

IDENTIFICATION OF ACTIVITIES CRITICAL TO EXAMINE THE NEED FOR
PERSONAL ATTENDANT CARE FOR INDIVIDUALS WITH SPINAL CORD
INJURY

By

JAMIE L. POMERANZ

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Jamie L. Pomeranz

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Abstract of Dissertation Presented to the Graduate School
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Jamie Pomeranz

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The purpose of this study was to determine the necessary items and constructs to be included in a measure of personal attendant care (PAC) for individuals with spinal cord injuries (SCI). Currently, there are between 219,000 and 279,000 individuals with SCI in the United States. Approximately half of those individuals require some type of personal assistance with daily care. Attendant care can include personal assistance, domestic services, community services, home nursing, home maintenance, childcare services, educational support and respite care. The Functional Independence Measure (FIM) has most often been selected as the instrument of choice to predict the total PAC needs of individuals with SCI. While the FIM has been shown to be effective in predicting activities of daily living (ADL) of individuals with neurological conditions, rehabilitation professionals tend to use this assessment to predict the entire range of attendant care for individuals with SCI. This research was intended to identify a full range of activities that should be included in a comprehensive assessment of PAC needs. Using the Delphi

method, 25 life care planners, experienced in determining PAC services identified specific activities to be considered when assessing the need for PAC. Additionally, qualitative interviews were conducted with veterans with SCI to understand their perspective regarding the activities that should be considered when making PAC recommendations. The study resulted in 191 activities to be considered by professionals when recommending PAC services. These results covered a wide range of activities relating to ADL's, home/yard maintenance, employment, education, and hobbies/leisure. Implications for future development of comprehensive measures of PAC needs were discussed as well as the impact of this research on public policy and clinical practice.

CHAPTER 1 INTRODUCTION

Background

Currently, there are between 219,000 and 279,000 individuals with spinal cord injury (SCI) in the United States (National Spinal Cord Injury Statistical Center, 2003). Approximately half of those individuals require some type of personal assistance with daily care (Blackwell, 2001). Personal attendant care (PAC) services can be one of the most common and costly aspects of daily living for individuals with SCI (Weitzenkamp, Whiteneck, & Lammertse, 2002).

Attendant care is the assistance received by people with physical disabilities for undertaking the full range of everyday tasks that able-bodied people normally do for themselves. It enables an individual to live independently and to exercise basic rights about lifestyle choice.
(Physical Disability Council of NSW, 2004)

PAC services, also referred to as personal assistance, are defined by the World Institute of Disability as assistance, under maximum feasible user control, with tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interactions within the community and society (Kennedy, 1997). PAC services are provided for domestic activities, community activities, home nursing, home maintenance, housecleaning, gardening, childcare activities, educational and vocational support and respite care (Motor Accident Authority, 2002).

For many individuals with SCI, absence of assistance with such day-to day activities can lead to health care problems that are every bit as serious as health problems that result from inadequate medical services. More specifically, lack of PAC services can

affect the musculoskeletal, circulatory, respiratory, and skin systems. Such problems can be extremely difficult and costly to resolve and can result in greater levels of disability and even greater need for health and support services (Dautel & Frieden, 1999). Furthermore, individuals with SCI experience a wide array of physiological and health-related changes associated with the aging process. Increasing health and function problems related to aging translate into a greater demand for PAC (Robinson-Whelen & Rintala, 2003).

Individuals who provide personal assistance to individuals with SCI are often referred to as personal care attendants (PCAs). Such individuals provide assistance with activities of daily living (eating, grooming toileting, etc.), transfers, safety precautions, household cleaning and maintenance, driving to and from appointments, running errands, minor home repair and yard maintenance, leisure activities and employment assistance.

PCA's may be skilled or unskilled workers, who might be unlicensed, licensed, registered nurses, nursing assistants, nurse's aides, home health aides, or an individual with no formal training. The level of care provided is often a reflection of an individual's needs and/or available resources. For example, an individual with ventilator dependent tetraplegia will require 24-hour awake care, which requires assistance from a Licensed Professional Nurse (LPN) or a Registered Nurse (RN). Conversely, an individual who has lower-level paraplegia may be self-sufficient and require less skilled assistance in housekeeping activities such as cooking and cleaning (Weed, 2004).

Depending on the skill level of the attendant care provider, a significant cost can be associated with attendant care services. Specifically, attendant care costs can comprise up to 44% of the total recurring rehabilitation costs for individuals with SCI (Harvey,

Wilson, Greene, Berkowitz, & Stripling, 1992). In fact, Hall et al. (1999) found that individuals with high tetraplegia used more than 135 hours of paid assistance weekly. This amount of assistance, if provided by someone receiving minimum wage would amount to over \$40,000 per year. This minimum salary would most likely be associated with PCA's employed by a Home Health Agency.

The majority of persons with disabilities in the United States currently receive paid personal assistance through home care agencies that contract with Medicaid offices (Doty, Kasper, & Litvak, 1996). Agency-selected care includes PCA's who are provided by home health type agencies or community agencies (Mitchell & Kemp, 1999). Funding for PAC services is sometimes made available through the extension of Medicaid Home and Community-Based Services (HCBS)(Kitchner, Ng, & Harrington, 2003). Such HCBS programs were developed as a direct result of the Supreme Court's ruling in Olmstead vs. L.C. and E.W. (Kitchner, Willmott, & Harrington, 2004). The Olmstead ruling resulted in an executive order mandating formal plans for ensuring community-based alternatives to institutions for all people with disabilities. The decision demands that whenever medically feasible and preferred by the recipient, appropriate care must be delivered to the individual in a non-institutional setting (Hagglund, Clark, Mokelke, & Stout, 2004).

Although the Olmstead Act facilitated the development of HCBS on a national level, each state has much latitude in determining the type of services offered, who can provide such services, and the conditions under which services are provided (Dautel & Frieden, 1999). Specifically, states have the option of using combinations of two Medicaid funded programs, the HCBS waiver and the Medicaid Personal Care Services

(PCS) program, to provide personal assistance either directly, or through a variety of contractual arrangements (LeBlanc, Tonner, & Harrington, 2001).

According to LeBlanc and associates (2001), there are a number of other government programs that support personal care services in the United States. These programs include Social Security, Older Americans Act funds, state general funds, Department of Veterans Affairs, and Ticket to Work Programs. Despite the existence of these programs, Medicaid home health remains the most significant government program offering personal assistance in the United States (LeBlanc et al., 2001).

In addition to government programs where the PCA is typically arranged and funded by a governmental agency, individuals with SCI also obtain PCA's either through consumer-selected care or through family members provided care (Mitchell & Kemp, 1999). Consumer-selected care consists of PCA's who are interviewed, hired, trained, and supervised by individuals with SCI. Family PCA's are typically family, friends, or neighbors who are not interviewed prior to being hired. According to LaPlante and associates (2004), over 85% of all hours of personal assistance with ADL's and IADL's are provided by family and friends. While government programs may pay for the services of these PCA's, they are also funded privately or, especially in the case of family members, they may not receive any compensation for their resources. In any case, all three avenues for personal assistance increase the chances that an individual with a disability will be able to live in the community.

The reintegration of individuals from institutions to home settings follows the philosophy of the independent living model of personal assistance. This philosophy of health care was developed by and for working-age adults with disabilities as an

alternative to the medical model of health care. The model endorses the full involvement of the individual with the disability in the selection, management, and training of a personal care attendant, with the final responsibility of care belonging to the person with the disability. The philosophy involves the belief that reliance on services of a professional health care provider in an institution may unintentionally reduce an individual with disabilities to the status of patients whose inputs are secondary to those of professionals (Mitchell & Kemp, 1999). Even though individuals with disabilities can have the responsibility to select, manage, and train their own personal care attendants, they must still often rely on professionals to accurately assess their need for personal assistance. Precise assessments of the need for personal assistance are essential for effective planning of disability support services (Kennedy, 2001).

Experts in Recommending PAC Services

One group of professionals who are often involved in the planning of disability support services, and thus make decisions in regards to PAC services, are Certified life care planners. The process of life care planning (LCP) involves the assessment of the total disability-related needs of an individual projected across the lifespan. Life care planning is defined as a dynamic document based upon published standards of practice, comprehensive assessments, data analysis, and research. The LCP provides an organized concise map for current and future needs with associated costs for individuals who have experienced catastrophic injury or have chronic health care needs (NARPPS, 1998). Topics that are covered under an LCP often include projected evaluations, projected therapeutic modalities, diagnostic testing/education assessment, wheelchair needs, wheelchair accessories and maintenance, aids for independent function, orthotics and prosthetics, home furnishings and accessories, drug and supply needs,

home/personal/facility attendant care, future medical care-routine, transportation, health and strength maintenance, architectural renovations, potential complications, future medical care/surgical intervention, orthopedic equipment needs, and vocational/educational needs (MediPro Seminars, 2004).

LCP's are frequently used in personal injury and other types of litigation and must be defensible in courts of law. As such, to prevent overestimation and underestimation of PAC needs, life care planners must rely on objective and accurate measures of rehabilitation needs and outcomes associated with therapeutic interventions. Overestimating attendant care needs will result in inaccurate, unjustifiable, and more expensive rehabilitation plans that are unfair to all parties involved (Weed, 2004). Underestimating attendant care needs can result in individuals receiving inadequate services to maintain themselves throughout their lifetimes and likely lead to a higher rate of complications and hospitalization, even possibly reducing life expectancy (Weed, 2004).

Necessity for a Standardized Instrument for Determining the Need for PAC

The need for a standardized instrument is critical for measuring the relationship between functional status and personal assistance (Samsa, Hoenig, & Branch, 2001). Many agencies, rehabilitation centers, and centers for independent living currently use functional status measures that assess activities with daily living (ADL) to establish recommendations for all aspects of PAC. Such assessments include the Functional Independence Measure (FIM) (Granger & Hamilton, 1986), the Minimum Data Set (MDS) (Health Care Financing Administration, 1998), and the Barthel Index (Mahoney & Barthel, 1965). Although these functional status measures are valuable tools used by rehabilitation professionals, they were not created for measuring all components of PAC

specifically for individuals with SCI. Furthermore an extensive review of the literature demonstrates that a scientific instrument specifically designed for determining the need for all areas of PAC by individuals with SCI does not exist.

In addition to the above functional status measures, PAC recommendations for individuals with SCI are often based on clinical practice guidelines. Specifically, life care planners often make PAC recommendations based on guidelines published by the Paralyzed Veterans of America (Mediproseminars, 2004). These guidelines, sponsored by the Consortium for Spinal Cord Medicine, list hours of personal care and homemaking assistance that may be appropriate to each level of injury. These guidelines were based on the consensus of clinical experts, data from the FIM, available literature on functional outcomes, and data compiled from Uniform Data Systems (UDS) and the National Spinal Cord Injury Statistical Center (NSCISC) (Consortium for Spinal Cord Medicine, 1999). The hours recommended were determined representative of skilled, unskilled, paid and unpaid assistance required for individuals who were one-year post-SCI.

These guidelines have been used by life care planners and are cited quite frequently in the life care planning literature. However, there are many limitations to the guidelines. First of all, the guidelines do not take into consideration the effects of aging on individuals with spinal cord injuries (Deutsch, 2003). Weed (2004) discusses evidence that individuals with spinal cord injuries tend to experience some of the changes commonly associated with aging earlier. Weed goes on to state that an individual, who has had a spinal cord injury for 20-25 years and has been using a manual wheelchair, will have more difficulty with upper extremity pain. Additionally, the individual may have more difficulty with transfers and self care needs and require a higher level of attendant

care. The guidelines also fail to break down the attendant care hours by the specific types of activities with which individuals with SCI require assistance. Furthermore, the above guidelines are based on a person with motor-complete SCI and do not reflect needs associated with incomplete injuries, changes in assistance that may be required over time, nor do they take into account other medical conditions, complications, age, obesity, cognitive abilities, psychosocial, and environmental factors (Blackwell, 2001). Although the above model serves as a general guide for attendant care and level of spinal cord injury, it fails in providing the specific and precise determinates for each component of PAC.

The limitations in the guidelines can be better understood by examining the FIM. The FIM, which was a primary functional status measure used in developing the above clinical guidelines, is the most widely used disability measure in rehabilitation medicine (Consortium for Spinal Cord Medicine, 1999). The FIM instrument describes the type and amount of human assistance required by a person when performing basic life activities. The items on the FIM describe two domains: motor and cognitive (Stineman et al., 2001). The motor domain includes 13 items, which are described as physical abilities. These items include: eating, grooming, bathing, upper body dressing, lower body dressing, toileting, bladder management, bowel management, transfers, locomotion, and stair climbing (Linacre, Heinemann, Wright, Granger, & Hamilton, 1994). The cognitive domain includes five items consisting of comprehension, expression, social interaction, problem solving and memory. The motor items are mainly self-care items or ADL's.

Jette and colleagues (2003) examined the item hierarchy of four functional status measures including the FIM, used in post acute care. Such a hierarchy allows the researcher to examine items listed in a distinct order of difficulty for a particular population (Velozo & Peterson, 2001). Jette and colleagues (2003) compared the hierarchical structure of the functional measures and determined that there were inherent measurement limitations to the instruments for use in post-acute care. The limitations included lack of range of content, breadth of coverage, and measurement precision.

This researcher compared the hierarchical structure of the FIM to a postulated hierarchical arrangement of items within postulated constructs often considered by life care planners in making PAC recommendations (Figure 1). These postulated constructs were created based on discussions with professional Life care planners, individuals with disabilities, as well as the current PAC and LCP literature. The hierarchical structure as seen in Figure 1 is based on difficulty level. For example as demonstrated on the FIM, *eating* requires less overall functional ability than *bathing*. Furthermore, *bathing* requires less overall functional ability than *stair climbing*. Additionally, if an individual can climb stairs independently, than there is a high probability that he/she can most likely be independent in performing items such as *grooming, bladder management, and bowel management*.

Figure 1 demonstrates that although the FIM is a valuable tool in assessing self-care need, it was not created for measuring other components of PAC such as homemaking, home/yard maintenance, and vocation/educational/leisure activities. These activities are considered instrumental activities of daily living (IADL's) and also include the use of a telephone, transportation, food or clothes shopping, meal preparation,

housework, medication use, and management of money (Kennedy, 2001). According to Kennedy (2001), an estimated 3.2 million adults in the United States have one or more unmet or undermet needs for personal assistance, with most reporting deficits in assistance with IADL's.

By listing the items under each construct in hierarchical order, one can see that the postulated constructs are likely to measure functional ability beyond what is measured by the FIM. For example, an individual who is independent in higher level ADL item listed on the FIM such as *Dress LE* (lower extremity dressing) may be identified as only needing PAC services for *locomotion and stair climbing*, though he/she may be unable to *take out the garbage, mop the floor, or mow the lawn* independently. In addition, according to the FIM, the lowest ability level associated with PAC is eating, when it is possible that an individual may need PAC with activities associated with lower functional ability such as using the, *reading and waking up in the morning*. The FIM, by design is most precise and relevant for post acute inpatients whose function is at the lower end of the continuum (Jette et al., 2003). The above examples suggest that a more comprehensive understanding of an individual's abilities is needed to more accurately determine the PAC needs of individuals with SCI.

Method for Understanding Comprehensive PAC Needs

One empirical method to develop a comprehensive understanding of PAC beyond what is measured by the FIM involves the implementation of the Delphi Method. The Delphi Method is frequently used to determine consensus among experts on a given issue and consists of a series of repeated questionnaires in a group of individuals whose opinions are of interest (Herdman et al., 2002). For this study, life care planners represented individuals whose opinions were of interest based on the requirements of

FIM	Housekeeping	Home/Yard Maintenance	Vocational/School/Leisure
More Ability			
F	Driving to/from appointments		
U	Grocery Shopping Taking out the garbage		
N			
C			
T	Washing car Cleaning windows		
I	Mopping the floor Cleaning dishes		
O	Cleaning windows Vacuuming		
N	Cleaning dishes Vacuuming		
A	Doing laundry Cooking		
L	Cooking Taking clothes out of closet		
A	Locomotion		
B	Dress LE Toilet Transfer		
I	Toileting Bathing		
L	Bathing Bowel Mgmt		
I	Bladder Mgmt Bed-Chair Trfs		
L	Bed-Chair Trfs Dress UE		
I	Dressing UE Grooming		
T	Grooming Eating		
Y	Eating		
Less Ability	Turning on television Waking up in the morning		

FIM scale estimates cited from Jette, Haley, and Pengsheng, 2003

Figure 1. Postulated PAC Measure Comparison With The FIM

their profession to often formulate PAC recommendations. Additionally, the Delphi method provides a means for extrapolating the opinions of such experts without the need to organize the professionals into one specific environment. In other words, the opinions could be obtained from experts dispersed throughout the country. This method appeared to be the most appropriate for meeting the goals of this researcher.

Goal of the Research

The primary goal of the present dissertation was to conduct qualitative research, which will lead to the development of a measure for predicting the need for PAC services.

Research Question 1

What are the critical items necessary to examine the need for PAC services for individuals with SCI from the perspective of LCP professionals?

Research Question 2

What are the critical items necessary to examine the need for PAC services from the perspective of veterans with SCI?

CHAPTER 2 LITERATURE REVIEW

Current State of Personal Assistance

In 1997, out of an estimated 33 million people with severe disabilities, 10 to 20 million required personal assistance (Hagglund, Clark, Mokelke, & Stout, 2004b; Allen & Mor, 1997). PAC services provided to adults with disabilities amounts to 21.5 billion hours of help per year with an economic value at around \$200 billion as of 1996 (LaPlante, Harrington, & Kang, 2002).

The need for PAC services for people with disabilities appears to be on the rise. In fact, home health care, which includes PAC services (75% of all home care needs), has been increasing at an annual rate of 20% to 25% since the 1980's (Mitchell & Kemp, 1999). One reason for this rapid increase is due to the recent advances in medicine and technology (Robinson-Whelen & Rintala, 2003). Such innovations are contributing to longer life expectancies for individuals with SCI. In fact, in the 1940's individuals with traumatic high tetraplegia rarely survived. Now, due to the establishment of trauma centers and model systems of care, if an individual with high tetraplegia survives the first year, even when ventilator-assisted, that individual has a 60% chance to survive an additional 15 years or more (Hall et al., 1999). According to Robinson-Whelen and colleagues (2003), increases in life expectancies lead to increasing care resulting in high demand for personal assistance.

Unfortunately, as the demand for personal assistance increases, the likelihood of those needs being unmet is increasing as a result of lack of public funding. This is due, at

least in part, to the fact that states are currently suffering from loss of tax revenue and as a result, state legislatures are targeting Medicaid programs in an attempt to make up ongoing budget shortfalls (Hagglund et al., 2004). Such cuts in public assistance contradict modern legislation effecting PAC.

Legislation and Policy Affecting Provision PAC Services

Legislative decisions have played a major role in the provision of PAC services to individuals with disabilities. One landmark case that facilitated the increase in such services was known as The Olmstead Decision. *Olmstead v. L.C. and E.W.* reached the Supreme Court when the Georgia Department of Human Resources appealed a decision by the 11th Circuit that it had violated the Americans with Disabilities Act (ADA)'s "integration mandate." This infringement occurred when two females with mental disabilities at a state psychiatric facility were segregated long after professionals had recommended their transfer to community care (The Center for An Accessible Society, 1999).

The Supreme Court decided that states would be violating Title II of the Americans with Disabilities Act (ADA) of 1990 if they provide care to people with disabilities in an institutional setting when they could be appropriately served in a home or community-based setting. Specifically, Title II applies to public services furnished by governmental agencies and provides in part that

No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity. (Allen, 2001; ADA, 1990)

The ADA defines a public entity as including a state or local government, a department, agency, special purpose district, or other instrumentality of a state, states, or

local government (ADA, 1990). In the Olmstead decision, the argument was made that public entities are required to provide services in the “most integrated setting appropriate to the needs of qualified individuals with disabilities” (Allen, 2001). In many situations the most integrated setting includes an individual’s home environment or community based setting.

In the Olmstead case, physicians at the state hospital had determined that services in a community-based setting were appropriate for the plaintiffs, and even though appropriate settings for services are determined on a case-by-case basis, states must continue to provide a range of services for people with different types of disabilities (Allen, 2001).

With the passage of Olmstead and with the ADA continuing to play a key role in the lives of individuals with disabilities, the establishment of a national system for the provision of PAC services remains a high priority for many disability groups (Kennedy, 1997). Current agenda relating to the modern development of personal assistance programs in the US can be linked to the passage of Titles XIX and XX of the Social Security Act (Litvak, 1991; Kennedy, 1997). This legislation facilitated the creation of Medicaid Home and Community Based Service (HCBS) Waivers and the Medicaid Personal Care Services (PCS) program. The HCBS waiver program received congressional authorization in 1981 and offers federal matched funding to the states to expand HCBS and accelerate movement away from long-term-care (LTC) services provided from institutions. The program allows the Department of Health and Human Services to “waive” certain Medicaid statutory requirements so that states can receive federal funds to expand HCBS and reduce existing institutional care. States can implement this program by targeting HCBS towards specific geographical areas,

populations, and conditions. Also, the states can provide services not otherwise covered by the Medicaid program such as respite care, homemaker services, personal care, and adult day care.

In addition to the HCBS program, funding for attendant care can come from the Medicaid Personal Care Services (PCS) Program. This optional benefit allows states to have considerable discretion in defining PCS but the programs typically involve hands-on assistance with ADL's to non-institutional residents of all ages with disabilities and chronic conditions. The services do not include domestic services such as housekeeping activities. PCS services can be provided in the home, outside the home, or a combination of both. The states cannot however, reimburse legally responsible relatives (typically parents of minor children with disabilities and spousal caregivers). In 2001, 28 states offered a PCS benefit, however, they varied in the amount and scope of the services provided (Kitchner et al., 2003).

These Medicaid policies and services were established with the passage of Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) (P.L. 97-248) of 1981. OBRA allowed states more flexibility in defining the "medically needy" and permitted states to vary Medicaid services by group. Regulations implementing OBRA permitted states to determine eligibility of individuals who were medically needy by varying financial requirements used for each medically needy group (Centers for Medicaid and Medicare Services, 2005).

OBRA legislation lead to the creation of Section 1915c of the Social Security Act, which authorized states to exercise the option of providing home and community-based alternatives to institutional care (LeBlanc, Tonner, & Harrington, 2001). According to

Kennedy (1997), such legislation allowed more progressive state governments to experiment with alternatives to institutional placement for people with disabilities. The main goal for such programs was to decrease nursing home expenditures by allowing states to redirect federal nursing home funds to HCBS waivers. Program expenditures were contingent on the decline in nursing home admissions.

The success of such current Medicaid programs may be in question since research on the provision of long-term services and supports under the Medicaid program has revealed a significant funding bias toward institutional care. Only about 27 percent of long term care funds expended under the Medicaid program, and only about 9 percent of all funds expended under that program, pay for services and supports in home and community-based settings. Also, only 27 states have adopted the benefit option of providing personal care services under the Medicaid program. In the case of Medicaid beneficiaries who need long term care, the only long-term care service currently guaranteed by Federal law in every state is nursing home care. Although every state has chosen to provide certain services under home and community-based waivers, these services are unevenly available within and across states, and reach a small percentage of eligible individuals. In fiscal year 2000, only 3 States spent 50 percent or more of their Medicaid long terms care funds under the Medicaid program on home and community-based care (Harkin & Spector, 2003). Furthermore, the ability of states to limit the number of waiver “slots” available in order to control program costs has resulted in long waiting lists across states for HCBS services. For example, in 2002, waiting lists for HCBS waivers in eight selected states (GA, IA, NC, NM, LA, MI, TX, and WA) totaled 155,884 with 74,244 in Texas alone (Kitchner et al., 2003).

Even though a lack of success of state Medicaid programs makes a strong case for a federal program, efforts to create an entitlement of PAC services at a national level have been unsuccessful (Glazier, 2001). In 1997, then Speaker of the House Newt Gingrich introduced the Medicaid Community Attendant Services Act (MiCASA) as H.R. 2020. MiCASA would have amended Title XIX of the Social Security Act and created a new Medicaid service called “Qualified Community-Based Attendant Services.” Such a service would have allowed the choice by any individual eligible for Nursing Facility Services (NF) or Intermediate Care Facility Services for the Mentally Retarded (ICF-MR) to use those dollars for “Qualified Community-Based Attendant Services.” The Federal Government would have allocated \$2 billion dollars over six years to help states transition from institutional to community-based services. This \$2 billion dollars was to be in addition to the Medicaid dollars the state would spend on people eligible for nursing homes and ICF-MR’s. Specifically, the program provides qualified community-based attendant services that are based on an assessment of functional need; provided in a home or community-based setting, including school, workplace, recreation or religious facility; include various delivery options including vouchers, direct cash payments, fiscal agents and agency providers; are selected, managed and controlled by the consumer of the services; include voluntary training on how to select, manage and dismiss attendants; and are provided according to a service plan agreed to by the person receiving services (National Council on Independent Living, 2005).

Unfortunately, even though the bill had considerable bipartisan support, it died a quick death (Glazier, 2001). There was a lot of discussion about MiCASA attracting

people who are eligible for institutional services but who would never go into an institution. The assumption is that they would jump at the chance to use MiCASA. The government called this the “woodwork” effect because they believe people would “come out of the woodwork”, costing more money (National Council on Independent Living, 2005). Furthermore, legislators expressed concern that the bill could cost the federal government \$10 to \$20 billion per year that would create an upheaval in service systems leading to the pitting of constituencies against each other for resources (Agosta, 1998).

The above legislative programs coincided with the disability rights movement. The disability rights movement involved a fight for an alternative approach to long-term care and sought to meet the specific needs of people with disabilities and their desires to live and participate actively in their communities (Dautel & Frieden, 1999). The disability rights movement lead to new programs and services as alternatives to institutionalization of people with disabilities with the goal of improving their integration in society. Societal integration includes living in the community, working in mainstream jobs, receiving education in regular classrooms along with non-disabled students, attending cultural and social events, maintaining a network of friends, and engaging in other leisure activities (Dautel & Frieden, 1999; Kaye & Longmore, 1998).

