. Chapter Four addresses the three research aims and presents study findings. Finally, Chapter Five provides a reflection on the findings and includes the discussion and conclusions.

CHAPTER 2 : THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Literature Review

The American population is aging at an unprecedented rate. American adults 65-years-old and older made up 4.1% of the U.S. population in 1900, 13.1% of the U.S. population 2010, and are expected to make up 21.9% of the U.S. population in 2060 or 92.0 million people (Administration on Aging [AoA], 2012, p. 2-3; United States Census Bureau, 2012, Table 2). This demographic shift is largely due to increased life expectancy at birth, which has increased dramatically from 47.3 years in 1900 to 78.7 years in 2010 (National Center for Health Statistics, 2012). Accompanying increased life expectancy, however, is an increase in morbidity. In *A Profile of Older Americans: 2011*, the AoA reports that 16% of all older adults and 29% of adults over 80 need assistance performing an ADL as a result of a severe disability (2011, p. 15). Thus, as the number of older adults rises, so does the number of older adults who require assistance from either a caregiver, an assistive device, or both (Agree & Freedman, 2003). Yet the majority of these caregivers are unpaid, informal caregivers who do not have adequate training in how to best provide assistance for their care recipients (Parmelee & Griffiths, personal communication, September 9, 2013).

Resources needed to support this portion of the population are limited. In 2013 sequestration required budget reduction across most government programs including the Home and Community-Based Supportive Services and the Family Caregiver Support Services which are the largest government-run programs that provides services for older adults (Administration on Aging, 2013). Budget cuts for services as the

population ages means there is less money per capita available when older adults need assistance. Cost-effective interventions must be developed to meet the needs of older adults with disabilities.

Aging in place and the home environment. Aging professionals often refer to these additional supports in the context of *aging in place*, advocating to provide caregivers, assistive devices or other resources so older adults can continue to live in their communities and avoid institutionalization. In reality, most older adults identify stronger with *home* which is associated with “a sense of attachment or connection, practical benefits of security and familiarity, and ... [a] sense of identity through independence and autonomy” (Wiles, Leibing, Guberman, Reeve, & Allen, 2012, p. 364). Therefore, it follows that a person-centered approach is needed where assistance is made available in whatever location the older adult identifies as *home*. Interventions are needed that provide assistance in older adults’ homes. When assistance is needed, it is typically provided through a device (assistive technology), personal assistance (caregivers), or a combination of the two (Agree & Freedman, 2003). These resources are discussed below.

Assistive technology. While assistive technology (AT) can refer to numerous types of equipment and devices, the Assistive Technology Act of 1998 states,

The term “assistive technology device” means any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. (Assistive Technology for Individuals with Disabilities, 1998).

Some examples of these devices are bath benches, wheelchairs, three-in-one commodes, bed rails, shower chairs, and grab bars. Essentially, these are devices that help bridge the gap between the functional limitations of the individual and the demands of the environment.

Potential benefits of properly using of AT include increasing independence for the impaired older adult, reducing physical strain and burden for caregivers, reducing injuries for caregivers and care receivers, and increasing ADL task-efficacy for care receivers (Darragh et al., 2013; The Lewin Group, 2011; Sanford et al., 2006; Scherer & Gleukauf, 2005). When AT users were asked how they felt about their devices, 94% reported that the equipment “supported them and improved their quality of life” (Scherer, Craddock, Mackeogh, 2011, p 816).

On the other hand, Becker, Wahl, Schilling, and Burmedi (2005) looked at older adults beliefs about using AT. They found that sometimes, “assistive devices are a clear symbol of competence loss to oneself and others, which may nurture a tendency not to use them” (p. 745). This tendency is often referred to as AT disuse or AT abandonment may lead to an increased risk of harm for the user if AT is needed to perform the activity safely. About 30% of AT is abandoned within a year after it is acquired which negates any benefits from AT use and wastes the valuable resources used to obtain the AT when resources for older adults are already limited (Scherer & Glueckauf, 2005).

The best ways to reduce AT abandonment are to involve the AT user—the caregiver, care receiver, or both, depending on who is using the equipment—in the selection of AT, train the AT user to use the equipment properly in his or her own home, and consider both what the AT user needs and wants (Darragh, et al., 2013; Scherer &

Glueckauf, 2005; Verza, Carvalho, Battaglia & Messmer, 2006). Furthermore, Mann, Ottenbacher, Fraas, Tomita and Granger (1999) found that interventions involving AT and environmental modifications facilitated aging in place by reducing the cost of healthcare and decreasing healthcare provider visits. There are clear advantages to providing AT to older adults who need assistance, but any intervention that provides this type of equipment needs to work closely with the impaired older adult's caregiver. Otherwise, if the caregiver disapproves of the equipment, the AT will not benefit the care recipient because it will not be used.

Caregivers. As the number of older adults rises, so will the number of caregivers. The AARP Public Policy Institute [AARP] Report (2011) states that at some point in 2009 one in five members of the US population cared for an adult with an ADL limitation. The vast majority were informal, or unpaid, caregivers who are given the difficult task of deciphering what type of care a loved one needs often without any formal training. If these caregivers were to be compensated, their value is estimated at 450 billion dollars; in Georgia alone informal caregivers are valued at 13.1 billion dollars (AARP Public Policy Institute, 2011; Houser & Gibson, 2007). These informal caregivers often provide enough assistance to permit older adults to age in place and stay out of institutions.

The valuable resource found in informal caregivers is at risk because, compared to non-caregivers, caregivers have more depressive symptoms, higher stress, lower self-efficacy and lower subjective well-being that may interfere with the quality of care the caregiver is able to provide (Pinquart & Sorensen, 2003). This trend is often referred to as caregiver stress or caregiver burden. Extensive research has been

conducted to identify these informal caregivers and their unmet needs so they may continue with their invaluable work.

Costs of caregiving. While caregiving can be a rewarding experience, caregivers unfortunately are at risk of experiencing several potentials costs of caregiving. These risk factors are a cause for concern because as the population ages the level of assistance with ADLs/IADLs and level of cognitive or physical impairment of caregivers is expected to rise (NAC, 2009; AoA, 2011). Often interventions focus on helping caregivers so they can in turn provide the assistance care recipients need. However, Schulz et al. (2009) found that interventions that are directed at both the caregiver and the care recipient are more beneficial for both members of the dyad. Identifying interventions that support informal caregivers and care recipients simultaneously produces larger benefits for both care-partners, though a dyadic approach alone is not sufficient to eliminate the risk of injury.

Parmelee and Griffiths (personal communication, September 9, 2013) discovered a potential cause of injury after interviewing caregivers of care recipients who required assistance with tasks because of a mobility or transfer impairment. Many of the informal caregivers for these care recipients provided significant assistance with ADLs, yet report receiving little or no training in how to help the care recipients with transfer tasks. Caregivers who need more education on caregiving tasks are nearly twice as likely to experience injury (Hinojosa & Rittman, 2009). This injury may be caused by improper lifting techniques, trip hazards in the environment, or poor communication between the caregiver and care recipient. Brown and Mulley (1997a, p. 22) found that 67% of caregivers experienced an injury such as back pain, muscular aches and pains, hernias,

or twisted knees and 39% of care recipients were injured due to a fall or collision with equipment. These injuries could be prevented with proper training, though this training is often provided in a hospital setting where care recipients are taught to perform basic ADLs rather than in the home where these tasks will actually occur.

An intervention intended to reduce injury must also consider the context of the environment where the training occurs. Hospital bathrooms typically have grab bars, lever handles, and wide door ways to allow wheel chairs to pass through, but many homes do not have these features. In addition many caregivers are in a position where AT devices (grab bars, raised toilet seats) or home modifications (widened doorways, tracks for overhead lifts installed) are needed, but cannot be easily acquired due to limited funding or complicated eligibility requirements for programs where resources are available (Pynoos & Nishita, 2003). To solve this issue, many caregivers improvise and make their own AT and home modifications. For example, Brown and Mulley (1997b) reported several cases where hazardous conditions or injuries occurred after using home-made devices: one caregiver created an overhead lift that produced acid fumes after continuous charging, another caregiver injured herself pulling her father out of a makeshift bath tub made from a large plastic bin, and a third caregiver injured his neck and back after using a towel and belt to lift his wife (pp. 35-36). Clearly home evaluations are needed to observe how these tasks are performed on a daily basis and to ensure dyads are performing tasks safely with the resources available to them.

Another factor that influences the risk of injury is the caregiver's perception of how much assistance the care recipient needs. Care recipients in a nursing home experienced excess disability, or premature loss of functioning, when caregivers

provided more assistance than necessary (Beck, et al., 1997). Newsom and Schulz (1998) found that 40% of care recipients had a negative emotional reaction to assistance when caregivers provided too much or too little help which may interfere with the efficacy of care provided (p.178). Conversely, when an appropriate level of assistance is provided, care recipients report a more positive affect and better attitude towards their caregiver improving the quality of their relationship (DePaulo, Brittingham, Kaiser, 1983). Informal caregivers' unmet need for knowledge and training on how to provide appropriate levels of assistance is a problem that affects both care-partners. Consequently, interventions that increase caregivers' abilities to provide the appropriate level of assistance are needed. Risk factors for informal caregivers include: the need for greater assistance with ADLs or IADLs, a spousal relationship to the care recipient, and greater cognitive or physical impairment of the caregiver (Beach, et al., 2005).

Veteran caregivers. Veterans are a special population with unique needs, and so are their caregivers. Veterans have increased levels of stress and anxiety (88%) and sleep deprivation (77%) compared to other care recipients (NAC, 2011). These stressors exist despite Veterans generally having access to more resources than civilians through the Veteran's Health Administration (VHA). One study found that Veterans used outpatient services exclusively through the VHA 18% of the time or through the VHA and Medicare 46% of the time (Hynes et al., 2007). Eligibility to VA services are based on Veteran status, connection of a disability to service, and income level among other factors. With these criteria, the VHA by nature primarily serves vulnerable populations. Providing care to these Veterans increases the probability of experiencing several negative caregiving outcomes as listed in Table 2.1. Moreover,

caregivers of Veterans experience emotional stress, physical strain, work-interruption, and financial hardships significantly more often than caregivers of non-Veterans (NAC, 2011).

Table 2.1 Impact of Caregiving on Veteran and Non-Veteran Caregivers (NAC, 2011)

<u>Negative Caregiving Outcomes</u>	<u>Caregivers of Veterans (N=462)</u>	<u>Caregivers of Adults Nationally (N=1307)</u>
High emotional stress	68%	31%
High physical strain	40%	14%
Stopped working/early retirement	47%	9%
High financial hardship	50%	13%

One potential explanation for this finding is that this segment of the population is more likely to meet the risk factors listed below. In Veteran populations, nine in ten (96%) of caregivers of Veterans are female and 70% provide care to their spouse or partner. Nearly one third (30%) of Veterans' caregivers remain in this role for ten years or more compared to only 15% of caregivers nationally (NAC, 2011). Finally, Veteran caregivers provide assistance with multiple ADLs including transferring in and of bed, bathing and toileting (NAC, 2011). Unfortunately, most Veterans with a spinal cord injury who require assistance with transfer ADLs reported that if the caregiver were unable to care for them, there was not anyone else who would be able to provide assistance (Robinson-Whelen & Rintala, 2003). An intervention is needed that focuses on assisting Veteran caregivers with these specific tasks.

Intervention

The intervention as implemented in the CG ASSIST project begins with a home visit where AT Experts makes individualized recommendations for AT, home modifications, and specific training techniques prior to implementing the intervention.

The AT Experts only recommend AT that directly assists the Veteran and caregiver to get in and out of bed, get on and off the toilet, or get in and out of the tub or shower after observing how these activities are performed. To increase the acceptance of these devices, both members of the dyad are involved in the discussion about what AT devices are provided (Johnston & Evans, 2005). Concerns from the Veteran *as well as* the caregiver are addressed when discussing these AT recommendations to minimize the risk of AT abandonment. When training the dyad on using new techniques, the AT Expert provides hands-on training by demonstrating what the caregiver should do while the caregiver plays the role of the Veteran care recipient. Lobchuk (2005) proposed that this perspective-taking process may improve how accurately caregivers perceive their care recipients' needs.

In the CG ASSIST pilot, caregivers and AT Experts reported how dependent care recipients were on caregivers to perform ADLs. Informal caregivers provided a subjective self-report while AT Experts provided an objective report. At baseline these reports only agreed on the ADL assistance provided for 32% of all observed tasks implying that caregivers are not providing the appropriate level of assistance (Griffiths, Sanford & Connell, 2009). However, objective reports by the AT Experts were not collected post-intervention so it is unclear what impact the intervention had on the actual assistance caregivers provided. It is expected that an in-home training intervention at the dyadic level will increase this agreement illustrating caregivers are providing appropriate assistance for more transfer tasks.

Caregivers who believe they are providing too little assistance but are actually providing too much assistance may underestimate the care recipient's ability. On the

other hand, caregivers who believe they are providing too much assistance but are actually providing too little assistance may overestimate the care recipients' ability. Many caregivers who underestimate the level of assistance needed will provide more assistance than is necessary. This places undue strain on the caregivers and increases the chance of atrophy and excess disability for the care recipient (Desai, Lentzner & Weeks, 2001; Rogers et al., 2000). When caregivers overestimate the level of assistance needed they may be inclined to provide less assistance than is necessary. This misperception can have negative consequences for the care recipient which may lead to pain and discomfort, injury including pressure ulcers and burns, and increased hospitalizations for the care recipient (Desai, Lentzner & Weeks, 2001; Sands et al., 2006).

One way to examine caregiver perception is to consider whether the caregiver believes appropriate assistance is provided. Norris, Stephens and Kinney (1990) stated appropriate assistance involves "providing no more or less assistance than what the patient (CR) needs" (p. 540). This can be accomplished by comparing reports for how much assistance is provided by the caregiver with reports of how much assistance is needed by the care recipient. Dassel and Schmitt (2008) investigated perceived ADL performance reported by caregivers and care recipients with cognitive impairments and found caregivers' cognitive functioning may impact the accuracy of caregiver reports. Objective and subjective measures of ADL performance can be used to assess whether a training program can increase the accuracy of caregivers' perceptions (Dassel & Schmitt, 2008). One study by de Jong-Hagelstein, Kros, Lingsma, Dippel, Koudstaal, and Visch-Brink (2012) used expert ratings to operationalize objective reports and

proxy-caregiver ratings to operationalize subjective reports for individuals with aphasia. Using these metrics, there was moderate agreement between the two ratings, particularly when the patient had mild aphasia (de Jon-Hagelstein et al., 2012). Ferri and Pruchno (2009) found the patient's health status also impacted a spouse's perceptions of the patient's functional ability, which in turn was positively correlated with the caregivers' reported quality of life. Increasing how accurately caregivers perceive care recipients' needs has many positive consequences including decreased caregiver stress, increased emotional support, and decreased negative reactions to care recipient demands (Martire et al., 2006).

Theoretical Framework

Two theoretical orientations are combined to create a comprehensive framework to evaluate how society influences caregivers' perceptions of older care recipients' abilities: the Social Construction Theory of Aging and the International Classification of Functioning, Disability and Health (ICF) (Gubrium & Holstein, 1999; WHO, 2001).

Social Construction Theory of Aging. The Social Construction Theory of Aging establishes that all individuals perceive the world differently by extracting meaning from ideas or constructs that are socially contrived (Gubrium & Holstein, 1999). An individual's point of view is the most important social construct and is created because individuals are social beings. Social constructs influence how an individual interprets and derives meaning from the social world (Gubrium & Holstein, 1999). For example, *dependence* is a construct to which an individual subscribes meanings based on societal norms and stereotypes. One individual may perceive *dependence* on a caregiver to mean a problem, weakness or deficiency. Another person may perceive

dependence upon a caregiver to mean freedom from responsibility, closeness to their partner, or an expected and accepted role transition. The manner in which an individual perceives this construct depends on the individual's societal influences. Another common social construct is *disability* which is often interpreted to mean different, incapable, or deficient (Anastasiou & Kauffman, 2011). Over half of individuals 75 and older report some type of disability (Brault, 2008). There is a tendency to classify older adults as either those undergoing *successful aging* or as the *frail elderly* (Richardson, Karunanathan, & Bergman, 2011). Which category a care recipient belongs in depends on how the caregiver perceives the constructs.

The term *successful aging*, oversimplified to mean having no disability, was coined by Rowe and Kahn (1987) to show that there is a positive side to aging. The construct is often manipulated to imply that if one does not meet Rowe and Kahn's criteria then one has failed at aging and hence is a *frail elder*. However, Richardson et al. (2011) highlight that while others may be perceived as *frail*, most older adults consider themselves to be *aging successfully* regardless of whether they identified as having a disability. An individual's perception of these constructs may even influence longevity. One study found that individuals who had a positive perception of themselves actually lived longer than individuals who had a negative self-perception (Levy, Slade, Kunkel, & Kasi, 2002). It stands to reason that a caregiver's perception of their limitations impacts their health, and how a caregiver perceives a care-partner's limitations will in turn impact his or her health.

International Classification of Functioning, Disability, and Health. The International Classification of Functioning, Disability and Health (ICF) is a framework

developed by the World Health Organization (WHO) as an integrative model that incorporates multi-disciplinary health perspectives. This framework illustrates the complex interactions between an individual's physical state, tasks, engagement with the world, environmental influences, and characteristics and how these interactions affect how the individual experiences life with a disability (Escorpizo & Stucki, 2013). Figure 2.1 below illustrates the ICF model of disability.

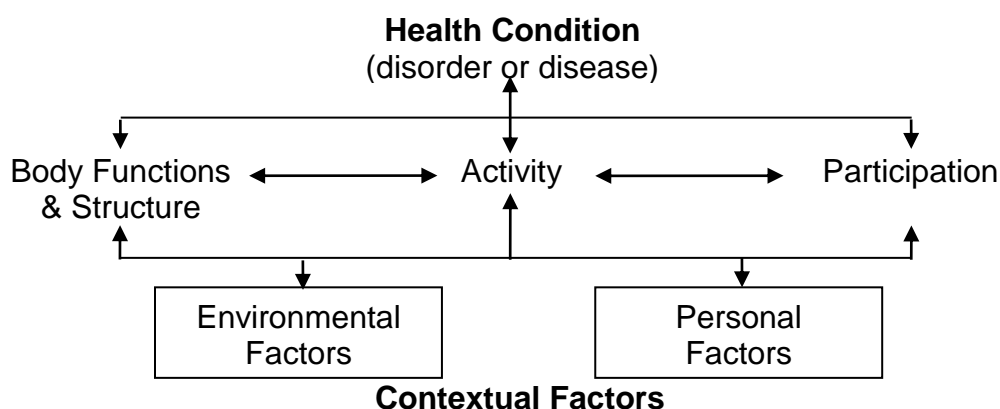


Figure 2.1 International Classification of Functioning, Disability & Health (WHO, 2002)

The model begins with the individual's health condition. This condition is affected by three dimensions of functioning: body functions and structures (physiology and anatomy), activities (executing tasks), and participation (engagement in life situations) (WHO, 2001). Body functions and body structures may have a loss or abnormality referred to as impairment; activities may be difficult to perform referred to as limitations; participation in life events may require overcoming barriers referred to as restrictions (Cieza & Stucki, 2005). In turn, these dimensions interact with environmental factors such as AT, home architecture, culture and resources, and personal factors such as gender, age, attitudes and beliefs, coping style, self-efficacy, and dependence known

collectively as contextual factors (Khan & Pallant, 2007; WHO, 2001). Contextual factors also influence each other. For instance, an individual with diabetes mellitus may use a raised toilet seat (environmental factor: AT) when toileting, but hide the device when grandchildren visit because he is embarrassed by the equipment (personal factor: attitudes and beliefs).

Hamed, Tariah and Hawamdeh (2012) interviewed individuals with multiple sclerosis using the ICF model and found positive feelings, social support, and community awareness improved the perception of their functioning, while negative feelings and social stigma worsened the perception of functioning. Societal and cultural influences are found throughout the ICF model in the environmental factors (cultural expectations), personal factors (attitudes and beliefs), and participation (engaging with family, friends, and society) to illustrate the numerous ways social norms impact how an individual experiences a health condition. The social support that improves function and the social stigma that impedes function are based on the perception of the community, indicating how others perceive an individual with a disability impacts the individuals functioning (Hamed, Tariah, & Hawamdeh. 2012).

ICF model for care-partners. The World Health Organization (WHO)

acknowledges that an individual's health condition can have a direct impact on a family

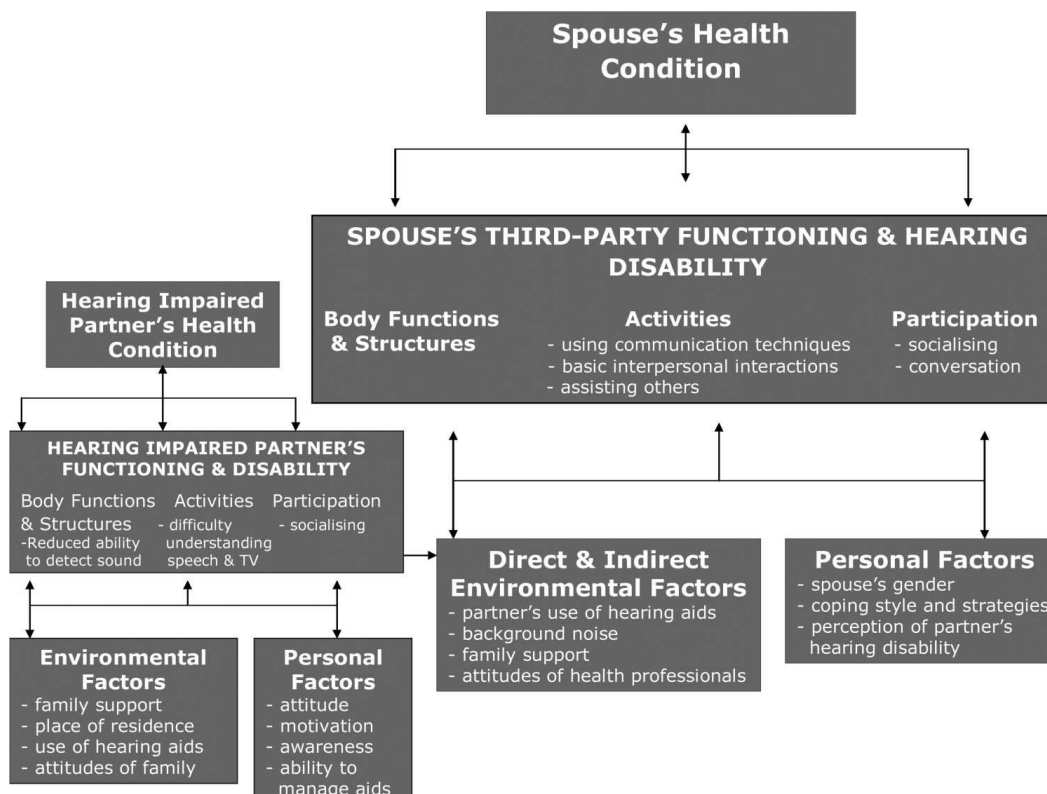


Figure 2.2 Illustration of Third-Party Disability Using the ICF Model

Reprinted from "The ICF and Third-party Disability: Its Application to Spouses of Older People with Hearing Impairment," by Scarinci, Worrall and Hickson, 2009, *Disability and Rehabilitation*, 31(25), p. 2091. Copyright 2009 by Taylor & Francis Ltd.

member's health and functioning, as a *third-party disability* (WHO, 2001). Scarinci, Worrall and Hickson (2009) illustrated *third-party disability* in Figure 2.2. In this depiction of third party disability, an individual with a hearing impairment's functioning and disability impact a spousal caregiver's environmental factors. This illustration suggests a single pathway through which third-party disability occurs.

However, within a dyad, interactions are dynamic and much more complex than depicted in the Scarinci, Worrall and Hickson (2009) model, particularly when the family member lives with the individual experiencing the health condition. Some of these

complexities are depicted in the alternative model of the ICF framework for cohabitating dyads shown in Figure 2.3. The key in Table 2.2 describes the relationships between

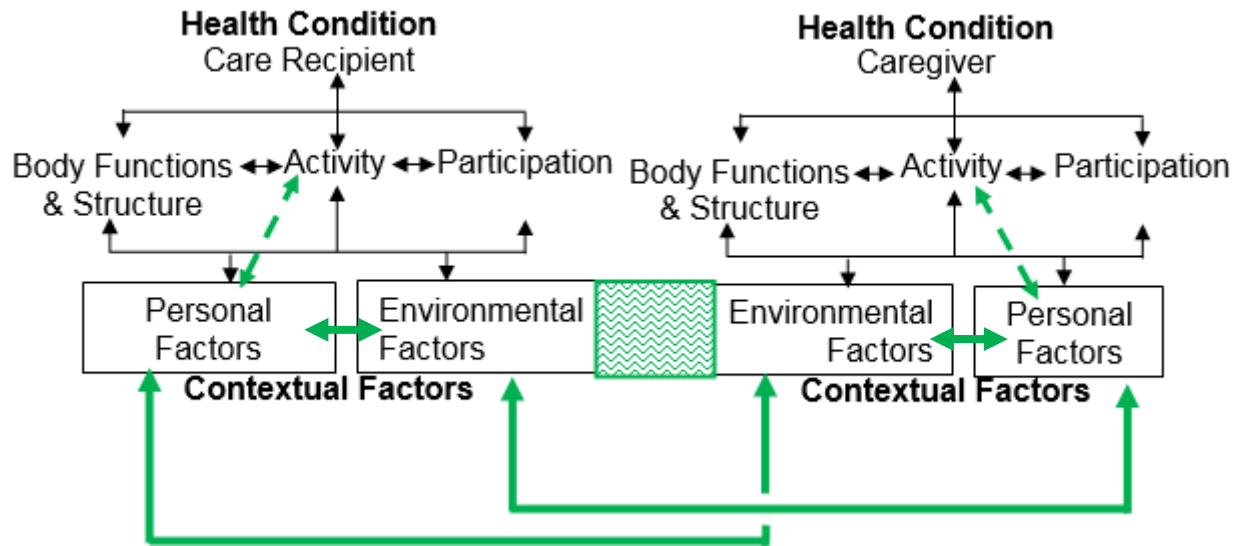





Figure 2.3 Modified ICF Framework for Caregiving Dyads

Table 2.2 ICF Key and Example

Symbol	Description	Care Recipient (CR) Spinal Cord Injury	Caregiver (CG) Rheumatoid Arthritis
	1) Shared environment	Shared: assistive technology (raised toilet seat, grab bars), bathroom Individual: assistive technology (wheelchair), personal resources (training from VA, sorority)	
	2) Reciprocal influence of personal factors and activity	CR believes CG will hurt herself if she assists with toilet transfer → CR attempts to complete toilet transfer on own and completing transfer is a struggle	CG's believes CR does not want her help with toilet transfer, and is frustrated with CR → CG tries to provide stand by assistance but only angers CR
	3) Reciprocal influence between and within contextual factors	CR refuses to have CG in bathroom when undressed → CG acts against cultural norms and does not assist CR	CG believes CR is safer completing toilet transfer on his own with a motorized Hoyer lift → Both CG and CR must use retirement savings to pay for the lift

an example dyad where a care recipient has paraplegia and a caregiver has rheumatoid arthritis. For this dyad, the personal factors are care recipient's and the caregiver's perceptions, beliefs and attitudes, the activity is transferring to and from a toilet, and the environmental factors are assistive devices, training, and the home.

First, because the dyads are cohabitating, many environmental factors are shared (shared assistive devices, bathroom) while others are unique to the individual (personal assistive technology and resources available to one care-partner). Second, there is the reciprocal relationship between personal factors and activities (Yeung & Towers, 2013). The care recipient's belief that the caregiver will hurt herself if she assists him with transfers means the caregiver is not given the opportunity to provide the assistance needed by the care recipient, which may frustrate the caregiver and cause issues with their relationship. Third, there is a reciprocal relationship between the care recipient's and caregiver's contextual factors, but also within each individual's environmental and personal factors. The perceptions or beliefs of one member of the dyad impacts the environmental factors and activities of both care-partners (Yeung & Towers, 2013).

The ICF framework and the Social Construction Model of Aging provide a perspective to study the in-home training intervention. This intervention, depicted in Figure 2.4 as a grey arrow, directly influences the environmental factors shared by the

dyad. Martire et al. (2006) found that caregivers who accurately perceived care

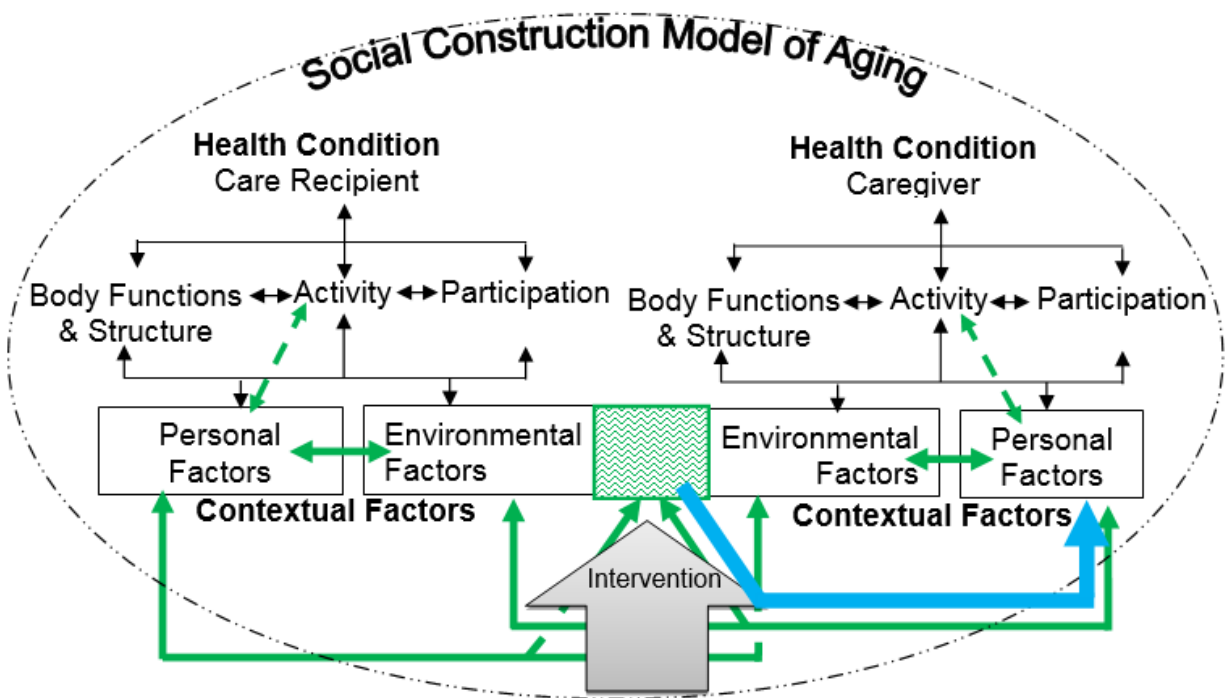


Figure 2.4 Presence of Intervention Effects on ICF Framework with Caregiving Dyads within Social Construction Model of Aging

recipients' pain were less negative and provided better support than caregivers who had inaccurate perceptions of care recipients' pain. Furthermore, caregivers who accurately perceived care recipient pain reported less stress and possibly less caregiver burden (Martire, et al., 2006). However, whether caregiver perceptions are impacted by changes in environmental factors is unknown. The Social Construction Model of Aging is crucial in studying perception, because the each individual's perception of various constructs is the reality for that individual. This thesis focuses on whether environmental factors impact one particular personal factor: caregiver perception.

Research Aims

The purpose of this study is to evaluate the effectiveness of a dyadic intervention—involving the provision of assistive technology and in-home training on how to safely perform transfer tasks—on caregivers' perceptions of assistance provided to Veteran care recipients. The research aims are as follows:

Aim 1: To understand caregivers' perceptions of the care given and required.

- (a) How do caregivers perceive the level of assistance they provide?
- (b) How do caregivers perceive the level of care needed by their Veteran care recipients?
- (c) How do caregivers perceive the appropriateness of their assistance?

Aim 2: To investigate intervention effects on caregivers' perceptions.

- (a) How does the intervention influence the caregivers' ability to accurately assess care recipients' needs?

Aim 3: To identify how shared environmental factors impact perceptions.

- a) How do environmental factors impact the accuracy and appropriateness of caregiver perceptions?

CHAPTER 3 : METHODS

This study is a subset of the VA Rehabilitation Research and Development-funded randomized controlled trial with an in-home training intervention for Veteran-caregiver dyads. Original data were collected from face-to-face interviews with open- and closed-ended questions that were added to the CG ASSIST project to meet the research aims discussed above.

Research Design

A mixed methods, randomized controlled trial design was used to exam how in-home training influences how caregivers perceive the level of assistance care recipients receive and need. Quantitative and qualitative data assessments were collected simultaneously during the baseline visit in Stage 1 and the outcomes visit in Stage 4 as illustrated in Figure 3.1.

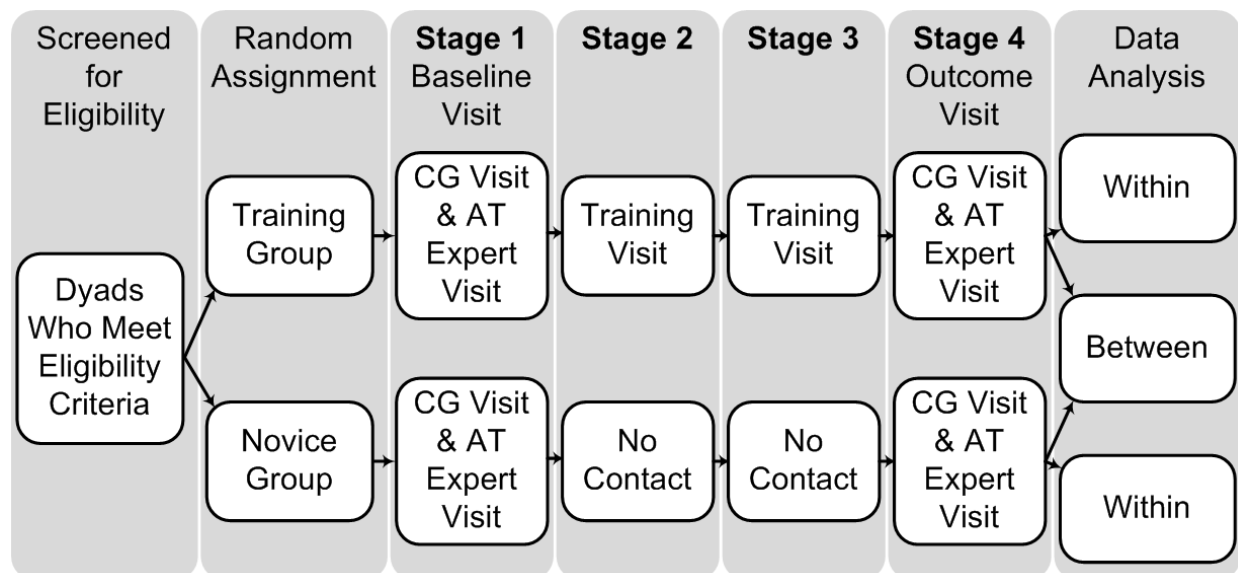


Figure 3.1 Research Schema

Measures

Data were collected from both informal caregiver self-reports and AT Expert observation-based reports. Table 3.2 below describes the variables and measures used in this study, data source, data type and the research aim addressed for each measure.

Table 3.1 Description of Measures and Associated Research Aims

Instrument	Description	Data Type	Research Aim
Modified FIM	Informal CG level of assistance <u>provided</u>	Ordinal	1, 2
	Informal CG level of assistance <u>needed</u>		1, 2
	AT Expert level of assistance <u>provided</u>		2
	AT Expert level of assistance <u>needed</u>		2
Description of Environmental & Social Factors	Societal influence (on assistance, perception of equipment, comfort) from CG	Nominal	3
	Societal influence (on assistance, perception of equipment, ability, comfort, relationship, resources) from AT Expert	Nominal	3

Primary outcomes. The primary outcome measure for this study is the FIM score for the level of assistance provided as reported by the informal caregiver and the AT Expert for each transfer task completed. The impact of the intervention on changes in the level of assistance provided are determined by comparing the reported LoA provided at baseline and outcomes assessments (Aim 1). Where a FIM score of 7 indicates “No Assistance” and a FIM score of 1 indicates “Total Assistance,” the following are the possible changes: 1) if the FIM score at baseline is lower than the FIM

score at outcomes, there is less assistance provided during outcomes, 2) if the FIM score is the same at baseline and outcomes, there is no change in the level of assistance provided, or 3) if the FIM score at baseline is higher than the FIM score at outcomes, there is more assistance provided during outcomes.

Secondary outcomes. Table 3.3 illustrates how a secondary outcome for this study, the appropriateness of the assistance provided, is computed comparing the level of assistance (LoA) provided and the LoA needed (Aim 2). The LoA provided is classified as being appropriate if the LoA provided by the caregiver matches the LoA needed by the Veteran care recipient. If there is more assistance provided by the caregiver than is needed by the Veteran, the caregiver provided too much assistance. On the other hand, if there is less assistance provided by the caregiver than is needed by the Veteran, the caregiver did not provide enough assistance.

Table 3.2 Calculating Appropriateness of Levels of Assistance Provided

Perspective	Primary Outcome (<i>provided</i>)		Primary Outcome (<i>needed</i>)	Result	
Caregiver	Level of Assistance Provided	>	Level of Assistance Needed	Perceived level of assistance	Too much assistance
		=			Just right amount of assistance
		<			Too little assistance
AT Expert	Level of Assistance Provided	>	Level of Assistance Needed	Actual level of assistance	Too much assistance
		=			Just right amount of assistance
		<			Too little assistance

The final secondary outcome is the accuracy of the caregiver's appraisal of care recipient's ability status, as shown in Table 3.3. This outcome is calculated by comparing the AT Expert reported appropriateness of assistance with the informal caregiver reported appropriateness of assistance. If the AT Expert reports the LoA is higher than the LoA reported by the informal caregiver, the caregiver underestimated the care recipient's ability which can lead to excess disability (Omu & Reynolds, 2012). On the other hand, if the actual level of assistance is lower than the perceived level of assistance, the caregiver overestimated the care recipient's ability. As a result the care recipient is at increased risk of injury, excess disability and hypertrophy (Griffiths &

Table 3.3 Caregiver's Perception of Care Recipient's Ability Status

AT Expert Appropriateness of LoA	CG Appropriateness of LoA	Caregiver's Appraisal of Care Recipient's Ability	Accuracy of perception
Too much assistance ↑	↑	accurately estimates	Increased stress/burden
	=	under-estimates	Increased risk of injury for CG Increased risk of atrophy for CR
	↓	dramatically under-estimates	
Just enough assistance =	↑	under-estimates	GOAL
	=	accurately estimates	
	↓	over-estimates	Increased risk of injury, excess disability, and hypertrophy to CR
Too little assistance ↓	↑	dramatically over-estimates	
	=	over-estimates	
	↓	accurately estimates	Increased stress/burden

Sanford, 2013). The caregiver accurately perceived the care recipient-Veteran's abilities when the actual and perceived levels of assistance matched.

The quantitative data discussed above only allows caregiver's perceptions to be categorized—there is no insight provided as to how or why these perceptions and misperceptions occur. In order to determine whether and how societal constructs influence these perceptions, open ended interview questions and probing questions were needed.

The interview (see Appendix B) explored the contributing characteristics to the effects the intervention had on caregiver's ability to provide appropriate levels of assistance. In turn these factors are used to investigate why the intervention affected caregiver's ability to provide appropriate levels of assistance. These constructs also provide more information to understand whether the intervention impacted how accurately caregivers perceive the care recipients ability status.

Instruments

Functional Independence Measure. A modified version of the Functional Independence Measure (FIM) was used for quantitative analysis (Keith, Granger, Hamilton, & Sherwin, 1987). The original FIM is a self-report measure with high internal consistency ($\alpha=0.93$) used to rate one's own level of independence (Dodds, Martin, Stolov, & Deyo, 1993). For this study, questions were modified to allow a second party rater to rate the Veteran care recipient's functioning. Rather than reporting their own dependence, caregivers and AT Experts reported second-hand the level of assistance that was *provided* by the caregiver and the level of assistance the care recipient

needed. Only questions that referred to the three ADLs observed were used. The original FIM listed ADLs and asked for a score on the 7-point¹ Likert scale for each ADL². Data from the CG ASSIST pilot revealed confusion and inconsistencies in how caregivers reported this information. To assist informal caregivers with this measure, this scale was broken into three questions whose answers map directly onto the original FIM scale as seen in below in Table 3.1. For consistency, both informal caregivers and AT Experts were asked to respond to three parallel questions (see Appendix A).

Table 3.4 How Original FIM Scores Map on to Questions Answered in Modified FIM

Original FIM Scores	Modified FIM Questions		
	Q1: Personal Mobility Devices?	Q2: Kind of Assistance?	Q3: Level of Physical Assistance?
7= Complete independence	No	None	N/A
6=Modified independence	Yes	None	N/A
5=Supervision or set-up	No or Yes	Verbal/Standby Only	N/A
4=Minimal Contact Assistance	No or Yes	Physical	Minimal Assistance
3=Moderate assistance	No or Yes	Physical	Moderate Assistance
2=Maximal assistance	No or Yes	Physical	Maximal Assistance
1=Total assistance	No or Yes	Physical	Total Assistance

¹ The original FIM has an 8-point Likert scale, 0-7, where a '0' means an activity did not occur. For the purposes of this study, if the activity did not occur, no data was collected and the FIM was scored as 'N/A', or Not Applicable).