The most recent legislation spawned by the disability rights movement includes a revision of MiCASA. The updated version of the previously unsuccessful bill was entitled the Medicaid Community Attendant Services and Supports Act (MiCASSA). Senators Tom Harkin and Arlan Spector filed the bill in the 106th Congress in November 1999 (Glazier, 2001). Major differences between MiCASA and MiCASSA include the following: mandate consumer choice of service delivery; states are to be bound by a

“maintenance of effort” requirement that prevents cutbacks in other service areas; inclusion of aging, persons with mental retardation, and persons with chronic mental illness; supports for persons with cognitive and sensory impairments, who may be independent in basic self care (Glazier, 2001). MiCASSA would lead to the provision of community attendant services and supports include assisting with activities such as eating, toileting, grooming, dressing, bathing, transferring, meal planning and preparation, managing finances, shopping, household chores, phoning, participating in the community, and health related functions like taking pills, bowel and bladder care, ventilator care, tube feeding, etc. Services would be provided at home, in school, at work and for leisure activities (ADAPT, 2004).

Unfortunately, similar to MiCASA, the more current bill has been unsuccessful due to concerns over the financial impact that such a program would have on the federal government. According to ADAPT (2004), it is feared that the “woodwork effect” as discussed earlier, would lead to people who are eligible for institutional services to jump at the chance to use MiCASSA even though they never intended to enter an institution in the first place. ADAPT (2004) asserts that the woodwork effect is blown way out of proportion. Specifically, there may be some increase in the number of people who use the services and supports at first, but the organization asserts that savings will be made on the less costly community based services and supports, as well as the decrease in the number of people going into institutions. In addition to the financial ramifications of MiCASSA, according to Glazier (2001), the fear of overwhelming unmet need seems to have stalled action to date in Congress. Unmet needs is defined as the number of times within the past month that an individual was unable to perform an ADL or IADL activity

due to lack of assistance (Hagglund et al., 2004b). Glazier (2001) points out that the dimensions of PAC need have a very wide range of interpretation. This is dependent on the definition of eligibility for PAC, which is usually set by the number of ADL's for which consumers need assistance. Furthermore, estimates of the need for PAC also vary according to whether one includes persons with limitations in performing ADL's, those who actually require another person's assistance with those ADL's, or those who need standby assistance or supervision.

ADL Assessments

ADL impairment associated with indirect costs of personal assistance is sometimes used to guide health care policy (Cotter, Burgio, Stevens, Roth, & Gitlin, 2002). Since, ADL assessments were used to reliably predict nursing home admissions, policy makers have suggested that such assessments should be used to determine eligibility for PAC services (Kennedy, 1997). ADL assessments are used to measure an individual's ability to independently perform essential daily living activities, e.g. bathing, dressing, transferring eating, and toileting (Allen et al., 1997; LaPlante, Kaye, Kang, & Harrington, 2004). The amount of PAC services received loosely corresponds to the level of disability and the ability to perform ADL's (Hagglund et al., 2004). According to Cotter and colleagues (2002), accurate assessment of ADL's is vital for documenting functional ability and decline. The authors point out that clinicians rely on proxy ratings of ADL performance when making recommendations, however, previous research has suggested that proxy reports of ADL performance may not accurately reflect the patient's true abilities or accurately reflect what actually occurs during an ADL interaction. Furthermore, a critical issue for advocates is whether the ADL criteria are too narrow. A constant framing of need for assistance in terms of the most rudimentary acts of survival

may have the insidious effect of truncating the perceived range of activities needing assistance and, thereby limiting the utility of the program benefits for a substantial portion of the population technically eligible for services (Kennedy, 1997).

Kennedy (2001) examined the accuracy of ADL assessments as a tool for effective planning of disability support services. The author points out that some researchers have used national estimates of need for ADL assistance to speculate on the eligibility of individuals for publicly funded PAC services. Kennedy acknowledges a problem with this methodology in that most of those who need disability assistance already receive ADL assistance in some form. Furthermore, such individuals who are stable and have satisfactory support arrangements are unlikely to seek out new publicly sponsored services, even if they are eligible to receive them. This may be the case if a family member is providing PAC services. Finally, the author stresses the need for a more comprehensive needs assessment for effective planning at the national level. Such an assessment should assess an individual beyond the level of independence with ADL's, describe the type and level of services currently received, and identify the perceived gaps in such services.

Functional Independence Measure (FIM)

As discussed in Chapter 1, one of the most commonly used instruments to assess the ability to perform ADL's is the FIM. A task force cosponsored by the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation developed the FIM as an indicator of disability measured in terms of required degree of assistance by another person (Hamilton, Deutsch, Russell, Fiedler, & Granger, 1999). The instrument, which was constructed to evaluate and monitor functional and cognitive status, was designed to be sensitive to change in the functional

independence of an individual over the course of a comprehensive inpatient medical rehabilitation program (Hall, Bushnik, Lakisic-Kazazic, Wright, & Cantagallo, 2001).

The FIM has been described as having two domains, a motor score domain (13 items) and a cognitive score domain (5 items) (Buchanan, Andres, Haley, Paddock, & Zaslavsky, 2003). This assessment tool requires that the individual administering the FIM be a trained clinician, (Samsa, Hoenig, & Branch, 2001). All items are rated on a 7-point scale with level 1 indicating total assistance and level 7 indicating complete independence (Hamilton et al., 1999). Item scoring is considered complex since scoring rules differ for each of the 18 items (Buchanan et al., 2003). For example, activities involving locomotion have an explicit distance requirement and the use of modified diets for swallowing can affect the scoring on the eating item. Furthermore, scoring is influenced by safety and time required to complete an activity (Buchanan et al., 2003).

Even though the FIM is considered a single measure, Rasch analysis of the instrument has revealed that the FIM is indeed made up of two separate interval measures, a cognitive activity measure and motor activity measure (Hamilton et al., 1999). The Rasch model creates a linear measure, with items placed hierarchically and with fit statistics indicating how well different items describe the group of subjects and how well individual subjects fit the whole group (Grimby et al., 1996). With the division of the FIM instrument into two components, many health care professionals rely on the motor portion of the FIM to predict the need for PAC.

Weitzenkamp and colleagues (2002) studied PAC need for individuals with SCI. Predictors of PAC included the FIM, length of hospital stay, days in a nursing home, neurological impairment level, work, living alone, government funding, gender, ethnicity,

age, and years post injury. The authors studied 2154 participants with SCI and compared data from the onset of injury to 1st, 5th, 10th, 20th, and 25-year post injury using the National Spinal Cord Injury Database. The results of the study demonstrated that of the 11 predictors of PAC need, ADL function, as measured by the motor portion of the FIM was the strongest predictor. Although function as measured by the FIM was shown to be the best predictor of PAC need, there were no other disability measures used for comparison. Furthermore, the findings are confounded by the fact that PAC, in this case, is defined in terms of ADL's, which is consistent with the FIM. This definition contradicts more modern concepts of function and PAC that include measures of more complex activities, social participation, and health-related quality of life (Latham & Haley, 2003).

Hamilton and colleagues (1999) examined the validity of the FIM in predicting paid personal assistance for individuals with SCI as a means for relating disability costs to function. The study involved 109 participants with a wide range of spinal cord injuries. Home visits were conducted over a one-year period by registered nurses who were trained in administering the FIM. The nurses administered the FIM, followed by a disability cost inventory. Participants were also instructed to use a stopwatch in order to record the minutes of assistance required for personal care activities. These activities included eating, dressing, bathing, grooming, bladder and blower care, transfers, and locomotion. The authors referred to these activities as "basic activities of daily living." The disability cost inventory included a personal assistance component, which was based on the average number of paid assistance minutes per day. Such care includes assistance with ADL's provided by attendants, nurses, and respite caregivers. The authors

concluded that participants with low FIM scores (higher dependence) required proportionally more daily assistance than participants with high FIM scores (high independence). Furthermore, the authors reported that the FIM is a significant predictor of the amount of daily assistance needed by persons with disabilities living in the community. The study specifically explored assistance with ADL's. The authors of the study noted several limitations, including problems in transferability of quantitative findings involving the prediction of minutes of assistance to the larger population of people with SCI because of biases. Such biases are due to the fact that the participants represented a convenience sample of current and former patients. Also, as pointed out by the authors, a low percentage of women, nonwhites, married persons, and those living in institutions were represented. As such, transferability of the results of this study to the general population of individuals with SCI would be questionable. Finally, it should be noted that half of the participants in the study received no personal assistance with personal care activities.

Saboe and colleagues (1997) examined the relationship between FIM scores and the need for personal assistance. This longitudinal study involved one hundred and sixty individuals with SCI. Two years post injury, participants were administered the FIM and assessed their current use of personal assistance for ADL's. The assessment of use of personal assistance with ADL's involved the client answering yes or no to one question regarding the need for personal assistance. The authors concluded that two years after SCI, 35% of the participants used personal care assistance. These individuals had significantly lower FIM scores than nonusers of personal care assistance. The authors reported a high amount of variability with this relationship. This was indicated by a large

standard deviation associated with FIM scores. As pointed out by the authors, the study was limited by a lack of focus on FIM scores relative to actual amounts of personal care assistance used. Furthermore, the only question asked to participants regarding personal assistance, was whether or not they received such a service. Responses to such a question could be misleading depending on the interpretation made by the participant. For example, an individual may be responding to personal assistance in terms of one, two, or many levels of assistance associated with ADL's, transportation, vocational activities, or leisure activities. As such, an individual may respond that they do not receive assistance because they are thinking of assistance in terms of ADL's when they receive assistance with vocational activities.

Limitations of the FIM

The FIM is derived from the Barthel Index (Mahoney & Barthel, 1965), and the predominant focus is on changes in functioning. Although the FIM is a reliable instrument and several studies have cited its validity as a valuable tool to assess functional independence with ADL's (Buchanan et al., 2003), the instrument was created for inpatient populations and does not include items that assess complex activities and social participation (Latham et al., 2003). As such, the instrument appears limited in addressing an individual's comprehensive PAC needs. Additionally, the FIM is based on a very limited construct of disability. Many higher order aspects of productive functioning are unrelated to the self-care tasks measured by the FIM (McAweeney, Forchheimer, & Tate, 1996). Specifically, these activities include IADL's, vocational/education and transportation activities. Such aspects of productive functioning allow an individual to participate in the community. Ignoring higher order of productive functioning demonstrates a limitation in the breadth of coverage associated with the FIM.

Jette and associates (2003) examined the breadth of coverage among functional status tools used in post-acute care. The authors explored an empirical comparison of the FIM and three other functional outcome instruments with respect to content, breadth of coverage, and measurement precision. The authors analyzed data from a sample of 485 post acute care patients with a variety of disabilities including SCI. The goal of the authors was to assess items from existing functional outcome tools used in post acute care so that they could be combined for analysis into one common scale. The functional outcome tools used for data collection included the FIM, the minimum data set (MDS) for skilled nursing and sub acute rehabilitation programs (Morris, Murphy, & Nonemaker, 1995); the Outcome and Assessment Information Set for Home Health Care (OASIS) (Shaughnessy, Crisler, & Schlenker, 1997), and the Short Form-36 (SF-36) for ambulatory care programs (Ware & Kosinski, 2001). A total of 58 activity items from all four instruments were administered to the participants. Items from the instruments were equated using the Rasch Model. This method was necessary to link the instruments to one common scale. Figure 2 shows the comparison of the instrument on the same scale representative of functional ability.

The authors point out that across all four instruments it can be seen that cognitive, communication, and bowel and bladder continence function items achieved the lowest functional ability estimates, which indicates that those items were usually less difficult for persons in the sample to perform compared with other items contained in the instrument. The PF-10 derived from the SF-36, lists items with the highest item functional ability calibrations, compared with the other three instruments. For example, items listed on the PF-10 such as carrying groceries, moderate activity, and vigorous

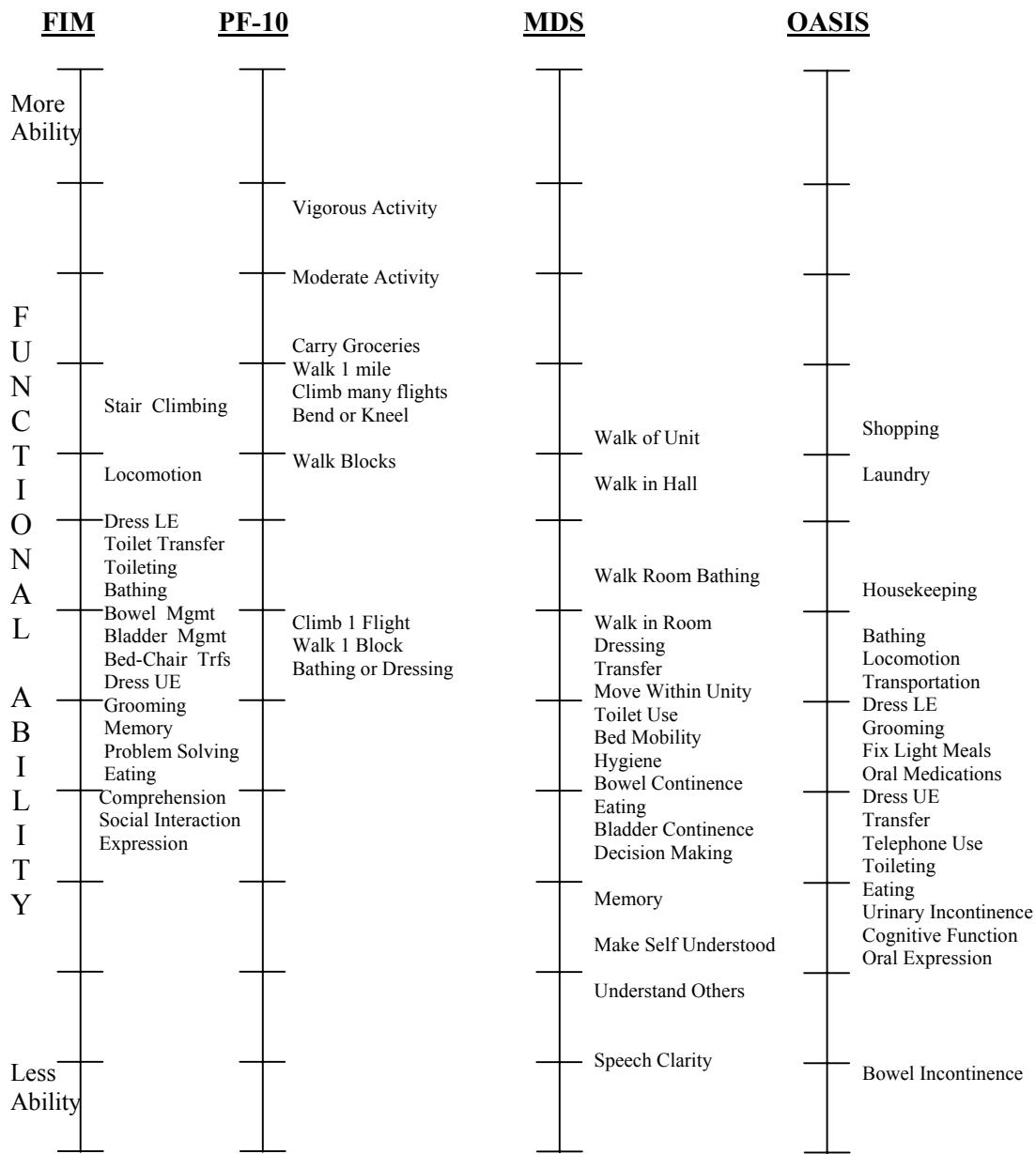


Figure 2. Comparison of Functional Status Tools

(Adapted from Jette et al., 2003)

activities, require the most functional ability to perform and would be considered the most difficult items out of the four instruments.

Jette and colleagues point out that of the four instruments depicted in Figure 2, the FIM is the most widely used outcome instrument in post acute care. As discussed earlier, the FIM has been documented in the literature as being a predictor of the need for personal assistance. According to Figure 2, the FIM covers a very small portion of functional ability, which would make the instrument most precise and relevant for inpatients whose function is at the low end of the continuum. Although many individuals with SCI might fall under this category, there are many individuals with SCI at higher level of function that still require personal assistance. Examples of such activities are listed in Figure 1 of Chapter 1. Upon examination of the items of the FIM as listed in Figure 2, one can see the possibility of ceiling effects and flooring effects. This is evident by the gaps on the FIM when compared with the other four instruments. For example, a ceiling effect is evident if one compares the PF-10 to the FIM. If an individual's functional ability allows him/her to *carry groceries*, as indicated in Figure 2, that level of function cannot be pinpointed by the FIM, since this level of function exceeds that required for *stair climbing*, which is the most difficult item on the FIM. A flooring effect is evident, if one compares the MDS to the FIM instrument. If an individual exhibits a maximum functional ability consistent with *understanding others* as indicated on the MDS, that same functional level cannot be accurately measured by the FIM, since *expression* is the lowest level of functional ability as measured by the FIM. As pointed out by the authors of this study, ceiling and floor effects severely reduce measurement precision and thus restrict the utility of the instruments.

Observations in this particular study coincide with previous research on the FIM that has highlighted ceiling and flooring effects as well as insensitivity to small differences in function (Berry et al., 2003). In fact, since, the FIM is a generic measure of functional status, there is a concern that the instrument is insensitive to changes in the functional status of people with SCI (Meyers, Andresen, & Hagglund, 2000). One has to question the ability to recommend PAC for an individual with SCI based on the FIM instrument, if such an instrument is neither comprehensive nor sensitive to complete functional ability.

Unmet Need

Limitations in the comprehensiveness of assessments like the FIM might contribute to higher frequencies of unmet need for PAC services. Unmet need is possibly the strongest indicator of the quality and adequacy of current PAC service delivery in the US (Hagglund et al., 2004). There are many studies that have examined unmet need for PAC services for individuals with disabilities.

LaPlante and Associates (2004) conducted a study that examined the unmet need for personal assistance services for individuals with disabilities. The authors specifically focused on ADL's and IADL's and compared perceived unmet need with reduced hours of help received. As stated previously, ADL's are comprised of activities such as bathing, dressing, transferring, toileting, and eating. IADL's include tasks such as taking medications shopping for groceries, managing money, and doing heavy housework. Data analyzed for this study came from a National Health Interview Survey, a large nationally representative survey of households in the US. LaPlante and colleagues concluded that unmet need is prevalent among adults of all ages who have substantial needs for PAC services. In fact, about 29% of adults needing help in two or more of the five basic

ADL's need more help than they receive. The authors also determined that an association exists between perceived unmet need and reduced hours of assistance, independent of level of disability, race, age, and income level. An important result of this study is that unmet need was not a measure of an individual's insatiable demands for more help (basically not really needing assistance and just wanting help). The authors also confirmed that unmet need is associated with higher rates of adverse consequences, including discomfort, going hungry, losing weight, dehydration, injuries due to falls, and burns.

Allen and colleagues (1997) examined the prevalence and consequences of unmet PAC need for individuals with disabilities. The authors investigated unmet need for assistance with ADL's, IADL's and transportation in a randomly selected sample of 632 adults with disabilities. The results of the study indicated that prevalence of unmet need for assistance with ADL's ranged from 4.1% to 22.6% of the full sample. Unmet need for IADL's was reported ranging from 15.9% to 34.6%. Participants under the age of 65 reported high amount of unmet need for transportation activities. In addition to prevalence of unmet need, the authors noted consequences resulting from unmet need. Specifically, more than 25% of the respondents had impairments in toileting and reported wetting or soiling themselves because they did not have help getting to the bathroom. Additionally, over 25% of the respondents reported not being able to have a bath, falling due to lack of assistance with transferring, high stress due to lack of assistance with housework, and missing doctor's appointments and recreation activities due to lack of assistance with transportation.

Kennedy (2001) conducted a similar study by delineating the type and magnitude of disability assistance needs across the US population, focusing on factors associated with perceived gaps in assistance. The author examined data estimates from the 1994 and 1995 Disability Follow-Back Surveys. Specifically Kennedy explored self-reported assistance deficits with ADL's and IADL's. The results of this study showed that an estimated 3.2 million adults with disabilities have at least one unmet assistance need, usually involving IADL's. Approximately 970,000 adults with disabilities reported one or more assistance deficits with basic ADL's. As pointed out by Kennedy, this population is a logical target for expanded state or federal personal assistance programming.

In order to determine whether the source of PAC services can have an effect on unmet need, Hagglund and colleagues (2004) compared consumer-directed and agency directed personal assistance services programs. The authors compared 61 individuals with physical disabilities who receive PAC through consumer-directed programs with 53 individuals with physical disabilities who received services through an agency-directed model. Participants in both the consumer-directed and agency-directed groups reported high levels of unmet needs in PAC services. Specifically, 42% of participants who needed assistance with ADL's had at least one unmet need in the last month, while 52% had at least one unmet IADL need in the past month. There were no significant differences between the two groups in terms of prevalence of unmet need. The authors point out that more attention needs to be targeted towards those at risk of not receiving adequate PAC services and that doing so, will increase the likelihood of increased

community and vocational activities and lower the chances of consequences such as high hospitalization rates.

Consumer Directed PAC

Legislators responding to issues related to PAC must first deal with the most highly contested issue facing policy makers, the quality of consumer-directed services (Tilly, Wiener, & Cuellar, 2000). According to Tilly and associates (2000), most government representatives as well as disability representatives consider beneficiaries with consumer direction to be much more satisfied with their PAC services. The authors point out that such opinion conflicts with the notion by home-care agencies and union representatives that there is no difference between agency-directed PAC services and consumer-directed PAC services. Interestingly, the literature demonstrates that most consumers with a disability are directing their own PAC and as a result are more satisfied with such services. This is clearly the case as family and friends of people with disabilities provide over 85% of all hours of assistance with ADL's and IADL's (LaPlante et al., 2002; LaPlante et al., 2004).

Hagglund and colleagues (2004) compared consumer-directed and agency-directed personal assistance services. Specifically, the authors examined consumer's report of unmet needs, empowerment, satisfaction, safety and quality of life associated with PAC. The authors studied 61 individuals with physical disabilities who received PAC through a consumer-directed program and 53 individuals with physical disabilities who received services through an agency-directed model. Participants were interviewed and administered satisfaction questions derived from the Patient Satisfaction Questionnaire (PSQ-III) and the Group Health Association of America (GHAA). The participants also received safety questions from the national Home Care Survey and the quality of life

questions from the SF-36. The authors concluded that participants in consumer-directed PAC programs reported more empowerment and satisfaction with such services than agency-directed PAC programs. Safety, and unmet needs were the same for both models; however, enrollment in a consumer-directed program was a predictor of enhanced quality of life.

Prince and associates (1995) found that a better quality of life associated with consumer-directed PAC may be due to lower medical problems, fewer hospitalizations, and better perception of health. The authors compared self-managed PAC versus agency-provided PAC for individual with high-level tetraplegia. The study involved 71 participants who had sustained spinal cord lesions between C1 and C4 and were at least one-year post injury. The participants receive a comprehensive battery of assessments that examined perceived functioning, life satisfaction, fulfillment and participation in society, personal assistance satisfaction, locus of control over various aspects of their lives and their psychological self-reliance. The authors concluded the self-managed group had many more hours of paid attendant care, fewer medical problems, fewer hospitalizations, and a better perception of health than the agency-directed group. Furthermore, the self-managed group reported a greater satisfaction in having a choice of a caregiver, spent less money and used more hours of paid care. Finally, the authors concluded that financial burden borne both by the individual and society and the emotional burden associated with families and friends were diminished by individuals managing their own PAC.

Cash and Counseling

In order to allow individuals with disabilities to manage their own PAC services, a program was developed that offers consumers with disabilities cash allowance in lieu of

agency delivered services (Mahoney, Simone, & Simon-Rusinowitz, 2000). The program is known as the Cash and Counseling Demonstration and Evaluation, is funded by the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services. A three state Cash and Counseling Demonstration was implemented to compare the Cash and Counseling consumer-directed model with the traditional agency-directed approach to delivering personal assistance services (Cash and Counseling, 2005). This consumer-direct model gives consumers a flexible monthly allowance to purchase disability-related goods and services (including hiring relatives as workers), provides counseling and financial assistance to help them plan and manage their responsibilities; and allows them to designate representatives to make decisions on their behalf (Foster, Bown, Phillips, Schore, & Lepidius, 2003).

The Cash and Counseling approach provides consumers with the ability to direct and manage their own personal assistance services and address their own specific needs. Cash and Counseling intends to increase consumer satisfaction, quality, and efficiency in the provision of personal assistance services. The vision guiding this expansion is the promise of "a nation where every state will allow and even promote a participant-directed individualized budget option for Medicaid-funded personal assistance services." As of 2004, ten states were awarded three-year grants of up to \$250,000 to implement the Cash and Counseling model and collect information to monitor the effectiveness of these programs. Due to the success of the Cash and Counseling Demonstration and Evaluation in Arkansas, Florida, and New Jersey, interest from other states, a supportive political environment, and President George Bush's New Freedom Initiative, The Robert Wood

Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation, and Administration on Aging have authorized an expansion of the Cash and Counseling program that will provide grants and comprehensive technical assistance to additional states that are interested in replicating, and in some states expanding, on this Cash and Counseling model (Cash and Counseling, 2005).

Consumer Management of PAC

With government funds, some PAC programs give consumers, rather than homecare agencies, control over who provides services and how the services are delivered (Tilly et al., 2000). Largely through the efforts of the independent living movement, consumers have been able to assume more control over the care-giving process by being able to recruit, hire, train, manage, and pay PCA's (Prince et al., 1995). A survey carried out by the World Institute on Disability of federal/state and state-only financed programs for homecare found that 75 programs used independent PAC providers. Of these programs, 80% allowed consumers to hire and fire their own PAC workers and half allowed consumers to train PAC workers (Doty & Kasper, 1994; Litvak & Kennedy, 1990). Managing PAC services by an individual with a newly sustained SCI can be quite an adjustment. Furthermore, lacking the knowledge of one's own PAC needs makes managing such services more difficult, especially when one considers the amount of services that that individual will need for the rest of his/her life.