² 1=Total assistance, 2=Maximal assistance, 3=Moderate assistance, 4=Minimal contact assistance, 5=Supervision or set-up, 6=Modified independence, 7= Complete independence.

The measures were divided by ADL so that each of the subsequent questions was asked first in the context of getting in and out of bed, then getting on and off the toilet and then getting in and out of the bath or shower. First caregivers were interviewed. Then the AT Expert asked the caregivers and care recipients to perform these activities—with clothes on!—so the AT Expert could observe and report the level of assistance provided and needed for each task.

The first question for the informal caregiver was whether the Veteran uses a personal mobility device³ to complete the ADL. The informal caregiver then reported what kind of assistance⁴ she provides and if applicable how much physical assistance she provides⁵. These scores combine to provide a global FIM score for the level of assistance the caregiver *provided* during the task. These baseline and outcomes scores are compared to determine if there is any change in the level of assistance the caregiver believes she provides. Next, the informal caregiver was asked whether the Veteran needs a personal mobility device, what kind of assistance the Veteran needs to perform the task, and how much physical assistance the Veteran needs to complete the task. These scores combine to provide a global FIM score for the level of assistance the care recipient *needed* during the task. These baseline and outcomes scores are compared to determine if there is any change in the level of assistance the caregiver believes her care recipient needs. Higher FIM scores indicate more independence. If the FIM score for the level of assistance (LoA) provided for

³ Wheelchair, walker, cane, orthotic/prosthetic device, or crutches.

⁴ 0=None, 1=Only verbal prompting, standby assistance, or setup, 2=Physical assistance

⁵ Caregiver assists by performing ___ of task: (4)Minimal=<25, (3)Moderate=25-50%, (2)Maximal=51-75%, (1)Total=>75%.

getting in and out of bed was higher than the FIM score for the LoA needed to get in and out of bed, the caregiver was providing too much assistance. If opposite LoA patterns are reported, the caregiver was providing too little assistance. And finally, if the caregiver provides the level of assistance needed, the caregiver was providing an appropriate level of assistance.

The questions the AT Expert responds to about the dyad performing the observed activities closely mirror the informal caregiver questions to maintain validity when comparing the scores. The first question was whether the Veteran used a personal mobility device to complete the ADL. The AT Expert then reported what kind of assistance the caregiver provided, and if applicable how much physical assistance the caregiver provided. These scores combine to provide a global FIM score for the level of assistance the AT Expert reported the caregiver *provided* for each task. Next, the AT Expert was asked whether the Veteran needed a personal mobility device, what kind of assistance the Veteran needed to perform the task, and how much physical assistance the Veteran needed to complete the task. These scores combine to provide a global FIM score for the level of assistance the AT Expert reported the care recipient *needed* for each task.

Differences between the LoA *provided* and the LoA *needed* as reported by the informal caregiver indicate whether the caregiver perceived she was providing the appropriate level of assistance. Then again, differences between the LoA *provided* and the LoA *needed* as reported by the AT Expert indicate whether the AT Expert observed the caregiver providing an appropriate level of assistance. In other words, these scores

indicate if the caregiver and the AT Expert believed too much, too little, or just enough support was provided—or the appropriateness of the LoA provided.

Comparing the caregiver's beliefs about the appropriateness of the LoA provided with the AT Expert's beliefs about the appropriateness of the LoA provided determined how accurately the caregiver perceives the care recipient's level of ability. The comparison of outcomes assessments for the Training Group (TG) and Novice Group (NG) are used to determine the effect of the intervention on caregiver's ability to accurately perceive care recipient's ability status, and to provide appropriate levels of assistance.

Expert interviews. The interview for AT Experts consisted of fifteen questions, five for each ADL, and is identical for baseline and outcome assessments. AT Experts were asked about the factors which lead them to score the LoA needed as they did since this measure is based on their expertise. They were then asked what the differences, if any, are between the LoA provided and the LoA needed. These questions help to understand what actually happened when AT Experts observe the dyad performing ADLs. The next question was about the Veteran's acceptance of any AT used for each ADL. For caregivers in the Novice Group these responses only concerned AT that was already acquired, and for caregivers in the Training Group these responses concerned both AT that was already acquired at baseline and AT provided by the intervention. This question was intended to provide an alternative perspective for insight into what factors influenced AT acceptance. The AT Expert was then asked about the care-partners' relationship. A change in how well the care-partners work together is expected for caregivers in the Training Group. This question was intended to

investigate whether the intervention improves dyads' ability to work together. Finally, the last question asked if any AT was recommended that is not typically provided to address any unforeseen anomalies.

Informal caregiver interviews. The interview for caregivers consisted of nine questions at baseline, three for each ADL. The first question gauged why these caregivers believed they were providing too much, too little, or an appropriate level of assistance. The second question was about the Veteran's acceptance of assistive technology. Caregivers in the Novice Group and the Training Group were asked about the acceptance of existing AT in the home, and caregivers in the Training Group provided insight about the acceptance of AT provided through the intervention. One additional question was asked during the outcome visit about whether the level of assistance the Veteran care recipient needed from the caregiver changed. Training Group caregivers provided more information on why the intervention affected their perceptions and the reasons behind those changes.

Participant Characteristics

Participants in this thesis are a subset of participants in the larger CG ASSIST study. Therefore, eligibility criteria and recruitment mechanisms were identical to those used in the CG ASSIST study. Eligible participants for this research study were Veteran care recipients who were 60 years-old or older, had an impairment that interfered with their ability to complete transfers independently, and who lived with an informal caregiver who assisted with at least one of the three transfer tasks in this study: transferring in and out of bed, toileting, bathing. There were no age requirements for caregivers, other than needing to be 18 or older to provide informed consent. All care-

partner relations were eligible for this study, but ten dyads were spouses and one was a sibling dyad. Eligible caregivers assisted the Veteran at least four days out of the week with one or more of the following ADLs: getting in and out of bed, toileting, and/or bathing.

Caregivers of Veterans were ineligible if there were plans to transition the Veteran out of the home or to a different living arrangement in the next six months. Caregivers who showed signs of mild cognitive impairment on the Saint Louis University Mental Status Examination, and their care recipients by association, were ineligible for this sub-study because a negative score on this measure is used to verify participants' cognitive capacity to provide informed consent (Tariq, Tumosa, Chibnall, Perry & Morley, 2006).

Sampling

Informal caregivers of older Veterans with mobility impairment were recruited from the Atlanta Veterans Affairs Medical Center (VAMC). Purposive sampling was used to focus on care-partners who meet the requirements listed above. Potential participants were identified using (1) the VA's Corporate Data Warehouse listing Veterans with International Classification of Diseases 9th revision diagnostic codes suggesting transfer impairment and with a next of kin identified who has the same address as the Veteran, (2) community events including the Emory Research Social and at community forums hosted by the Emory Alzheimer's Disease Research Center, and (3) care provider, friend, and self-referrals. There were 11 participants consented for this project; six caregivers in the Training Group and five caregivers in the Novice Group. This small sample size is due to the time and resource constraints of this study.

Attrition. Two caregiving dyads in the Training Group withdrew from the study prior to the outcomes assessment. In both cases withdrawal was necessary because the care recipient was hospitalized for an indefinite period of time.

Site selection and description. All data were collected in eligible dyads' homes within the 60 mile radius of the Atlanta VA Medical Center. Because the intervention involved the provision of AT, home modifications, and training on how to perform ADLs in the dyads' natural home environment, collecting data during face-to-face home visits was necessary.

Ethics approvals. This study was approved by the Emory Institutional Review Board (IRB), the Atlanta VA Medical Center's Rehabilitation Research and Development (RR&D) board, the Georgia Institute of Technology IRB, and the Georgia State University IRB. The amendment adding the interview questionnaire was approved by Emory's IRB on December 4th, 2013 and by RR&D on December 12th, 2013. Georgia State University's IRB approved this sub-study on January 23rd, 2014. Informed consent and Health Insurance Portability and Accountability Act (HIPAA) Authorization were obtained in the dyads' homes prior to beginning the baseline assessment. All research personnel were trained to follow HIPAA's and the IRB's regulations including that all responses are confidential and any data are published anonymously. The participants were informed of these regulations and, to ensure comprehension, asked to repeat the regulations in their own words prior to signing the informed consent form. Data were de-identified—personal health information including name, address, medical history, and date of birth removed.

Procedures

Individuals interested in participating in this study were screened to determine eligibility. Eligible participants were randomly assigned to either the Training (Intervention) Group that received the in-home training or the Novice (Control) Group that was observed without receiving additional training. Figure 3.1 above illustrates the schematic for this research design.

Training group. Participants in the Training Group first completed the self-report baseline home assessments with research staff followed by a home visit from an AT Expert during stage one. The AT Expert observed the dyad perform the three ADLs—getting in and out of bed, toileting, and bathing—in the location where activities are performed most often. The AT Experts were provided a script to maintain consistency between raters in how dyads were instructed during home visits. After observing each ADL, the AT Expert completed the observation-based baseline assessments. Next, the AT Expert made recommendations for assistive technology (AT) devices and home modifications that may assist the dyad with the three ADLs. AT and home modifications that can be provided within the scope of this project were discussed with the caregiver and the Veteran. Before leaving the dyads' homes, the AT Expert reviewed the recommendations with the dyads to elicit feedback about the recommendations and to record any preferences. Various functional and aesthetic options were discussed. As stated above, AT was only ordered, provided and installed if the dyad approved of the recommendations and consented to use and install the equipment.

During stage two, the AT Expert returned to the participants' homes to install AT, implement home modifications⁶, and conduct the training intervention. The hands-on training started with the AT Expert demonstrating how an activity should be performed. Then, the caregiver role-played the part of the care recipient while the AT Expert acted in the role of the caregiver. Next, the caregiver practiced these techniques with the AT Expert. Finally, the caregiver and care recipient practiced these skills together. This procedure was repeated to incorporate feedback from the AT Expert, caregiver, and care recipient until everyone was comfortable with how the task was performed. In stage three the AT Expert returned to the participants' homes to follow up and reinforce the intervention by repeating aspects of the training intervention as needed.

During stage four the AT Expert traveled to the day's home to conduct outcomes assessments. Once again the AT Expert observed the caregiving dyads perform the three ADLs⁷ in the location where activities were performed during stage one. After the AT Expert visit, the original research staff then returned to the participants' homes to complete the outcomes assessment.

The AT Expert provided a standardized assessment of the level of assistance the caregiver provided and the level of assistance the care recipient needed. Individual bias from the AT Expert was controlled by using six independent AT Experts. Interrater agreement was established using intra-class correlation coefficients (ICC) with a two-way mixed model to determine absolute agreement. All AT Experts independently

⁶ Grab bars and hand held shower heads were be installed by a contractor with Certified Aging in Place Specialist (CAPS) credentials. These credentials ensure the contractor has the necessary knowledge and experience to install these devices in older adults' homes.

⁷ Transferring in and out of bed, toileting, and bathing.

viewed thirty videos of dyads performing the three ADLs observed in this study. (Morris, Uswatte, Crago, Cook, & Taub, 2001). None of the dyads in the videos were a part of the study.

Novice group. Participants in the Novice Group had a baseline visit identical to the Training Group, with the research staff collecting the subject reports and an AT Expert observing the three ADLs. However, the caregiver did not receive any AT, home modification or training recommendations from the AT Expert. During the second and third stages, the participants had no contact with the research staff other than to schedule the outcomes visit for stage four. This outcomes visit was again identical to the outcomes visit described for the Training Group with a new AT Expert observing the four ADLs and providing reports and the research staff collecting the reports from the caregiver.

Approach. A mixed methods approach was used to investigate whether the training intervention changed caregivers' beliefs about the level of assistance provided to care recipients. Quantitative and qualitative data were collected simultaneously to develop a more comprehensive understanding of what factors could potentially influence caregivers' perceptions of the level of assistance needed by their care recipients (Creswell, Klassen, Plano Clark, & Smith, 2011). Quantitative data alone would not explain an abstract concept like perception, so qualitative data were needed to further investigate the impact the intervention had on modifying caregivers' beliefs. To illustrate an alternative perspective and to assess the accuracy of these beliefs, quantitative and qualitative data were collected from both informal caregivers and AT Experts.

Data Analysis Procedures

First, quantitative data were used to calculate descriptive factors using Statistical Package for the Social Sciences (SPSS) 21 software. Then data from the modified FIM was used to determine the level of assistance (LoA) caregivers report they provided and the LoA AT Experts report the caregiver provided to determine if caregivers are providing appropriate levels of assistance. The informal caregiver and AT Expert's reported LoAs were then used to determine the accuracy of the caregiver's beliefs about the care recipient's needs.

The Center of Excellence in Visual and Neurocognitive Rehabilitation's statistician (B. Delaune, personal communication, October 16, 2012) was consulted to determine the appropriate quantitative analysis for the current study. Due to the small sample size, no measure of statistical relevancy can be provided. The effect of the intervention on the level of assistance provided was measured by comparing changes in the number of caregivers who provide appropriate LoAs in the Training Group with changes in the number of caregivers who provide appropriate LoAs in the Novice Group. The effect of the intervention on caregiver's perceptions of care recipient's ability was measured by comparing changes in the number of caregivers who accurately perceive the care recipient's ability status in the Training Group with changes in the number of caregivers who accurately perceive the care recipient's ability status in the Novice Group.

The software NVivo 10 was used to organize data to identify similarities between and within subjects and to create nodes or codes for different concepts. Inductive content analysis was used because individual reports were used to explain the general

experiences of how the intervention affects the assistance caregivers provide and their beliefs about their care recipient's abilities (Elo & Kyngäs, 2008). These connections provided additional insight into how and why the intervention changed caregivers' perceptions of care recipients' abilities and in the Training Group compared to the Novice Group.

CHAPTER 4 : RESULTS

Sample Description

The demographics information for the caregivers and their care recipients are listed in Table 4.1. All of the caregivers were female and all of the Veteran care recipients were male. Care recipients (CR) in the Training Group (TG) were younger on average than CRs in the Novice Group (NG) (TG $M=76.3$, $SD=10.3$; NG $M=84.2$, $SD=4.0$). Caregivers (CGs) in the TG were also younger on average than the NG CGs

Table 4.1 Baseline Demographics for Caregiving Dyads

		Age		# Health Problems		Caregiver Characteristics		
<i>Training Group</i>								
ID	CG	CR	CG	CR	Race	Relation to CR	Formal Caregiver (Yes/No)	
201	64	72	4	16	White	Spouse	No	
202	71	80	0	25	White	Spouse	Yes	
206	57	62	2	15	White	Spouse	No	
207	75	92	1	7	Black	Spouse	No	
209	79	81	2	26	White	Spouse	Yes	
210	61	71	5	16	White	Spouse	Yes	
		M (SD)			White (%)	Spouse (%)	Formal Caregiver (%)	
		67.8 (8.5)	76.3 (10.3)	2.3 (1.9)	17.5 (7.1)	83%	100%	50%
<i>Novice Group</i>								
ID	CG	CR	CG	CR	Race	Relation to CR	Formal Caregiver (Yes/No)	
203	73	81	2	20	White	Spouse	No	
204	77	84	1	18	White	Spouse	No	
205	75	86	0	34	White	Spouse	Yes	
208	80	90	3	16	White	Spouse	Yes	
211	78	80	5	11	Black	Sister	No	
		M (SD)			White (%)	Spouse (%)	Formal Caregiver (%)	
		76.6 (2.7)	84.2 (4.0)	2.2 (1.9)	19.8 (8.6)	80%	80%	40%

(TG $M=67.8$, $SD=8.5$; NG $M=76.6$, $SD=2.7$). All of the caregivers were younger than their care-partners. The CGs and CRs in both groups reported approximately the same number of health conditions, though the CRs had many more health conditions than the CGs (TG CG $M=2.3$, $SD=1.9$; TG CR $M=17.5$, $SD=7.1$; TG CG $M=2.3$, $SD=1.9$; TG CR $M=17.5$, $SD=7.1$). All the caregivers were white (TG 83%, NG 80%) or black (dyad 207 and dyad 211). Most of the caregiving dyads were spouses (91%), but dyad 211 is a sibling dyad. Though all dyads are composed of an informal cohabitating caregiver and a Veteran care recipient, three dyads in the TG (50%) and two dyads in the NG (40%) also received assistance from a formal, hired caregiver.

Figure 4.1 illustrates the recruitment flowchart for this thesis. There were 604 potential participants assessed for eligibility. There were 593 participants excluded because they did not meet the inclusion criteria ($n=50$), declined to participate ($n=144$),

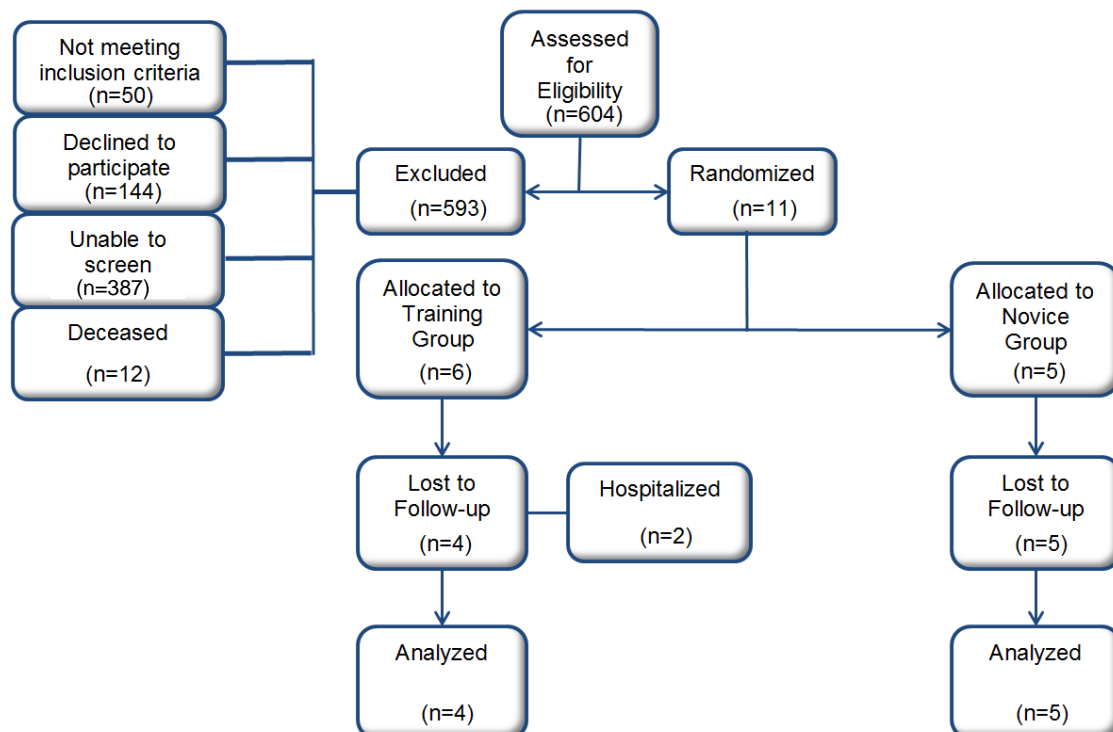


Figure 4.1 Recruitment Flowchart

were unavailable to be screened (n=387), or were deceased (n=12). There were 11 participants assigned to the Training Group (n=6) and the Novice Group (n=5). In the TG, two Veterans were hospitalized between the baseline and outcomes assessments and the dyad withdrew from the study. In the NG, all of the dyads completed the outcomes assessment. The transfers completed by each dyad are illustrated in table 4.2 with a checkmark (✓) to indicate the transfer was completed or an explanation for

Table 4.2 Transfer Tasks Observed by Dyad

ADL Transfer Task	<u>Training Group</u>						<u>Novice Group</u>					
	201	202	206	207	209	210	203	204	205	208	211	
Bed	✓	CR Hospitalized	✓	✓	CR Hospitalized	✓	✓	✓	✓	✓	✓	
Toilet	✓		✓	Catheter		✓	✓	✓	✓	✓	✓	✓
Bath	✓		✓	Bed bath		Formal CG only	✓	✓	✓	Bed bath	✓	✓
Total	3	0	3	1	0		2	3	3	3	2	3

why the activity was not observed. Therefore, there were four completers in the TG and five completers in the NG. For each dyad, up to three ADLs could have been observed: Transferring in and out of bed, on and off the toilet, and in and out of the bath or shower. Only nine of the 18 possible ADLs were completed by dyads in the TG and 14 of the possible 15 transfers were completed by dyads in the Novice Group. Six of the transfers were not observed in the TG because the participants withdrew, two were not observed because the CR did not perform those transfers (incontinent with diapers, and received bed baths), and one was not reported by the CG because she never assisted with that transfer (dyad 210-shower transfer). The AT Expert did observe the shower

transfer for dyad 210 between the CR and the formal caregiver to determine if the CG could assist with the transfer after receiving the training intervention. There was only one transfer not reported for the NG, and the CR did not perform this transfer task because he received bed baths.

Environmental Modifications

Table 4.3 below lists the AT, home modifications, and training provided to each dyad in the Training Group during the CG ASSIST intervention. Descriptions of the interventions follow.

Table 4.3 Training Group Environmental Modifications

Dyad	AT	Home Modifications	Training
201	(Walk-in shower, 3-in-1 commode) Bed rail, overhead trapeze bar, grab bar, soap dispenser, bariatric 3-in-1 commode, shower head	Reorganize furniture	Practice transfers, limiting number of showers, education on safety and work simplification
206	(Walker, cane) Bed rail, 3-in-1 commode, grab bars, shower head	Remove rug, remove furniture	Dry feet before transfer, set hot water heater to 120°F
207	(Wheelchair, Hoyer lift, bed rail*) Gait belt, transfer board	Move bed rail to second bed, change rooms, raise bed	How to user Hoyer or new AT, bend at knees, avoid transfers when CR agitated
210	(Walker) Bed rail, leg lifter, grab bar, soap dish grab bar, shower head, transfer bench, off-set hinges	Change rooms, remove clutter	Use non-slip material with step stool, how to use AT, transfer techniques

Dyad 201 environmental modifications. The AT Expert recommended a bed rail, overhead trapeze bar, grab bar by the toilet, a hand-held shower head, and a wall-mounted soap dispenser. A wide-set bariatric 3-in-1 commode was also provided to

replace the commode prescribed for the CG. Extensive training was recommended for this dyad included reorganizing the bedroom furniture, practicing transfers, limiting the number of showers each week, and education on general “safety, energy conservation and work simplification” practices (201 AT Expert). Dyad 201 discussed their dissatisfaction with their hospital bed with the AT Expert who reported the “[CR’s] mattress is old, and no longer supports [CR] properly. Current mattress also increases difficulty in getting out of bed. [CR] and [CG] plan to request a new bed from VA.” Separate from the intervention, dyad 201 was able to acquire a new bed after receiving the above equipment, but was not able to use the bed rail with the hospital bed.

Dyad 206 environmental modifications. The AT Expert recommended and provided a bed rail to assist with getting in and out of bed, a three-in-one commode over the toilet to assist with toileting transfers, and two 2-foot grab bars and a flexible extended hand held shower head for bathing transfers. The AT Expert recommended removing a rug in the bedroom, removing furniture near the toilet, drying feet before transferring out of the shower and setting the hot water heater to 120°F or below. The dyad was also trained to use proper body mechanics and practiced the new transfer techniques. The AT Expert provided education on proper positions for the CG, proper techniques for the Veteran, and helpful strategies for the dyad.

Dyad 207 environmental modifications. Dyad 207 had several AT devices, though not all were used. In particular, the dyad had a wheelchair and a Hoyer lift, but the lift was missing the sling. The AT Expert recommended replacing the sling, but the CG found the sling before the AT Expert returned for the training. The dyad also already had a bed rail that the AT Expert reported would appropriately meet the dyad’s

needs. However, the AT Expert recommended moving the CR to another, larger room, so there would be enough room to maneuver the Hoyer lift. The AT Expert provided a gait belt and a transfer board and moved the bed rail to the second bed. One focus of the training was moving the CR to the larger room including to “remove [a] small area rug... remove all clutter, and maximize open floor space to make room for Hoyer.”

Extensive training was provided on how to use the Hoyer lift and how to use the gait belt and transfer board if there were any issues with the Hoyer lift. Specific training was provided to keep the bed high “to help CG’s body mechanics,” to “bend at [the] knees, not hips,” to “make sure needed objects and controls [were] within easy reach,” and when possible to avoid transfers when the CR is agitated.

Dyad 210 environmental modifications. The CR indicated to the AT Expert that he would like to sleep in the master bedroom with the CG. The mattress was on box springs and risers so the CG could store items under the bed, so the bed was very high. The AT Expert recommended removing the box spring or risers, but the CG was reluctant to lose the storage space. Instead a bed rail with pockets and a leg lifter was provided to assist with this transfer. Dyad 210 also already had a step stool that the CR previously used to get in and out of bed. The AT Expert recommended placing a non-slip material under the step stool and trained the dyad to use the stool in a way that would reduce falls.

For the toilet transfer two sets of off-set hinges were provided to add about two inches to the doorway making it easier for the CR to enter the bathroom with his walker. It was recommended that dyad 210 consider installing motion-sensor night lights in the bathroom so the CR, “Won’t have to risk injury by reaching around [the] wall to turn [the

light] switch on.” Instead, the CR stored a flashlight in the pocket of his bed rail and used this light to get to the restroom in the middle of the night. To assist with the bath transfer, several AT devices were recommended: a 24-inch grab bar, a combined soap dish grab bar, a transfer bench, and a hand-held shower head with a pause button to stop the water flow in the bathtub. The two grab bars were recommended so the CR had a secure place to hold onto while transferring in and out of the bath instead of the standard soap dish and shower rod which could not support the CR’s weight. The AT Expert also recommended removing the towels and robes hanging between the tub and the entrance. Training was provided with the CR and both the formal and informal CG on how to properly transfer in and out of the tub using the bath bench. The informal CG requested that both caregivers be trained with the CR with this task because the AT Expert served as an authority and the informal CG felt the CR would be more likely to transfer as trained if the dyad and formal CG were trained together. Transfer techniques—particularly log rolling and side sitting—were recommended for the CR to reduce strain on his back. Other basic educational training was provided on how to adjust equipment before beginning a transfer, check the water temperature before getting into the bath, and drying the CR’s feet before transferring out of the tub.

Functional Independence Measure (FIM) Scores

The scores in the tables below are the original FIM scores on a scale from 1 to 7 computed from the three modified FIM questions as described in Chapter 3. Table 4.4 lists the FIM scores informal caregivers and AT Experts reported the Veteran care recipients were *provided* while Table 4.5 are the FIM scores informal caregivers and AT Experts reported the Veteran care recipients *needed*. A FIM score for the either LoA

Table 4.4 FIM Scores for Assistance Provided by Each Dyad

ID	Getting in and out of Bed				Getting on and off of Toilet				Getting in and out of Tub/Shower			
	<u>Informal CG</u>		<u>AT Expert</u>		<u>Informal CG</u>		<u>AT Expert</u>		<u>Informal CG</u>		<u>AT Expert</u>	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Training Group												
201	4	5	4	4	5	7	5	5	7	5	4	4
202	1	N/A	2	N/A	N/A	N/A	1	N/A	N/A	N/A	1	N/A
206	2	1	3	3	5	5	2	5	5	1	3	5
207	1	1	1	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
209	5	N/A	4	N/A	5	N/A	6	N/A	3	N/A	6	N/A
210	5	6	6	5	5	6	6	6	N/A	N/A	4	5
Novice Group												
203	3	3	7	3	5	5	7	4	5	5	5	4
204	7	7	5	5	5	5	7	5	5	5	7	5
205	5	5	5	4	7	7	5	5	5	5	5	5
208	1	1	2	2	1	1	2	2	N/A	N/A	N/A	N/A
211	7	7	6	6	6	6	6	6	5	5	6	6

Table 4.5 FIM Scores for Assistance Needed by Each Dyad

ID	Getting in and out of Bed				Getting on and off of Toilet				Getting in and out of Tub/Shower			
	<u>Informal CG</u>		<u>AT Expert</u>		<u>Informal CG</u>		<u>AT Expert</u>		<u>Informal CG</u>		<u>AT Expert</u>	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Training Group												
201	5	5	4	4	7	7	7	5	5	5	4	5
202	1	N/A	2	N/A	N/A	N/A	1	N/A	N/A	N/A	1	N/A
206	2	1	3	3	6	5	2	5	5	1	3	5
207	1	1	1	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
209	5	N/A	4	N/A	5	N/A	6	N/A	5	N/A	5	N/A
210	6	6	6	5	5	6	6	6	3	5	4	5
Novice Group												
203	3	3	7	3	5	5	5	4	7	5	5	4
204	3	7	4	5	4	5	7	4	4	5	4	4
205	5	5	5	4	7	5	5	5	5	5	5	5
208	1	1	2	2	1	1	2	2	N/A	N/A	N/A	N/A
211	7	7	6	6	6	6	6	6	5	5	6	6

provided or needed was not necessarily reported for each ADL. No FIM score was reported if a Veteran care recipient did not perform a transfer task (i.e. Veteran received bed baths or was incontinent) or if the informal caregiver was not the primary person who assisted with a transfer task (i.e. a formal caregiver bathed Veteran every morning). These 'missing' scores, as well as the scores for the two dyads who left the study, are reported in the tables as 'N/A'.

Aim 1: Informal Caregiver Perceived Level of Assistance

Level of assistance provided and needed. For both the Training and Novice

Table 4.6 Informal Caregiver Changes in Level of Assistance (LoA) Provided
Key: < Less = Same > More

Training Group				Novice Group			
ID	Baseline	Outcomes	LoA Change	ID	Baseline	Outcomes	LoA Change
201	4	5	<	203	3	3	=
	5	7	<		5	5	=
	7	5	>		5	5	=
202	1	N/A	N/A	204	7	7	=
	N/A	N/A	N/A		5	5	=
	N/A	N/A	N/A		5	5	=
206	2	1	>	205	5	5	=
	5	5	=		7	7	=
	5	1	>		5	5	=
207	1	1	=	208	1	1	=
	N/A	N/A	N/A		1	1	=
	N/A	N/A	N/A		N/A	N/A	N/A
209	5	N/A	N/A	211	7	7	=
	5	N/A	N/A		6	6	=
	3	N/A	N/A		5	5	=
210	5	6	<				
	5	6	<				
	N/A	N/A	N/A				

Groups, the changes in the Level of Assistance (LoA) reported by informal caregivers before and after the intervention are illustrated. Table 4.6 lists the LoA caregivers (CGs) provided to their Veteran care recipients (CRs) while table 4.7 lists the LoA CGs believe their CRs needed to accomplish the three transfer tasks. Both tables list the FIM score during the baseline and outcomes assessment and whether the assistance at baseline was more than (>), equal to (=), or less than (<) the assistance during the outcomes assessment.

Table 4.7 Informal Caregiver Changes in Level of Assistance (LoA) Needed
Key: < Less = Same > More

Training Group				Novice Group			
ID	Baseline	Outcomes	LoA Change	ID	Baseline	Outcomes	LoA Change
201	5	5	=	203	3	3	=
	7	7	=		5	5	=
	5	5	=		7	5	>
202	1	N/A	N/A	204	3	7	<
	N/A	N/A	N/A		4	5	<
	N/A	N/A	N/A		4	5	<
206	2	1	>	205	5	5	=
	6	5	>		7	5	>
	5	1	>		5	5	=
207	1	1	=	208	1	1	=
	N/A	N/A	N/A		1	1	=
	N/A	N/A	N/A		N/A	N/A	N/A
209	5	N/A	N/A	211	7	7	=
	5	N/A	N/A		6	6	=
	5	N/A	N/A		5	5	=
210	6	6	=				
	5	6	<				
	3	5	<				

The baseline and outcomes report comparisons for the LoA provided are illustrated in Figure 4.2. Four of the Training Group transfers were completed with less assistance (44%), two with the same assistance (22%), and three with more assistance (33%) during outcomes, while all 14 (100%) of the transfers in the Novice Group were completed with the same LoA at outcomes. In comparison Figure 4.3 illustrates that for the fewest number of transfer tasks Training Group CGs believed their CRs needed less assistance (20%) after the training. For the majority of transfer tasks, CGs believed their CRs needs did not change (50%) and 30% reported their CRs need more assistance following the training.

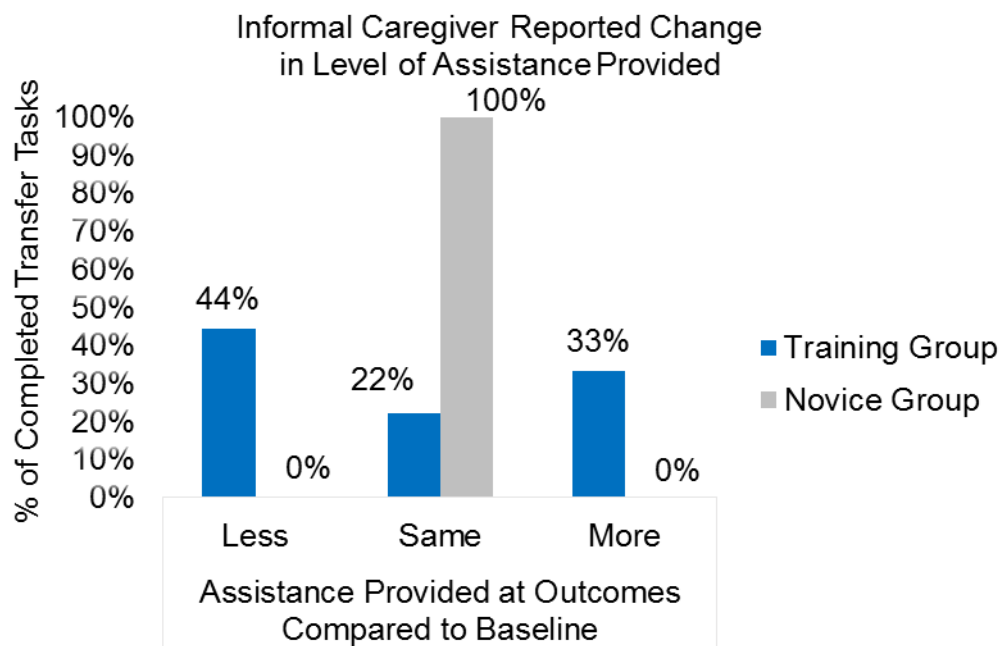


Figure 4.2 Level of Assistance Caregivers Report Providing

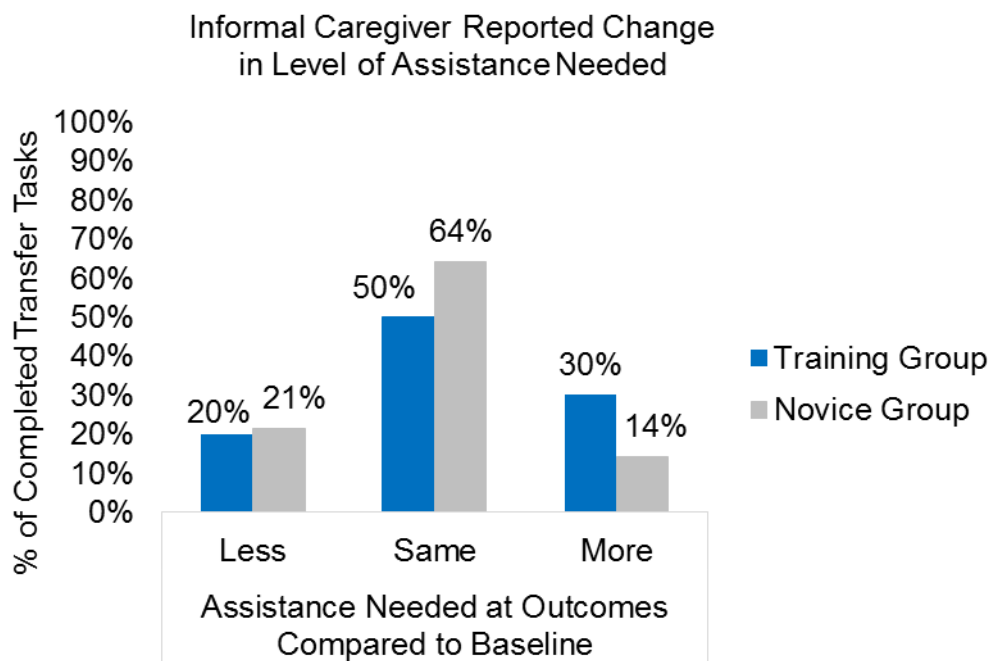


Figure 4.3 Level of Assistance Caregivers Report Veterans Need

Appropriateness of assistance. Whether a caregiver believes she provided an appropriate level of assistance was determined by comparing the level of assistance (LoA) caregivers (CGs) reported they *provided* and the LoA CGs reported their care recipient (CR) *needed*. The appropriateness of the assistance provided was classified as ‘Just Right’ (=) assistance if the level of assistance (LoA) *needed* was the same as the LoA *provided*. When the LoA *needed* was higher than the LoA *provided* (higher FIM score *needed* than *provided*), there was ‘Too Much’ (↑) assistance provided. Likewise, when the LoA *needed* was lower than the LoA *provided* (lower FIM score *needed* than *provided*), there was ‘Too Little’ (↓) assistance provided.

Table 4.8 compares the LoA provided, the LoA needed, and the perceived appropriateness of assistance reported by CGs in the Training Group at baseline and

Table 4.8 Training Group Caregiver's Reported LoA Provided and Needed

Result Key: Too Much (↑) Just Right (=) Too Little (↓)

ID	<u>Baseline Assessment</u>			<u>Outcomes Assessment</u>		
	Level of Assistance		Result	Level of Assistance		Result
	Provided	Needed		Provided	Needed	
201	4	5	↑	5	5	=
	5	7	↑	7	7	=
	7	5	↓	5	5	=
202	1	1	=	N/A	N/A	N/A
	N/A	N/A	N/A	N/A	N/A	N/A
	N/A	N/A	N/A	N/A	N/A	N/A
206	2	2	=	1	1	=
	5	6	↑	5	5	=
	5	5	=	1	1	=
207	1	1	=	1	1	=
	N/A	N/A	N/A	N/A	N/A	N/A
	N/A	N/A	N/A	N/A	N/A	N/A
209	5	5	=	N/A	N/A	N/A
	5	5	=	N/A	N/A	N/A
	3	5	↑	N/A	N/A	N/A
210	5	6	↑	6	6	=
	5	5	=	6	6	=
	N/A	N/A	N/A	N/A	N/A	N/A

outcomes assessment. Caregivers in this group responded to a total 13 transfers with a self-reported LoA *provided* and *needed* during the baseline assessment. At baseline,

the caregivers reported providing too much assistance five times, providing the right amount of assistance seven times, and providing too little assistance once. At the

outcomes assessment, caregivers responded to only nine transfer tasks, though the LoA *provided* and *needed* for each task was the same.

Each transfer caregivers in the Training Group completed was categorized by appropriateness. Figure 4.4 illustrates how frequently caregivers perceived their assistance provided to be too little, just right, or too much. During the baseline assessment caregivers reported they provided appropriate assistance for just over half (54%) of the transfer tasks completed. Many (38%) reportedly were completed with the caregivers providing a higher level of assistance (lower FIM score) than needed, while one (8%) was completed where the caregiver reported providing a lower level of assistance than needed. However, during the outcomes assessment, caregivers reported *providing* the level of assistance the care recipient *needed* for all completed transfer tasks (100%).

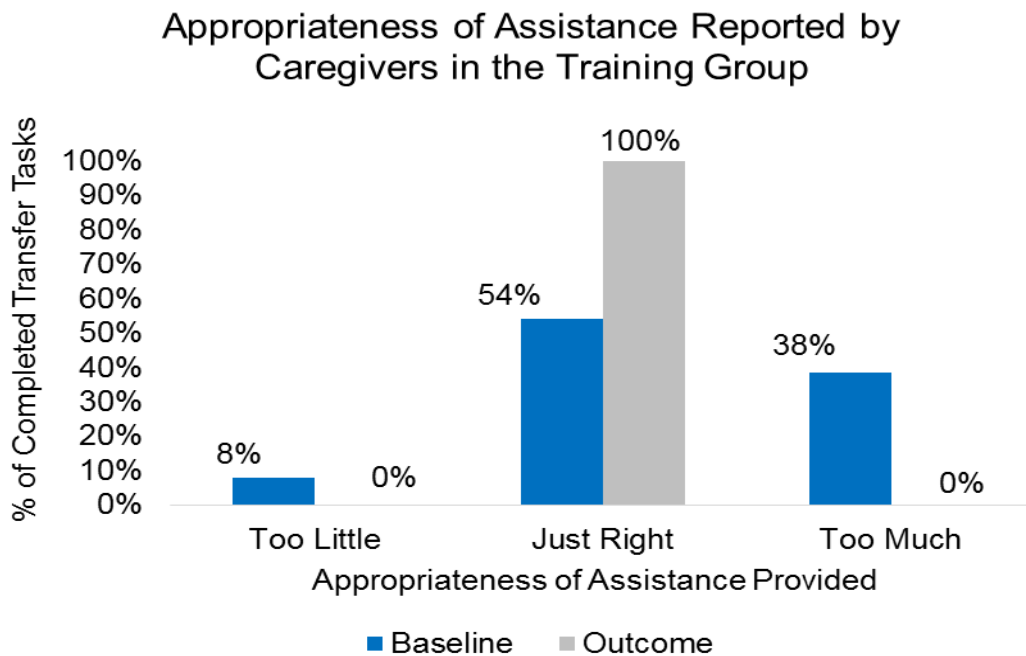


Figure 4.4 Perceived Appropriateness of Assistance Provided by Training Caregivers

For caregivers in the Novice Group the percent of completed transfer tasks for which caregivers perceived to provide appropriate levels of assistance increased during the outcomes assessment. During both assessments, caregivers completed 14 transfers. As illustrated in Table 4.9 and Figure 4.5 caregivers reported providing too little assistance for three tasks (20%), too much assistance for one task (7%), and appropriate assistance for ten tasks (73%). Then, at outcomes assessment, caregivers reported providing too little assistance for one task (7%) and appropriate levels of assistance for the other 13 tasks (93%). No caregivers in the Novice Group reported providing too much assistance for any of the transfer tasks.