In order to utilize attendant care services, people with disabilities must quickly develop an understanding of their PAC needs in order to organize and manage their PAC services. Understanding personal care needs can have life long implications and the impact of inadequate personal care assistance on physical, emotional, and social well being can be tremendous (Lanig, Chase, Butt, Hulse, & Johnson, 1996).

The knowledge of an individual's personal care needs is crucial in being able to hire and train individuals to provide PAC services. One of the most commonly cited problems regarding attendant services is consumers' lack of training and supervision skills (Ulicny, Adler, & Jones, 1990). Skills that are necessary to utilize a personal care attendant include skills in management, supervision, interviewing, hiring, training, organization, and assessment of personal care needs. The following quote describes the difficulty of transitioning to managing a personal care attendant:

One of the biggest challenges is changing your mindset. You can't look at a personal assistant as someone who is just helping you out. You really need to approach it as managing an employee or running your own small business. You're not asking the person to do you a favor. You're hiring them to provide an important service for you. (Weas, 2002)

Such challenges are the reason that many Independent Living Centers provide training to consumers in order for them to be able to assess their own personal attendant care needs. For example, Community Resources for Independence offers a training manual for persons with disabilities receiving attendant care services (Community Resources for Independence, 2002). The manual offers a detailed personal needs inventory that can help consumers to define their range of specific needs for personal assistance. The self-assessment is a comprehensive inventory that includes questions regarding ADL's, IADL's, School/Education, Social and Community Activities, Transportation, Personal Finances, Communication, Health, and Vacation Activities. The manual allows an individual to be prepared to hire and train PCA's to provide attendant care services. This type of assessment is an excellent example of a comprehensive instrument and should serve as a model for breadth of its scope in the development of assessments of PAC for individuals with SCI. It seems clear that assessments that

explore individuals' needs beyond functional ability to perform ADL's would be more successful in predicting PAC need.

Personal Assistance and a Model of Disablement

New rehabilitation models examine disability by exploring many constructs in addition to functional status. According to Disler and colleagues (1993), a paradigmatic shift in outcome rehabilitation occurred with the introduction of the World Health Organizations (WHO)'s International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The authors point out that the scope of this model was far broader at it attempts to introduce taxonomy of consequences of illness, and introduces standard terms of impairment, disability, and handicap. Substantial revisions to the ICIDH have led to the most recently developed disability model known as the International Classification of Functioning (ICF) (Arthanat, Nocajski, & Stone, 2004).

The theoretical framework of the ICF Model demonstrates limitations of just examining and individual's ability to be independent with ADL's for determining all PAC needs. This model provides a unified and standard language and framework for the description of health and health-related states. The ICF model is made up of two parts (Figure 3). The first part includes components of functioning and disability. This component includes the body function component, which fall under two classifications. One classification is for functions of body systems, which involves physiological or psychological functions. The other classification is for body structures, which includes anatomic parts of the body such as organs, limbs, and their components (WHO, 2001). Activities and participation cover a complete range of areas denoting aspects of functioning from both an individual and societal perspective. Activities are defined as "an execution of a task or involvement in a life situation in a uniform environment."

Participation is described as “the execution of a task or involvement in a life situation in an individual’s current environment” (WHO, 2001).

The second part of the ICF model includes components of contextual factors, which are external features of physical, social, and world attitudes, which can have an impact on the individual’s performance in a given domain. These features are described as Environmental factors and can impact the functioning and disability part of the model. Organization of these contextual factors is based on sequence from the individual’s most immediate environment to the general environment. Personal Factors is also a component of contextual factors but they are not classified in the ICF because of the large social and cultural variance associated with them. (WHO, 2001). All components within the two domains of the ICF contribute to a model of disablement.

The disablement scheme of the ICF model involves central goals to delineate the major pathways from disease or active pathology to various types of functional consequences (Jette, 1994). The pathway described by the ICF is bi-directional. This bi-directional approach contrasts previous models such as the Nagi Model and the National Center for Medical Rehabilitation Research (NCMRR) model (See Figure 3).

A case example can help to better understand how the ICF model can serve as a guide for understanding an individual with SCI’s PAC needs. The following example is based on an individual with a diagnosis of complete C6 tetraplegia. According to the ICF model, the *health condition or disease* would be the spinal cord injury. The individual could have significant functional limitations, which may lead to requiring assistance with activities of daily living. The paralysis as a result of the level of spinal cord injury and

physiological deficits would fall under *bodily functions and structures*, while ADL's would make up the *activities* component of the model. The individual's *participation*

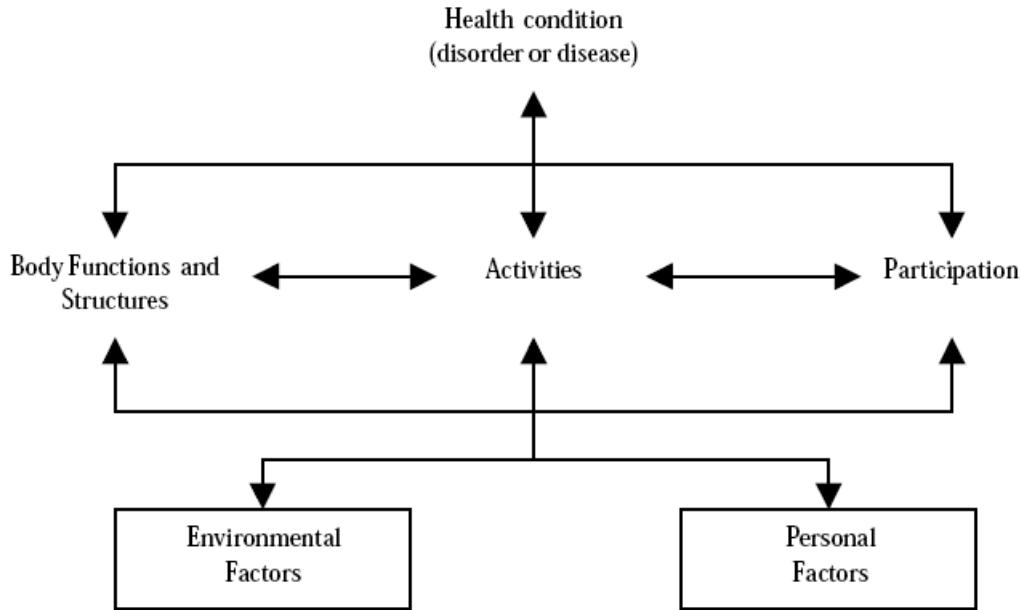


Figure 3. ICF Model

would include the ability to execute tasks in society such as leisure, home/yard maintenance, vocational, and educational activities. According to Hagglund and colleagues (2004) more research is critically needed in the area of participation to document increased participation with increases in PAC services. Such evidence would help legislators respond, especially if it were to show economic advantages and benefits of increased participation in the community.

Such participatory tasks may be limited due to other components of the model such as secondary *health conditions*, *environmental factors*, and *personal factors*. Secondary health conditions may be acute illnesses, respiratory problems, or conditions associated with spinal cord injuries. *Environmental factors* may include lack of funding to support

PAC. Lack of funding, leading to lack of PAC, will most likely lead to deficits in the *functional, activities, participation, and possibly health conditions* arenas. *Personal factors* refer to the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level (WHO, 2001).

The bi-directional pathway of the ICF model incorporates the medical and social model. The medical model views disability as a personal problem, directly caused by a disease, trauma, or other health condition, which requires medical care. The social model views disability, not as an attribute of an individual, but rather a complex collection of conditions, many of which created by the social environment. The social components (environmental, participation, activities) can impact or be impacted by the medical components (body structure, health condition) (WHO, 2001).

The FIM appears to be ignoring many social components of the ICF Model, likely due to the fact that the FIM was created for assessing inpatient functional dependence. The ICF Model demonstrates how neglecting any component of an individual's disability needs, can lead to not only deficits in overall PAC, but deficits in an individual's quality of life and health. A comprehensive assessment of PAC need that incorporates all components of the ICF Model appears warranted.

Role of the Life Care Planner

Life care planners, as discussed in Chapter 1, assess people with disabilities' needs well beyond function. In order to make such an assessment, the life care planner must develop a consistent methodology for analyzing the needs created by the onset of disability (Deutsch, 1995). Such a methodology includes a comprehensive review of all available medical, psychological, psychosocial, and rehabilitation-related information. In addition the life care planner reviews records for school-aged children and comprehensive work histories for adults. It is important that the life care planner be aware of all medical and rehabilitative aspects of the case and determine what other evaluations may be needed to identify the individual's disability-related needs.

The life care planner must consistently communicate with other rehabilitation professionals involved in the case (Mediproseminars, 2004). Such professionals may include: physical therapists, occupational therapists, speech therapists, physicians, nurses, psychologists, and any other professionals involved. Professionals who often conduct life care plans include: catastrophic case managers, rehabilitation psychologists, rehabilitation counselors, or rehabilitation nurses (Deutsch & Kitchen, 1994).

A major role of the life care planner is to utilize research and resources to substantiate recommendations. Life care planning recommendations must be data-supported, rather than based on simple opinions. Data should be collected from many resources, getting information about the individual client as well as exploring relevant research studies which have been published, related to needs of similar individuals with disabilities (MediPro Seminars, 2004).

Table 1 is an example of an attendant care component of a life care plan, which includes specific types of personal attendant care services, specific items for each service,

frequency of services, and the annual cost for such services. As seen in Table 1, attendant care may include assistance in home health issues or medical issues, housekeeping, home maintenance and repair, and yard care and maintenance. The life care planner must conduct a thorough evaluation of an individual's PAC needs before recommending such services. As seen in Table 1, recommendations may change as individual progresses through his/her lifespan. For example, as seen in Table 1, this the frequency of an individual 's PAC increases after the age of 55. This is due to decrease in functional ability associated with the aging process. The life care planner must be able to make a comprehensive assessment of an individual with a disability needs so that the appropriate care is designated throughout his/her lifespan.

LCP Knowledge and Competencies—Framework of the ICF Model

The ICF appears to be an excellent model for life care planners in evaluating needs and services for individuals with disabilities. Life care planners must have a thorough knowledge of the medical and social and environmental aspects of disability. As evident by the ICF model (Figure 2), medical and social implications can greatly impact each other, thus affecting the overall level of disability.

Knowledge of the contextual factors as outlined in the ICF model is critical for life care planners in making recommendations. Each individual is different, in that he/she resides in his/her own environment. Life care planners must be attentive to certain barriers that often limit persons with specific disabilities to complete activities and participate in society. Barriers may exist at different levels and may vary depending on type of disability. The life care planner must be aware of resources, which may include technology that is available to minimize such barriers and restrictions. As evident by the

ICF model, such restrictions can affect *health conditions* and *body systems*, thus reducing life expectancy.

Table 1. PAC Component of a LCP

Description/Service:	Rationale:	Through Age:	Cost:	Frequency:	Annual Cost:
Home Health Aide/Personal Aide or Personal Care Attendant	Provide assistance with transfers, safety precautions	Beginning: 2002 Ending: Age 55	\$9.41-\$10.68/hr	Avg 3 hrs/day 365 days/year (approx 21 hours/week)	\$10,304 - \$11,695/year
		Beginning Age 55 Ending: Life Expectancy	\$19.00-\$23.00/hr	Avg 5 hrs/day 365 days/year (approx 35 hours/week)	\$34,675-\$41,975/year
Housekeeper	Provide assistance with household cleaning, maintenance, driving to and from appointments, errands	Beginning: 2002 Ending Age 55	\$7.99-\$8.65/hr	Avg 3 hrs/day 365 days/year (approx 21 hours/week)	\$8,725-\$9,446/year
		Beginning Age 55 Ending: Life Expectancy	\$7.99-\$8.65/hr	Avg 4 hrs/day 365 days/year (approx 28 hours/week)	\$11,633-\$12,594/year
Home Maintenance and Repair	Replacement services for minor home repair and maintenance	Beginning 2002 Ending: Life Expectancy	\$10.00-\$12.00/hr	Avg 5 hrs/month 50 weeks/year	\$600-\$720/year
Yard Care and Maintenance	Replacement services for yard care	Beginning 2002 Ending: Life Expectancy	\$10.00-\$12.00/hr	Avg 8 hrs/month 9 months/year	\$720-\$864/year

The life care planner must also be aware of how the aging process and life experience of individuals with disabilities can affect *activities* and *participation*. For example, individuals with SCI who utilize a manual wheelchair (*activity and participation*) for most of their lives will often develop rotator cuff tribulations (*health condition*). Such problems can trigger the need for that individual to require a motorized

wheelchair. Such complications need to be projected in a life care plan so that the individual receives adequate services when the problems arise.

Finally, life care planners are consistently required to educate themselves as to the research associated with catastrophic disabilities. As technology advances, and as new techniques are developed to treat various disabilities, the needs of those individuals will change as well. Other areas include projected complications related to injury, the recommendations of assistive devices, the need for medications, the need for therapeutic modalities, and the need for PAC. Strong research support can determine whether a life care plan is accepted and provide a means for educating all parties involved. For example, empirical studies that demonstrate the potential for individuals with spinal cord injuries to develop pressure sores would support the recommendation for assistance with transfers if the individual is not capable of transferring independently.

Life care planners consider all components of the ICF model. The bi-directional map of the components within the ICF model appears to be similar to the approach that is taken by Life Care Planners when evaluating an individual with a disability. The ICF model demonstrates the dynamics behind disability, thus it is similar to the dynamics of a LCP. It would seem that the perspective of a professional life care planner, skilled in evaluating disability needs from all aspects of the ICF model, would be a valuable in assessing an individual with SCI's PAC needs.

Summary and Rationale for a Comprehensive PAC Instrument

As indicated in this chapter, the need for PAC services is on the rise as individuals with disabilities are living longer and healthier lives. In response to this increase, legislators and people with disabilities have made a strong effort to increase public funding for PAC services. Programs involving such funding have been functioning at the

state level, although more recently, disability advocates have been pushing for a national system of PAC. The lack of success of a national program is in part due to a high level of unmet PAC need and the concern that such lack of current assistance will lead to an enormous financial burden on the federal government. Unfortunately, the financial burden to provide PAC assistance has fallen upon state Medicaid programs and such programs have been unsuccessful. Furthermore, the lack of met need has the potential of causing individuals to have many health related problems. It would appear that these health related consequences such as hospitalizations, institutional care, and higher medications would have a major economic impact on current government funded health care programs. Thus, reducing unmet need would ease the burden of funding health related consequences. In addition, the federal government's fear of the "wood work" effect as discussed earlier might be decreased if legislators have an accurate and precise understanding of individuals with disabilities' PAC needs. Such an instrument could be used to estimate the cost of providing such services. Having such information will allow legislatures to compare the cost of providing such services with the cost of paying off health related consequences associated with unmet need. In addition, such knowledge could be used by disability rights activists when lobbying for national legislation to fund PAC.

Currently, the only instrument being used to predict cost of PAC as demonstrated by the literature is the FIM. The FIM have been lauded for being able to predict PAC needs, however, there are many limitations of this instrument including inadequacy in breadth of coverage and lack of sensitivity to complete functional ability. As discussed in this chapter, researchers, in order to predict the cost associated with PAC needs have

relied on the FIM. Such studies have been limited due to the fact that FIM focuses on self-care tasks when there are many higher order aspects of productive functioning associated with disability. In order to truly predict the cost of PAC services, one has to consider such services beyond the assistance with self-care tasks.

Agencies contracting with the government need to be able to rely on better cost predictors of PAC in order to be able to utilize public funding to provide such services. In addition, a comprehensive assessment would allow agencies to have an enhanced understanding of the PAC services required by individuals with SCI. Knowledge obtained by such an assessment will ensure that appropriate assistance is provided to meet all the PAC needs of an individual with SCI resulting in less prevalence of unmet need.

In addition to agency directed care, as indicated in this chapter, it is evident that individuals with SCI are directing their own PAC services. As such, a comprehensive assessment of PAC needs will allow individuals with SCI to appropriately hire, train, and manage individuals to provide such services. It would seem reasonable that a comprehensive understanding of one's own PAC needs would have a positive impact on the success, type and amount of assistance received. In order to obtain a comprehensive understanding of all the activities associated with PAC, the development of such an assessment should incorporate the first-hand knowledge of individuals with SCI.

In addition to integrating the perspective of individuals with SCI, the development of a complete PAC assessment should follow modern models of disablement. New models examine disability by exploring many constructs in addition to functional status. Models such as the ICF incorporate a synthesis of different perspectives of health from a

biological, individual, and social perspective. Life care planners experienced in making PAC recommendations for individuals with SCI often make recommendations using methodologies that coincide with many aspects of the ICF Model. As such, life care planners would be valuable in the development of a comprehensive assessment of PAC need for individuals with SCI.

CHAPTER 3 METHODOLOGY

The aim of this study was to collaborate with life care planning experts as well as veterans with SCI, to understand the critical constructs and items, necessary to examine the need for PAC. To achieve these research goals, two separate qualitative techniques were implemented and discussed below. The University of Florida Health Science Center Institutional Review Board (IRB-01) and the Veterans Administration (VA) Subcommittee for Investigations approved the present study prior to the enrollment of participants.

Research Question 1

What are the critical constructs and items necessary to examine the need for PAC services for veterans with SCI from the prospective of the professional?

Subjects

Certified life care planning experts (n=100) were selected from a mailing list provided by the MediPro Seminars Life Care Planning Certification Program. The experts selected had worked for at least three years as a life care planner in order, to assure that they could make knowledgeable recommendations for PAC. Based on a review of the literature and in order to obtain diversity in opinion, the investigator set a goal of twenty-four experts to be participants in all three rounds. Participants were selected using a purposeful sampling strategy (Patton, 2002). As described by Patton, (2002), purposeful sampling is a concept that involves the selection of cases that are “information-rich and illuminative, that is they offer useful manifestations of the

phenomenon of interest.” (p. 40). Since the job of a life care planning expert is extremely demanding, there was a concern of a possibility for a lower return rate of participant responses. Therefore, this researcher selected 100 participants from whom to solicit responses, in hopes of reaching the goal of obtaining responses from at least 24 experts.

Sampling Procedure

A web-based Delphi technique was used for the development of constructs and items to be included within a PAC measure. The Delphi technique is a method of soliciting and combining the opinions of group experts. This technique originated from research at the RAND Corporation as a means for predicting the future policy developments (Brown, Cochran, & Dalkey, 1969). The method involves a rapid and efficient way to combine the knowledge and abilities of a diverse group of experts by quantifying variables that are either intangible or vague (Linderman, 1981). The Delphi Technique is essentially a series of questionnaires. The first questionnaire asks the participants to respond to a series of open-ended questions; the second round questionnaire consists of a series of closed-ended questions that are built upon the responses to the first round of questioning. Successive questionnaires give participants feedback on the collective responses of the group, providing the opportunity for subjects to modify their responses. The ultimate goal of this technique is to achieve an overall consensus or level of agreement for a specific inquiry (Williams et al., 1994). The process builds on the qualitative responses of experts and measures the group’s responses quantitatively (McBride, Pates, Ramadan, & McGowan, 2003).

Key characteristics of the Delphi approach are: 1) anonymity of survey panel members, 2) anonymity of responses, 3) multiple iterations, 4) statistical analysis of panel response, and 5) controlled feedback of responses to panel members. This approach

prevents any one member of the panel from unduly influencing the responses of other panel members. Through the statistical summaries and minority reports, panel members communicate with each other in a limited, goal-centered manner. The systematic control lends an air of objectivity to the outcome, which provides a sharing of responsibility that is reassuring and releases the participants from group inhibition (Linderman, 1981). This technique has been regularly used in medical and health services research (Herdman et al., 2002) and is suitable for problems where there is insufficient or contradictory scientific evidence.

The Delphi Study methodology offers a number of advantages to the study of PAC. First, the method allows for the development of expert opinion without bias, which can readily occur, in comparable techniques such as committee meetings or group discussions. Such techniques can lead to panel members being intimidated or inhibited from expressing their views due to stronger individuals dominating the group. As such, the Delphi Method encourages honest opinion that is free from peer group pressure. Additionally, panel members have the opportunity to have more time to think about the issues being discussed with the added capability to retract, alter or add further views (Williams et al., 1994). Finally, the Delphi approach ensures the ability to collect data from a diverse panel in terms of geographic location, experience, gender, and education.

Delphi Procedure

This investigator developed a list of open-ended questions based on review of the literature, standards of practice, and preliminary data from brainstorming with life care planning experts in regards to significant issues to explore in developing a PAC assessment for individuals with SCI. In addition, demographic questions were developed

to assess diversity in terms of gender, age, education and training, occupation, and experience.

The next step involved applying the first round of questioning onto a web-based format. The Quask Form Artist® software program was used to develop online forms that would be easily accessible to the participants. This web form design program enables the user to collect and analyze data through a wide range of export and statistical analysis functions (Quask, 2004). The rationale for using a web-based approach is to expedite the data collection process and allow participants the convenience of completing online forms as opposed to having to mail responses. The software program provided a means for obtaining the data from participants immediately following the completion of the survey. Furthermore, the program provided a means to easily track the response rate of participants.

Once the initial round of questions was developed, the survey was alpha tested on four expert life care planners affiliated with the University of Florida. These participants were notified via email and were directed to the website location to participate in the survey. The participants were asked to respond with comments and suggestions for making the first round questionnaire more appropriate and comprehensible. This investigator incorporated the recommendations from the alpha testing into the initial round of questions to be sent to the 100 life care planning experts (Appendix A).

Delphi round 1

All 100 experts were contacted via email and requested to participate in the Delphi Study (Appendix B). As incentive for participation, the experts were informed that they would receive five continuing education credits (CEU's) towards their life care planning certification. This investigator obtained pre-approval to provide the CEU's

from the Commission on Health Care Certification. In addition, an endorsement letter from Paul Deutsch, a leading expert who innovated the concept of life care planning, was included with the initial email (Appendix B). The email directed the participants to the website to complete Round 1. The website was located on the College of Public Health and Health Professions secure server. Once the participant accessed the website, they were required to review a page containing a waiver of documentation of consent which explained their rights as a research subject (Appendix A). If the respondent selected “yes”, they indicated they understood their rights as a research subject and were directed to the survey. If the respondent select “no”, the web browser closed and the respondent did not see the questionnaire. At the end of the survey, the respondents were instructed to submit their responses along with their email address once the survey was completed. A friendly reminder email was sent to the experts two weeks following initial contact (Appendix C).

Delphi round 2

Once the data was received, it was analyzed for content using NVivo® Qualitative Software. NVivo® is designed for researchers who need to combine subtle coding with qualitative linking, shaping and modeling. The program works as a fine-detailed analyzer by integrating the processes of interpretation and focused questioning. Rich text records are freely edited and coded and linked with multimedia. The software enables researchers to take qualitative inquiry beyond coding and retrieval, supporting fluid interpretation and theory emergence (QSR International, 2002).

The software facilitated the retrieval of rich text records from the Quask® Web Software. Once the data was imported, this investigator coded all of the responses based on emerging themes to be included for the second round questionnaire. Since the

purpose of this study was to generate items and constructs to be included on a PAC measure, specific activities related to PAC services were coded and used to develop the items for Round 2 of the Delphi Study. Round 2 of the Delphi Study consisted of closed questions in which participants were asked to rate the importance of each item when recommending PAC services in a LCP. Each item was to be rated on a Likert Scale from 1 (strongly disagree) to 4 (strongly agree). Participants also had the option of selecting “not sure” to an activity if they could not come up with an applicable rating.

Following the same methodology for Round 1, an email (Appendix D) was sent to all the experts directing them to the website to complete Round 2 (Appendix E). At the end of the survey, participants had an opportunity to respond with specific comments in regards to Round 2. Additionally, the respondents were instructed to submit their responses along with their email address once the survey was completed. Similar to Round 1, a friendly reminder email was sent to the experts two weeks following initial contact (Appendix F).

Once the Round 2 questionnaires were received, they were analyzed to determine the consensus among all of the experts. Currently, there are no universally agreed upon standards for establishing consensus (Fink, Kosekcoff, Chassin, & Brook, 1984). However, Rowe & Wright (1999) reviewed empirical studies looking at the effectiveness of the Delphi technique and indicated that typical Delphi studies involve consensus techniques that include the presentation of medians and interquartile ranges. For each item from Round 2, interquartile ranges were calculated as measures of dispersion and median scores were calculated as measures of central tendency. The combination of these indices was used to determine the degree of importance and consensus for each activity.

Medians rather than means were used in reporting back to the respondents in order to diminish the effects of outliers (Currier, 2001). The median and interquartile range of responses for each of the items were calculated using SPSS® software (SPSS Inc., 2001).

Delphi round 3

Once the consensus data was calculated, these results were sent along with a third questionnaire to the experts (Appendix G). The experts were presented with the same activities listed in Round 1 along with their previous responses and consensus data. The participants were then asked to review their previous responses along with the consensus data and reconsider or revise their answer.

Following the same methodology for Rounds 1 and 2, an email (Appendix H) was sent to all the experts directing them to the website to complete Round 3. At the end of the survey, the respondents again had the opportunity to provide comments in regards to the Round 3 and were instructed to submit their responses along with their email address once the survey is completed. Similar to previous rounds, a friendly reminder email was sent to the experts two weeks following initial contact (Appendix I).

Research Question 2

What are the critical constructs and items necessary to examine the need for PAC services from the prospective of veterans with SCI?

Rationale for Interviewing Veterans with SCI

The rationale for interviewing veterans with SCI is that they are the individuals experiencing the disability first hand, and it can be argued that no one better understands the challenges they face. Additionally, not involving the population for which the PAC assessment is to be utilized would appear to be a limitation in the development of such an instrument.

Subjects

A convenience sample comprised of eight veterans with SCI, from the Malcolm Randall Veterans Administration Medical Center in Gainesville, FL was used for this study. Participants were selected using a purposeful sampling strategy (Patton, 2002) as discussed earlier. This technique was chosen since it involves selecting a small sample of information-rich cases that yield insights and in-depth understanding rather than empirical generalizations. Patton (2002) discusses an example:

If the purpose of an evaluation is to increase effectiveness of a program in reaching lower-socioeconomic groups, one may learn a great deal more by studying in depth, a small number of carefully selected poor families than by gathering standardized information from a large statistically representative sample of the whole program p.230.

This researcher met with his committee members and determined that 8 veterans with variable levels of SCI would be adequate enough to yield an in-depth understanding of PAC.

Procedure

The purposeful sampling strategy follows an approach used in qualitative research. Over the past ten years, qualitative methods have become more commonplace in health services research (Mays & Pope, 2000). The goal of qualitative research is the development of concepts which help researchers understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all participants under study (Pope & Mays, 1995).

This investigator selected qualitative interviews as a method for fully understanding the impact of PAC on individuals with SCI. Qualitative interviewing is a flexible and powerful tool, which can assist the researcher in obtaining diverse opinions of research participants (Britten, 1995). In order to facilitate this qualitative approach,

the standardized open-ended interview approach as described by Patton (2002) was implemented. This type of interview consisted of a set of questions carefully worded and arranged with the intention of taking each respondent through the same sequence and asking each respondent the same questions with essentially the same words. The technique involved the use of an interview guide (Appendix J) in order to ensure that the same basic lines of inquiry were pursued with each person. The advantage of an interview guide is that it makes certain that the interviewer has carefully decided how best to use the limited time available in an interview situation (Patton, 2002). Additionally the approach guarantees that the respondents answered the same questions, thus increasing comparability of responses. These semi-structured interviews allow for a divergence between the interviewer and interviewee in order to pursue an idea in more detail (Britten, 1995). Additionally, this approach also facilitated collection, organization, and analysis of the data (Patton, 2002).

All eight interviews were recorded using a digital voice recorder. Before the interview took place, all participants were required to sign a consent form, which acknowledged their rights as research subjects. At the completion of each interview, this researcher digitally transferred the interview onto a CD-ROM. The CD-ROM was sent to a transcriber, who provided the researcher with an electronic transcription of the interview in rich text format. All eight interviews averaged around 45 minutes in length.

Data Analysis

Data analysis was conducted using NVivo® Qualitative Software. As discussed earlier, NVivo® is intended for researchers who need to combine subtle coding with qualitative linking, shaping and modeling. NVivo® provides the researcher with a means for handling qualitative data records and information about them, for browsing and

enriching text, coding it visually or at categories, and annotating and gaining access to data records accurately and swiftly (QSR International, 2002). In order to answer the current research question, this researcher browsed and coded the data based on specific constructs and items to be included within an instrument that assess PAC for individuals with SCI. Additionally, the qualitative data was further scrutinized to obtain a full understanding of the PAC needs for individuals with SCI. Such information will facilitate further development of the currently created PAC assessment, which will include determining if the items generated by this study are truly representative of the needs of individuals with SCI.

Coding

In order to extrapolate the information discussed above, coding techniques were implemented. Coding in NVivo® involves the creation of nodes based on the qualitative documentation. Using coding techniques, this researcher converting the qualitative data into a crudely quantifiable form as to answer the research question. This method led to the coding of items to be included in a PAC assessment. Once all the data was coded, the nodes were then analyzed. The analysis is aimed at constituting proof for a given proposition, in this case the contribution of items towards a PAC assessment (Glaser & Strauss 1967).

This researcher utilized the Constant Comparative Method to analyze the qualitative data. According to Glaser & Strauss (1967), this approach combines specific coding procedures with theory development. The author points out that this method can lead to an attainment of complex theory that corresponds closely with the data since constant comparisons force the analyst to consider much “diversity” in the data. According to these authors “diversity” refers to the comparison of each incident with

other incidents in terms of similarities and differences. Making such comparisons helps the researcher overcome bias since concepts can be compared amongst all the participants (Corbin & Strauss, 1990).

Researcher Bias

There is a concern with qualitative research relating to the extent to which predispositions or biases of the evaluator may affect data analysis and interpretations (Patton, 2002). Often data from and about humans inevitably represent some degree of perspective rather than absolute truth (Patton, 2002). To overcome this concern, this researcher made every effort to maintain “reflexivity”. According to Malterud (2001), “reflexivity” refers to an attitude of attending systematically to the context of knowledge construction especially to the effect of the researcher at every step of the research process. The author states that once reflexivity is maintained, personal issues can be valuable sources for relevant and specific research.

This researcher took many steps to attend systematically to the context of knowledge construction at every stage of the research process, thus limiting researcher bias. The first step of meeting this goal was to take applicable coursework in qualitative methods from professors experienced in conducting qualitative research. Through this coursework, this researcher developed the interview guide (appendix J) used for data collection. The next step involved getting trained by a professional qualitative researcher in the utilization of statistical software for analyzing qualitative data. This step was crucial for not only providing an understanding of how to use software program, but for facilitating the understanding of coding techniques commonly used in qualitative research. The training professional was also available for consultation throughout the research process. Next, this researcher frequently consulted with my committee

chairperson in regards to themes emerging from the data. This step allowed for continual validation of my research findings. Finally, this researcher continuously recognizes his personal bias that can influence this qualitative process. A personal bias statement is discussed below.

Personal Bias Statement

I have been involved with people with disabilities my entire life and career. Growing up with a brother with a developmental disability has definitely influenced my desire to ensure that people with disabilities receive services necessary to live productive lives as independently as possible. As a rehabilitation counselor, my work involves assisting individuals in with disabilities in returning to work, obtaining public funding, and adjusting to personal issues relative to their disabilities. Through my education and career, I have been very familiar with barriers affecting people with disabilities from participating in society as well as current and past disability legislation and policy. I believe that personal assistance is an important service that can allow individuals with disabilities to participate in society. Additionally, I support legislation that ensures individuals with disabilities receive funding support for attendant care services. As such, my personal bias may influence my interpretation of the qualitative data supporting the receipt of more types of PAC for individuals with SCI.

CHAPTER 4 RESULTS

Introduction

This chapter reports the results of two methodologies used to determine the necessary items to be included in a measure of PAC for individuals with SCI. The first section includes the results of the Delphi Study involving expert Life Care Planners and the second section is comprised of results of qualitative interviews with veterans with SCI.

Delphi Study

Alpha Testing Round 1

Once the questionnaire for Round 1 of the Delphi Study was completed and placed on the web server, four local expert Life Care Planners affiliated with the University of Florida were requested to review the survey. A summary of the expert's comments and actions taken by this researcher are included in Table 2 and discussed below.

The first comment regarded the level of SCI the experts should consider when preparing to respond to the questions. There was a concern that if individuals were asked to consider someone whose injury was at too high of a level such as C-1, C-2 or C-3, experts would simply state that the individual needs 24-hour PAC and not carefully consider the necessity of each individual service. This level of lesion is often associated with the need for total assistance in activities relating to ADL's, domestic activities, transportation, respiration, and mobility (Consortium for Spinal Cord Medicine, 1999; Authority, 2002). In order to ensure that participants in the Delphi Study responded to

the specific activities requiring PAC, participants were asked consider individuals with level C-4 or below, complete or incomplete spinal cord injuries.

The next comment referred to providing a clear definition of personal assistance and replacement services. Life care planning Experts are required to examine individual's activities performed prior to their time of injury. This process makes certain that proposed recommendations include assistance with activities that were performed independently prior to the injury. Such recommendations are often referred as replacement services. Since replacement services play a major role in the decision process of Life Care Planners when making PAC recommendations, the following definition of such services was provided:

Personal Assistance is defined as services to assist with maintaining personal hygiene, general health services, personal appearance, activities of daily living, general comfort in life environment, safety, and interactions with the community and society that are related to requirements imposed by the disability. *Replacement Services* are defined as essential services needed post onset of disability that represent responsibilities and services related to household activity, yard and property maintenance, and home/auto maintenance that were performed independently prior to the disability

The next comment referred to informing the experts of the number of questions they will be required to complete in order to finish Round 1 of the Delphi. The experts felt that having such knowledge would reduce the chance that participants would not complete the entire survey. As such, the instruction page included a statement regarding the number of questions to be completed and each question was titled with the question number along with the total number of questions (e.g. Question 1 of 11, 2 of 11, etc...).

The subsequent comment involved the need to provide examples for each of the questions in order to guarantee that the experts have a clear understanding of how they

are expected to respond. There was a concern that the experts would not be specific when responding, which would inhibit the generation of items to be included on a PAC assessment. As such, questions regarding housekeeping, activities of daily living, home/yard maintenance, transportation, work, education, and leisure activities included one or more examples. For example when participants were asked to list all specific housekeeping activities they consider when recommending services in a Life Care Plan, examples of washing dishes and vacuuming were included.

One of the experts indicated he had a difficult time reading the questions due to the fact that a blue background with white fonts were used in creating web survey. In order to rectify the issue, all the background colors were changed to gray and white and the font colors were changed to black.

Another issue that resulted from the alpha test related to participants having to be repetitive in their responses. This resulted in the experts responding with text such as “see previous question.” This issue directly related to questions regarding how the experts determine the need for PAC services for all activities that they report. Most of the experts stated that very often refer to the personal interview, physician recommendations, and therapist evaluations/recommendations for all types of PAC. As such, they were frustrated with having to keep repeating the same response for each questions relating to the topic of determining PAC need. The action taken to remedy this problem included providing one question, which stated the following:

In determining the need for personal assistance or replacement services for all the activities you previously listed, most Life Care Planners refer to the personal interview, physician recommendations, and therapist evaluations/recommendations. Are there any additional sources you use to determine the need for personal assistance or replacement services for the following types of activities?

The final comment referred to the use of assistive devices to make up for the need for PAC. Some of the experts indicated that they would not recommend PAC services if there was the availability of assistive devices. For example, an individual that may need personal assistance in transferring may be able to acquire a hooyer lift. Such a device can allow an individual with a SCI to transfer independently. As a result, the individual may not require personal assistance for transferring activities. This researcher was concerned that not all individuals have accessibility to such devices and may still require personal assistance. To curtail professionals from limiting recommendations based on assistive devices, the following statement was included:

We realize the importance of assistive devices/technology in regards to personal assistance. However, when asked to specify activities that constitute ADL's or replacement services, please list possible activities without regard to the availability of assistive devices/technology.

Table 2. Comments and Actions from Alpha Testing of Round 1

Comment	Action Taken
Provide a specific level of Spinal Cord Injury as an example that would require an individual to require a significant amount of personal assistance	Included a statement on the instruction page requesting information in regards to an individual with a C-4 and below incomplete or complete SCI.
Provide a clear definition of personal assistance and replacement services.	Personal Assistance and Replacement Services were clearly defined in the instruction page.
Specify the number of questions so that the participant can monitor his/her progress.	The instruction page included a statement informing the participants the number of questions they will be asked to respond to.
Provide examples associated with the questions relating to generating items.	Questions regarding housekeeping, activities of daily living, home/yard maintenance, transportation, work, education, and leisure activities included one or more examples.
Change the font and background colors to make it easier to read for older Life Care Planners with visual limitations	All colors were removed from the survey and only gray, black, and white colors were used.
Condense questions regarding sources used to make PAC recommendations for each construct to reduce need to repeat responses throughout the survey	All questions regarding sources used to make PAC recommendations were incorporated into one page with examples.
Difficult to consider PAC without acknowledging the availability of Assistive Devices for replacement services and ADL's.	Participants were asked to specify activities that constitute ADL's or replacement services, without regard to the availability of assistive devices/technology.

Panel Demographics

Of the 100 expert Life Care Planners solicited for this study, 31 participated in Round 1. Participant experience ranged from 3 to 29 years. Participant age ranged from 36 to 65 years. Additional information describing these participants is listed in Table 3. There was a higher representation of females (87.1%) than males (12.9%) in the sample. This gender proportion is consistent with the high proportion of females to males among Life Care Planners in general. Next, there were diverse responses to the question regarding the highest level of education attained. One (3.2%) participant indicated the highest degree as being a High School Diploma. Five (16.1%) indicated that the Bachelor's degree was the highest degree earned. Sixteen (51.6%) reported their highest degree as a Master's Degree. Two (6.5%) individuals held Doctoral degrees. One (3.2%) individual reported his/her highest degree earned as a technical degree. Finally, six (19.4%) of the participants selected 'other' when choosing the highest educational degree earned. It should be noted that one of the individuals who responded with 'other', also indicated he/she had obtained a Bachelor's degree. In addition to education, the participants provided a plethora of credentials, which are described in Table 4. As indicated in Table 4, there are many certifications associated with Professional Life Care Planners. It is often the case that Life Care Planners hold numerous certifications. This sample included 29 (93.6%) individuals who currently have the Certified life care planning (CLCP) credential. Also, a large portion of the participants (84%) held at least one type of nursing credential. Nine (29%) of the participants reported being a Certified Rehabilitation Counselor (CRC), while 19 (61.3%) reported being Certified Case Managers (CCM)'s.

Table 3. Panel Demographics

Factor		Frequency	Percentage
Gender			
	Males	4	12.9
	Females	27	87.1
Education Level			
	Bachelor's Degree	5	16.1
	Master's Degree	16	51.6
	Doctoral Degree	2	6.5
	Technical	1	3.2
	High School	1	3.2
	Other	*6	19.4

One individual responded to having a bachelor's degree and a degree designated as 'other'

Table 4. Panel Credentials

Credential Name	Abbreviation	Count	Percentage %
Certified Rehabilitation Counselor	CRC	9	29
Certified Case Manager	CCM	19	61.3
Certified Life Care Planner	CLCP	29	93.6
Certified Rehabilitation Registered Nurse	CRRN	7	22.6
Certified Disability Management Specialist	CDMS	9	29
Certified Vocational Evaluator	CVE	1	3.2
Licensed Professional Counselor	LPC	3	9.7
Registered Nurse	RN	17	54.8
Speech Language Pathologist	SLP	2	6.5
Occupational Therapist	OT	1	3.2
Certified Legal Nurse Consultant	CLNC	2	6.5
Other Credential Not Specified	Other	13	41.2

Delphi Round 1

Experts responded to Round 1 of the Delphi with 198 activities to consider when making PAC recommendations for individuals with SCI. The activities are listed in Table 5. These activities were based on responses from questions regarding PAC for ADL's, housekeeping, home/yard maintenance, transportation, leisure activities and work/education.

Table 5. Delphi Study Results

Activity	Round 2 (N=25)			Round 3 (N=25)			Med. Δ		
	Med.	IQR		Med.	IQR				
Bowel/Bladder Mgmt.	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Cooking	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Communication Activities	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Laundry	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Dressing	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Grooming	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Drinking	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Eating	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Endurance Activities	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Health Management	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Hygiene	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
ADL's	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Judgment/Decision Making	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Managing Medication	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Mobility	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Maintain environ. controls	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Orthotics Management	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Lifting activities	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Safety	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Self-Care	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Adaptations setup	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Stair Climbing	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Teeth Brushing	4.00	3.50	-	4.00	4.00	4.00	-	4.00	0
Telephone Use	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Toileting	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0

Table 5. (cont)

Activity	Round 2 (N=25)			Round 3 (N=25)			Med. Δ		
	Med.	IQR		Med.	IQR				
Transferring	4.00	4.00	-	4.00	4.00	4.00	-	4.00	0
Washing	4.00	4.00	-	4.00	4.00	3.50	-	4.00	0
Fine motor movement	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Emergency egress	4.00	3.00	-	4.00	4.00	3.50	-	4.00	0
Muscle strengthening	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Shopping	3.50	3.00	-	4.00	4.00	3.00	-	4.00	+.50
Shopping (transport.)	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
MD/Therapy appts. (transport.)	4.00	3.25	-	4.00	4.00	3.00	-	4.00	0
Pharmacy (transport.)	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Professional activities (transport.)	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
School (transport.)	4.00	3.00	-	4.00	4.00	3.00	-	4.00	0
Clean up after meals	3.00	3.00	-	3.50	3.00	3.00	-	3.00	0
Clean crown molding	3.00	2.00	-	3.00	3.00	2.00	-	3.00	0
Clean dishes	3.00	3.00	-	4.00	3.00	3.00	-	3.00	0
Clean drapes/curtains	3.00	2.00	-	3.00	3.00	3.00	-	3.00	0
Clean closets	3.00	2.00	-	3.00	3.00	3.00	-	3.00	0
Clear cobwebs	3.00	2.00	-	3.00	3.00	3.00	-	3.00	0
Clean garage	2.50	2.00	-	3.00	3.00	2.00	-	3.00	+.50
Dusting	3.00	3.00	-	3.00	3.00	3.00	-	3.00	0
Clean roof gutters	3.00	2.00	-	3.00	3.00	2.00	-	3.00	0
Cleaning light fixtures	3.00	2.00	-	3.00	3.00	2.00	-	3.00	0
Grocery management	4.00	3.00	-	4.00	3.00	3.00	-	4.00	-1.00
Handling paperwork	3.00	3.00	-	4.00	3.00	3.00	-	3.00	0
Clean A/C vents	3.00	2.00	-	3.00	3.00	2.50	-	3.00	0
Spring/Fall cleaning	3.00	3.00	-	4.00	3.00	3.00	-	3.00	0
Ironing	3.00	2.25	-	3.00	3.00	2.25	-	3.00	0
Computer Activities	3.00	3.00	-	3.00	3.00	3.00	-	4.00	0
Personal Business	3.00	3.00	-	3.00	3.00	3.00	-	3.00	0
Maintain storage area	3.00	2.00	-	3.00	3.00	2.00	-	3.00	0
Maintain clothing	3.00	3.00	-	4.00	3.00	3.00	-	4.00	0
Retrieve/Open/Read Mail	3.00	3.00	-	3.00	3.00	3.00	-	3.50	0
Maintain alarm system	3.00	3.00	-	4.00	3.00	3.00	-	4.00	0
Making Beds	3.00	3.00	-	4.00	3.00	3.00	-	4.00	0
Managing daily schedule	3.00	3.00	-	4.00	3.00	3.00	-	4.00	0
Managing household finances	3.00	3.00	-	4.00	3.00	3.00	-	4.00	0
Mopping floors	3.00	3.00	-	4.00	3.00	3.00	-	3.00	0
Rearranging environment	3.00	2.00	-	3.00	3.00	2.00	-	3.00	0
Open/Close windows	3.00	2.25	-	4.00	3.00	2.00	-	3.00	0
Organizing Kitchen	3.00	2.00	-	3.50	3.00	2.00	-	3.00	0
Pet-Care	3.00	2.00	-	3.00	3.00	2.50	-	3.00	0
Furnace/AC Maintenance	3.00	2.00	-	3.00	3.00	2.00	-	3.00	0
Sweeping with a broom	3.00	3.00	-	4.00	3.00	3.00	-	3.00	0
Childcare	4.00	3.00	-	4.00	3.00	3.00	-	4.00	-1.00

Table 5. (cont)

Activity	Round 2 (N=25)			Round 3 (N=25)			Med. Δ	
	Med.	IQR		Med.	IQR			
Turning over mattress	3.00	2.00	-	3.00	2.00	-	3.00	0
Using a dishwasher	3.00	3.00	-	3.00	3.00	-	3.00	0
Vacuuming	3.00	3.00	-	3.00	3.00	-	4.00	0
Washing walls	3.00	2.00	-	3.00	2.00	-	3.00	0
Washing windows	3.00	2.00	-	3.00	2.25	-	3.00	0
Taking out the garbage	3.00	3.00	-	3.00	3.00	-	4.00	0
Garden management	3.00	2.00	-	3.00	2.00	-	3.00	0
Filling gas tank	3.00	3.00	-	3.00	3.00	-	3.00	0
Disposing of debris	3.00	2.00	-	3.00	2.00	-	3.00	0
Lawn mowing	3.00	3.00	-	3.00	3.00	-	3.00	0
Leaf blowing	3.00	2.00	-	3.00	3.00	-	3.00	0
Changing light bulbs	3.00	3.00	-	3.00	3.00	-	3.00	0
Outdoor repairs	3.00	2.00	-	3.00	2.00	-	3.00	0
Snow management	3.00	3.00	-	3.00	3.00	-	3.00	0
Restore power outages	3.00	2.00	-	3.00	2.00	-	3.75	0
Using a string trimmer	3.00	2.00	-	3.00	2.00	-	3.00	0
Raking	3.00	2.00	-	3.00	2.00	-	3.00	0
Watering garden/grass	3.00	2.00	-	3.00	2.00	-	3.00	0
Volunteer (transport.)	3.00	3.00	-	3.00	3.00	-	3.75	0
Theater (transport.)	3.00	3.00	-	3.00	3.00	-	3.00	0
Social outings (transport.)	3.00	3.00	-	3.00	3.00	-	4.00	0
Carrying work/school supplies	3.00	3.00	-	3.00	3.00	-	3.00	0
Test taking	3.00	2.75	-	3.00	3.00	-	4.00	0
Taking a break at work/school	3.00	2.00	-	3.00	3.00	-	3.00	0
Typing reports	3.00	2.75	-	3.00	3.00	-	3.00	0
Tutoring	3.00	2.00	-	3.00	3.00	-	3.00	0
Dictate reports/letters/notes/etc.	3.00	3.00	-	3.00	3.00	-	3.00	0
Entering/Exit work/school	3.00	3.00	-	3.00	3.00	-	4.00	0
Getting on/off elevators	3.00	3.00	-	3.00	3.00	-	4.00	0
Escort at work/between classes	3.00	3.00	-	3.00	3.00	-	4.00	0
Fax/Copy/Sort/File activities	3.00	3.00	-	3.00	3.00	-	3.00	0
Work/School related lifting	3.00	3.00	-	3.00	3.00	-	4.00	0
Job coaching	3.00	2.75	-	3.00	3.00	-	4.00	0
Note taking	3.00	3.00	-	3.00	3.00	-	4.00	0
Parking	3.00	3.00	-	3.00	3.00	-	3.00	0
Using portable ramps	3.50	3.00	-	3.00	3.00	-	4.00	-.50
Work/School preparation	3.00	3.00	-	3.00	3.00	-	4.00	0
Computer/Tech assistance	3.00	3.00	-	3.00	3.00	-	4.00	0
Transcribing	3.00	3.00	-	3.00	3.00	-	3.00	0
Admin./Registration Issues	3.00	2.75	-	3.00	3.00	-	3.75	0
Library usage	3.00	3.00	-	3.00	3.00	-	3.50	0
Homework	3.00	3.00	-	3.00	3.00	-	4.00	0
Manage work/school activities	3.00	3.00	-	3.00	3.00	-	3.00	0

Table 5. (cont)

Activity	Round 2 (N=25)			Round 3 (N=25)			Med. Δ	
	Med.	IQR		Med.	IQR			
Organizing school projects	3.00	3.00	-	3.00	3.00	-	3.00	0
Reading	3.00	3.00	-	3.00	3.00	-	4.00	0
Setup school supplies	3.00	3.00	-	3.00	3.00	-	3.00	0
Recording lectures	3.00	3.00	-	3.00	3.00	-	3.00	0
Obtain work/school supplies	3.00	3.00	-	3.00	3.00	-	3.00	0
Sport activities	3.00	3.00	-	3.00	3.00	-	3.00	0
Adapted P.E.	3.00	3.00	-	3.00	3.00	-	4.00	0
Therapeutic horseback	3.00	2.00	-	3.00	2.00	-	3.00	0
Annual recreation camps	3.00	3.00	-	3.00	3.00	-	3.00	0
Adapted skiing	3.00	2.00	-	3.00	2.00	-	3.00	0
Adapted aquatics	3.00	3.00	-	3.00	3.00	-	3.00	0
Camping	3.00	2.00	-	3.00	2.00	-	3.00	-
Church/Comm. activities	3.00	3.00	-	3.00	3.00	-	3.75	0
Wheelchair rec. programs	3.00	3.00	-	3.00	3.00	-	4.00	0
Cycling activities	3.00	3.00	-	3.00	3.00	-	3.00	0
Emotional well-being activities	3.50	3.00	-	3.00	3.00	-	4.00	0
Exercise/Gym activities	3.00	3.00	-	3.00	3.00	-	4.00	0
Fishing	3.00	2.00	-	3.00	2.00	-	3.00	0
Hobbies	3.00	3.00	-	3.00	3.00	-	3.75	0
Hunting	2.00	2.00	-	3.00	2.00	-	3.00	+1.0
Internet Access/email	3.00	3.00	-	3.00	3.00	-	4.00	0
Kayaking	2.00	2.00	-	3.00	2.00	-	3.00	0
Watching movies	3.00	2.00	-	3.00	2.00	-	3.00	0
Outward bound	3.00	2.00	-	3.00	2.00	-	3.00	0
Pre-injury activities	3.00	3.00	-	3.00	3.00	-	4.00	0
Spontaneous events (transport.)	3.00	3.00	-	3.00	3.00	-	3.00	0
Clean baseboards	3.00	2.00	-	3.00	3.00	-	3.00	0
Social recreation	3.00	3.00	-	3.00	3.00	-	4.00	0
Volunteering	3.00	2.00	-	3.00	3.00	-	3.00	0
Support groups	3.50	3.00	-	3.00	3.00	-	4.00	-.50
Clean blinds	3.00	2.00	-	3.00	3.00	-	3.00	0
Running errands	4.00	3.00	-	3.00	3.00	-	4.00	0
Sporting Events (transport.)	3.00	3.00	-	3.00	3.00	-	3.00	0
Recreation (transport.)	3.00	3.00	-	3.00	3.00	-	4.00	0
Bank (transport.)	3.00	3.00	-	3.00	3.00	-	4.00	0
Church/Comm. (transport.)	3.00	3.00	-	3.00	3.00	-	4.00	0
Dry Cleaning (transport.)	3.00	3.00	-	3.00	3.00	-	3.75	0
Driving children to school	3.00	3.00	-	3.00	3.00	-	3.00	0
Video store (transport.)	3.00	2.00	-	3.00	2.00	-	3.00	0
Clean cabinets	3.00	2.00	-	3.00	3.00	-	3.00	0
Getting a haircut	3.00	3.00	-	3.00	3.00	-	4.00	0
Social Cognition	3.00	3.00	-	3.00	3.00	-	4.00	0