Table 4.9 Novice Group Caregiver's Reported LoA Provided and Needed

Result Key: Too Much (↑) Just Right (=) Too Little (↓)

ID	<u>Baseline Assessment</u>			<u>Outcomes Assessment</u>		
	<u>Level of Assistance</u>		Result	<u>Level of Assistance</u>		Result
Provided	Needed	Provided		Needed		
203	3	3	=	3	3	=
	5	5	=	5	5	=
	5	7	↑	5	5	=
204	7	3	↓	7	7	=
	5	4	↓	5	5	=
	5	4	↓	5	5	=
205	5	5	=	5	5	=
	7	7	=	7	5	↓
	5	5	=	5	5	=
208	1	1	=	1	1	=
	1	1	=	1	1	=
	N/A	N/A	N/A	N/A	N/A	N/A
211	7	7	=	7	7	=
	6	6	=	6	6	=
	5	5	=	5	5	=

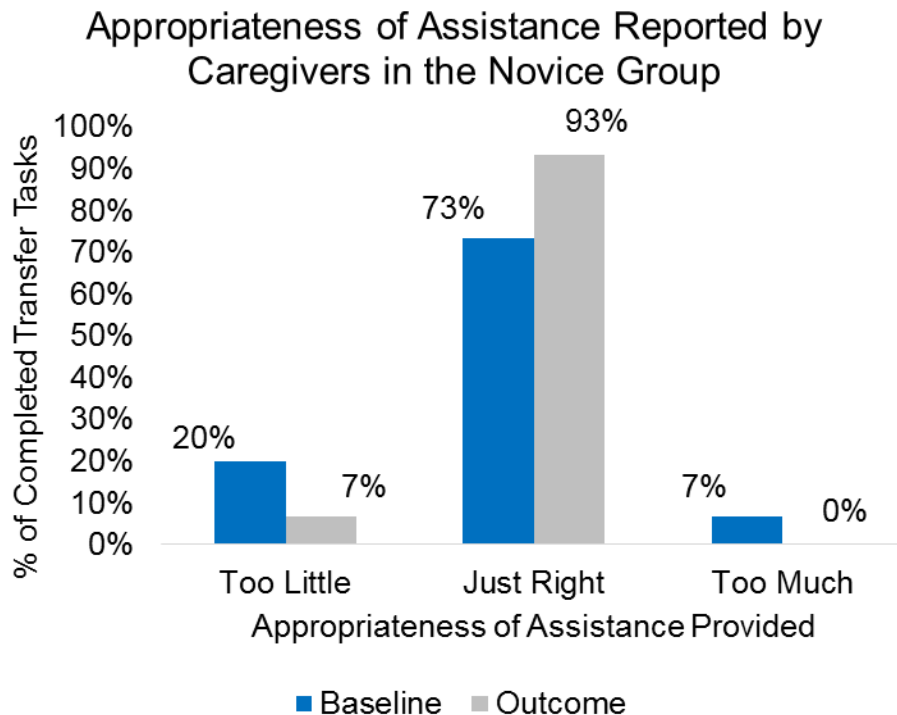


Figure 4.5 Perceived Appropriateness of Assistance Provided by Novice Caregivers

Aim 2: Accuracy of Caregivers' Perceptions

The accuracy of caregivers' perceptions were determined by comparing the appropriateness of the assistance provided as reported by the informal caregiver and the appropriateness of the assistance provided as reported by the AT Expert. Caregivers either under-estimate CR ability, accurately estimate CR ability, or over-estimate CR ability as defined above in Table 3.3. Table 4.10 lists the inferences drawn from each comparison between the AT Expert and informal caregiver reports for dyads in the Training Group.

Table 4.10 Training Group Caregiver Accuracy of LoA Care Recipients Need Assistance Provided is... Too Much (↑) Just Enough (=) Too Little (↓)

ID	Baseline Assessment			Outcomes Assessment		
	Reported Appropriateness		Appraisal of CR Ability	Reported Appropriateness		Appraisal of CR Ability
	AT Expert	CG		AT Expert	CG	
201	=	↑	Under-estimate	=	=	Accurate
	↑	↑	Accurate*¹	=	=	Accurate
	=	↓	Over-estimate	↑	=	Under-estimate
202	=	=	Accurate	N/A	N/A	N/A
	=	N/A	N/A	N/A	N/A	N/A
	=	N/A	N/A	N/A	N/A	N/A
206	=	=	Accurate	=	=	Accurate
	↑	=	Under-estimate	=	=	Accurate
	=	=	Accurate	=	=	Accurate
207	=	=	Accurate	=	=	Accurate
	N/A	N/A	N/A	N/A	N/A	N/A
	N/A	N/A	N/A	N/A	N/A	N/A
209	=	=	Accurate	N/A	N/A	N/A
	=	=	Accurate	N/A	N/A	N/A
	↓	↑	Over-estimate ^{§1}	N/A	N/A	N/A
210	=	↑	Under-estimate	=	=	Accurate
	=	=	Accurate	=	=	Accurate
	=	N/A	N/A	=	N/A	N/A

There were three under-estimates, two over-estimates, and nine accurate estimates of the care recipients' ability out of 13 transfers reported at baseline for caregivers in the Training Group. Following the intervention, there were nine transfers reported with one under-estimate and eight accurate estimates of the care recipients'

reported as under-estimates and over-estimates decreased from 23% to 11% and 15% to 0% respectively, and the percentage of transfers reported as accurate estimates

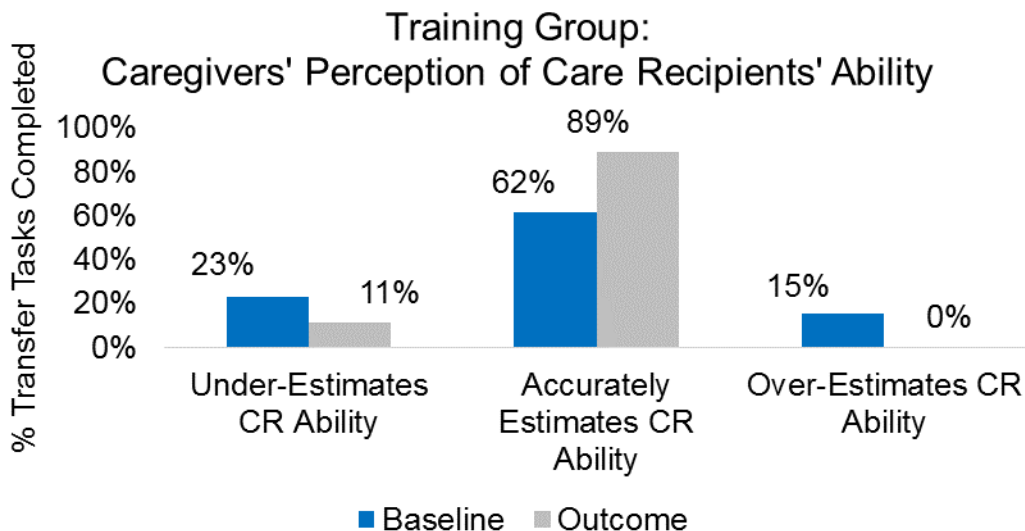


Figure 4.6 Accuracy of Training Group Caregivers' Appraisals of Care Recipients' Limitations. Figure 4.6 illustrates the change in the percent of completed transfer tasks that are reported as under, accurate, and over estimates of the care recipient's ability. Following the intervention, the percentage of transfers performed by the Training Group increased from 62% to 89% respectively.

Table 4.11 lists the inferences drawn from each comparison between the informal caregiver self-reports and the AT Expert observation-based reports for dyads in the Novice Group. For the Novice Group, there were 14 transfer tasks observed at baseline and outcomes. There was one under-estimates, two over-estimates, and 11 accurate estimates of the care recipients' ability reported at baseline. During outcomes, there were three transfer tasks reported as an over-estimate and 11 accurate estimates of the care recipients' ability.

Table 4.11 Novice Group Caregiver Accuracy of LoA Care Recipients Need Assistance Provided is... Too Much (↑) Just Enough (=) Too Little (↓)

ID	Baseline Assessment			Outcomes Assessment		
	Reported Appropriateness		Appraisal of CR Ability	Reported Appropriateness		Appraisal of CR Ability
	AT Expert	CG		AT Expert	CG	
203	=	=	Accurate	=	=	Accurate
	↓	=	Over-estimate	=	=	Accurate
	=	↑	Under-estimate	=	=	Accurate
204	↓	↓	Accurate**8	=	=	Accurate
	=	↓	Over-estimate	↓	=	Over-estimate
	↓	↓	Accurate**13	↓	=	Over-estimate
205	=	=	Accurate	=	=	Accurate
	=	=	Accurate	=	↓	Over-estimate
	=	=	Accurate	=	=	Accurate
208	=	=	Accurate	=	=	Accurate
	=	=	Accurate	=	=	Accurate
	=	N/A	N/A	=	N/A	N/A
211	=	=	Accurate	=	=	Accurate
	=	=	Accurate	=	=	Accurate
	=	=	Accurate	=	=	Accurate

Figure 4.7 illustrates the change in the percent of completed transfer tasks that are reported as under, accurate, and over estimates of the care recipient's ability for caregiver assigned to the Novice Group. Following the intervention, the percentage of transfers performed by the Novice Group reported as under-estimates decreased from 7% to 0%, over-estimates increase from 14% to 21%, and the percent of accurate estimates remain the same (79%).

⁸⁻¹³ Though accurate, both the AT Expert and Caregiver report too little assistance.

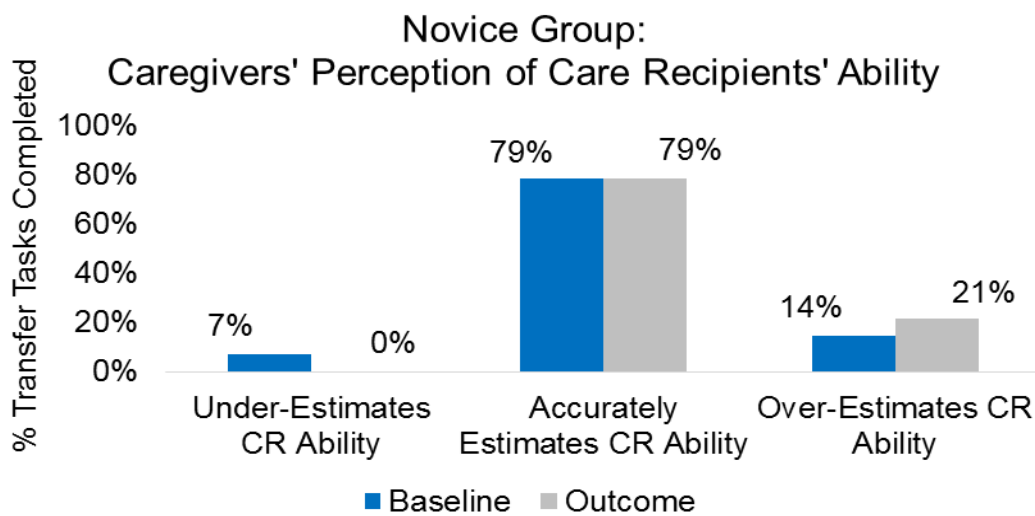


Figure 4.7 Accuracy of Novice Group Caregivers' Appraisals of Care Recipients' Limitations

Aim 3: Impact of Environmental Factors on Caregiver Perceptions

The specific environmental factors modified varied across participants to meet the unique needs of the caregivers and Veteran care recipients. Environmental factors are presented through a review of case examples. Outcomes data were not collected for dyad 202 and 209 because the Veteran was hospitalized and removed from the home for an indefinite period of time, causing the dyads to withdraw from the study. Qualitative outcomes data are also missing for dyad 207, but data from baseline and on environmental modifications are reported.

Training group. The dyads in the Novice Group did not receive any training intervention.

Dyad 201 baseline assessment. Dyad 201 had recently remodeled their bathroom to include a walk-in tub and grab bars by the entrance to the bathroom—there was a step up to get in the room—after the Veteran's diagnosis with Parkinson's

Disease. The caregiver had back surgery in the past five years, and was wary of lifting the CR. At baseline, the caregiver reported providing more assistance than her husband needed with the bed transfer and reported providing too little assistance with the shower transfer. The CG described her assistance with the bed transfer saying, “I’ll tell him to sit up. He’ll put his feet down, then use the bed rail to sit up—it’s sort of difficult for him. He’ll pull himself up, sit up straight, then reach for the bed rail to get himself up.” For transferring out of the shower, the CG reported, “If he sits down in the tub, it’s hard for him to get up. He prefers showers...He’s comfortable, but it’s a little difficult getting in and out of it.” The AT Expert indicated appropriate assistance was provided for the bed and shower transfer.

However, both the caregiver and the AT Expert reported too much assistance was provided transferring on and off the toilet. The dyad had a three-in-one commode over the toilet, but this device was prescribed for the caregiver following a previous back surgery. The AT Expert observed that the caregiver’s assistance was “90% accurate,” but reported concern that the commode was “too narrow and not as sturdy as it should be,” and the Veteran “need[ed a] larger size [commode] and a sturdier model.” The CG at indicated the CR had difficulty cleaning himself as the toilet seat on the toilet chair was small and impeded access:

He needs a handicapped toilet. It needs to be higher so he doesn't have to go down so low. What he has now is adjustable, but it's too complicated a gizmo. You need to bolt the raised base to the toilet, but that's not very hygienic. When he urinates it's hard for him to aim where he needs to go and you need to wipe it

off, but you can't get to it with that system.... [The commode is] small. He just doesn't have the [space]...

Dyad 201 outcomes assessment. Following the intervention, the caregiver and AT Expert both reported appropriate and accurate levels of assistance being provided for the bed and toilet transfer tasks. Still, there was a concern with transferring in and out of the bed. The CG indicated she provided less assistance than at baseline stating:

With the new hospital bed, I have a problem with the trapeze bar. The bar [chain] is now too long. The bar is right by him and that needs to be adjusted. He's kind of afraid of the trapeze bar.... (Why is he afraid?).... He's afraid it will hit him in the head! Because, it's hanging over his head. Now that's a concern, but not before. When he heard "clank, clank" as I was pulling [the chain] down, it bothered him. He thought it was going to hit him.

With toileting, CG described the change in assistance she provides for the toilet transfer, indicating the CR now completes this task independently. She stated, "If he were sitting I would have to pull up before... I'd give him a hand as the AT Expert trained him to do. The AT Expert stated the CR, "was physically independent as observed. He may not have needed the verbal instructions at all. CG may have been prompting by habit." While the CG reported providing appropriate assistance, but the AT Expert reported that more assistance was provided than the CR needed, stating "CG operated the latch of the tub door in a move that appeared automatic—CR not given a chance to do [this]." The CG also stated another concern, saying, "I just want you to know, I'm concerned that he will slip. I want to make sure I can grab him," indicating her concern may lead her to provide more assistance than needed.

Dyad 206 baseline assessment. The Veteran in dyad 206 had an orthotic lift for one leg and used a cane the majority of the time, though he also had a wheelchair and walker. The CG reported occasional pain in her neck, shoulders, and wrist. The CG and CR were spousal care-partners who spoke English as a second language, and the CG occasionally asked her husband to verify her translations. During the baseline assessment, the caregiver reported providing appropriate assistance for transferring to and from the bed and shower. For the bed, the CG and AT Expert reported physical assistance was provided, but were in agreement that this assistance was necessary.

For getting on and off the toilet, based on FIM scores, the CG believed she provided too much assistance. The AT Expert's FIM scores indicate that an appropriate level of assistance was provided, but reported that "CG helped more than required to stand-sit on commode." This contrasts with the CG's description of stand by assistance where she explained, "I say 'Are you ready? What do you need? Are you finished?' All the time I'm in my room watching TV, but I'm still attending to him. I'm checking on him to see if he needs my help."

Finally, for getting in and out of the shower, both the CG and AT Expert reported appropriate levels of assistance, though the CG reported providing standby assistance and the AT Expert reported observing moderate physical assistance where the CG performed over half of the transfer task. The CG stated:

I know that I have to care for him because he lost his balance and I'm afraid he'll fall down. He lost his balance now. And the water can burn him and I care about making sure the water is right. [As for the equipment (AT)], sometimes he feels

unsure with the cane. He feels more comfortable with the walker, but it won't fit in the bathroom.

Meanwhile the AT Expert reported the CR "used [the] shower frame and towel bar incorrectly as AT – [putting him] at risk for injury. [The] CG assisted as needed, [but the CR] would have benefitted [from CG assistance] when pulling inappropriately on [the shower] frame and [towel] bars to transfer in and out [of the shower]."

Dyad 206 outcomes assessment. Following the training, the CG reported providing total assistance with 75% or more of the shower transfer, but described the same stand by assistance for the toilet transfer. However, qualitative responses from both the CG and the AT Expert suggest that the Veteran actually needed—and received—less assistance when using the AT. The CG reported for the bed transfer, "The bedrail makes it a lot easier with the help of the cane, but I still need to help him with the legs," while the AT Expert reported, "The CG now has to provide less assistance than before the installation of the equipment." There were similar responses for the shower transfer. Despite reporting a FIM score indicating more assistance was needed, the CG said, "He needs both physical total assistance... It's [the bathroom transfer is] a lot better," while the AT Expert reports "CG actions suggested a routine has been established by the dyad, and verbal communication and hands on help are only provided if needed." Finally, for the toilet transfer, the CG and AT Expert both reported appropriate stand by assistance was provided. It is unclear why the CG reported contradicting FIM scores and open ended responses compared to baseline.

Dyad 207 baseline assessment. The CR in dyad 207 was diagnosed with Alzheimer's disease and was completely dependent on the CG to complete the majority

of ADLs. The CG reported her husband never uses the bathroom and receives bed baths. Because the CR does not perform toilet or shower transfers, only information on the bed transfer was reported. The CG and AT Expert both reported the CG provided total assistance with the bed transfer as needed by the CR. The CG reported “He is not mobile, so I need to give him total help.” The CG also reported “He seems fairly comfortable” with the AT used. However, the AT Expert reported the “CR is very confused and can be combative during the transfer. The CG was very patient but eventually had to transfer him without his agreeing or assistance.” Although the AT Expert reported the CG provided total assistance (help with 75% or more of the task) and the CR needed total assistance, it was also reported the CG “could not offer the appropriate amount of assistance safely. [The CR] almost slid off bed.”

Dyad 207 outcomes assessment. During the outcomes assessment, the caregiver and AT Expert both reported that the same level of assistance (total assistance, or help with 75% or more of the task) was provided and needed. However, the CG reported she was having a difficult time using the transfer board because she felt it was too narrow. She also reported that equipment could only do so much to assist her with the transfer because of her CR’s dependence level. The AT Expert reported the CG used the Hoyer lift and transfer board when observed, but “It did not appear that she had practiced much with it.” The transfer with the Hoyer lift was slower, but safer than the transfer with the transfer board. The caregiver indicated she did not think she would use the lift very often because she was not comfortable with the device.

Dyad 210 baseline assessment. Dyad 210 were sleeping in different rooms during the baseline assessment—the CG in the bedroom, and the CR in a day bed in

the living room. The CR required assistance from the CG, his wife, because of a back injury. The CR was able to walk, but had extreme pain and experienced general weakness in his lower extremities. The amount of assistance the informal CG could provide was limited because her hip was replaced in the past five years, and would flare up if she strained her hips. The dyad had a walker, gait belt, lumbar support (back brace), and raised toilet seat with attached safety frames already in the home, and a formal caregiver was at the home to assist the CR an average of six hours a day.

The CG reported providing more assistance than necessary with the bed transfer, although the AT Expert observed the CG appropriately provided no assistance where the CR completed the task independently with the use of personal mobility devices. The AT Expert and CG reported that the CR's pain levels vary and significantly impact the amount of assistance he requires. The CR was reportedly in significantly more pain during the CG assessment than during the AT Expert assessment. The reported assistance provided refers only to the assistance provided by the informal caregiver, who was the CR's wife in dyad 210. For the bed transfer the CG stated, "I try not to help him too much. I want to see what he can do on his own. That's why I do a lot of standby... I don't want to jeopardize his safety!" The AT Expert reported, "No assistance required today but as CR experiences pain, more assistance is needed to help him lift his legs in and out of bed."

For the toilet transfer the CG reported appropriately providing stand by assistance, although the AT Expert again observed the CR completing the task independently with only the use of his walker. The CG reported:

I'm concerned he'll hit his head on the floor and I won't be able to block him from doing that or I won't be able to pick him up with proper methods. He doesn't have a sense of chronological time, so he doesn't have a sense of how long he's been on the toilet if he falls asleep.... The morphine makes him sleepy... [and] gives him a sense of bladder frequency, but they're false alarms or something, and then he falls asleep. It's a constant—sometimes I'll say "Mr. [CR's lastname]!?" He'll think it's a [formal] caregiver and snap out of it. If I say [CR's first name] he doesn't always respond (chuckle). He spends a lot of time on the toilet.

For comfort with AT, the CG reported, "I used to have to bungee cord the bedside commode to the toilet so it wouldn't flip over because it was so light weight. The elevated toilet seat that you can lock onto the toilet with the side bars is much better. He feels more secure." The AT Expert observed that for the toilet transfer "when CR is in pain he hurries to the commode and he has difficulty side stepping through the narrow doorway." Proper use of the elevated toilet seat and walker was reported.

The informal CG, the CR's wife, reported she does not typically assist with the bath transfer—the formal caregiver assists with this task—but reported the CR needed moderate assistance (help with 25-50% of the task). The CG stated, "I find it more useful to let the caregivers in our employ with bathing. I think it has to do with the dynamic of a married couple, as opposed to a caregiver who's trained to provide that kind of assistance. ...The actual shower process, that tends to be burdensome."

The informal CG described the CR's comfort with AT for bathing:

He holds on to the faucet or the soap rack to get out. We have a corner bracket soap ceramic that was mortared into the wall, and I'm afraid he'll pull on it too

had and pull it out of the wall. Or pull one of the towel bars out of the wall so I think we need better hand grips. He's also used the shower curtain rod to steady himself. We had suction cup grab bars but I took them off because they weren't helping him. They would slide off.

When the AT Expert observed that the CR it was observed that the CR “seemed nervous holding onto the curtain rod and the soap dish” and again stated that the assistance required varies with pain.

Dyad 210 outcomes assessment. Following the training, the CR was able to successfully sleep in the preferred location—the master bedroom. Regarding the bed transfer, the CG reported:

[We were] trying to get more normal so he could regain some feeling and get into a more normal routine, just to make our life more normal. Not that we're having marital relations or anything, but that's now another goal. Being separated at night made us feel like we were 'married singles'.

When asked how the training has impacted the relationship between her and her husband, the CG stated they had not been able to have intercourse for over two years. The possibility of having intimate relations in the future was a huge change for them. When asked how comfortable the CR was with the equipment and training, the CG reported the CR loved the AT provided. She stated the training with the step stool, “makes me feel much more confident that he'll be alright,” the bed rail “expanded [CR's] life,” the flashlight in the bedrail made it possible for the CR to get out of bed in the middle of the night without waking up the CG, and that the leg lifter “really helps him tremendously” particularly when he's experiencing a lot of pain. She also spoke highly

of the AT Expert, saying, "Just having someone as knowledgeable as [AT Expert] to talk things through and show how to do things differently or better has been great." The AT Expert echoed the feedback from the CG that the tasks were easier and assistance was more appropriate for CR's needs.

The CG and AT Expert report the majority of the time the CR was able to perform the toilet and shower transfer independently with the use of personal mobility device (walker). There was one problem, however, with the off-set door hinge replacement. The door was originally supported by three hinges, but was replaced with two off-set hinges. Then the door was dragging on the ground making it difficult to close the door. Following the outcomes visit, a third off-set hinge was installed which realigned the door properly. The informal CG reported the shower transfer was much easier for the CR and that he found all of the equipment helpful, although the formal caregiver provided assistance the majority of the time. The CG stated, "Having the transfer bench and shower head has allowed him to relax more. He can sit in the shower chair and relax, more and control the shower head. The whole thing is a lot less stressful and more efficient for him." The AT Expert reported appropriate stand by assistance was needed, although she observed the CR "didn't seem as comfortable with the bath bench. It was offset a little in the tub and was a bit wobbly, and when the caregivers attempted to offer guidance on what the CR should be doing, the CR snapped at them declaring 'I am trying to figure out what to do!'" More time may be needed with the equipment to become comfortable with its use.

Novice group. The dyads in the Novice Group did not receive any training intervention.

Dyad 203 baseline assessment. Dyad 203 is a spousal caregiving dyad where the CR was recently diagnosed with Parkinson's disease. The CG expressed concerns about her ability to continue for her husband as his disease progressed. The CG reported providing appropriate assistance for the bed transfer, and did not feel AT was necessary. She said, "I feel like, right now, I'm capable of doing these things...right now." The AT Expert also reported appropriate assistance was provided and observed the "CR is physically capable at this time. CG only provides verbal cues, and some stand by [assistance], and occasionally a hand at getting up." For the toilet transfer, the CG reported providing stand by assistance, while the AT Expert observed the CR completing the task independently when he needed some stand by assistance, stating "[the] CG could provide [a] hand to help pull [the] CR up just to make it easier and faster, but it is not needed." In other words, the CG provided standby assistance, but the CR could complete the task on his own. Finally, for shower transfers, the CG reported that she provided more assistance than was necessary, stating, "I am merely being cautious," though the AT Expert reported her assistance was appropriate for the CR's needs.

Dyad 203 outcomes assessment. Though all reports at outcomes indicated there was appropriate assistance with all transfers, the CG and AT Expert only reported identical FIM scores for the bed transfer. The AT Expert observed moderate physical assistance (help with 25-50% of the task) saying, "[The] CG is providing appropriate assistance, but with certain equipment [the] CG would not have to provide any assistance." This score is a marked change from baseline, when the CR was rated as completely independent. For bed and toilet transfers, the CG reported the assistance

provided was the same as during baseline. The AT Expert reported the dyad worked together “very well” and that the CG provided the assistance the CR needed. There was no mention of why the AT Expert reported the CR needed more assistance than during baseline assessment. For the final shower transfers, the CG reported the CR now needed stand by assistance, rather than being able to complete the task independently, pointing out where he grabs the door getting into the shower, which was not mentioned during baseline. The AT Expert again reported FIM scores indicating the CR received *and* needed more assistance, but indicated there were no changes in assistance in responses to interview questions. Of note, when the CG was asked how this study has impacted the assistance she provides to her husband, she replied, “Yeah, it’s been helpful,” although she had not received any training or equipment.

Dyad 204 baseline assessment. Dyad 204 is a spousal caregiving dyad. The CR has been diagnosed with early on-set dementia, though is able to perform all transfer tasks with minimal assistance from the CG. The dyad has an elevated toilet installed, but no other pre-existing equipment. The CG reported not providing enough assistance for all three transfers. Though the AT Expert also reported observing too little assistance for the bed and shower transfer, appropriate assistance was reported for the toilet transfer. For transferring in and out of bed, the CG reported, “He rejects my help and wants to do it by himself. He tends to want to do everything himself. He uses the foot board to help himself off the bed, but he is still wobbly when he does that. I don’t know why he won’t use a walker or cane. He complains about being dizzy a lot.” The AT Expert observed, “CG stood by, but could have provided [minimal assistance].” For toilet transfers the CG again reported difficulty providing assistance to the CR and

the AT Expert reported the CR would benefit from additional AT. With shower transfers, despite saying the CR needed some physical assistance, the CG states, “I provide the assistance he needs. I stay in the shower with him to watch him to make sure he does not fall.” However, the AT Expert report stated the CR performed this task independently, and instead focused on safety concerns with a shower head—used as a grab bar—that was becoming detached from the wall. The AT Expert reported, “The flex shower head system... has not been properly installed, and therefore, is very unsafe. It would be preferable for wife to provide closer SBA [stand by assistance] and/or prn [as needed assistance] especially until the flex hose shower head... can be reinstalled properly and an additional grab bar can be added.”

Dyad 204 outcomes assessment. During the outcomes assessment, the CG reported providing the assistance the CR needed for all three transfers. However, the AT Expert reported there was only appropriate assistance for the bed transfer and that the CG provided less assistance than the CR needed for the toilet and shower transfers. For the toilet transfer the CG reported the CR “needs a bar or handle to help him brace himself while going down and pull himself up,” which is similar to the AT Expert’s observation that the “CR needs equipment more than CG assistance.” Finally, the CG reported, “I give him the amount of assistance that he will accept, he wants to be independent but that is why we run into some problems. He is reluctant to accept help.” The AT Expert only reported the “CG prepares shower area, then provides stand by observation.” There is no further explanation for why the FIM scores indicate less assistance is provided than needed for this transfer.

Dyad 205 baseline assessment. Dyad 205 is another spousal caregiving dyad where the CR has been diagnosed with dementia and a formal caregiver is in the home to assist an average of 20 hours a week. During the baseline assessment, both the CG and the AT Expert reported that appropriate levels of assistance were provided for all three transfer tasks. The bathroom had recently been redesigned specifically to assist the CR as the dementia progressed. There were two grab bars near the toilet, one grab in the shower, and a bath seat (transfer bench) in the shower from the renovation. By both accounts, the CR was able to perform all tasks with no more than stand by assistance. The CG reported she provided stand by assistance for the bed and shower transfers, but the CR was able to complete the toilet transfers independently. The AT Expert observed that stand by assistance was needed and provided for all transfer tasks, saying the CR is “still independent physically. CG appeared to have good routine practice in providing verbal guidance. CG verbally guided CR, [and] CR did what was suggested.” For all tasks, the AT Expert reported verbal prompting was required to complete the task. In particular for the toilet transfer, the CG indicated, “He has everything provided, handrails, toilet paper where he can reach it...When he’s not steady I watch to make sure he’s steady coming.” The formal caregiver did not assist with any transfer tasks.

Dyad 205 outcomes assessment. During the outcomes assessment, the CG reported there was a death in the family. In addition, the CR had injured his hand, and the tendonitis and emotional strain appeared to alter the level of assistance he needed from the CG. The CG reported that she did not provide enough assistance with toilet transfers, stating, “He needs a bar or handle to help him brace himself while going down

and [to] pull himself up.” The CG described the other two transfers as appropriate, whereas the AT Expert reported all assistance provided was appropriate.

For getting in and out of bed, the CG described an atypical technique she uses to assist the CR saying, “I get a hug each morning after he's standing up and fully balanced. That way I can test—and get a hug. It's a two way street.” The toilet transfer the CG reported she typically does not provide any assistance, but that day the CR needed stand by assistance because of his injury. The AT Expert observed the CR needed—and received—more assistance than during baseline and reported, “CG gave verbal prompting, which CR responded to. The CR needed a little more than verbal prompting, as was evidenced by his grasping the door frame in order to get up.” Despite there being a grab bar next to the toilet, the AT Expert reported “no AT [was] used. [The CR] was pretty much on his own, except for grabbing the door frame to get up.”

Dyad 208 baseline assessment. Dyad 208 is also a spousal caregiving dyad. The CR has been diagnosed with dementia and has had a stroke. Like dyad 207, the CR is very dependent on the CG to perform most activities. This dyad also has two formal caregivers who are at the home about 40-hours a week. There is AT in the home including a Hoyer lift that is rarely used, a transfer board, a trapeze bar, and a modified bathroom with a safety frame and removed wall. The formal caregiver always bathes the CR in bed, so only bed and toilet transfers were reported. The CG has arthritis, and there are conflicting reports over whether she or the formal caregiver performs the activities most often. The AT Expert observed both transfers performed by both the primary formal caregiver and the CR's wife, the informal CG, although AT

Expert reports suggest the formal caregiver provided the majority of the assistance. Both the CG and the AT Expert reported the caregiver provided appropriate levels of assistance for both transfer tasks.

For getting in and out of bed, the CG stated, “I don’t feel that I can give him enough support. It’s because [of] my age and my arthritic condition. I have someone come in to help.” She also reported the CR seemed resistant to receive help from her, “I know he tightens up because he is afraid he might hurt me. He holds back.” When observing this task, the AT Expert observed, “The wife stated she does not transfer the CR in/out of bed. The wife and hired caregiver stated that they have a Hoyer lift and use it ‘occasionally.’” The CG relayed the steps performed to help her husband on the toilet, starting with “I have to do more. I have to do... everything as far as clean up...” and transitioning to, “Then you need to stand him up. And then you need to turn him...” The AT Expert echoed the CG’s reports that toileting was difficult, but only described how the *formal* caregiver performed this transfer. While the informal CG may assist with this transfer, the AT Expert did not observe this assistance beyond the CG standing by while the formal caregiver and the CR perform the transfer tasks.

Dyad 208 outcomes assessment. During the outcomes assessment, the CG again reported the assistance she provided, while the AT Expert reported the assistance the formal caregiver provided. The Veteran’s needs were consistent with baseline for both the CG and AT Expert. The only difference from last time was the CG’s emphasis on the interaction between her and the CR. She explained, “I feel that he holds back because he doesn't want to help me. I'm frustrated and I holler. I'm not real calm with that. I'm calling commands--you know. I'm not real calm when I do it.

That's because I'm afraid he might fall." The same is true with the toilet transfer where she said, "Sometimes it's not a very pleasant situation if he's already gone... [I] try to put humor into the task. Use humor and it's okay. I'm cussing and he's laughing."

Dyad 211 baseline assessment. Dyad 211 is a sibling caregiving dyad where the CG is the CR's sister. The CR moved in with his sister shortly after being diagnosed with a heart condition and early onset Parkinson's disease. Both the CG and the AT Expert report that appropriate levels of assistance were provided for all three transfer tasks. Though the actual levels of assistance differ between the CG and AT Expert, no physical assistance was ever reported as provided or needed. The CG reports are different. For the bed transfer, the CG states, "I had to assist him to get out the bed. In general, he gets in and out of the bed. But he's been in that position a couple of times." The AT Expert observed, "The CR did admit occasionally getting a hand up from the CG to get out of bed, but was quick to qualify that was rare... CG seemed to think it was more often, but observations on this visit did not support the need for this type of assistance." Both the CG and the AT Expert report the CG was independent, though the AT Expert observed, "He was a bit unsteady on his feet, so having someone else in the house during activity performance is probably a good idea." For the shower transfer, the CG explains, "Mainly, it's stand by [assistance]. I'm concerned that he could fall. Three months ago he didn't get in... now, he gets in and out of the shower. I'm still concerned." These sentiments are reiterated by the AT Expert who describes the shower transfer saying, "[The] CG has asked that [the] CR not do bathing activities unless someone else is home. The [CG] isn't needed for assistance, just as a protection for getting up and out of the tub if a fall should occur."

Dyad 211 outcomes assessment. No changes in the FIM scores were reported by either the CG or the AT Expert for all three transfers since the baseline assessment, and the CR's health improved since the baseline assessment. In general, the AT Expert observed the CR is "independent, [the] CG lets him be that way." The CG reports that despite considerable health improvements, the CR still is "not as steady on his feet as he thinks he is." When the CG was asked about AT she mentioned, "His doctor saw him dragging the cane. He [CR] thinks he can walk without it, but he's not steady enough on his feet. Sometimes he'll leave it somewhere around the house and we have to go back and get it. He needs the cane, I think." The AT Expert reported similar feedback from the CR, explaining "[The CR] thought he wasn't going to need the cane much longer, going so far as to move between rooms a couple of times without the cane. [AT Expert] cautioned CR that he should use the cane until his physician cleared him to move about without it."

Finally, the CG described her relationship with the CR noting there was a change from before he became sick. She commented, "Our relationship is good... It's different. We get along fine... but it's different. We used to be best friends. And he got divorced and got sick and came to live with me, and it's just different. I'm sure it is for him too. In his own way, I think he relies upon me for everything."

Caregiver concern. One of the surprising findings from this analysis is that caregivers continue to report safety concerns even after receiving the in-home training intervention. Responses from dyad 210 that the training made the CG feel much more confident and comfortable with the CR completing transfers on his own were expected. Dyad 201 understandably reported being concerned for her husband's safety when after

receiving the trapeze bar during the intervention, the AT was not appropriate for the new hospital bed. The chain was hanging in the CR's face and the CR was scared by the loud noises the chain on the trapeze bar made. The environment for this dyad changed, so the AT was no longer appropriate, and the CG and CR were concerned that the equipment was no longer safe.

On the other hand the CG in dyad 210 did report being concerned for her husband's safety—but because she will always be worried about her husband. Similar responses observed in dyads from both groups including dyad 201 (TG), dyad 207 (TG), dyad 208 (NG), and dyad 211 (NG). Perhaps the strongest example of this would be the CG in dyad 203 who, when asked why she provided more assistance than her husband needed, replied, "I am being cautious." When asked if there was anything that could be done to make her feel more comfortable she said the CR was her husband, and she would always be worried about him—no matter what.

Caregiver contradictions. Even though dyads 208 and 206 and their AT Experts reported several contradictions, the FIM data were not modified. For dyad 208 the CG reported she provided the assistance, but the AT Expert observed the formal caregiver providing the assistance, but as discussed above, the CG believed her assistance was hiring the formal caregiver and being able to perform the tasks if the formal caregiver was not around. She believed caring for her husband was her responsibility. The CG in dyad 206 also believed caring for her husband was her responsibility, but to the extent that she reported providing total assistance, and then described stand by assistance. While language barriers may have been an issue for 206, with both caregivers, the important information was how they perceived their

assistance, not the actual level reported. The way the appropriateness and accuracy of assistance were analyzed negated the importance of the actual numerical value for the level of assistance reported, so it was determined that modifying the responses for these cases was not required.

Relationships. Much of the perseverating CG's concern for the CR may be related to the dyads' relationship with one another. The CG in dyad 205 reported a good relationship with her CR, as demonstrated with the bed transfer—having him give her a hug so she can check his balance. The CR consistently gathers the energy to get out of bed each morning to hug his wife when he sometimes struggles to find the energy to complete other tasks. Although the CG in 208 reported that her husband was reluctant to let her help her, the CG reported that transfers are easier if she makes jokes about how awkward the transfers can be and makes her husband laugh. On the other hand, the CG in dyad 204 reported the CR refused to accept her help, and indicated that caring for her husband has been difficult at times, but that they were arguing before his diagnosis. Then again, the CG in dyad 211 reported a complete change in the relationship she has with her brother. When before they were “best friends,” they now have redefined their relationship and reported differing opinions about whether the CR needed stand by assistance from the CG or needed to use his cane. Yet—possibly because of the strength of their previous relationship—the CR continued to do as the CG requested. Overall, it appears that not only the quality of the current relationship, but also the quality of the relationship in the past, impacts the CR's acceptance of the CG's assistance. More research on relationships between care-partners is needed. There are conflicting reports of whether a relationship is an environmental factor or a

personal factor, but regardless of how they are labelled, relationships are a contextual factor that impact both members of the dyad. Implications of these findings and how they relate to the FIM scores are discussed in the next chapter.

Environmental factors. The environmental factors considered for this analysis were the in-home training provided by AT Experts including the AT devices installed in the dyads' homes and the home modifications implemented as a part of the training. Some of the training provided included training dyad 210 to use the log rolling and side sitting techniques to reduce the strain on the Veteran CR's back, training dyad 206 to lower the hot water heater's thermostat, and training the CR in dyad 201 to push on the built-in bench in the shower since the material the shower was made of prevented grab bars from being installed. The provision of AT included training dyads to use the provided equipment. For example, training dyad 201 to use the trapeze bar, dyad 206 to use the grab bars in the shower, dyad 207 to use the transfer board and dyad 210 to use the shower bench. Home modifications referred to moving furniture around as with dyad 201, 207 and 210 and removing rugs as with dyad 206.

Several dyads reported some concern with either the AT provided or the AT that already existed in the home. For example, dyad 210 used a bungee cord to fasten a 3-in-1 commode to the toilet, the Veteran dyad 211 did not want to use his cane, dyads 210 and 204 had safety risks where they grabbed on to walls and shower curtain rods that could not support their weight, and dyads 207 and 208 had a Hoyer lift that was not used because the CG did not know how to use the equipment. These concerns existed across both groups. With training, the reported concerns decreased dramatically, although 207 still reported dissatisfaction with the transfer board. All aspects of the

training appear to have impacted the Training Group dyads, and how the CGs perceived the assistance they were providing and the assistance the CR needed.