Table 5. (cont)

Activity	Round 2 (N=25)				Round 3 (N=25)				Med. Δ
	Med.	IQR		Med.	IQR		Med.	Δ	
Getting take out food	3.00	2.75	-	3.00	3.00	3.00	-	3.00	0
Hardware store (transport.)	3.00	3.00	-	3.00	3.00	3.00	-	3.00	0
Clean bathtubs	3.00	3.00	-	3.75	3.00	3.00	-	3.00	0
Library (transport.)	3.00	2.75	-	3.25	3.00	3.00	-	3.00	0
Movies (transport.)	3.00	2.75	-	3.00	3.00	3.00	-	3.00	0
Pay bills (transport.)	3.00	3.00	-	4.00	3.00	3.00	-	3.00	0
Clean refrigerator	3.00	3.00	-	3.00	3.00	3.00	-	3.00	0
Post office (transport.)	3.00	3.00	-	4.00	3.00	3.00	-	4.00	0
Clean oven	3.00	2.25	-	3.00	3.00	3.00	-	3.00	0
Restaurants (transport.)	3.00	3.00	-	3.00	3.00	3.00	-	3.00	0
RV-ing	3.00	2.00	-	3.00	2.50	2.00	-	3.00	-.50
Check tire pressure	2.50	2.00	-	3.00	2.50	2.00	-	3.00	0
Waxing furniture	3.00	2.00	-	3.00	2.50	2.00	-	3.00	-.50
Using a screwdriver	3.00	2.00	-	3.00	2.50	2.00	-	3.00	-.50
Seasonal fertilizer	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Climbing ladders	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Hammering	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Hanging pictures	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Home decorating	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Landscaping	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Washing car	2.50	2.00	-	3.00	2.00	2.00	-	3.00	-.50
Baling hay	2.00	1.00	-	2.00	2.00	2.00	-	2.00	0
Carpentry repairs	3.00	2.00	-	3.00	2.00	2.00	-	3.00	-1.00
Bush hogging	2.00	1.00	-	3.00	2.00	2.00	-	2.00	0
Dead-heading	2.00	1.00	-	3.00	2.00	2.00	-	3.00	0
Edging	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Electrical work	2.00	1.75	-	3.00	2.00	2.00	-	3.00	0
Cutting firewood	2.00	1.00	-	3.00	2.00	2.00	-	3.00	0
Start fire in fireplace	2.00	1.00	-	3.00	2.00	1.25	-	3.00	0
Fixing squeaky doors	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Woodworking	2.00	2.00	-	3.00	2.00	2.00	-	2.50	0
Putting down mulch	2.00	1.50	-	3.00	2.00	2.00	-	3.00	0
Changing oil	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Shrub maintenance	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Painting	2.50	2.00	-	3.00	2.00	2.00	-	3.00	-.50
Plumbing	2.50	2.00	-	3.00	2.00	2.00	-	3.00	-.50
Pool maintenance	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Spa maintenance	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Pruning	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Putting up fixtures	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Maintain sprinkler system	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Remodeling	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0
Roof repair	2.00	1.25	-	3.00	2.00	2.00	-	3.00	0
Trim work	2.00	2.00	-	3.00	2.00	2.00	-	3.00	0

Questions Not Included In Subsequent Rounds

Due to the concern regarding participant attrition, questions not related to specific activities to consider when recommending PAC were not included in subsequent rounds (round 2 and round 3). Responses to these are listed in Table 6 and discussed below:

Categories used to organize PAC in a Life Care Plan: The experts responded to this question with a breakdown of how they designate PAC recommendations in a LCP. The categories used to depict PAC often help the individual reviewing a LCP to understand the basis for the recommendations.

Objective assessments to determine the need for Personal Assistance in a Life Care Plan: As evidenced by Table 5, Life Care Planners rely on numerous assessments to determine PAC. While some Life Care Planners rely on ADL assessments such as the FIM, other experts utilize the client interview in determining PAC need.

Sources used to determine the need for personal assistance or replacement services: Sources used for determining PAC need were summarized for all activities including: ADL's, home/yard maintenance, transportation, work/education, and leisure activities. Clearly, Life Care Planners explore many sources of information that will help them make recommendations for PAC. These sources range from collaborating with church and community members to reviewing neuropsychological evaluations.

Associating need with the number of hours for each type of service: The purpose of this question was to identify methods by which Life Care Planners associate the need for PAC with the number of hours to perform the recommended services. As evidenced by Table 6., there does not appear to be an objective method for associating time to perform a service with need for such as service. It appears that experts are utilizing qualitative

techniques to answer this question. The main themes that emerged from this question included: client interviews, observation, and extensive consultations.

Table 6. Questions Not Included In Subsequent Rounds

Question	Responses
Under what categories do you organize the parts of your Life Care Plan that address types of personal assistance and replacement services?	Home Care, Nursing Care, Personal Care Assistance, Aide Level Services, Aids for Independent Living, Assistive Living Care, Attendant Care Services, Facility Care, Household/Home Maintenance, Replacement Services.
What objective assessments do you use to help you determine the need for Personal Assistance in a Life Care Plan?	ADL assessments, Family/Caregiver interview, Assessments/Evaluations of the Treatment Team, CHART, Client Interview, Clinical Practice Guidelines, Discharge evaluation, FAM, FCE, FIM. Foundational functional reports, Home Assessment, Independent Medical Evaluation, LCP Training Material
Sources you use to determine the need for personal assistance or replacement services.	Church and community members, Client real-life situation, Family, Friends, Internet searches, Leisure check list, Leisure Evaluation, Medical Records, Medical literature, Nature of disease course, Research, School records, College Office of Disabilities, Educational Evaluation, Employment Literature, family, historical goals, IEP, Institutional/academic advisor/counselor, Observe classes, Parents education level, Personal observation, Neuropsychological evaluations, School Records/Academic performance, Services provided by school district, Spinal Cord Injury Resource Center, State and Federal regulations, Teacher's recommendations, Therapists, Vocational Evaluation, Work History, Employer, Employment Research Guidelines, Historical needs, Job Coach , AAA, Adult day programs, Community agency programs, Driving Evaluation, expert in field of van/auto modification, Realtors Association statistics

Table 6. (cont)

Question	Responses
How the experts associate need with the number of hours for each type of service?	Client interview, Clinical outcomes guidelines, Collaboration with treatment professionals, Common sense, Configure hours towards needed service, Consider time to perform activities, Agency stipulation, Personal experience as a Life Care Planner, Consult with employers, Follow-up evaluations Friends, Known demands of the activity, Level of care required, Literature, Needs assessment, Peer consultation, physical capacities evaluation, Physician documentation, Professional training, research, Suggestions of care givers, Triangulation of observation, Allow the client to function as he did prior to injury, enough care to allow for some spontaneity and some ability to conform to other people's schedules.

Delphi Round 2

For the second round of the Delphi, 25 of the original 31 participants responded with their level of agreement to whether each of the 198 items listed in Table 5 should be considered when making PAC recommendations for individuals with SCI. The median (Med) and interquartile ranges (IQR) were calculated for each item and reported in Table 5. The interquartile range is the distance between the first and third quartiles (middle 50%) of the responses in a distribution. These results correspond to the following Likert scale used to measure the agreement for each item: 1=strongly disagree, 2=disagree, 3=agree, and 4= strongly agree.

There was an initial high level of consensus after the second round of the Delphi study. This was evident due to the fact that after Round 2, 173 of the items had an

interquartile range of 1 or less. In other words, 87 percent of the activities demonstrated a low variability in level of agreement of responses from the participants.

Delphi Round 3

For the third round of the Delphi, 25 participants had the opportunity to reconsider their level of agreement to whether each of the 198 items listed in Table 5 should be considered when making PAC recommendations for individuals with SCI. The activities are listed in order of consensus relating to the strongest agreement (indicated by the number 4) with the activities, and ending with items representing a disagreement (indicated by 2) to whether the activities should be considered when making PAC recommendations.

As with the previous round, median and interquartile ranges were reported as well as the change (Med. Δ) in Round 2 and Round 3 medians. Overall, 15 items resulted in a change in median from Round 2 to Round 3. Of the 198 total items, 183 (92%) resulted in no median change from Round 2 to Round 3.

The results of the Delphi revealed an even greater consensus had been achieved among an even larger number of items as compared to Round 2. Evidence of this increase in consensus was seen in the greater convergence of the interquartile ranges. Specifically, Round 3 resulted in 196 items having an interquartile range of 1 or less. Therefore, the number of items having a low variability in level of agreement increased to 99 percent.

Additionally, at the conclusion of Round 3, there was a total of 34 items (17%) that resulted in a final Median score below 3 (agree). These items are listed in Table 7. Among these items, there were 3 activities (waxing furniture, carpentry repairs, and using a furniture) that had median values of 3 (agree) in Round 2. These items appear to

be directly to home maintenance type activities. Further discussion regarding these activities is included in the next chapter.

Table 7. Items with a Median below 3.

Activity	Round 2 (N=25)			Round 3 (N=25)			Med. Δ
	Med.	IQR		Med.	IQR		
Waxing furniture	3.00	2.00	- 3.00	2.50	2.00	- 3.00	-.50
Using a screwdriver	3.00	2.00	- 3.00	2.50	2.00	- 3.00	-.50
Check tire pressure	2.50	2.00	- 3.00	2.50	2.00	- 3.00	0
RV-ing	3.00	2.00	- 3.00	2.50	2.00	- 3.00	-.50
Carpentry repairs	3.00	2.00	- 3.00	2.00	2.00	- 3.00	-1.00
Bush hogging	2.00	1.00	- 3.00	2.00	2.00	- 2.00	0
Dead-heading	2.00	1.00	- 3.00	2.00	2.00	- 3.00	0
Edging	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Electrical work	2.00	1.75	- 3.00	2.00	2.00	- 3.00	0
Cutting firewood	2.00	1.00	- 3.00	2.00	2.00	- 3.00	0
Fixing squeaky doors	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Climbing ladders	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Hammering	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Hanging pictures	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Home decorating	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Landscaping	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Putting down mulch	2.00	1.50	- 3.00	2.00	2.00	- 3.00	0
Changing oil	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Painting	2.50	2.00	- 3.00	2.00	2.00	- 3.00	-.50
Plumbing	2.50	2.00	- 3.00	2.00	2.00	- 3.00	-.50
Pool maintenance	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Pruning	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Putting up fixtures	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Remodeling	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Roof repair	2.00	1.25	- 3.00	2.00	2.00	- 3.00	0
Start fire in fireplace	2.00	1.00	- 3.00	2.00	1.25	- 3.00	0
Seasonal fertilizer	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Shrub maintenance	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Spa maintenance	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Maintain auto sprinkler system	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Woodworking	2.00	2.00	- 3.00	2.00	2.00	- 2.50	0
Trim work	2.00	2.00	- 3.00	2.00	2.00	- 3.00	0
Washing car	2.50	2.00	- 3.00	2.00	2.00	- 3.00	-.50
Baling hay	2.00	1.00	- 2.00	2.00	2.00	- 2.00	0

Interviews with Veterans with SCI

Participant Demographics

Eight interviews were conducted with veterans who had sustained spinal cord injuries. Demographic information is described in Table 8. All eight interviews were male and the age of the participants ranged from 50 to 75 years. The participants reported having various levels of SCI with the lowest level being L-5 and the highest level at C-3/C-4. Only one of the eight veterans with SCI stated that they had a complete SCI. Years since the time of injury ranged from 2 to 38 years.

Table 8. Participant Demographics

Participant	Gender	Age	Level of Injury	Complete or Incomplete	Years Since Injury
V1	M	65	T-5/T-6	Complete	30
V2	M	50	C-6	Incomplete	3
V3	M	52	T-4	Incomplete	38
V4	M	58	C-4/C-5	Incomplete	2
V5	M	57	C-5/C-6	Incomplete	2
V6	M	75	L-5	Incomplete	*
V7	M	55	C-3/C-4	Incomplete	2
V8	M	61	T-12/L-1/L-2/S-2	Incomplete	27

* Denotes missing data

Specific Activities Coded

The first part of the qualitative analysis of the interviews involved coding the data to identify specific types of activities for which the participants required PAC. The coding resulted in 63 activities that are listed in Table 9. All 63 activities are related to PAC for hygiene, household chores and maintenance, and hobbies and leisure activities. The participants reported needing assistance with these activities currently or in the past.

Table 9. PAC Activities Reported From Veterans

Bowel care	Electrical work
Catheterization *	Grocery shopping
Applying creams/salves/lotions*	Mowing Grass
Dental hygiene*	Edging
Dressing	Washing house*
Ears cleaned*	Washing the car
Administering eye drops*	Heavy lifting
Eating	Pool maintenance
Getting into the bath to shower*	Tilling the yard*
Combing/brushing hair*	Planting*
Nails trimmed*	Sweeping floors
Nose cleaned out*	Vacuuming
Caring for pressure wounds*	Baking*
Shaving*	Taking out garbage
Putting on support hose*	Cutting tree limbs*
Transfers	Raking
Washing	Carpet cleaning*
Wound dressing*	Cleaning ceiling fans*
Laundry	High work*
Transportation	Range of motion exercises*
Table tennis*	Mechanical Activities
Activities requiring reaching high*	Getting on/off a motorcycle*
Carpentry	Getting wheelchair onto the grass*
Computer activities	Going to Church
Farming Activities*	
Bailing hay	
Gardening	
Feeding the dog	

* Denotes activities that were different than those identified by the Delphi Participants

Upon initial examination of the activities reported by veterans with SCI, 27 out of 63 items were different than the activities reported by the Delphi participants. These activities specifically related to self-care and home maintenance activities (Table 9).

Emerging PAC Themes

While participants considered their responses to questions relating to specific activities that they require PAC, other themes materialized that appeared to have had a major impact on there need for such services. Specifically, the following topics emerged and are discussed below: effect of mental state, independence, PAC services in place, scheduling, PAC during hospital stays, trustworthiness, and spousal care.

Effect of mental state

A few of the participants discussed the importance of understanding an individual with SCI's mental status when assessing PAC. The veterans indicated that individuals with SCI can be depressed immediately following their injury and it inhibits them from figuring out what they want to do with their lives. As such, these inhibitions would make it difficult to understand one's total PAC needs. In the following example, VM2 discusses the stress and acceptance of a spinal cord injury in relation to getting on with one's life. The participant refers to Tampa, which is the location of a Veterans Health Administration Rehabilitation Facility for veterans with SCI.

In Tampa I see a lot of people get caught up in the now. You know, they stay stressed out. Some of them never come out of it. You have to think about what is going to happen and just find things you like doing and try to stick to that until you come out of that and stay there and then you enjoy yourselves. It doesn't happen if you don't change. You would be surprised how many people stay stuck in their own, but that didn't happen to me. When they say that, I know when you get sad, like that, it is hard to get out of it. When I woke up from my injury...when I woke up here rather, I knew something bad had happened. So I dealt with it from day one. I never came into denial.

VM5 discusses the relationship between mental state and personal assistance.

You know I am not going to tell you I am not down some times but in terms of the help that I received, assistance, family and friends and community, I guess, my needing to be more independent, it has worked well for me. Certainly I feel sorry for myself every once in a while, all of us do once in awhile, why me, why did this happen to me, I have more things I want to do. It is a challenge that I have faced and it has given me some new insight.

The consensus among the participants seems to be that an individual's mental status relates to the struggle of not being able to be independent and having to rely on others to provide services such as PAC. VM8 discusses his personal experiences with others with SCI and their struggle with independence issues.

The earlier and the sooner you can get a guy to depend on himself, and get into that, depending on himself, rather than depending on somebody else, the better. You don't want to push, to a breaking point but then again, you don't want to keep waiting on them...Then the less that they dwell on oh, poor me...Why wasn't it somebody else or what did I do God? It keeps the mind off yourself...Focus on what they can do and what they can improve on rather than telling them, well, you can't do this and you can't do that. Because when I first went in they said, you are not going to walk, you will have no bowel and bladder control, forget your sex life. All that is bullshit. I told them they were full of it. Of course, that is me. That is the type of person that I am. I was six years in the Marine Corps. and I have been riding Harley Davidsons with a club for 50 years. I started building and riding Harleys when I was 13. My dad rode and my two uncles rode and I built my first one and I started building my first Harley when I was 13. But it was the way I was brought up. You don't depend on other people. You do your own thing but you do not be stubborn about it. There are things that I cannot do. But, I always have access to someone that can do it for me. You can't get these guys to just sit around all day. I spent 13 months the first time in the hospital but when I started getting around, and these young kids would be there, oh, boo hoo this and that, I would follow them up in their beds because they would get up and I would push all the buttons and make them get out of bed...I would fold the bed in on them and they would get mad at me. But I would get them out of the bed. I would say, I want to show you something. I would take them down to the weight room... Get them started. If they pursue it they do. If they don't, hey, I gave it a shot. In some way it was rehab for me. Helping the other guys.

Based on the personal reports, the veterans with SCI often reported difficulty working through their emotional struggle with adjusting to their injury.

Independence

The struggle for independence was a general theme among some of the participants. The veterans participating in this study expressed the importance of staying as independent as possible but at the same time, were aware of certain situations when an individual may need the help of others. VM3 discusses this issue:

When I got injured I was 30 something. I did not know I was going to need this much assistance. Then I was told about having a caregiver, even though I was strictly taught through rehab to be independent. I stay independent as much as I can possibly. But always look ahead at the fact that you are going to have some bad days and you need someone there. There is no being totally independent. Get that out of your mind. You may feel that you are totally independent but you must have someone, a back up. Someone you can call on, a friend, or a neighbor, though you are independent, that you can call on and get help. Because rescue may not be fast enough.

As pointed out by this participant, even though an individual may be independent in certain activities, there may situations when assistance is needed and it is important to have such services available.

A different viewpoint was reflected in the statement of VM4. This participant seeks to avoid the need to rely on assistance altogether and uses independence as a means to get stronger:

I don't like people helping me. When I need them they won't be there. I just I don't probably there are a lot of things that could have helped me. They would have helped me but they would have made me weaker. That is how I feel about an assistive device. I don't use any more than I have to. I don't like pills or pain pills. I don't do anything that I can possibly get by without. I think the less personal care if I can get by without it I do. I am fortunate. I have been blessed. I remember the time when I had to be catheterized and I had to have help run a bowel movement, helped out of bed. Helped be turned over but, I think that refusal and denial using assistant devices has help me get stronger. That is one of the reasons that I

have gotten better...I don't believe there is nothing I can't do. I believe that if a ballet dancer can dance on her toes and an ice skater can skate on ice, I can walk on size 11 shoes. That is my theory and I trying real hard to do it and I am getting to where I can do it a little better. I can get better and pretty soon I will be doing it normal. That is what I am counting on.

PAC services in place

The previous themes focused on mental health and the issue of independence. Another theme that emerged that can impact adjustment to a SCI and to a lack of independence involves ensuring that services are in place before an individual is discharged from acute care. VM5 discusses this issue:

When I was getting ready to go out of rehab, there were things that needed to be done, in my home, to get ready for me to come home, like a ramp had to be built, the floor of the bathroom and those kind of things. It was not a great amount of need but things needed to be done. I had some assistance from the state spinal cord association. The girl did not follow through.... I think those kinds of things for people who have their needs to be more planned. It is a scary thing coming home and not being able to do things you could do before, having somebody to wait on you. The biggest thing is the coordination efforts so there is not that much stress on the individual...The people I talked to in rehab, most of us were not prepared certainly for going through things like that. You know, no matter where you lived, your home was not ready for something like that. I live on a rock road. I live in the country. It would not be easy to move around. We have had those things built so I could get up and down.

This participant struggled with the fact that his attendant care services were not in place when he was discharged from rehabilitation. Having the stress of not having these services would appear to greatly impact the ability of an individual with SCI to adjust to his/her disability.

Scheduling

In addition to having PAC services in place following discharge from a rehabilitation hospital, scheduling of such services should coincide with the needs of the individual utilizing such services. The scheduling of PAC can impact the ability of individuals with SCI to be involved in other life activities such as employment. VM2 discusses the impact of PAC for bowel management on his vocational activities:

Bowel care which takes literally a half a day...only way to do it is to just sit and get a suppository and wait for the results. Then it comes out and you put it in the bag. They wait for about an hour for the suppository to come back out. If it doesn't come out, it stays in, you know...explosions.. That is really embarrassing. That is why the guys that have it in the evening, they don't get caught like that.... I would rather it be after six. If you are doing it in the evening and you are being in the bed, it won't be disgusting in front of people... That way when voc rehab does find something for me to do, I can work fulltime instead of part time.

This participant expressed concerns about the ability to schedule PAC for his bowel management. Unfortunately, the PCA comes in the morning, which means that he may have to wait a few hours for a bowel movement. If he doesn't have a bowel movement, the participant is then concerned that that he could have an accident later on during the day. At this time the participant may be working or taking part in activities outside his/her home. This can very embarrassing and becomes a barrier to participating in community activities. As pointed out by this participant, proper scheduling of such services, for example, in the evening would reduce the embarrassment since, he would be home if it occurred.

PAC during hospital stays

An important theme that transpired from the interviews was the issue of PAC during stays in the hospital. As pointed out in Chapter 2, there are many potential complications associated with SCI, which can result in an individual having to stay in a hospital for some duration. VM5 discusses a problem of transitioning from PAC in a rehab setting to PAC at the hospital:

I know the hospital, I was at Shands two times...The hospital staff was good but when I got to rehab, it was different. Shands rehab was a totally different experience. Those people were there for you. They were there. At the hospital they need to make sure you are surviving and make sure you get acute care. But the time when I went back in the hospital, I have been so spoiled and taken so well cared for at the rehab, if you know, you do need to have an aide if you have a button and you push it and somebody was there right. When I went back in the hospital, I pressed the button and it might be five minutes that I have to press it again. I understand that they were very busy, but you know, one the things that when I need a urinal bottle I could not wait. Finally, when a nurse came in and said, can I help you, I said, it was too late. Now you have to clean the bed up. I got back to rehab and I said, I am so glad I am back here. You people took good care of me. They were Johnny on the spot.

Trustworthiness

Adjusting to the fact that an individual has to rely on another individual for personal assistance can be a difficult adjustment for a veteran with SCI. One theme that materialized relating to this issue was the effort to find someone trustworthy enough to provide such services. VM1 discussed an example:

I think the biggest thing is trustworthiness. Because people who are going to have this kind of care are going to have a live in and if they are not living in they are not going to help you much. If you have to pick up the phone to call them and get them and whether or not they are there. There are times when she is not there and goes off and does things on her own. But the majority of the time I can rely on her. Now, the trustworthiness, because she is living in your house, because right now I go off by myself when she is there.

This same participant goes on further to discuss trust in terms of being comfortable and adjusting to embarrassment associated with the opposite gender of the person providing PAC services:

It is hard to find a man that would be an attendant caregiver for a guy. A woman would not mind doing it, but for the guy to get over the initial embarrassment to me that is probably the hardest part... Well, both of us would to some extent. When she first came down to help me, we sat down and I had a long talk with her and I said, you know, this is not going to be an easy job. Most of the time I take care of myself and I don't need help but there will be a few times I will. I tried to explain stuff the best way that I could, then you are thinking now I left out the part that I am going to be naked... There is an embarrassing point in there where you just got to get over that hill and everything is fine after that... If your were married or something it might be a different situation. You are requiring him from time to time to help you with personal hygiene, you know, and stuff like that. There is an embarrassing factor there to start with.

Spousal care

A final theme that emerged from the interviews related to the importance of having a spouse provide PAC and concerns with such care:

VM6: You just have to make sure the personal care attendant can handle taking care of you. My wife does it as long as she is able. That could change. Right now she is where she could do it. But, if not there are things that I would have to do. My wife had knee surgery and had blood clots. I could do a lot of it but I could not without say a van. For instance I could not drive it by myself somebody would have to go with me... One time I was on a bicycle doing exercises with the hand thing and it works the leg too. I slipped off on the floor. My wife walked out of the room and when she came back she said, what are you doing on the floor? I just slipped off. How are we going to get you up? I had to scoot over to the couch with my wife lifting and helping me and she got me up on the couch. I got the chair back up. But there are times when we holler for the grandkids. One time the lights went off and I fell in the living room with the wheelchair and it is a drop down. Instead of being still until my wife got the candles, she got on the phone and got the grandkids and they all came flying over. They put me back. We have good grandkids...we have a good family. Some people have family that is really bad.

This participant expressed a concern that even though his spouse can handle his PAC, there might be a time when her health condition or inability to handle strenuous activities can impact the veteran. He also stated the importance of having other family members available to provide PAC services as well.

Another participant explains the financial strain associated with having a spouse as the caregiver, and including the caregiver in the rehabilitation process:

VM7: It is like I took care of the bills. I was the one that made the money. Her little bus driver job did not pay a whole lot, every two weeks and it threw us into a hole. She was dealing with losing her job, to do this, my insurance, everything. It is just like, there is no help out there for the caregiver, none. Although they are expected to be here 24 hours a day she is a diabetic and she cannot go to a doctor because she lost her insurance. It was over a year and a half before she went and got her diabetes pills, because she had none. ...When I was sent to Shands rehab they told my wife how to take care of me from head to toe, how to deal with my trach and she cleaned it out. She changed, she did everything down to the feeding tubes and she cleaned that, and she fed me...She did my bowel care and bladder catheter and everything.... Let the caregiver be a part of the process. It is going to be hers sooner. She is part of it. She would be more relaxed if she were part of it when we were ready to go home.

The next chapter will include a discussion regarding these themes and how they implicate future research related to PAC.

CHAPTER 5 DISCUSSION

Introduction

This study involved acquiring and examining the activities necessary to consider when making PAC recommendations for individuals with SCI. This chapter is divided into four sections, which discuss the findings presented in the previous chapter. The first section includes an overview of the significant findings from both the Delphi Study and the Qualitative Interviews. The second section describes limitations of this study. The third section illustrates implications of the findings for practice and policy. The final section includes recommendations for further research and development of the findings of this study.

Overview of Significant Findings

Delphi Study

Of the 100 experts, solicited for this project, 25 completed all three rounds of the Delphi study. The results of the study indicated that the Delphi technique was effective in generating a large item bank of activities that one should consider when making PAC recommendations for individuals with SCI. Furthermore, consensus techniques allowed this researcher to determine that there was a strong agreement that professionals should consider at least 164 of the generated activities when recommending PAC for individuals with SCI. The approach to assessing the level of consensus included comparing the medians and the interquartile ranges of all the items between the second and third round.

The items generated by the experts were comprehensive and were comprised of activities related to self-care, home/yard maintenance, transportation leisure, work, and education. Self-care activities such as dressing, grooming, bowel/bladder management, and eating were similar to items included in current ADL assessments such as the FIM (Granger & Hamilton, 1986), the MDS (Health Care Financing Administration, 1998), and the Barthel Index (Mahoney & Barthel, 1965). Other items relating to home/yard maintenance, transportation, leisure, work, and education corresponded to other constructs, not currently being assessed by other instruments used for predication PAC. As such, the views of the life care planner participants would appear to support the position that assessment for the provision of PAC services is a comprehensive process that should not be limited by relying solely on an assessment of ADL's.

Results and the ICF model

As pointed out in Chapter 2, recommending PAC based solely on individual's ability to be independent with ADL's is inconsistent with the ICF Model of disablement. This model combines biological and social views of disability. Specifically, The ICF model, describes disability in terms of *health conditions, body function, activities and participation, and the environment*. The pathway described by the ICF is bi-directional and which means that each component of the model can impact another component of the model and vice versa (World Health Organization (WHO), 2001).

The 164 activities from this study would fall under the *activities and participation* components of the ICF model. As discussed in Chapter 2, *activities and participation* cover a complete range of areas denoting aspects of functioning from both an individual and societal perspective. *Activities* are defined as “an execution of a task or involvement in a life situation in a uniform environment.” *Participation* is described as “the execution

of a task or involvement in a life situation in an individual's current environment" (World Health Organization (WHO), 2001).

The results of Delphi study demonstrated that of the 164 activities to be considered when recommending PAC services, only eight of the activities represented ADL activities. These activities included: bowel/bladder management, dressing, grooming, drinking, eating, hygiene, toileting, and transferring. Based on the ICF, ADL's would make up a small portion the *activities* component of this modern model of disablement. A majority of the other activities resulting from the Delphi study represent the additional *activities* and *participation* components of the ICF model. These activities allow an individual with a disability to execute tasks in society such as leisure, home/yard maintenance, vocational, and educational activities.

As pointed out earlier, the ICF model is bi-directional and as such, deficits in certain components of the model can have major consequences on other components. For example, if an individual does not receive assistance with activities that contribute to quality of life such as work, leisure and education, that individual could suffer detrimental health consequences. Such consequences include the possibility of depression, decline in physical function due to lack of activity, and fear and anxiety in regards to not being able to be a productive member of society. Furthermore, as discussed in Chapter 2, funding for PAC services is currently focused towards assistance with ADL's (Kennedy, 1997). As such, the bi-directional pathway of the ICF model demonstrates how lack of funding to support PAC for additional activities resulting from this study and could lead to deficits in the *functional, activities, participation, and possibly health conditions* arenas.

Items to be excluded

The LCP participants not only reached consensus on the items that should be considered when recommending PAC for individuals with SCI, but also reached considerable agreement in regards to what activities should not be considered when making such recommendations. Specifically, there was consensus that 34 items, most of which related to maintenance type activities should not be considered when making PAC recommendations. These included activities such as pool maintenance, painting, electrical work, landscaping, cutting firewood, roof repair, and carpentry repairs. Further scrutiny of these items is necessary to determine why the LCP participants felt that these items should not be considered when recommending PAC services. One possible theory for the exclusion of the items could be the unequal distribution amongst the experts. The percentage of females (87.1%) under study was much greater than the percentage of males (12.9%). There is a possibility that because these maintenance items are more commonly performed by males, females might feel that the need for assistance in conducting these activities is not injury related and would therefore, exclude them from consideration in a Life Care Plan. Additionally, a majority of the life care planning participants were nurses (77.4%) and may be primarily trained to assess personal assistance with self-care activities. Finally, maintenance activities, although often referred to as replacement activities or activities that an individual may have performed independently prior to injury, are not performed independently by people without disabilities. As such, participants may have decided that such maintenance activities should not necessitate the need for personal assistance because the individual would have hired someone to perform the activity whether or not they had a spinal cord injury. These

possible theories demonstrate the subjectivity that can impact the techniques utilized by Life Care Planners when making PAC recommendations.

Such subjectivity was demonstrated by the expert's responses to Round 1 questions relating to techniques employed when making recommendations for PAC (Table 6). These included techniques for categorizing recommendations, current assessment tools, utilization of sources in making PAC recommendations, and strategies for applying frequency and duration of need in association with specific PAC services. It is apparent that LCP experts as a group are not relying on any one method for making PAC recommendations. Rather, they are utilizing an eclectic approach that incorporates the recommendations of the LCP professional as well as the opinions of rehabilitation collaborators.

Qualitative Interviews

Qualitative interviews were conducted to obtain the perspective of veterans with SCI in regards to the necessary constructs and items to consider when making PAC recommendations. Utilizing the constant comparative method described by Corbin & Strauss (1990), the researcher coded a number of activities to which veterans with SCI currently require PAC. These 63 items were comprised of activities relating to personal hygiene, leisure and hobbies, and housekeeping/home maintenance. There were 27 items that were different than the activities reported by experts in the Delphi study. These items appeared to be activities related to personal hygiene and maintenance activities. Additionally, the veterans were a little more specific in their descriptions of the activities with which they require assistance. For example, the experts listed general hygiene related activities while the veterans stated explicitly, specific grooming activities such as combing hair, applying lotions, and shaving.

Even though many of the activities described by the veterans further validated the responses from the experts, the veterans appeared to currently not have issues related to the amount of PAC received, however, their issues related to the quality of PAC services. As such, probing questions relating to assistance revealed a number of themes that impacted the participants' need for PAC. These themes included issues of mental state, independence, PAC services in place prior to discharge, scheduling, trustworthiness, hospital setting, and spousal care, each of which are discussed below.

Mental health

According to the participants, the issue of decline in mental health due to awareness of physical limitations had a strong influence on the rehabilitation process of these individuals with SCI immediately following their injuries. This finding is consistent with previous research that suggests that individuals with SCI may immediately recognize the long-term consequences of their injuries when they discover the extent of their paralysis (Lohne & Severinsson, 2004). In this study, veterans suggested that depressive symptoms might lead to lack of motivation among individuals with SCI to focus on activities that can be performed as opposed to activities that cannot be performed. As such, individuals lacking motivation to be independent due to depressive symptoms might appear more dependent than they really are. For example, if an individual does not have the motivation to explore his/her abilities to perform specific activities, then that individual may appear to require additional PAC services. These findings implicate further research into the effects of mental health on the need for PAC. If further research substantiates this theory then, a psychological screening tool to determine if there is an association between need for assistance and mental status should be administered prior to conducting an assessment of PAC need.

Independence

In addition to mental status, several veterans reported a struggle with independence issues in view of functional limitations associated with their SCI. As discussed earlier in this chapter, the veterans struggled to describe activities with which they require personal assistance. A possible theory related to this struggle could be a cultural issue associated with male veterans. A majority of the veterans under study appeared to portray strong will and conviction to be able to perform activities independently. In fact many of the veterans appeared to view assistance as a weakness. The question remains whether these views represent a culture associated with gender or culture associated with veterans. In any case, both views may represent a masculinity issue. In fact, according to the literature, cultural beliefs about male physical strength becomes an issue as men with disabilities try to make cultural ideals of manhood fit with their physical limitations. Furthermore, men can get caught between the pressure exerted by a dominant masculinity, on the one hand, and the limitations and perceived weakness that come with that disability (Stansbury et al, 2003) Further research is warranted to explore cultural issues in relation to PAC.

PAC services in place prior to discharge

An interesting finding that emerged from this study was the importance that participants ascribe to establishing PAC services prior to discharge from a rehabilitation facility. The veterans talked about the difficulty of adapting to one's home environment after sustaining a SCI. Having PAC services in place prior to entering the home environment could facilitate the adjustment of an individual with SCI by ensuring that activities can be performed even if certain environmental barriers still exist. For example, as one participant pointed out, many homes are not equipped to accommodate

an individual with SCI, which can result in an increase in the need for personal assistance. These findings suggest that when assessing the need for PAC, clinicians should determine not only what services are needed, but also when those services will be implemented and the impact of the accessibility of the individual's home environment on such services.

Scheduling

The issue of scheduling PAC was identified to be an important theme associated with societal participation. One veteran discussed the struggle of revolving his daily activities around personal assistance with bowel care. In this case, PAC services were in place, however, the participant had a difficult time scheduling vocational activities due to the fact that he was required to adhere to the scheduling of the PAC provider. The veteran expressed a desire to be able to manage the scheduling of PAC according to his own daily needs. The challenges of managing a PCA have been cited frequently in the literature as an issue of major importance (Ulicny, Adler, & Jones, 1990; Lanig, Chase, Butt, Hulse, & Johnson, 1996; Busta, 1992; Weas, 2002). Consistent with the literature, the participants in this current study felt that the process of recommending PAC services should coincide with education on how to manage such services. Managing a PCA requires the skills of interviewing; personal management, and task design and can affect the relationship between the client and the PCA (Busta, 1992).

Trustworthiness

The productivity of the relationship between the PCA and individuals with SCI appears to be directly related to how well a client perceives the PCA as being trustworthy. The theme of trust appeared to be a primary concern among the veterans when discussing the issue of PAC. As noted in the last chapter, veterans appear to have

great difficulty in finding someone to whom they can entrust all of their PAC needs. One frequently voiced concern related to the fact that there are situations in which an individual with a SCI may have unanticipated complications arise that requires immediate assistance. The veterans stated the importance of having confidence that assistance will be there when it is needed. This issue, like that of scheduling, appears to relate to managing PCA's. As part of the management process, careful screening of potential PCA's is crucial to ensure that a trustworthy individual is hired. According to Lanig and associates (1996) for those individuals hiring privately or who have latitude with agency personnel options, careful screening of potential PCAs is an important component of the attendant care experience. Furthermore, spending more time on the hiring and training process can yield the payoff of a good caregiver who will continue working with the individual for an extended period of time (Lanig et al, 1996).

Hospital setting

According to the veterans, managing PAC becomes difficult during situations in which an individual has to transition to a hospital setting due to potential complications. Examples of potential complications commonly associated with SCI include: respiratory complications, pressure ulcers, renal disease, long bone fractures, thromboembolic disease, and autonomic dysreflexia (McKinley, Jackson, Cardenas, & DeVivo, 1999). Participants reported a lack of consistency between the care received at home compared with the care received during hospital stays. This can be a frequent and ongoing problem, especially in situations when an individual incurs frequent and/or multiple complications. Further inquiry should focus on the transition and provision of PAC services from the home environment to the hospital.

Spousal care

The final theme related to PAC services discussed by the veterans, included spousal care and the burden associated with providing such care. There was a consensus among married veterans that although there are benefits to having a spouse be a provider of PAC services, there are consequences as well. Such consequences include the physical, emotional and financial strain on the spouse and the family. This issue is often referred to as “burden of care” and has been examined quite frequently in the literature (Post, Bloemen, & de Witte, 2005; Chan, 2000; Holicky & Charlifue, 1999; Weitzenkamp, Gerhart, Charlifue, Whiteneck, & Savic, 1997). Burden of care has been associated with depression, stress, nervousness, sleeplessness, anger, and resentment among spousal caregivers of individuals with SCI (Weitzenkamp et al., 1997). Furthermore, caregiver burden associated with spouses of individuals with SCI, may lead to low levels of satisfaction with their life situation and marital adjustment (Chan, 2000). Since a strong correlation exists between level of physical disability and caregiver burden, careful monitoring of spouses and family members providing PAC is warranted (Post et al., 2005).

Limitation of this Study

Delphi Study

A main limitation of the Delphi study related to the high proportion of females to males. Although the proportion was representative of Life Care Planners, a higher proportion of males might have brought additional insights to the study. As pointed out earlier in this chapter, subjectivity can impact the techniques utilized by Life Care Planners when making PAC recommendations. As such, there is the possibility that gender can impact the subjective opinion of Life Care Planners. For example, males

might have felt that certain maintenance that were considered not essential when making PAC recommendations, should have been included.

Another limitation involves the use of medians and interquartile ranges as a technique for representing consensus among the participants. Even though utilizing medians and interquartile ranges is commonly used to describe levels of consensus in the Delphi literature, it is possible that the experts were unfamiliar with these measures of central tendency. This researcher did provide a detailed example to the participants on how to interpret this information; however, it is still possible that the information might have been confusing.

One other limitation to the study of examining activities to consider when making PAC recommendations was limiting the experts to Life Care Planners. These professionals are primarily making recommendations for PAC for litigation or forensic purposes. As such, the opinions of such experts may not be representative of all professionals involved in recommending PAC services or individuals assessing their own PAC needs. Other professionals that might offer additional insight into the recommendations of PAC services include: Professionals working at Independent Living Centers, Social Workers, Individuals providing PAC services such as nurses aides/home health aides, or spouse/family members.

Qualitative Interviews

Similar to the Delphi Study, a limitation of the qualitative interviews appeared to be recruitment of a diverse sample. All of the participants in this part of the study were males and therefore, the experiences of females were not represented in study. In addition to females, non-veterans participants were not recruited for this study. As discussed previously in this chapter, there was a potential bias associated with veterans

responding to questions regarding this study. Such biases related to cultural beliefs associated with male veterans. As such, diversity in knowledge could have been obtained by studying the PAC needs of female non-veterans as well.

Diversity of knowledge in terms of type of SCI was also a limitation of this study. Although there was a wide range of level of SCI among the participants, only one of the veterans had sustained a complete SCI. Individuals sustaining complete spinal cord injuries are likely to have a higher functional impairment. As such, individuals with complete spinal cord injuries may require assistance with additional activities not discussed by the current participants of this study.

Another limitation associated with diversity of the sample related to the fact that all the participants were over the age of 50. Many researchers have examined the issue of aging and its relation to SCI (Capoor & Stein, 2005; McColl, Charlifue, Glass, Lawson & Savic, 2004; Weed, 2004; Scivoletto, Morgant, Ditunno, Ditunno & Molinari, 2003; McColl & Rosenthal, 1995;). As discussed in chapter 1, aging can lead to increasing health and function problems which translate into a greater demand for PAC (Robinson-Whelen & Rintala, 2003). It is possible that younger individuals with SCI might have different needs for PAC. For example, according to Scivoletto and colleagues (2003), younger individuals with SCI have more favorable outcomes than older individuals in regards to walking and bladder/bowel independence. As a result, individuals who are older might require PAC for activities associated with walking and bladder/bowel management. As such, younger individuals with SCI might have different, if not less, PAC needs than older participants. Further study is necessary to obtain the PAC needs of

young individuals with SCI to increase the reliability of utilizing a PAC assessment on a younger population of individuals with SCI.

In addition to demographic limitations, as discussed in Chapter 3, qualitative research methodologies inherently assume that predispositions or biases of the evaluator may affect data analysis and interpretations (Patton, 2002). As discussed in Chapter 3, this researcher efforts to overcome bias commonly associated with qualitative research. This included maintaining “reflexivity” as described by Malterud (2001), which refers to an attitude of attending systematically to the context of knowledge construction especially to the effect of the researcher at every step of the research process. Once reflexivity is maintained, personal issues can be valuable sources for relevant and specific research (Maltrud, 2001). The steps taken to maintain ‘reflexivity’ were discussed in Chapter 3 and are reiterated below:

- Studied applicable coursework in qualitative methods from professors experienced in conducting qualitative research.
- Developed an interview guide (appendix J) used for data collection.
- Underwent training by a professional qualitative researcher in the utilization of statistical software for analyzing qualitative data.
- Consulted with committee chair in regards to themes emerging from the data.
- Continuously recognized personal bias that can influence this qualitative process. A personal bias statement was discussed in Chapter 3.

Implication for Clinical Practice and Policy

Clinical Practice

The results of this study should provide much useful information to allow rehabilitation professionals to gain a comprehensive knowledge of attendant care for individuals with SCI. Such knowledge can serve as a tool for professionals working with individuals with SCI. Specifically, the wide range of activities identified in this study should facilitate PAC in clinical practice. Areas that might be impacted by these activities include public funding, managing PAC, life care planning, discharge planning, and case management.

In terms of applying for public assistance, professionals can assist individuals in applying for public assistance for PAC by thoroughly exploring a comprehensive list of activities that often require personal assistance by individuals with SCI. Once professionals have a basis for the activities necessitating PAC, they can more accurately determine the costs associated with providing PAC services. As a result, individuals utilizing PAC services will be able to better manage their finances and be better prepared to apply for public assistance. In addition, individuals privately funding their PAC services could use such knowledge to hire and manage PCA's.

Knowledge about the full range of services required in PAC could be an invaluable aid in education and training of individuals requiring PCA management. In fact, such a large amount of activities identified from this study could serve as a checklist for people with disabilities. Further development of such a checklist in terms of a computer adaptive self-report could be very advantageous to a consumer not wanting to take a long time to complete a self-assessment of his/her PAC needs. With an individual being able to expeditiously determine his/her own PAC needs, managing of services to

meet those needs may become less of a burden. The training and managing of PCA's is often conducted in Independent Living Centers. Independent Living Centers are typically non-residential, private, non-profit, consumer-controlled, community-based organizations providing services and advocacy by and for individuals with all types of disabilities. The main goal of the centers is to assist individuals with disabilities to achieve their maximum potential within the context of their families and communities. In addition, Independent Living Centers provide strong advocacy on a wide range of national, state and local issues. They work to guarantee physical and programmatic access to housing, employment, transportation, communities, recreational facilities, and health and social services (ILUSA, 2005). All of the PAC activities resulting from this study clearly relate to all of these issues. Additionally, educating and training individuals to understand their PAC needs appears to be consistent with the goals of Independent Living Centers in ensuring that individuals with disabilities achieve their maximum potential in their immediate and social environment.

Education is not limited to the recipient of PAC services. Professionals can utilize the activities from this study to train other clinicians in regards to areas to examine when dealing with PAC issues. Such an education can allow inexperienced professionals to develop a comprehensive understanding of the PAC needs for individuals with SCI. An example of a growing profession that involves recommending PAC services includes the field of life care planning. Individuals who go through LCP training programs are exposed to many service requirements for people with catastrophic disabilities. Often Life Care Planners must collaborate with other professionals and utilize valid research to support their recommendations. Studies such as this one can serve as not only a guide to

understanding the PAC needs for individuals with SCI, but also as research to support many types of PAC recommendations.

In addition to educational benefits, PAC activities identified in this study could serve as a useful tool for professionals involved in discharge planning. Discharge planning is a process used to determine a client's needs for a smooth transition from one level of care to another. This process is usually performed by a social worker or other health care professional and includes transition from a hospital to a nursing home or to home care (Centers for Medicaid and Medicare Services, 2004). Professionals involved in discharge planning could utilize the results of this study to more thoroughly and adequately explore the home care needs of individuals leaving an in-patient setting. As such, the professional can ensure that appropriate PAC services are in place once an individual enters his/her home environment.

The responsibility of guaranteeing that appropriate PAC services are in place also falls upon case managers. Case management involves the provision of services as a means for achieving client wellness and autonomy through advocacy, communication, education, identification of service resources and service facilitation. The case management process involves identifying appropriate providers and facilities throughout the continuum of services, while ensuring that available resources are being used in a timely and cost-effective manner in order to obtain optimum value for both the client and reimbursement sources. (Case Management Society of America, 2005). As evidenced by this definition, case managers need to have a sound basis for identifying appropriate providers for a continuum of services and communicating about the needs for such services with clients. In order to better identify specific providers to provide PAC

services, case managers can examine the different types of activities that came out of this study. For example, separate PAC providers may be necessary for assistance with transportation activities and assistance with work related activities. In any case, case managers utilizing a comprehensive instrument such as the one under study, could facilitate the efficient and successful outcomes associated with PAC services.

Public Policy

As pointed out in Chapter 2, many disability advocates have made efforts to influence legislators to pass a national agenda for PAC. Unfortunately, these efforts have failed due, at least in part, to the concern that such programs will lead to an enormous financial burden on the federal government. The basis for this worry appears to be due to the reports of overwhelming amount of unmet needs associated with PAC. As such, there is a belief that the cost for meeting those needs would be enormous. Additionally, there is a concern that if a federally funded government program existed, individuals currently not receiving PAC services would seek funding if it became available. There are many problems with focusing on the immediate cost associated with the provision of such services to the exclusion of consumer right to assistance and to long-term cost effectiveness. Legislators seeking to limit access to a full range of PCA services may not be examining the comprehensiveness of PAC services and how they facilitate the participation of people with disabilities in many types of activities. As discussed in Chapter 2, lawmakers are simply examining PAC in terms of assistance with ADL's. Limiting government funding leads to problems with access to assistance with basic self-care activities. Additionally, the results of this study demonstrate that even those receiving assistance for PAC may be receiving insufficient assistance with activities relating to home maintenance, education, work, leisure, and social participation. In fact,

ADL's only relate to 21 of the 194 activities resulting from this study. In other words, based on this study, legislators when making decisions based on funding PAC services are only focusing on 10 percent of the total activities that people with SCI require PAC. Hopefully, the results of this study may inform the decisions of policy makers and encourage consideration of the need to fund the full range of services needed by individuals with SCI to participate in everyday activities.

In addition to recognizing the impact of limiting people with disabilities' ability to participate in everyday activities, the issue of cost has yet to be comprehensively examined. To date, no one has examined the true cost of the provision of all types of activities requiring PAC. In fact, as discussed in Chapter 2, a comprehensive instrument used to predict the cost of PAC does not exist. Currently, the only instrument described in the literature as being used to predict cost of PAC is the FIM. The FIM does not examine the need for personal assistance beyond dependence with ADL's. Again, as pointed out earlier, ADL's only make up a small percentage of activities that necessitate PAC services. In order for policy makers to be able to truly understand the financial implications of a comprehensive national agenda for the provision of PAC services, they must examine the cost of PAC services for all types of PAC services in addition to ADL's. Lawmakers could then compare issues such as lack of funding for PAC services against the cost of funding potential complications likely to arise from the under funding of various types of PAC. As evidenced by this study, potential complications should now be examined beyond issues associated with lack of assistance with self-care activities. Policy makers should examine the consequences an individual may experience if he/she is unable to work, receive an education, and participate in leisure activities.

Additionally, policy makers might view PAC differently since as is evident by the results of this study, PAC allows people with disabilities to achieve in areas that our current society values the most such as social status, education, employment, and financial gain. Thus, limiting funding for PAC services would appear to lead to a limitation of individuals with disabilities to be productive members of society. Such policies are not consistent with landmark disability legislation such as the Americans with Disabilities Act (ADA). This legislation was implemented in order to promote individuals with disabilities to be able to be productive members of society by decreasing barriers, supporting civil rights, and promoting deinstitutionalization.

In addition, the benefits of providing adequate PAC appear to outweigh the costs of institutional care. According to ADAPT (2004), currently, billions of dollars are spent on institutional care in the US, which is six times as much money spent on community-based services such as PAC. Furthermore, even if no money were allocated from the federal budget, 25% of the current Medicaid institutional dollars could be redirected to fund a national PAC program (ADAPT, 2004)

Disability advocates lobbying for a national PAC program would benefit from a comprehensive PAC measurement tool. Having such an instrument will enable disability advocates to utilize empirically derived information to develop their agenda for a federally funded PAC program. Additionally, advocates for a national agenda for PAC can utilize this instrument to point out limitations in current state funded programs. These include state Medicaid Programs that provide funding based on the need for assistance with ADL's. As is evident by this study, individuals with SCI require assistance with many activities in addition to ADL's. Disability advocates could utilize

this study to indicate that individuals with SCI are not receiving public assistance for 90% of activities relating to PAC.

Further Research and Development of the Findings of This Study

This study resulted in a comprehensive item bank of activities to consider when recommending PAC services. Such an item bank will allow researchers, clinicians, and policy makers to have a thorough knowledge of all activities relating to the need for PAC. As pointed out in Chapter 2, according to the literature, there is a large amount of unmet need for PAC associated with a majority of the activities resulting from this study. As such, professionals should be able to refer to this item bank for use in future research on unmet PAC needs.

Further exploration of the activities developed from this study is warranted in order to determine whether separate PAC constructs exist and items generated are truly representative of the PAC needs of individuals with SCI. Such an investigation will allow for the creation of an instrument to be used to assess the PAC needs of an individual with SCI. As evident by the results of this study, professionals making PAC recommendations are not relying on any objective means for predicting such care. Furthermore, these professionals are often utilizing a variety of subjective methods for making PAC recommendations. As such a valid instrument could be useful to ensure that the PAC needs of individuals with SCI are precisely and accurately assessed. Additionally, such an instrument that has been validated and proven to be reliable by appropriate research techniques could enhance the credibility of PAC recommendations from professional such as professional Life Care Planners.