Caregiver perception as a personal factor. Caregiver perception in this sample includes whether the caregiver believed she provided appropriate assistance and how accurate her perceptions were compared to AT Expert observations. The provision and training with AT appeared to make transfers easier for dyads 201, 206, and 210. With dyad 207, the home modifications reportedly made the bed transfer easier, but because of the CR's dependence level, there was no change reported in the FIM scores. CG perception also changed as with the bed transfer for dyad 210 where the CR was able to sleep in the master bedroom with his wife after receiving the intervention. The CG first underestimated the assistance her husband needed to complete the bed transfer but was able to appropriately and accurately provide assistance after the couple received training, the bed rail, information on how to use the step stool, and training with the leg lifter and flashlight. However, the reason the CR did not sleep in the master bedroom previously was because the bed was too high. When the AT Expert suggested lowering the bed, the CG confided in the AT saying that she didn't want a lower bed and needed the storage space raising the bed allotted.

There were reported improvements for Novice Group caregivers, but the majority of these improvements involve responses from the CG that mirror responses from the AT Expert. For example, the CG in dyad 203 reported during outcomes that the study had been "very helpful", though the dyad had not received any training or equipment. However, they had received recommendations from the AT Expert. These recommendations were provided because, in the larger CG ASSIST study, caregivers in

the Novice Group received the training intervention in visits after the outcomes assessment for this thesis. AT Experts reviewed their recommendations with the dyads in the Novice Group, but did not provide any training or equipment. A week later these caregivers were interviewed to gather their feedback for this study. However, it appears that based on these discussions, many CGs changed their perspectives. Therefore, when higher changes in the Training Group than in the Novice Group are reported, it is more likely that these changes are due to the actual training and equipment rather than the power of suggestion. Nonetheless, future studies may consider changing the order of the outcomes assessment so the caregiver reports are collected before the AT Expert observes the dyad and makes recommendations.

Impact of personal factors on environmental factors. Just as the training intervention (environmental factors) impacted caregiver perception (personal factors), caregiver perception also influenced the shared environmental factors of the caregiving dyad. This influence is seen with dyads 205, 207, 208 and 210 who all believed they could not provide the assistance their CR needed on their own and hired a formal caregiver to provide assistance their CR needed. The formal caregiver is a resource and therefore a shared environmental factor. With these dyads there were some inconsistencies in the reported assistance provided. Dyad 208 (NG) and dyad 210 (TG) said they provided assistance that the AT Expert observed being provided by the formal caregiver. These caregivers seem to believe they were providing the assistance their CR needed by hiring the formal caregiver. The apparent reciprocal relationship between personal and environmental factors in older adults when completing a transfer

tasks contributes to Yeung and Towers's (2013) finding that there are multidirectional relationships in children's contextual factors.

CHAPTER 5 : DISCUSSION AND CONCLUSION

Interpretation

When comparing caregiver reports of the level of assistance (LoA) provided to their Veteran care recipients in both groups, caregivers in the Training Group demonstrate more variability from baseline to outcomes. CGs in the Training Group reported changing the LoA provided for 77% of the completed transfer tasks while Novice Group CGs did not report any change in the LoA provided for any of the completed tasks. This is a strong indication that the training intervention contributed to much of the changes observed in the Training Group. These results are expected because there is strong support for the efficacy of in-home dyadic training with AT and home modifications to improve a dyad's ability to complete transfer tasks (Pynoos & Nishita, 2003). A change in the LoA provided is not inherently preferable—the desired outcomes varies from dyad to dyad and across transfer tasks. If a caregiver is providing the assistance a care recipient needs at baseline, then the ideal outcome would be for there to be no change in the assistance provided.

Aim one. The first goal for the intervention is understand caregiver' perceptions of the care given to and required by the care recipients. Caregivers who received the training intervention reported a change in the assistance they provided for nearly all of the completed transfers, while control caregivers did not report any change in the assistance they provided. Although these results may not be statistically significant, the training intervention had a clinically significant impact on how caregivers' perceived the assistance they provided. As suggested by Lobchuck, the training where caregivers are

asked to imagine themselves from the care recipients' perspective appears to impact how caregivers provide care (2005). This study furthers Lobchuck's findings by demonstrating that perspective-taking can be a physical activity, in addition to a cognitive or intellectual task, which impacts how physical assistance is provided. Further study as to why caregivers report these changes, whether these changes are beneficial to the Veteran care recipient, and how these changes influence caregiver and care recipient quality of life is needed. Comparing the change in the level of assistance provided by Training Group and Novice Group caregivers suggests that the training intervention has an impact on the LoA CGs report providing, but provides little information about the caregivers' perceptions. These changes could be explained by the change in the CR's health status, such as in the CR in dyad 205 who developed tendonitis, or by a miscommunications with the CG as with dyad 206.

Because changes in the assistance needed occurred similarly in both groups, mediating factors most likely contributed to this change rather than the training intervention itself. These results suggest that caregivers' perceptions of how much assistance their care recipients need will change over time—this was true for all caregivers in this study regardless of whether they received training or equipment.

Every transfer task completed by a caregiver who received training was reportedly performed with appropriate levels of assistance, though nearly half of these transfers were perceived to involve too little or too much assistance at baseline. While this may imply the training increased the likelihood that caregivers would perceive themselves to provide appropriate assistance, transfer tasks completed by caregivers who did not receive training were also reportedly performed appropriately during

outcomes. The similarity implies there may be confounding factors influencing how caregivers perceive the appropriateness of the assistance they provide their care recipients. Once again, these comparisons seem to suggest the training intervention is altering how caregivers perceive the assistance they provide their care recipients. However, caregivers in the Novice Group also report they believe they are providing appropriate assistance at outcomes for nearly all (93%) of the completed transfer tasks—a 20% increase from baseline. The larger increase in the percent of transfers caregivers believe are completed with appropriate assistance in the Training Group (46%) compared to the Novice Group (20%) may be because the intervention is impacting caregiver's beliefs and perceptions. An alternative explanation is that caregivers are modifying their beliefs because someone is coming into their home, observing them perform these tasks, and they respond with an observation bias which is driving the changes in perceived appropriateness. This observation bias combined with a ceiling effect because the Novice Group caregivers believed they were providing appropriate assistance at baseline for 73% of the completed transfers, are strong confounding factors. While the training intervention may impact caregiver perception, further analysis is needed to rule out these confounds.

Aim two. Just as de Jong-Hagelstein, Kros, Lingsma, Dippel, Koudstaal, and Visch-Brink (2012) used expert and proxy ratings to assess the accuracy of perceived assistance, this study used AT Expert and caregiver reports. Caregivers who receive training and AT appear to more accurately perceive the level of assistance provided compared to AT Experts' reports. A caregivers' beliefs about the assistance provided—whether there is too much, just enough, or too much assistance—are accurate if they

match AT Expert beliefs about the assistance provided. For the Training Group, there is a 27% increase (from 62% to 89%) in the percent of transfer tasks where caregivers accurately perceived the assistance they provide their care recipient from baseline to outcomes. In contrast, there is no difference in the accuracy of caregiver perceptions in the Novice Group. There is evidence to suggest the training intervention impacts the accuracy of caregivers' perceptions.

Aim three. Previous research found perceptions, beliefs, and attitudes are personal factors within the ICF framework that impact how an *individual* experiences a health condition (Hamed, Tariah & Hawamdeh, 2012; Huber, Sillick & Skarakis-Doyle, 2010; Khan & Pallant, 2007). In turn, research has also demonstrated caregivers' attitudes and beliefs about care recipients and their health conditions impact the quality of the care provided (Johnston & Evans, 2005). This thesis focuses on how the modified environmental factors from the training intervention alter caregiver perceptions about how they assisted their care-partners with transfer tasks.

The environmental factors considered for this analysis were the in-home training provided by AT Experts including the AT devices installed in the dyads' homes and the home modifications implemented as a part of the training. Some of the training provided included training dyad 210 to use the log rolling and side sitting techniques to reduce the strain on the Veteran CR's back, training dyad 206 to lower the hot water heater's thermostat, and training the CR in dyad 201 to push on the built-in bench in the shower since the material the shower was made of prevented grab bars from being installed. The provision of AT included training dyads to use the provided equipment. For example, training dyad 201 to use the trapeze bar, dyad 206 to use the grab bars in

the shower, dyad 207 to use the transfer board and dyad 210 to use the shower bench. Home modifications referred to moving furniture around as with dyad 201, 207 and 210 and removing rugs as with dyad 206.

Several dyads reported some concern with either the AT provided or the AT that already existed in the home. For example, dyad 210 used a bungee cord to fasten a 3-in-1 commode to the toilet, the Veteran dyad 211 did not want to use his cane, dyads 210 and 204 had safety risks where they grabbed on to walls and shower curtain rods that could not support their weight, and dyads 207 and 208 had a Hoyer lift that was not used because the CG did not know how to use the equipment. These concerns existed across both groups. With training, the reported concerns decreased dramatically, although 207 still reported dissatisfaction with the transfer board. All aspects of the training appear to have impacted the Training Group dyads, and how the CGs perceived the assistance they were providing and the assistance the CR needed.

Personal factors: Caregiver perception. The primary personal factor considered in this analysis is caregiver perception. This includes whether the caregiver believed she provided appropriate assistance and how accurate her perceptions were compared to AT Expert observations. The provision and training with AT appeared to make transfers easier for dyads 201, 206, and 210. With dyad 207, the home modifications reportedly made the bed transfer easier, but because of the CR's dependence level, there was no change reported in the FIM scores. CG perception also changed as with the bed transfer for dyad 210 where the CR was able to sleep in the master bedroom with his wife after receiving the intervention. The CG first underestimated the assistance her husband needed to complete the bed transfer but was able to appropriately and

accurately provide assistance after the couple received training, the bed rail, information on how to use the step stool, and training with the leg lifter and flashlight. However, the reason the CR did not sleep in the master bedroom previously was because the bed was too high. When the AT Expert suggested lowering the bed, the CG confided in the AT saying that she didn't want a lower bed and needed the storage space raising the bed allotted.

The same caregiver asked the AT Expert to train the CR with her and the formal caregiver combined because she thought the CR would see the AT Expert as an authority figure. This may be how the CR actually perceived the AT Expert, or may have been a projection from the CG herself. Either way, the CG's perception modified how the training was conducted for the tub transfer. The presence of the AT Expert also changed the behavior for the CG in dyad 206. While this CG described listening to her husband while watching TV as he transferred to and from the toilet, the AT Expert observed the CG providing physical assistance that was not needed. It is possible for this dyad, the CG did not show the assistance that was typically provided, but instead provided the assistance she thought her husband would need. After the training on what kind of assistance her husband needed, the AT Expert observed the appropriate assistance reported by the CG.

Mediating factors. The CR's health condition was one of the CR's personal factors that influenced the amount of assistance provided. This was particularly true for dyads 207 (TG) and 208 (NG) where the CR required total assistance with tasks. Because the Veteran CR's dependence was so high, no change was reported with the FIM scores, though 207 reported the task being easier after receiving training. The CR's health

status was also a mediating factor. Based on Ferri and Pruchno's (2009) work where changes in how a spouse's perception of a patient's functional ability changed how caregivers perceived their care recipients' quality of life, the data from this study imply a decline in health mediates a change in the accuracy of caregiver perception. However, when the CR's health declined, as with dyad 205 who developed tendonitis, the caregiver's accuracy decreased when the caregiver over-estimated the care recipient's ability. Then again when health improved as with dyad 211, there was no change in the caregiver's accuracy—the caregiver consistently reported accurate levels of assistance. More research is needed to investigate the impact of care recipient health on the accuracy of caregiver perceptions.

Another personal factor was the Veteran CR's perception. Dassel and Schmitt (2008) interviewed caregivers and care recipients and determined an objective measure of task performance was needed. Particularly given this is a dyadic intervention, the Veteran CR's perception is crucial to understand the mechanism behind the relationship between environmental and personal factors in cohabitating dyads. More information is needed to determine how the CRs perceived the assistance provided, but there were several observations and reports that implied the CR was frustrated with AT, the caregiver, or the transfer training including dyad 204 who refused to accept help from his wife, dyad 211 who adamantly stated he could do his tasks on his own, or dyad 207 who was generally agitated the day the AT Expert conducted the baseline assessment. The Veteran CR's perspective should be considered to investigate the concordance between the CG, CR, and the AT Expert. Evaluating the concordance from all three

reports will provide a much more comprehensive understanding of how environmental factors impact personal factors.

Implications

Some of the similarities between the scores from AT Experts observing dyads in the Novice Group may be explained by the AT Experts, rather than to which group the caregivers were assigned. The baseline and outcome assessments were conducted by two different AT Experts for dyads in the Training Group, but by only one AT Expert who returned twice for dyads in the Novice Group. This discrepancy is due to the design of the larger CG ASSIST project which has an independent outcomes AT Expert assess the Novice Group at a later point in the study not included in this analysis. Because of time constraints, including the entire length of the CG ASSIST study in this analysis was not possible. However, whether the caregivers were observed by two AT Experts or one would not impact how the caregivers reported the assistance provided and needed to research staff.

Limitations and Future Directions

This study can inform future studies and speaks to the need to ensure that different AT Experts are reporting results at baseline and outcome assessments for both groups. Additional and continuous training is needed to ensure that AT Experts are responding appropriately to each question. The questions asked of the caregivers should also be reconsidered. While several caregivers reported different FIM scores for the assistance provided and the assistance needed, few caregivers realized they were reporting a different levels of assistance. Instead of highlighting a discrepancy,

caregivers should be asked to describe the assistance they provided their care recipient.

To further develop this study, the screening criteria should be modified. Both caregivers and Veterans should be required to speak English proficiently on their own in order to participate in this study. Dyads who have a formal caregiver in their home to assist with transfer tasks should be asked how much time the formal caregiver works in the home and how often the informal CG performs each transfer task compared to the formal CG. Formal caregivers who perform the transfer tasks as often, or more often, than the informal caregiver should be included in this study. An unfortunate consequence of studying older adults who require assistance from a caregiver to perform ADLs is that a high level of attrition is anticipated. The rate seen in this sample was higher than expected, and had a more significant impact because both dyads who left the study were from the Training Group. The impact was further exacerbated by data missing from dyad 207, also assigned to the Training Group. A larger sample size would help to account for uncontrollable events including attrition and missing data.

Future studies are also needed to define personal factors so the World Health Organization can determine whether perception is an appropriate variable in this domain. If not, serious consideration should be given as to where perceptions are most appropriately represented within the ICF framework, because there are clear implications that perception influences how individuals experience various health conditions. Another area for future research within the ICF framework is to examine the impact of CG perception on environmental factors to test whether this relationship is reciprocal. These environmental factors should expand beyond training, AT, and home

modifications to include cultural beliefs, societal expectations, financial resources, community resources, and other shared environmental resources. In turn, future studies are needed to examine the impact of CG perception on activity performance beyond assistance with transfer tasks.

Significance

The current FIM and proposed model for third-party disability inadequately represent the connections within cohabitating caregiving dyads. A revised model is necessary to ensure that clinicians appreciate the significance of including the caregiver in discussions that impact the shared home environment. As with the CG in dyad 210, if a physical therapist recommended the CR use a bed rail to get in and out of bed and the CR removes the risers under the bed, the CR would not have been able to transition to sleeping in the master bedroom. Because the caregiver was involved in these recommendations, the AT Expert knew removing the risers was not an option for this dyad. Instead, alternative recommendations and training were provided to account not only for the care recipient's beliefs and preferences to sleep in the master bedroom, but also account for the caregiver's beliefs and preferences to keep store space under the bed and both care-partners appear to have benefitted exponentially.

Dassel and Schmitt (2008) proposed that an objective measure of task performance could be used to improve the accuracy of caregivers' perceptions of care recipients' needs—the results from this thesis support this assertion. As Martire et al., (2006) suggested, caregivers who accurately perceive care recipient needs report providing positive support to their care recipient, which in turn improves outcomes for their care recipients. Interventions that decrease caregiver burden are particularly

beneficial for this population due to Robinson-Whelen and Rintala's (2003) discovery that over half of Veterans with a spinal cord injury would not have any assistance if their primary caregiver were no longer able to care for them. It is crucial to provide support for caregivers on Veterans so they can continue to provide the assistance that allows Veterans to age in place. There are also economic incentives to implementing this environmental intervention. Although a cost analysis was not conducted, prior research has shown the provision of AT and in-home training similar to this intervention decreases provider visits and healthcare costs (Mann, Ottenbacher, Fraas, Tomita, & Granger, 1999). Further research is needed to determine the feasibility and efficacy of implementing this intervention on a larger scale.

Until the reciprocal relationship between environmental factors and personal factors is explored further, the proposed revisions to the ICF illustrating third-party disability for caregiving dyads remain untested. Another vital factor for future analysis is the Veteran care-recipient's perception of the environmental modifications. Without the Veteran's perspective, it is difficult to assess how training, AT, and home modifications impacted the dyad as a whole. This study focuses on caregiver perception, but care recipients' personal factors are also expected to impact both shared and individual contextual factors. Never the less, this study illustrates some preliminary evidence that an intervention that impacts environmental factors, like the home-based training on the use of recommended AT and home modifications, also modifies caregiver perceptions. Regardless of how third-party disability is conceptualized, it is essential that future models consider three factors: 1) cohabitating caregiving dyads have environmental factors that cannot be separated, 2) caregivers are a valuable resource for health care

providers seeking to improve how a care recipient experiences health conditions, and 3) altering shared environmental factors impacts caregiver perceptions which in turn influence how effectively care recipients are able to perform daily activities.

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APPENDICIES

Appendix A : Measures

Modified Functional Independence Measure (FIM) (Caregiver)

- 1) Does [Veteran] **USE** any personal mobility devices to get in and out of bed?
(Wheelchair, walker, cane, orthotic/prosthetic device, or crutches.)
- 0 No
1 Yes
- 2) What kind of assistance do you **PROVIDE** to help [Veteran] to get in or out of bed?
- 0 None
1 Only verbal prompting, standby assistance, or setup
2 Physical assistance

If 2) = 'Physical,' go to question 3). Otherwise continue to question 4).

- 3) How much assistance do you **PROVIDE** to help [Veteran] to get in or out of bed?
Caregiver assists by performing...

<u>Level of Assistance PROVIDED</u>	<u>Description</u>
<input type="checkbox"/> 4 Minimal assistance	< 25% of the task; incidental hands-on help only
<input type="checkbox"/> 3 Moderate assistance	25-50% of the task
<input type="checkbox"/> 2 Maximal assistance	51-75 % (over half) of the task
<input type="checkbox"/> 1 Total assistance	>75% or all of the task

4) Does [Veteran] **NEED** any personal mobility devices to get in and out of bed? (Wheelchair, walker, cane, orthotic/prosthetic device, or crutches.)

- 0 No
- 1 Yes
- 66 No Response

5) What kind of assistance does [Veteran] **NEED** to get in or out of bed?

- 0 None
- 1 Only verbal prompting, standby assistance, or setup
- 2 Physical assistance
- 66 No Response

If 5) = 'Physical,' go to question 6). Otherwise continue to branching logic below.

6) How much assistance does [Veteran] **NEED** to get in or out of bed? Veteran needs assistance with....

<u>Level of Assistance PROVIDED</u>	<u>Description</u>
<input type="checkbox"/> 4 Minimal assistance	< 25% of the task; incidental hands-on help only
<input type="checkbox"/> 3 Moderate assistance	25-50% of the task
<input type="checkbox"/> 2 Maximal assistance	51-75 % (over half) of the task
<input type="checkbox"/> 1 Total assistance	>75% or all of the task

**Modified Functional Independence Measure (FIM)
(Assistive Technology Specialist)**

- 1) Did the Veteran **USE** any personal mobility devices to get in and out of bed?
(Wheelchair, walker, cane, orthotic/prosthetic devices, or crutches.)
- 0 No
 - 1 Yes

- 1a) What kind of assistance did the caregiver actually **PROVIDE** to help the Veteran to get in and out of bed?
- 0 None
 - 1 Only verbal prompting, standby assistance, or setup
 - 2 Physical

If 1a) = 'Physical,' go to question 1b). Otherwise continue to question 2).

- 1b) How much assistance did the caregiver actually **PROVIDE** to the Veteran to get in and out of bed?
Caregiver assists by performing...

<u>Level of Assistance</u> PROVIDED	<u>Description</u>
<input type="checkbox"/> 4 Minimal assistance	< 25% of the task; incidental hands-on help only
<input type="checkbox"/> 3 Moderate assistance	25-50% of the task
<input type="checkbox"/> 2 Maximal assistance	51-75% (over half) of the task
<input type="checkbox"/> 1 Total assistance	>75% or all of the task

2) Did the Veteran **NEED** any personal mobility devices to get in and out of bed?
(Wheelchair, walker, cane, orthotic/prosthetic devices, or crutches.)

- 0 No
- 1 Yes

2a) What kind of assistance did the Veteran actually **NEED** to get in and out of bed?

- 0 None
- 1 Only verbal prompting, standby assistance, or setup
- 2 Physical

If 2a) = 'Physical,' go to question 2b). Otherwise continue to branching logic below.

2b) How much assistance did the Veteran actually **NEED** to get in and out of bed?

Veteran requires assistance with...