To accomplish this task, a paper and pencil instrument should be developed and administered to individuals with SCI, which will allow professionals to evaluate each

activity in terms of their client's necessity for PAC. Next, a factor analysis of the results from the administration should be performed to determine if all the activities make up a unidimensional construct or if the instrument is made up of multiple constructs. Rasch methodologies would then be employed to determine the hierarchy of the items within the instrument. Determining the hierarchy of such a large bank of items will provide a basis for the development of a Computer Adaptive Assessment. Computer adaptive testing could allow professionals to expeditiously and precisely determine the PAC needs for a specific individual. As discussed in earlier chapters, every individual with a SCI is different in terms of age, level of injury, and lifestyle/cultural issues. As such, PAC can vary amongst individuals with SCI.

The next step in the instrument development process should include a component that allows for determining duration of assistance with specific activities. One possible technique for determining duration would be to develop an assessment that would allow participants to describe the duration of assistance required to complete an activity. The assessment could then be administered to individuals currently receiving personal assistance and the results could be compared to the duration of personal attendant care currently received by that individual. Being able to associate duration of PAC with a specific activity will allow professionals to be able to more accurately predict the actual cost for personal assistance services. Understanding the true cost associated with providing PAC services will assist policy makers in their decision making regarding funding such services. Additionally, people with disabilities will have an understanding of the financial impact of funding such services. Finally rehabilitation professionals such as Life Care Planners could be more accurate in their cost predictions associated with their PAC recommendations for people with disabilities.

In addition to the instrument development, results of the qualitative interviews warrant further evaluation. The goal of the qualitative interviews was to generate items to be considered when making recommendations for PAC. During the interviews many themes emerged relating to the PAC needs of individuals with SCI. Future research is warranted in order to explore those themes and how they impact PAC. Specifically, areas needing further research include the association of PAC services with: mental health, burden of care, environmental barriers, and PCA management.

Conclusion

This study resulted in 194 activities for professionals to consider when recommending PAC services for individuals with SCI. These activities are the results of opinions of experts experienced in recommending PAC and veterans with SCI. While few of these activities are specific to ADL's, a large proportion of the items relate to home/yard maintenance, employment, education, and leisure. These non-ADL activities represent activities currently undermet by PAC services for individuals with SCI. Additionally, these activities specifically integrate into modern models of disablement such as the ICF model. As such, the knowledge obtained by this study could impact public policy, clinicians, and researchers dealing with the issue of PAC. Further research is needed in order to utilize the item bank resulting from this study to develop a comprehensive assessment for PAC. Recommendations for such development are described below.

1. Develop a paper and pencil instrument utilizing the activities resulting from this study.
2. Conduct cognitive interviews with individuals with SCI representing a variable sample based on gender, age, and level of injury in order to further

validate the PAC activities for this population. This process would involve administering the instrument and simultaneously obtaining feedback from the participants in regards to the appropriateness of the activities for PAC

3. Conduct a principal components analysis to determine the unidimensionality of the constructs within the instrument and the hierarchy of the items within each construct.
4. Develop a Computer Adaptive Test to allow professionals to precisely determine the PAC needs associated with individuals with SCI.
5. Examine methodologies for associating PCA needs with duration of care.
6. Research the relationship of mental health, burden of care, environmental barriers, and PCA management with PAC.
7. Research the potential complications along with associated costs of individuals with SCI not receiving public assistance with PAC.

APPENDIX A
DELPHI ROUND 1



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**ALL PROFESSIONAL LIFE CARE PLANNERS
PARTICIPATING IN OUR RESEARCH STUDY**

The Rehabilitation Science Department at the University of Florida is conducting a research study that involves collecting data on personal assistance and replacement services needed by individuals with Spinal Cord Injury (SCI). The title of this study is "Creating a Personal Attendant Care Measure for Individuals with SCI"

The purpose of this proposed study is to acquire benchmark data that can provide validity checks to Life Care Planners while assessing and addressing personal assistance and replacement services. The study involves obtaining the opinions of expert Life Care Planners in regards to the necessary constructs and items to be considered when recommending personal attendant care services. There are no discomforts or risks to the expert by taking part in this study. Participants will not be charged for participation, however, they will receive 5 CEU's towards their Life Care Planning Certification (CLCP) for completing all three rounds of the study.

CONTINUE

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Only authorized persons from the University of Florida involved in this research study have the legal rights to review the research records and will protect the confidentiality of those records to the extent permitted by law. The research records will not be released without your consent unless required by law or a court order. If the results of this research are published or presented at scientific meetings, the expert's identity will not be disclosed at any time. None of the researchers involved in this study will benefit from an expert's participation in this study.

Please contact Jamie Pomeranz, Ph.D., CRC at (352) 273-6566 with any questions regarding this study. If you have any questions regarding your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

YES By clicking yes, you are indicating that you understand your rights as a research subject and would like to participate in our study.

NO By clicking no, you are indicating that you would not like to participate in our study.

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Delphi Questions Round 1 Life Care Planners

The first round consists of 11 questions which provides the opportunity for each of you to engage in individual brainstorming so as to generate as many ideas as possible for dealing with the issue of Medical and Non-Medical Personal Assistance and Replacement Services.

Personal Assistance is defined as services to assist with maintaining personal hygiene, general health services, personal appearance, activities of daily living, general comfort in life environment, safety, and interactions with the community and society that are related to requirements imposed by the disability.

Replacement Services are defined as essential services needed post onset of disability that represent responsibilities and services related to household activity, yard and property maintenance, and home/auto maintenance that were performed independently prior to the disability.

If you do not consider the indicated service when completing life care plans, please put N/A.

Please provide your responses to these open-ended questions in relation to individuals with level C-4 or below, complete or incomplete spinal cord injuries. All of your responses will remain anonymous and confidentiality will be maintained throughout this study. Please respond in a clear and concise manner.

We realize the importance of assistive devices/technology in regards to personal assistance. However, when asked to specify activities that constitute ADL's or replacement services, please list possible activities without regard to the availability of assistive devices/technology.

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Demographic Information

How Long have you been a Life Care Planner?

What is your gender?

What is your age in years?

In what city and state do you work?

Credentials: (Check all that apply)

<input type="checkbox"/> CRC	<input type="checkbox"/> LMHC
<input type="checkbox"/> CCM	<input type="checkbox"/> LPC
<input type="checkbox"/> CLCP	<input type="checkbox"/> CDMS
<input type="checkbox"/> CDMS	<input type="checkbox"/> RN
<input type="checkbox"/> CVE	<input type="checkbox"/> SLP
<input type="checkbox"/> CNA	<input type="checkbox"/> OT
<input type="checkbox"/> LPN	<input type="checkbox"/> PT
<input type="checkbox"/> CRRN	<input type="checkbox"/> CLNC

Highest Level of Schooling: (Check all that apply)

<input type="checkbox"/> High School
<input type="checkbox"/> Bachelor's Degree
<input type="checkbox"/> Master's Degree
<input type="checkbox"/> Ph.D.
<input type="checkbox"/> Ed.D.
<input type="checkbox"/> Technical
<input type="checkbox"/> Other

[Next Page](#)

?

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Question 1 of 11

Under what categories do you organize the parts of your Life Care Plan that address types of personal assistance and replacement services (e.g. nursing care, maintaining living environment)?

INSTRUCTION PAGE DEMOGRAPHIC PAGE NEXT QUESTION

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Question 2 of 11

What objective assessments (e.g. FIM, CHART) do you use (if any) to help you determine the need for Personal Assistance in a Life Care Plan?

INSTRUCTION PAGE PREVIOUS QUESTION NEXT QUESTION

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Question 3 of 11

Please list all specific activities of daily living (e.g. eating, dressing, bowel and bladder management) you consider when recommending services in a Life Care Plan.

INSTRUCTION PAGE PREVIOUS QUESTION NEXT QUESTION

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Question 4 of 11

Please list all specific housekeeping activities (e.g. washing dishes, vacuuming) you consider when recommending services in a Life Care Plan.

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Question 5 of 11

Please list all specific home and yard maintenance activities (e.g. mowing lawn, changing light bulbs) you consider when recommending services in a Life Care Plan.

INSTRUCTION PAGE PREVIOUS QUESTION NEXT QUESTION

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Question 6 of 11

How might you utilize a personal assistant for transportation related activities (e.g. driving to appointments, grocery store)?

INSTRUCTION PAGE PREVIOUS QUESTION NEXT QUESTION

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Question 7 of 11

How might you utilize a personal assistant for work related activities (e.g. assistance with opening doors, transfers)?

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Question 8 of 11

How might you utilize a personal assistant for education or training activities (e.g. homework, note taking)?

INSTRUCTION PAGE PREVIOUS QUESTION NEXT QUESTION

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Question 9 of 11

Please list all types of leisure activities (e.g. sports, social recreation) you consider when recommending services in a Life Care Plan.

INSTRUCTION PAGE PREVIOUS QUESTION NEXT QUESTION

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Question 10 of 11

In determining the need for personal assistance or replacement services for all the activities you previously listed, most life care planners refer to the personal interview, physician recommendations, and therapist evaluations/recommendations. Are there any additional sources you use to determine the need for personal assistance or replacement services for the following types of activities? If there are no additional sources, then please indicate by inputting "N/A"

ACTIVITIES OF DAILY LIVING	TRANSPORTATION	LEISURE
<input type="text"/>	<input type="text"/>	<input type="text"/>
HOUSEKEEPING	WORK	EDUCATION/TRAINING
<input type="text"/>	<input type="text"/>	<input type="text"/>
HOME/YARD MAINTENANCE		
<input type="text"/>		

PREVIOUS QUESTION NEXT QUESTION

?

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Question 11 of 11

When considering all the activities you listed in the previous questions, what steps do you take in order to associate need with the number of hours for each type of service (e.g. direct observation, refer to client's report of duration of activities, experience developing previous Life Care Plans)?

INSTRUCTION PAGE PREVIOUS QUESTION CONTINUE

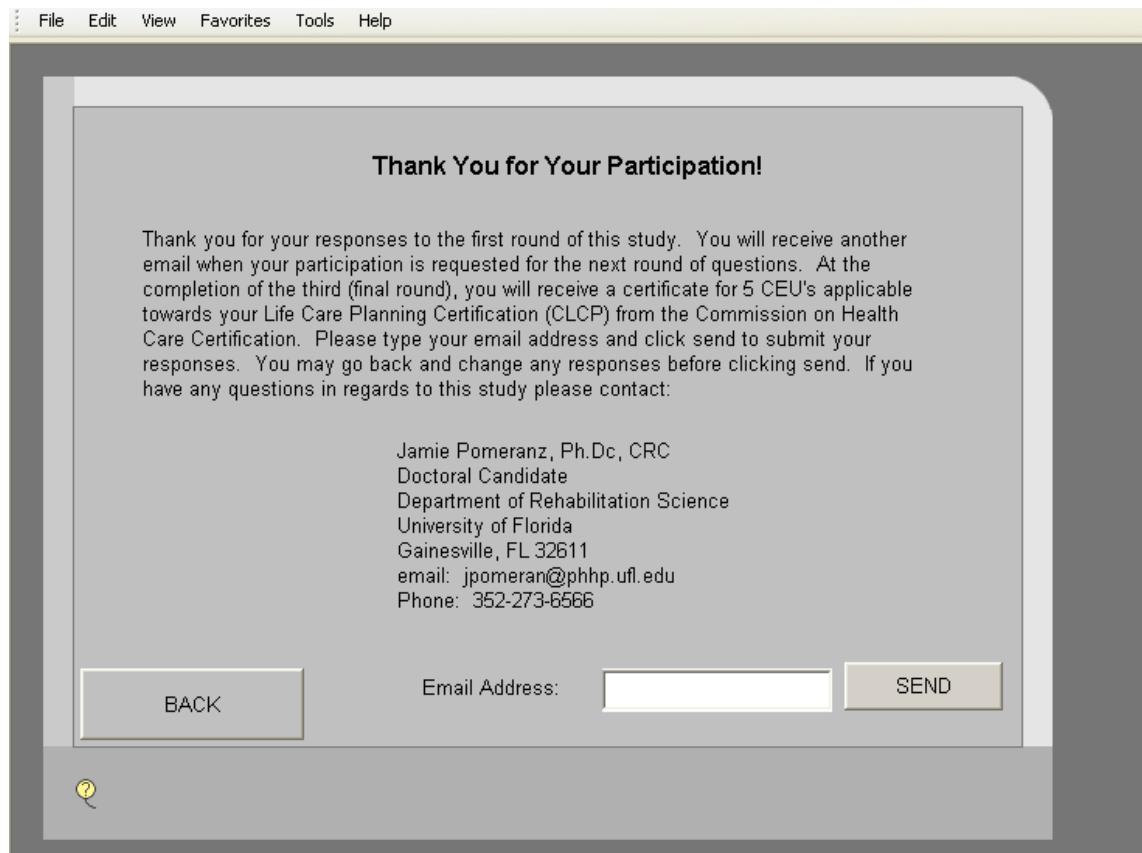
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Please list any comments you have in regards to this survey.

PREVIOUS QUESTION CONTINUE

?



APPENDIX B

INITIAL EMAIL TO LIFE CARE PLANNING EXPERTS

Dear _____:

Your name was provided by MediPro Seminars LLC (formally Intelicus Life Care Planning Certification Program).

My name is Jamie Pomeranz and I am a doctoral candidate from the Department of Rehabilitation Science at the University of Florida. I am conducting a study that involves obtaining the opinions of expert Life Care Planners in regards to the necessary constructs and items to be considered when recommending personal attendant care services.

The purpose of this proposed study is to acquire benchmark data that can provide validity checks to Life Care Planners while assessing and addressing personal assistance and replacement services.

There are no discomforts or risks to the expert by taking part in this study. Subjects will receive five CEU's towards their Life Care Planning Certification (CLCP) for completing the study.

This Delphi study will consist of three rounds of survey questions, which can be completed via the web. At the completion of all three rounds you will receive the five Continuing Education Credits towards your Life Care Planning Certification. If we haven't received your responses to the data, two weeks from the initial email before each round, we will email you once with a friendly reminder to complete the survey. You may withdraw from the study at any time.

If you agree to participate, please click the link below or cut and paste the link into your browser. It is recommended that you use a later version of Internet Explorer or Netscape to view the survey.

http://www.hp.ufl.edu/~jpomeran/quasksurvey/delphi_final_version_round_1.htm

Please see the attached letter from Paul M. Deutsch Ph.D., providing his support for this study.

Please contact Jamie Pomeranz, Ph.D(c), CRC at (352) 273-6566 with any questions regarding this study.



Paul M. Deutsch & Associates, P.A.

10 Windsormere Way, Suite 400 • Oviedo, Florida 32765 ~ P.O. Box 622049 • Oviedo, Florida 32762-2049
(407) 977-3223 • FAX (407) 977-0311

April 2, 2004

To My Colleagues in Life Care Planning

From time to time each of us is asked to participate in one study or another from a professional organization or budding doctoral dissertation student. Many of us pass over such requests with a brief glance or no glance at all. Some think, we will get to it later with good intent, but by the time we do the deadline has passed.

I truly understand the difficulties in taking time from a busy practice to fill out these questionnaires. Not all are worthy of your time. Not all are well designed. But one absolute truth does exist: If the sub-specialty of life care planning does not begin to generate more field-based research on its practices and processes it will not survive the challenges to its continued existence in the future. We will then have all the time in the world to answer such questions, unfortunately there will be no one to ask them.

Now that I have your attention, I would sincerely like to take the time to endorse the dissertation study of Jamie Pomeranz, MHS, CRC. I am very familiar with the members of his doctoral committee and Jamie has seen fit to keep the Foundation for Life Care Planning Research informed of the details of his research, as his project has been developing. His goal is to establish the necessary constructs and items which should be considered when recommending personal care assistance and replacement services within the Life Care Plan. He is seeking to base his conclusions on a survey of a requisite number of practitioners who graduated from MediPro Seminars LLC and went on to practice within the sub-specialty.

Jamie has committed to not only completing an excellent doctoral level research project but he has committed to the Foundation his intent to submit the completed study for publication in the Journal of Life Care Planning. This is critical to the field and our growing body of research literature. I sincerely hope all of those chosen to participate will give this serious thought and take the few minutes out of their time to answer his survey questions.

I would like to thank each of you in advance for helping Jamie and for assisting in adding to the body of field-based research literature we so very much need in Life Care Planning.

Sincerely,

Paul M. Deutsch Ph.D., CRC, CCM, CLCP, FIALCP
Licensed Mental Health Counselor, (FL MH#0000117)

CERTIFIED REHABILITATION COUNSELORS

APPENDIX C

DELPHI ROUND 1 FRIENDLY REMINDER EMAIL

Dear _____:

Approximately two weeks ago, an email was sent to you in regards to taking part in our research project. This is a friendly reminder you still have the opportunity to advance our knowledge in this important aspect of Life Care Planning by participating in this study.

My name is Jamie Pomeranz and I am a doctoral candidate from the Department of Rehabilitation Science at the University of Florida. I am conducting a study that involves obtaining the opinions of expert Life Care Planners in regards to the necessary constructs and items to be considered when recommending personal attendant care services.

The purpose of this proposed study is to acquire benchmark data that can provide validity checks to Life Care Planners while assessing and addressing personal assistance and replacement services.

There are no discomforts or risks to the expert by taking part in this study. Subjects will receive five CEU's towards their Life Care Planning Certification (CLCP) for completing the study.

This Delphi study will consist of a three rounds of survey questions, which can be completed via the web. At the completion of all three rounds you will receive the five Continuing Education Credits towards your Life Care Planning Certification. If we haven't received your responses to the data, two weeks from the initial email before each round, we will email you once with a friendly reminder to complete the survey. You may withdraw from the study at any time.

If you agree to participate, please click the link below or cut and paste the link into your browser. It is recommended that you use a later version of Internet Explorer or Netscape to view the survey.

http://www.hp.ufl.edu/~jpomeran/quasksurvey/delphi_final_version_round_1.htm

If you elect not to participate, please reply to this email and put in the subject line "not interested."

Please contact Jamie Pomeranz, Ph.D., CRC at (352) 273-6566 with any questions regarding this study.

APPENDIX D
ROUND 2 EMAIL TO LIFE CARE PLANNING EXPERTS

Dear _____:

Thank you for completing the first round of questioning for our study entitled "Creating a Personal Attendant Care Measure for Individuals with SCI".

We apologize for the delay in the development of the second round survey, which was caused by the recent bombardment of hurricanes that hit Florida. The second round of questioning is now ready for your participation. This round is considerably quicker and simpler to complete and should take you about 15-20 minutes to finish. This is the second of three rounds of questioning. Participants will receive 5 CEU's towards their Life Care Planning Certification (CLCP) for completing all three rounds of the study.

A stated previously, there is no discomfort or risks to the expert by taking part in this study. The purpose of this proposed study is to acquire benchmark data that can provide validity checks to Life Care Planners while assessing and addressing personal assistance and replacement services.

To begin the second round of this study, please click the link below or cut and paste the link into your browser. It is recommended that you use a later version of Internet Explorer or Netscape to view the survey.

http://www.phhp.ufl.edu/~jpomeran/quasksurvey/delphi_round_2_version_4.htm

Please contact Jamie Pomeranz, Ph.D(c), CRC at (352) 273-6566 with any questions regarding this study.

APPENDIX E
DELPHI ROUND 2

The screenshot shows a web-based survey interface. At the top, there is a header bar with the text "college of" on the left, "University of Florida" in the center, and "Public Health and Health Professions" on the right, accompanied by a small building icon. Below the header, the main title "Delphi Study" is displayed in large blue text. Underneath the title, the survey purpose is described: "Professional Life Care Planners Round 2". A red rectangular button labeled "Take Survey" is positioned below this text. At the bottom of the page, there is a logo for the "Rehabilitation Outcomes Research Center" which is identified as a "VA HSR&D and RR&D Center of Excellence". The logo features a stylized profile of a person's head with an orange arrow pointing upwards and to the right.

ALL PROFESSIONAL LIFE CARE PLANNERS PARTICIPATING IN OUR RESEARCH STUDY

Thank you for completing the first round of questioning for our study entitled "Creating a Personal Attendant Care Measure for Individuals with SCI". The second round is considerably quicker and simpler to complete and should take you about 15-20 minutes to finish. This is the second of three rounds of questioning. Participants will receive 5 CEU's towards their Life Care Planning Certification (CLCP) for completing ALL THREE ROUNDS of the study.

A stated previously, there are no discomforts or risks to the expert by taking part in this study. The purpose of this study is to acquire benchmark data that can provide validity checks to Life Care Planners while assessing and addressing personal assistance and replacement services. The study involves obtaining the opinions of expert Life Care Planners in regards to the necessary constructs and items to be considered when recommending personal attendant care services.

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DELPHI STUDY ROUND 2 INSTRUCTIONS FOR LIFE CARE PLANNERS

Your responses to the first round of questioning have been analyzed and used to create the second round of this study. You will now be asked to rate your agreement or disagreement with each item listed on whether the activities should be considered when making recommendations for Personal Assistance and Replacement Services.

Personal Assistance is defined as services to assist with maintaining personal hygiene, general health services, personal appearance, activities of daily living, general comfort in life environment, safety, and interactions with the community and society that are related to requirements imposed by the disability.

Replacement Services are defined as essential services needed post onset of disability that represent responsibilities and services related to household activity, yard and property maintenance, and home/auto maintenance that were performed independently prior to the disability.

All of your responses will remain anonymous and confidentiality will be maintained throughout this study.

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DELPHI STUDY ROUND 2 INSTRUCTIONS FOR LIFE CARE PLANNERS

Please respond based on individuals with a SPINAL CORD INJURY. We understand that recommendations change for every individual based on level of disability, gender, demographics, etc. Please indicate your agreement or disagreement with the items from a global perspective. For example, an individual who has a T-11 level spinal cord injury may not require personal assistance for many activities such as transportation, eating, and grooming. However, an individual with a C-4 level spinal cord injury will most likely require assistance for many ADL activities such as transferring, dressing, and personal hygiene. Therefore, when responding to a question about whether you should consider transportation needs in determining the extent of PCA services for individuals with SCI, you should consider whether there are any individuals with SCI for whom that would be an important consideration. All the categories have been combined for this round, which include: ADL's, Housekeeping, Home/Yard Maintenance, Work, Education, Transportation, and Leisure. There are a total of 196 items included on this survey. Again this round should take you approximately 15-20 minutes to complete. Thank you for your participation.

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
1. Bowel/Bladder Management	<input type="checkbox"/>				
2. Childcare	<input type="checkbox"/>				
3. Communication Activities	<input type="checkbox"/>				
4. Computer Activities	<input type="checkbox"/>				
5. Dressing	<input type="checkbox"/>				
6. Grooming	<input type="checkbox"/>				
7. Drinking	<input type="checkbox"/>				
8. Eating	<input type="checkbox"/>				
9. Endurance Activities	<input type="checkbox"/>				
10. Health Management	<input type="checkbox"/>				
11. Hygiene	<input type="checkbox"/>				
12. ADL's	<input type="checkbox"/>				
13. Judgement/Decision Making	<input type="checkbox"/>				
14. Managing Medication	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
15. Mobility	<input type="checkbox"/>				
16. Retrieve/Open/Read Mail	<input type="checkbox"/>				
17. Orthotic Management	<input type="checkbox"/>				
18. Personal Business	<input type="checkbox"/>				
19. Safety	<input type="checkbox"/>				
20. Self-Care	<input type="checkbox"/>				
21. Social Cognition	<input type="checkbox"/>				
22. Stair Climbing	<input type="checkbox"/>				
23. Teeth Brushing	<input type="checkbox"/>				
24. Telephone Use	<input type="checkbox"/>				
25. Toileting	<input type="checkbox"/>				
26. Transferring	<input type="checkbox"/>				
27. Washing	<input type="checkbox"/>				
28. Writing	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan.

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
29. Fine motor movement	<input type="checkbox"/>				
30. Clean A/C vents	<input type="checkbox"/>				
31. Clean baseboards	<input type="checkbox"/>				
32. Clean blinds	<input type="checkbox"/>				
33. Clean cabinets	<input type="checkbox"/>				
34. Clean refrigerator	<input type="checkbox"/>				
35. Clean oven	<input type="checkbox"/>				
36. Clean bathtubs	<input type="checkbox"/>				
37. Clean up after meals	<input type="checkbox"/>				
38. Clean crown molding	<input type="checkbox"/>				
39. Clean dishes	<input type="checkbox"/>				
40. Clean drapes/curtains	<input type="checkbox"/>				
41. Clean closets	<input type="checkbox"/>				
42. Clear cobwebs	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan.