<u>Level of Assistance PROVIDED</u>	<u>Description</u>
<input type="checkbox"/> 4 Minimal assistance	< 25% of the task; incidental hands-on help only
<input type="checkbox"/> 3 Moderate assistance	25-50% of the task
<input type="checkbox"/> 2 Maximal assistance	51-75% (over half) of the task
<input type="checkbox"/> 1 Total assistance	>75% or all of the task

Appendix B : Interview Questions

(Caregiver)

Once again, I'd like to remind you that all of your responses are completely confidential. Your responses will be used for research purposes only. I may need a moment between questions to make sure I write down exactly what you say. Your feedback is very important, and I want to make sure I don't leave anything out.

Right now I'd like to talk to hear your thoughts about how you help your partner with transfer tasks. Some caregivers feel they are not able to provide enough support, others feel they provide more support than the Veteran needs, while others feel they are able to provide the right amount of support.

After FIM

1) *Why did you indicate earlier that you are able to provide (more/less/the same) assistance (than what/that) your Veteran needs to get in or out of bed?*

a. *If more or less assistance, What would be an example?*

2) *If any assistive devices are used, How comfortable does the Veteran appear to be with the assistive devices used to get in or out of bed? Examples of assistive devices are grab bars, shoe horns, and bedrails.*

Outcomes visit only

1) *How has this study impacted the level of assistance your Veteran needs from you?*

(Assistive Technology Specialist)

After FIM for each ADL

- 1) *Other than your direct observations, what influenced how you rated the level of assistance the Veteran **needed** to get in or out of bed? (Please elaborate.)*

- 2) *How would you describe any differences between the assistance the caregiver provided and the assistance the Veteran needed to get in or out of bed? (Please elaborate.)*

- 3) *If AT was used, how comfortable did the Veteran appear to be with the AT used to get in or out of bed? (Please elaborate.)*

- 4) *How well did the Veteran and caregiver work together to get in and out of bed? (Please elaborate.)*

During Visit 1 Only

- 5) *If applicable, why did you recommend AT to help the Veteran get in or out of bed that are not typically provided? (Please elaborate.)*

Appendix C : Informed Consent Form

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Study No.: «ID»



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ATLANTA VA MEDICAL CENTER
Consent to be a Research Subject
In-Person Participant

TITLE: Evaluating the CG ASSIST Program for Caregiving Dyads

PRINCIPAL INVESTIGATOR: Patricia C. Griffiths, Ph.D.

SPONSOR'S NAME: Department of Veterans Affairs

INTRODUCTION/PURPOSE: We are asking Veterans who receive help from their spouse, partner or adult child with activities of daily living to participate in a research study. We are also asking the spouse, partner or adult child who helps with these activities like mobility, transfer or positional change to participate. Both of you must agree to participate in order for either of you to participate.

As people get older, they often need help doing many of the things they used to do for themselves. This can be hard on the person providing help as well as the person being helped. The purpose of this part of the study is to try to make caregiving easier and safer for you both. We hope to do this by providing assistive technologies, small scale home changes and training. Your participation in this study will be about 24 weeks from the time of our first visit to your home. We are hoping to enroll a total of 180 Veteran/caregiver couples for this study.

PROCEDURES: Please read this consent form. Before you decide to take part, discuss any questions or concerns with the research team. If you agree to be in this study, you will need to sign this consent form and a HIPAA form before starting in the study. Then, these things will take place:

Each couple will be randomly assigned – like flipping a coin – to either Group 1 or Group 2. Both groups will participate in the same activities, although Group 1 will have total of eight home visits and Group 2 will have a total of ten visits. For Group 1, three visits are from two research assistants (RAs)(Staff Visit), and five are from an assistive technology specialist (ATS)(Expert Visit). For Group 2, four visits are from two RAs (Staff Visit) and six are from an Assistive Technology Specialist (Expert Visit). An ATS is trained in the correct use of home equipment and changes. During the Staff Visits, you will each be asked a series of questions. During the Expert Visits, the ATS will assess your

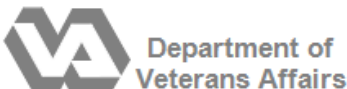
VA Form 10-1086 (8-23-2013)
Version Date: 11/14/2013
Page 1 of 7

Research Participant's Full Printed Name:

SSN:

(add only to the copy to be scanned in the medical record)

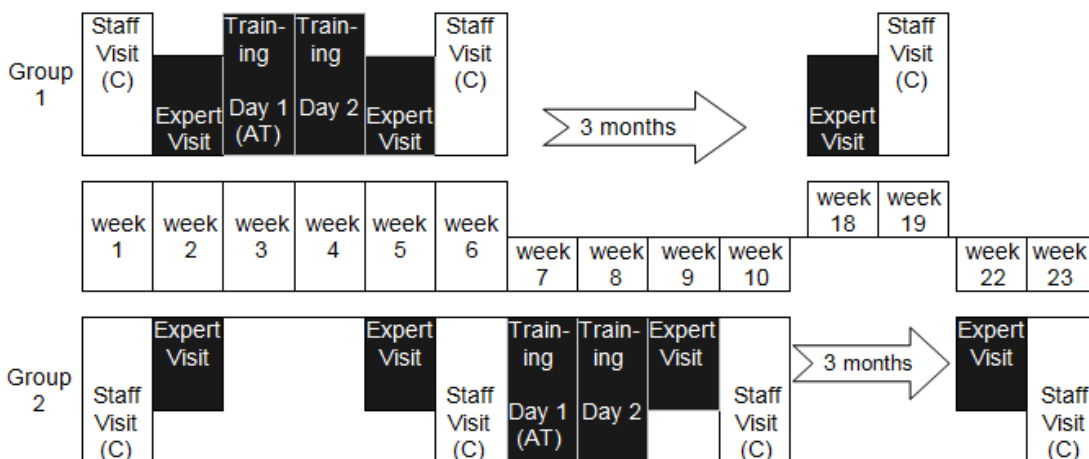
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caregiving techniques and equipment needs. Up to three different members of the Assistive Technology Specialist team will go to your home for these visits.

The following table illustrates when visits will occur, when assistive devices may be provided (AT), and when compensation will be provided (C).



The table below outlines the timing of the visits.

Group 1				Group 2			
Visit	Who	# of Visits	Time*	Visit	Who	# of Visits	Time*
Staff Visit (\$)	RAs	3	2 ½ hrs	Staff Visit (\$)	RAs	4	2 ½ hrs
Expert Visit	ATS	3	1 hrs	Expert Visit	ATS	4	1 hrs
Training Day 1 (\$)	ATS	1	1 ½ hrs	Training Day 1 (\$)	ATS	1	1 ½ hrs
Training Day 2	ATS	1	1 hrs	Training Day 2	ATS	1	1 hrs

Total number of visits: 8

Total number of visits: 10

*Times are an approximate number of hours. AT = Assistive devices may be provided, but not in all circumstances. C = Compensation provided.

Staff Visit: RAs will ask each of you separately a series of questions about how you are thinking and feeling. He/she will also ask what equipment you use during caregiving activities and about safety concerns you may have as a caregiving couple.

Expert Visit: The ATS will ask both of you together to show him/her how the

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Veteran gets in/out of bed, the tub, and on/off the toilet. The ATS may take measurements and pictures of key areas in your home. This is to help others working on this project understand the kinds of assistive technology devices and home changes that work for you. We will not take any pictures of either of you. The length of these visits will depend on how many activities the caregiver helps with and how much help the caregiver provides.

During week 2 for Group 1 and week 5 for Group 2, the ATS may recommend specific assistive technology (AT) and/or home changes. The ATS will make sure you understand and agree with what is planned before starting Training Day 1. The ATS will also make a plan to train you on easier and/or safer caregiving techniques. The ATS may recommend some items we can provide and some we cannot. Some of the items and changes we can provide may available through an AT installer and, if so, the ATS may discuss your schedule availability for AT installation.

Training Day 1: The ATS will provide skills training and instruction on use of new assistive technology/home changes as soon as possible after these are provided. The ATS will review the training plan and list of assistive technology and changes with you. The ATS will make sure you understand and agree to what is planned before starting the intervention. The ATS will leave materials with you to help you practice and will be available by phone to answer questions later. The length of this visit will depend on how much and what kind of training is being done.

Training Day 2: The ATS will see how well the new techniques and assistive technology/home changes are working. The ATS will provide more training if it is needed. The length of this visit will depend on how much and what kind of training is needed.

RISKS: You may be uncomfortable answering the questions we ask of you. The study team is trained in interviewing older adults. However, you do not have to answer any questions you do not want to answer. You can refuse to answer any questions at any time.

You might be uncomfortable having someone watching you giving or receiving care. The ATS is trained to help people such as yourselves, but if you don't want to let him/her see some aspect of caregiving, you don't have to. If you get tired, you may take a break. There may be other risks that we don't know about.

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BENEFITS: You may not personally be helped by taking part in this study, but we may learn things that will help others in the future. You may find transfers/positional changes to be easier and safer for you both. Some care recipients may find they will be able to do more things for themselves than they used to as a result of participating. Some caregivers may find helping less stressful. Your participation may lead to knowledge that helps to make it easier for caregiving couples to complete daily activities easily and safely.

CONFIDENTIALITY: We will keep information about you, including any research records we create, strictly confidential to the extent required by law. We may be required to release your record if we receive a subpoena or a court order. The study staff will keep your study files locked in a file cabinet in a private office. We will use a study number rather than your name on study records when we can. Your name and other facts that might point to you will not appear when we present this study or publish its results. People other than those doing this research study may have access to your medical and study records including:

- The Office for Human Research Protections (OHRP)
- The Government Accountability Office (GAO)
- The Office of Research Oversight (ORO)
- The Inspector General
- The Emory University Institutional Review Board and other offices in Emory University that help run and/or oversee studies
- The Atlanta VA Research Compliance Officer
- VA research staff within the VA Hospital or at Emory university (when data is stored at Emory)
- Any appropriate state or federal governmental agencies that make rules and policy about how research is done that are not listed above.

If you are participating in a study where a test and/or procedure may be performed at Emory and you are not and have never been an Emory patient, you do not have an electronic medical record. Please note that an Emory medical record will be created if you have any services or procedures done by an Emory provider or facility for this study.

All research records and/or identifiers will be destroyed in accordance with the VA record retention schedule.

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If you are a Veteran who is a patient at the Atlanta VA Medical Center, a copy of your signed and dated consent and HIPAA forms will be placed in your medical record(s). If you are a non-Veteran receiving clinical services (i.e., use of the laboratory, radiology, audiology, etc.) as part of this study, you will have an electronic medical record created for you. You will also be given a VA Notice of Privacy Practices (NOPP), and we will ask you to sign a form saying that you have received this notice.

If you are in an FDA sponsored clinical trial: A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. Law. This website will not include information that can identify you. At most, the website will include a summary of the results. You can search this website at any time.

COMPENSATION: Each couple in Group 1 will be compensated \$25.00 after steps 1, 6 and 20; a total of \$75.00 for Group 1 completing the study. Each couple in Group 2 will be compensated \$25.00 after steps 1, 6, 10, and 14; a total of \$100 for completing the study. Recall that each couple is randomly assigned—like flipping a coin—to either Group 1 or Group 2. You will also receive the caregiver training and any assistive technology and home changes we provide at no cost to you.

You will get emergency medical care if you get injured from being in this study. Under Federal Law, you will qualify for follow-up treatment if the injury was related to the research study. You may or may not get further compensation if you are injured in this study. This rule would not apply if you do not follow study procedures. If you believe you have been injured by this research, you should contact Dr. Patricia C. Griffiths at 404-321-6111 ext. 7138.

COSTS: Some Veterans are required to pay co-payments for medical care and services provided by the VA. These co-payment requirements will continue to apply to medical care and services that are not part of this study. There are no medical procedures required for study participation.

CONTACT PERSONS: If you have any questions, concerns, or complaints about this study you can call a member of the study staff: Ashley Harrill, Study Coordinator, at the Atlanta VA at 404-321-6111 ext. 1191.

If you have been harmed from being in this study call: Dr. Patricia C. Griffiths at 404-321-6111 ext 7138.

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If you want to speak to someone who is not a member of the study to discuss problems, ask questions or voice concerns, you can call:

The Emory University Institutional Review Board (404) 712-0720 or toll free at 1-877-503-9797

Or

The Research Compliance Officer at (404) 321-6111 ext. 6964 or the Clinical Studies Center Director at (404) 321-6111 ext. 6933.

If you have any questions about your rights as a participant in this research study, call the Emory University Institutional Review Board at (404) 712-0720 or toll **free at 1-877-503-9797**.

NEW FINDINGS: We may learn new things during the study that you may need to know. We can also learn about things that might make you want to stop participating in the study. If so, you will be notified about any new information.

VOLUNTARY PARTICIPATION AND WITHDRAWAL: Your participation is completely voluntary and you have the right to refuse to be in this study. You can stop at anytime after giving your consent. This decision will not affect in any way your current or future medical care or any other benefits to which you are otherwise entitled. The study investigator may stop you from taking part in this study at any time if they decide it is in your best interests or if you do not follow study instructions.

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We will give you a copy of this consent form to keep. If you are willing to volunteer for this research, both the caregiver and care recipient need to sign, date, and record the time below. If the Veteran is unable to sign for him- or herself, the legally authorized representative needs to sign on the designated line.

RESEARCH PARTICIPANT'S SIGNATURE AND DATE:

Research Participant's name

Research Participant's Signature

Date
(to be entered by participant)

Time

Participant's Legally Authorized
Representative (LAR) (include ONLY if
a third party is being consented)

Date
(to be entered by the LAR)

Time

Name of Approved Individual
Obtaining Consent

Signature of Approved Individual
Obtaining Consent

Date
(to be entered by Approved Individual)

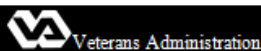
Time

An Approved Individual is one who has completed HRPP training and is officially approved to consent subjects for this specific study. The signature and date of this individual certifies that this is the most current approved consent document for this study.

Appendix D : HIPAA Authorization Form

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Study No.: «ID»


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 Project Approval Expires On: «ExpireDate»

 Atlanta Veterans Affairs Medical Center
 Authorization for Release of Protected Health Information for Research
 Version: 03/04/2013

 Complete Study Title: **Evaluating the CG ASSIST Program for Caregiving Dyads**

 Principal Investigator: **Patricia C. Griffiths, Ph.D.**

- 1) This form provides an explanation about the use and disclosure (share with others) of your health information for this research and requests your permission to use and share your individual health information.
- 2) An Informed Consent Form will be presented and explained to you separately for the research study and a separate signature will be requested before any research procedures begin.
- 3) Access to information about you, Protected Health Information (PHI) will be obtained during the course of this research study under the direction of the Principal Investigator (PI), **Patricia C. Griffiths, Ph.D.**
- 4) This will include information, that is used to determine your eligibility for this study and information collected from the procedures that are carried out as a part of the research study. These may include the following type of medical information: **Hospital records, clinical records, and interviews, surveys or questionnaires will be collected asking questions about demographics, self-efficacy, your ability to execute transfers, depression scales, self-mastery, daily falls, assistive technology use and disuse, environmental features of your home, functional abilities, cognitive abilities, resources used, frequency of falls, falls and task efficacy, and self-reported health status. In addition expert observation of caregiving activities; documentation (measurement, photographs) of locations in homes of participants where daily activities occur will be collected. No photographs will be taken of caregivers or care recipients.**

- Medical History: **History that indicates possible issues with transfers**
- Psychiatric History: **History of dementia or Alzheimer's Disease**
- Physical Examination: **History of physical examination that may be pertinent to ensure that safe transfers occur**
- Laboratory Results: **(e.g. blood work, radiological tests, and other diagnostics)**
- HIV, Diagnosis and Treatment information
- Sickle Cell Anemia, Diagnosis and Treatment information
- Drug and/or Alcohol Abuse, Diagnosis and Treatment information
- Imaging (X-ray, CT, MRI, etc.)
- Photographs, videos and/or audio recordings (requires VA Form 10-3203; may also require VA Form 10-5345)
- All dates related to study visits
- Responses to study treatment received
- Mental Health (not psychotherapy)
- Demographics **(Check Below)**
- Other Records: **interviews & questionnaires, observations, and field notes from home visits.**

Check the specific PHI items which will be used/disclosed:

- Name
- Address (including Geographic Subdivision Smaller than State)
- Any form of date (including but not limited to birth date, date of appointment, admission/discharge dates or other dates directly related to you)
- Telephone or fax number

 Authorization for Release of Protected Health
 Information (02142013)

 MRC 2008 Sep 02 10-2105
 OP 017 (508)

Research Participant's Full Printed Name: _____

 SSN: _____
 (add only to copy to be scanned in medical record)

Study No.: «ID»


 Document Approved On: «ApproveDate»
 Project Approval Expires On: «ExpireDate»

- Email address
- Social Security Number (scrambled or unscrambled)
- Medical Record Numbers
- Health Plan Beneficiary Numbers
- Account Numbers
- Certificate/License Numbers
- Vehicle Identifiers
- Serial and License Plate Numbers
- Device Identifiers and Serial Numbers
- Web URLs
- IP address
- Biometric Identifiers (including voice and fingerprints)
- Full-Face Photographs
- Any other unique identifying number, characteristic or code

- 5) With your permission you will authorize the VA, the Principal Investigator and his/her support staff, to access information identifying you for research purposes.
- 6) An Authorization for research uses and disclosures need not have a fixed expiration date or state a specific expiration event; the form can list "none" or "the end of the research project." However, although an Authorization for research uses and disclosure need not expire, a research subject has the right to revoke, in writing, his/her authorization at any time. Authorization to access your protected health information will continue (choose one)
- Until the end of the research study.
 - None

- 7) **[If applicable]** With your permission you will authorize the disclosure of this information upon request, to **research staff only.**

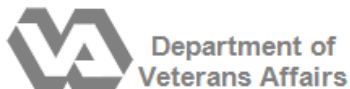
In addition the following people or groups will be conducting the Research Study or have the job of monitoring and regulating research and might have access to your health information as part of the study process. These may include:

- US Food and Drug Administration,
- Government Accountability Office,
- Office of Human Research Protection,
- Office of the Inspector General,
- any appropriate state or federal government agencies that make rules and policy about how research is done that have not been listed,
- Atlanta Research and Education Foundation (when they administer the study funds)
- Emory Healthcare- If you have any medical services or procedures done by an Emory provider or facility for this study, then Emory Healthcare will create an electronic medical record for you and will create a record your visit. The medical record will be used if there are any health issues arising from your visit to an Emory provider or facility.
- Emory University- Emory University Institutional Review Board. If you are participating in a federally-funded research project that is administered by Emory University, then your PHI may be disclosed to and used by Emory for record-keeping purposes and to administer the study.

- 8) Your research data will be stored at the following location(s):

- Atlanta VAMC
- Other: **(list places outside the VA where data will be stored)**

Study No.: «ID»



Document Approved On: «ApproveDate»
Project Approval Expires On: «ExpireDate»

- Your research data will be re-used by: **(list who will re-use the study data and why)**
- Your research data will not be re-used.

- 9) You have the right to see and copy any of the information gathered about you, but not until the study is complete.
- 10) You also have the right to withdraw these permissions at any time by either providing a written request to **Patricia C. Griffiths, Ph.D., 151R, 1670 Clairmont Road, Decatur Georgia 30033** or by returning the HIPAA Revocation Letter. When you withdraw your permission, no new health information that might identify you will be gathered after that date. Information that has already been gathered may still be used and given to those previously authorized.
- 11) **Dr. Patricia C. Griffiths and the Atlanta VA Medical Center** agrees to keep your PHI confidential, which will minimize the risk that it will be released to others without your permission.
- 12) By signing this authorization form you authorize these uses and disclosures of your protected health information. If you do not authorize these uses and disclosures you will not be able to participate in the study.
- 13) VHA may not condition treatment, payment, enrollment or eligibility for benefits based on the subject completing the HIPAA authorization.
- 14) Individually-identifiable health information disclosed pursuant to this authorization may no longer be protected by Federal laws or regulations and may be subject to re-disclosure by the recipient.

The Atlanta VA Medical Center complies with the requirements of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and its privacy regulations and all other applicable laws that protect your privacy. The VHA Handbook 1605.1, Privacy and Release of Information, provides more information on how we protect your information.

HIPAA Authorization: *My signature below indicates that I have read and understood this HIPAA authorization and had ample opportunity to ask questions. I certify that this request has been made freely, voluntarily and without coercion. I understand that I will receive a copy of this form after I sign it. I may revoke this authorization, in writing, at any time except to the extent that action has already been taken to comply with it. Written revocation is effective upon receipt by the Principal Investigator Dr. Patricia C. Griffiths and the Release of Information Unit at the Atlanta VA Medical Center.*

Printed Name of Research Participant		
Signature of Research Participant		Date
Printed Name of Participant's Personal Representative (if required)		
Signature of Participant's Personal Representative (if required)		Date