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
43. Clean garage	<input type="checkbox"/>				
44. Dusting	<input type="checkbox"/>				
45. Clean roof gutters	<input type="checkbox"/>				
46. Cleaning light fixtures	<input type="checkbox"/>				
47. Grocery management	<input type="checkbox"/>				
48. Handling paperwork	<input type="checkbox"/>				
49. Start fire in fireplace	<input type="checkbox"/>				
50. Cooking	<input type="checkbox"/>				
51. Ironing	<input type="checkbox"/>				
52. Laundry	<input type="checkbox"/>				
53. Lifting activities	<input type="checkbox"/>				
54. Maintaining storage area	<input type="checkbox"/>				
55. Maintaining clothing	<input type="checkbox"/>				
56. Maintaining environmental controls	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
57. Maintain fire/smoke/security alarm	<input type="checkbox"/>				
58. Making Beds	<input type="checkbox"/>				
59. Managing daily schedule	<input type="checkbox"/>				
60. Managing household finances	<input type="checkbox"/>				
61. Mopping floors	<input type="checkbox"/>				
62. Moving furniture/Rearranging Environment	<input type="checkbox"/>				
63. Opening/Closing windows	<input type="checkbox"/>				
64. Organizing Kitchen	<input type="checkbox"/>				
65. Pet-Care	<input type="checkbox"/>				
66. Waxing furniture	<input type="checkbox"/>				
67. Sweeping with a broom	<input type="checkbox"/>				
68. Spring/Fall cleaning	<input type="checkbox"/>				
69. Turning over mattress	<input type="checkbox"/>				
70. Using a dishwasher	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
71. Vacuuming	<input type="checkbox"/>				
72. Washing walls	<input type="checkbox"/>				
73. Washing windows	<input type="checkbox"/>				
74. Woodworking	<input type="checkbox"/>				
75. Baling hay	<input type="checkbox"/>				
76. Carpentry repairs	<input type="checkbox"/>				
77. Bushhogging (clearing rough terrain)	<input type="checkbox"/>				
78. Dead-heading (removing dead flower buds).	<input type="checkbox"/>				
79. Edging	<input type="checkbox"/>				
80. Electrical work	<input type="checkbox"/>				
81. Cutting firewood	<input type="checkbox"/>				
82. Emergency egress	<input type="checkbox"/>				
83. Fixing squeaky doors	<input type="checkbox"/>				
84. Furnace/AC Maintenance	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
85. Taking out the garbage	<input type="checkbox"/>				
86. Garden management	<input type="checkbox"/>				
87. Filling gas tank	<input type="checkbox"/>				
88. Disposing of debris	<input type="checkbox"/>				
89. Climbing ladders	<input type="checkbox"/>				
90. Hammering	<input type="checkbox"/>				
91. Hanging pictures	<input type="checkbox"/>				
92. Home decorating	<input type="checkbox"/>				
93. Landscaping	<input type="checkbox"/>				
94. Lawn mowing	<input type="checkbox"/>				
95. Leaf blowing	<input type="checkbox"/>				
96. Changing light bulbs	<input type="checkbox"/>				
97. Putting down mulch	<input type="checkbox"/>				
98. Changing oil	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
99. Outdoor repairs	<input type="checkbox"/>				
100. Painting	<input type="checkbox"/>				
101. Plumbing	<input type="checkbox"/>				
102. Pool maintenance	<input type="checkbox"/>				
103. Restore power outages	<input type="checkbox"/>				
104. Pruning	<input type="checkbox"/>				
105. Putting up fixtures	<input type="checkbox"/>				
106. Raking	<input type="checkbox"/>				
107. Remodeling	<input type="checkbox"/>				
108. Roof repair	<input type="checkbox"/>				
109. Using a screwdriver	<input type="checkbox"/>				
110. Seasonal fertilizer	<input type="checkbox"/>				
111. Shrub maintenance	<input type="checkbox"/>				
112. Snow management	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
113. Spa maintenance	<input type="checkbox"/>				
114. Using a string trimmer (Weedeater®)	<input type="checkbox"/>				
115. Maintain automatic sprinkler system	<input type="checkbox"/>				
116. Watering garden/grass	<input type="checkbox"/>				
117. Check tire pressure	<input type="checkbox"/>				
118. Trim work	<input type="checkbox"/>				
119. Washing car	<input type="checkbox"/>				
120. Carrying work/school supplies	<input type="checkbox"/>				
121. Test taking	<input type="checkbox"/>				
122. Taking a break at work/school	<input type="checkbox"/>				
123. Typing reports	<input type="checkbox"/>				
124 Tutoring	<input type="checkbox"/>				
125. Dictating reports, letters, notes, etc. (work or school)	<input type="checkbox"/>				
126. Entering/Exit work/school environment	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
127. Getting on/off elevators	<input type="checkbox"/>				
128. Escort at work or between classes	<input type="checkbox"/>				
129. Faxing/Copying/Sorting/Filing activities	<input type="checkbox"/>				
130. Work/School related lifting	<input type="checkbox"/>				
131. Job coaching	<input type="checkbox"/>				
132. Notetaking	<input type="checkbox"/>				
133. Parking	<input type="checkbox"/>				
134. Using portable ramps	<input type="checkbox"/>				
135. Work/School preparation	<input type="checkbox"/>				
136. Technology/Computer assistance	<input type="checkbox"/>				
137. Transcribing	<input type="checkbox"/>				
138 Handling Administration/Registration Issues	<input type="checkbox"/>				
139. Library usage(retrieving books, checkout, etc.)	<input type="checkbox"/>				
140. Homework	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
141. Managing work/school activities	<input type="checkbox"/>				
142. Obtaining work/school supplies	<input type="checkbox"/>				
143. Organizing school projects	<input type="checkbox"/>				
144. Reading	<input type="checkbox"/>				
145. Setup school supplies	<input type="checkbox"/>				
146. Recording lectures	<input type="checkbox"/>				
147. Adaptations setup	<input type="checkbox"/>				
148. Sport activities	<input type="checkbox"/>				
149. Muscle strengthening	<input type="checkbox"/>				
150. Adapted physical education	<input type="checkbox"/>				
151. Therapeutic horseback riding	<input type="checkbox"/>				
152. Annual recreation camps	<input type="checkbox"/>				
153. Adapted skiing	<input type="checkbox"/>				
154. Adapted aquatics	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
155. Camping	<input type="checkbox"/>				
156. Church/Community activities	<input type="checkbox"/>				
157. Wheelchair recreation programs	<input type="checkbox"/>				
158. Cycling/Hand cycling activities	<input type="checkbox"/>				
159. Activities for emotional well-being	<input type="checkbox"/>				
160. Exercise/Gym activities	<input type="checkbox"/>				
161. Fishing	<input type="checkbox"/>				
162. Hobbies	<input type="checkbox"/>				
163. Hunting	<input type="checkbox"/>				
164. Internet Access (email)	<input type="checkbox"/>				
165. Kayaking	<input type="checkbox"/>				
166. Watching movies	<input type="checkbox"/>				
167. Outward bound	<input type="checkbox"/>				
168. Pre-injury activities	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
169. RV-ing	<input type="checkbox"/>				
170 Shopping	<input type="checkbox"/>				
171. Social recreation	<input type="checkbox"/>				
172. Volunteering	<input type="checkbox"/>				
173. Support groups	<input type="checkbox"/>				
174. Transportation to go shopping	<input type="checkbox"/>				
175. Running errands	<input type="checkbox"/>				
176. Transportation to sporting events	<input type="checkbox"/>				
177. Transportation to recreation activities	<input type="checkbox"/>				
178. Transportation to the bank	<input type="checkbox"/>				
179 Transportation to church/community activities	<input type="checkbox"/>				
180. Transportation to the dry cleaners	<input type="checkbox"/>				
181. Driving children to school	<input type="checkbox"/>				
182. Transporation to the video store	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
183. Transportation to appointments (General/MD/Therapy)	<input type="checkbox"/>				
184. Getting take out food	<input type="checkbox"/>				
185. Transportation to the hardware store	<input type="checkbox"/>				
186. Getting a haircut	<input type="checkbox"/>				
187. Transportation to the library	<input type="checkbox"/>				
188. Transportation to the movies	<input type="checkbox"/>				
189. Transportatation to pay bills	<input type="checkbox"/>				
190. Transportation to the pharmacy	<input type="checkbox"/>				
191. Transportation to the post office	<input type="checkbox"/>				
192. Transportation to professional activities	<input type="checkbox"/>				
193. Transportation to restaurants	<input type="checkbox"/>				
194. Transportation to school	<input type="checkbox"/>				
195. Transporation to the theater	<input type="checkbox"/>				
196. Transportation to social outings	<input type="checkbox"/>				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Sure
--	----------------------	----------	-------	-------------------	----------

197. Transportation to spontaneous events

198. Transportation to volunteer.

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Please list any comments you have in regards to the second round of this study:



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Thank You for Your Participation!

Thank you for your responses to the second round of this study. You will receive another email when your participation is requested for the third round of questions. Round 3 will include results from round 2 responses in which you will be asked to compare your responses with the mean responses of all the participants for each item listed. At the completion of the third (final round), you will receive a certificate for 5 CEU's applicable towards your Life Care Planning Certification (CLCP) from the Commission on Health Care Certification. Please note you must complete all 3 rounds in order to receive your CEU's. Please type your email address and click send to submit your responses. You may go back and change any responses before clicking send. If you have any questions in regards to this study please contact:

Jamie Pomeranz, Ph.D(c), CRC
Doctoral Candidate
Department of Rehabilitation Science
University of Florida
Gainesville, FL 32611
email: jpomeran@phhp.ufl.edu
Phone: 352-273-6566

BACK

Email Address:

SEND

APPENDIX F
DELPHI ROUND 2 FRIENDLY REMINDER EMAIL

Dear _____:

Approximately two weeks ago, an email was sent to you in regards to the second round of questioning for the Delphi Study involving Life Care Planners. This is a friendly reminder you still have the opportunity to complete the second round survey and advance our knowledge in this important aspect of Life Care Planning by participating in this study. This round is considerably quicker and simpler to complete and should take you about 15-20 minutes to finish. This is the second of three rounds of questioning.

Participants will receive 5 CEU's towards their Life Care Planning Certification (CLCP) for completing all three rounds of the study.

To begin the second round of this study, please click the link below or cut and paste the link into your browser. It is recommended that you use a later version of Internet Explorer or Netscape to view the survey.

http://www.phhp.ufl.edu/~jpomeran/quasksurvey/delphi_round_2_version_4.htm

Please contact Jamie Pomeranz, Ph.D(c), CRC at (352) 273-6566 with any questions regarding this study.

APPENDIX G
DELPHI ROUND 3

college of University of Florida
Public Health and Health Professions

Delphi Study

Professional Life Care Planners
Round 3

Take Survey

Rehabilitation Outcomes Research Center 
VA HSR&D and RR&D Center of Excellence

ALL PROFESSIONAL LIFE CARE PLANNERS PARTICIPATING IN OUR RESEARCH STUDY

Thank you for completing the first and second rounds of questioning for our study entitled "Creating a Personal Attendant Care Measure for Individuals with SCI". The goal of this round is to achieve consensus regarding whether or not each item listed should be considered when making recommendations for personal attendant care and replacement services in a Life Care Plan. You will now have the opportunity to review consensus data from all the participants' responses to each of the items listed in the second round.

This data includes the Median and the Interquartile range. The Median is the point below which 50% of the responses fell. The Interquartile Range contains the middle 50% of the responses. This range gives an indication of how widely the responses differed from one another. You are now instructed to do the following:

1. Review the Median and Interquartile Range for each item.
2. Review your previous response to each item.
3. Decide whether or not you would like to keep or change your response to each item.

The values in the data are associated with each part of the rating scale.

1="Strongly Disagree"

2="Disagree"

3="Agree"

4="Strongly Agree"

There is not a value associated with "Not Sure" and therefore those responses were not reported in this round of the study.

The next page shows an example of the data being represented.

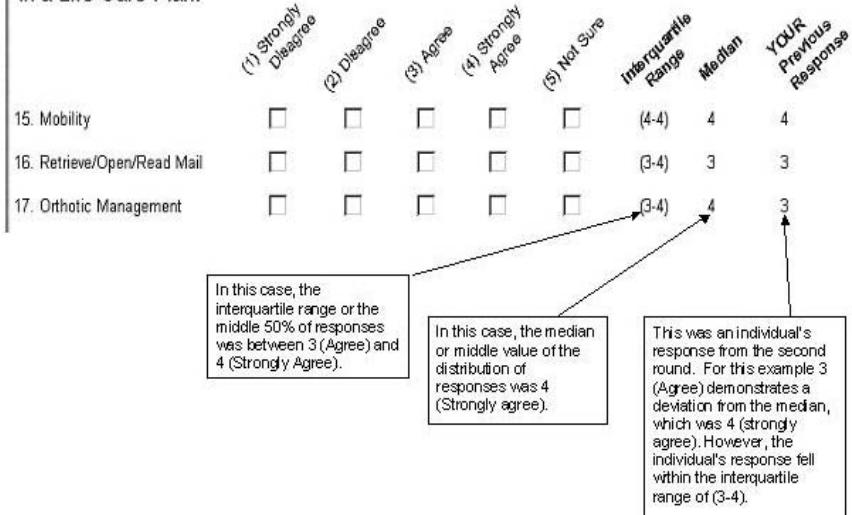
Similar to the second round, the third round is considerably quick and simple to complete and should take you about 15-20 minutes to finish. This is the third of three rounds of questioning. Once the data is received from this final round, participants will receive an email requesting contact information in regards to where you would like to receive your certificate for 5 CEU's towards your CLCP. The CEU'S have been approved by the Commission on Health Care Certification.

As stated previously, there are no discomforts or risks to the expert by taking part in this study. The purpose of this study is to acquire benchmark data that can provide validity checks to Life Care Planners while assessing and addressing personal assistance and replacement services. The study involves obtaining the opinions of expert Life Care Planners in regards to the necessary constructs and items to be considered when recommending personal attendant care services.

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EXAMPLE

The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:



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DELPHI STUDY ROUND 3 INSTRUCTIONS FOR LIFE CARE PLANNERS

As stated in the previous rounds, please respond based on individuals with a SPINAL CORD INJURY. We understand that recommendations change for every individual based on level of disability, gender, demographics, etc. Please indicate your agreement or disagreement with the items from a global perspective. For example, an individual who has a T-11 level spinal cord injury may not require personal assistance for many activities such as transportation, eating, and grooming. However, an individual with a C-4 level spinal cord injury will most likely require assistance for many ADL activities such as transferring, dressing, and personal hygiene. Therefore, when responding to a question about whether you should consider transportation needs in determining the extent of PCA services for individuals with SCI, you should consider whether there are any individuals with SCI for whom that would be an important consideration. All the categories have been combined for this round, which include: ADL's, Housekeeping, Home/Yard Maintenance, Work, Education, Transportation, and Leisure. Thank you for your participation.

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
1. Bowel/Bladder management	<input type="checkbox"/>	(4-4)	4	4				
2. Childcare	<input type="checkbox"/>	(3-4)	4	3				
3. Communication activities	<input type="checkbox"/>	(3-4)	4	4				
4. Computer activities	<input type="checkbox"/>	(3-4)	3	3				
5. Dressing	<input type="checkbox"/>	(4-4)	4	4				
6. Grooming	<input type="checkbox"/>	(4-4)	4	4				
7. Drinking	<input type="checkbox"/>	(4-4)	4	4				
8. Eating	<input type="checkbox"/>	(4-4)	4	4				
9. Endurance activities	<input type="checkbox"/>	(3-4)	4	3				
10. Health management	<input type="checkbox"/>	(4-4)	4	4				
11. Hygiene	<input type="checkbox"/>	(4-4)	4	4				
12. ADL's	<input type="checkbox"/>	(4-4)	4	4				
13. Judgement/Decision making	<input type="checkbox"/>	(3-4)	4	4				
14. Managing medication	<input type="checkbox"/>	(3-4)	4	4				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	(5) Not Sure	Interquartile Range	Median	YOUR Previous Response
15. Mobility	<input type="checkbox"/>	(4-4)	4	4				
16. Retrieve/Open/Read Mail	<input type="checkbox"/>	(3-4)	3	3				
17. Orthotic Management	<input type="checkbox"/>	(3-4)	4	4				
18. Personal Business	<input type="checkbox"/>	(3-4)	3	3				
19. Safety	<input type="checkbox"/>	(4-4)	4	4				
20. Self-Care	<input type="checkbox"/>	(3-4)	4	4				
21. Social Cognition	<input type="checkbox"/>	(3-4)	3	3				
22. Stair Climbing	<input type="checkbox"/>	(3-4)	4	4				
23. Teeth Brushing	<input type="checkbox"/>	(3.5-4)	4	4				
24. Telephone Use	<input type="checkbox"/>	(3-4)	4	4				
25. Toileting	<input type="checkbox"/>	(4-4)	4	4				
26. Transferring	<input type="checkbox"/>	(4-4)	4	4				
27. Washing	<input type="checkbox"/>	(3-4)	4	4				
28. Writing	<input type="checkbox"/>	(3-4)	3.5	3				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan.

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
29. Fine motor movement	<input type="checkbox"/>	(3-4)	4	4				
30. Clean A/C vents	<input type="checkbox"/>	(2-3)	3	3				
31. Clean baseboards	<input type="checkbox"/>	(2-3)	3	3				
32. Clean blinds	<input type="checkbox"/>	(2-3)	3	3				
33. Clean cabinets	<input type="checkbox"/>	(2-3)	3	3				
34. Clean refrigerator	<input type="checkbox"/>	(3-3)	3	3				
35. Clean oven	<input type="checkbox"/>	(2.25-3)	3	3				
36. Clean bathtubs	<input type="checkbox"/>	(3-3.75)	3	3				
37. Clean up after meals	<input type="checkbox"/>	(3-3.5)	3	3				
38. Clean crown molding	<input type="checkbox"/>	(2-3)	3	3				
39. Clean dishes	<input type="checkbox"/>	(3-4)	3	3				
40. Clean drapes/curtains	<input type="checkbox"/>	(2-3)	3	3				
41. Clean closets	<input type="checkbox"/>	(2-3)	3	3				
42. Clear cobwebs	<input type="checkbox"/>	(2-3)	3	3				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan.

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
43. Clean garage	<input type="checkbox"/>	(2-3)	2.5	2				
44. Dusting	<input type="checkbox"/>	(3-3)	3	3				
45. Clean roof gutters	<input type="checkbox"/>	(2-3)	3	2				
46. Cleaning light fixtures	<input type="checkbox"/>	(2-3)	3	3				
47. Grocery management	<input type="checkbox"/>	(3-4)	4	3				
48. Handling paperwork	<input type="checkbox"/>	(3-4)	3	3				
49. Start fire in fireplace	<input type="checkbox"/>	(1-3)	2	1				
50. Cooking	<input type="checkbox"/>	(3-4)	4	4				
51. Ironing	<input type="checkbox"/>	(2.25-3)	3	3				
52. Laundry	<input type="checkbox"/>	(3-4)	4	4				
53. Lifting activities	<input type="checkbox"/>	(3-4)	4	4				
54. Maintaining storage area	<input type="checkbox"/>	(2-3)	3	2				
55. Maintaining clothing	<input type="checkbox"/>	(3-4)	3	4				
56. Maintaining environmental controls	<input type="checkbox"/>	(3-4)	4	4				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
57. Maintain fire/smoke/security alarm	<input type="checkbox"/>	(3-4)	3	4				
58. Making Beds	<input type="checkbox"/>	(3-4)	3	4				
59. Managing daily schedule	<input type="checkbox"/>	(3-4)	3	3				
60. Managing household finances	<input type="checkbox"/>	(3-4)	3	3				
61. Mopping floors	<input type="checkbox"/>	(3-4)	3	3				
62. Move furniture/arrange environment	<input type="checkbox"/>	(2-3)	3	3				
63. Opening/Closing windows	<input type="checkbox"/>	(2.25-4)	3	4				
64. Organizing Kitchen	<input type="checkbox"/>	(2-3.5)	3	3				
65. Pet-Care	<input type="checkbox"/>	(2-3)	3	3				
66. Waxing furniture	<input type="checkbox"/>	(2-3)	3	3				
67. Sweeping with a broom	<input type="checkbox"/>	(3-4)	3	3				
68. Spring/Fall cleaning	<input type="checkbox"/>	(3-4)	3	3				
69. Turning over mattress	<input type="checkbox"/>	(2-3)	3	3				
70. Using a dishwasher	<input type="checkbox"/>	(3-3)	3	4				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
71. Vacuuming	<input type="checkbox"/>	(3-4)	3	4				
72. Washing walls	<input type="checkbox"/>	(2-3)	3	4				
73. Washing windows	<input type="checkbox"/>	(2-3)	3	4				
74. Woodworking	<input type="checkbox"/>	(2-3)	2	2				
75. Baling hay	<input type="checkbox"/>	(1-2)	2	2				
76. Carpentry repairs	<input type="checkbox"/>	(2-3)	3	3				
77. Bushhogging	<input type="checkbox"/>	(1-3)	2	2				
78. Dead-heading	<input type="checkbox"/>	(1-3)	2	2				
79. Edging	<input type="checkbox"/>	(2-3)	2	3				
80. Electrical work	<input type="checkbox"/>	(1.75-3)	2	2				
81. Cutting firewood	<input type="checkbox"/>	(1-3)	2	2				
82. Emergency egress	<input type="checkbox"/>	(3-4)	4	4				
83. Fixing squeaky doors	<input type="checkbox"/>	(2-3)	2	2				
84. Furnace/AC Maintenance	<input type="checkbox"/>	(2-3)	3	2				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
85. Taking out the garbage	<input type="checkbox"/>	(3-4)	3	4				
86. Garden management	<input type="checkbox"/>	(2-3)	3	2				
87. Filling gas tank	<input type="checkbox"/>	(3-3)	3	4				
88. Disposing of debris	<input type="checkbox"/>	(2-3)	3	2				
89. Climbing ladders	<input type="checkbox"/>	(2-3)	2	3				
90. Hammering	<input type="checkbox"/>	(2-3)	2	2				
91. Hanging pictures	<input type="checkbox"/>	(2-3)	2	2				
92. Home decorating	<input type="checkbox"/>	(2-3)	2	2				
93. Landscaping	<input type="checkbox"/>	(2-3)	2	2				
94. Lawn mowing	<input type="checkbox"/>	(3-3)	3	3				
95. Leaf blowing	<input type="checkbox"/>	(2-3)	3	3				
96. Changing light bulbs	<input type="checkbox"/>	(3-3)	3	3				
97. Putting down mulch	<input type="checkbox"/>	(1.5-3)	2	2				
98. Changing oil	<input type="checkbox"/>	(2-3)	2	2				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
99. Outdoor repairs	<input type="checkbox"/>	(2-3)	3	3				
100. Painting	<input type="checkbox"/>	(2-3)	2.5	2				
101. Plumbing	<input type="checkbox"/>	(2-3)	2.5	2				
102. Pool maintenance	<input type="checkbox"/>	(2-3)	2	2				
103. Restore power outages	<input type="checkbox"/>	(2-3)	3	2				
104. Pruning	<input type="checkbox"/>	(2-3)	2	2				
105. Putting up fixtures	<input type="checkbox"/>	(2-3)	2	2				
106. Raking	<input type="checkbox"/>	(2-3)	3	3				
107. Remodeling	<input type="checkbox"/>	(2-3)	2	2				
108. Roof repair	<input type="checkbox"/>	(1.25-3)	2	2				
109. Using a screwdriver	<input type="checkbox"/>	(2-3)	3	3				
110. Seasonal fertilizer	<input type="checkbox"/>	(2-3)	2	2				
111. Shrub maintenance	<input type="checkbox"/>	(2-3)	2	2				
112. Snow management	<input type="checkbox"/>	(3-3)	3	2				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
113. Spa maintenance	<input type="checkbox"/>	(2-3)	2	3				
114. Using a string trimmer/Weedeater®	<input type="checkbox"/>	(2-3)	3	3				
115. Maintain automatics sprinkler system	<input type="checkbox"/>	(2-3)	2	2				
116. Watering garden/grass	<input type="checkbox"/>	(2-3)	3	3				
117. Check tire pressure	<input type="checkbox"/>	(2-3)	2.5	3				
118. Trim work	<input type="checkbox"/>	(2-3)	2	2				
119. Washing car	<input type="checkbox"/>	(2-3)	2.5	3				
120. Carrying work/school supplies	<input type="checkbox"/>	(3-3)	3	4				
121. Test taking	<input type="checkbox"/>	(2.75-4)	3	3				
122. Taking a break at work/school	<input type="checkbox"/>	(2-3)	3	3				
123. Typing reports	<input type="checkbox"/>	(2.75-3)	3	4				
124. Tutoring	<input type="checkbox"/>	(2-3)	3	4				
125. Dictating reports, letters, notes, etc. (work or school)	<input type="checkbox"/>	(3-3.25)	3	4				
126. Entering/Exit work/school environment	<input type="checkbox"/>	(3-4)	3	4				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	Y CUR Previous Response
127. Getting on/off elevators	<input type="checkbox"/>	(3-4)	3	4				
128. Escort at work/between classes	<input type="checkbox"/>	(3-4)	3	4				
129. Faxing/Copying/Sorting/Filing	<input type="checkbox"/>	(3-3)	3	4				
130. Work/School related lifting	<input type="checkbox"/>	(3-4)	3	4				
131. Job coaching	<input type="checkbox"/>	(2.75-4)	3	4				
132. Notetaking	<input type="checkbox"/>	(3-4)	3	4				
133. Parking	<input type="checkbox"/>	(3-4)	3	4				
134. Using portable ramps	<input type="checkbox"/>	(3-4)	3.5	4				
135. Work/School preparation	<input type="checkbox"/>	(3-4)	3	4				
136. Technology/Computer assistance	<input type="checkbox"/>	(3-4)	3	4				
137. Transcribing	<input type="checkbox"/>	(3-3)	3	4				
138. Handling Admin/Registration issues	<input type="checkbox"/>	(2.75-4)	3	4				
139. Library usage(retrieving books, checkout)	<input type="checkbox"/>	(3-4)	3	4				
140. Homework	<input type="checkbox"/>	(3-4)	3	4				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
141. Managing work/school activities	<input type="checkbox"/>	(3-4)	3	4				
142. Obtaining work/school supplies	<input type="checkbox"/>	(3-3.75)	3	4				
143. Organizing school projects	<input type="checkbox"/>	(3-3)	3	4				
144. Reading	<input type="checkbox"/>	(3-4)	3	4				
145. Setup school supplies	<input type="checkbox"/>	(3-3.25)	3	4				
146. Recording lectures	<input type="checkbox"/>	(3-3.75)	3	4				
147. Adaptations setup	<input type="checkbox"/>	(3-4)	4	4				
148. Sport activities	<input type="checkbox"/>	(3-3)	3	3				
149. Muscle strengthening	<input type="checkbox"/>	(3-4)	4	3				
150. Adapted physical education	<input type="checkbox"/>	(3-4)	3	3				
151. Therapeutic horseback riding	<input type="checkbox"/>	(2-3)	3	2				
152. Annual recreation camps	<input type="checkbox"/>	(3-3.75)	3	2				
153. Adapted skiing	<input type="checkbox"/>	(2-3)	3	2				
154. Adapted aquatics	<input type="checkbox"/>	(3-3)	3	2				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
155. Camping	<input type="checkbox"/>	(2-3)	3	2				
156. Church/Community activities	<input type="checkbox"/>	(3-3.75)	3	3				
157. Wheelchair recreation programs	<input type="checkbox"/>	(3-3.75)	3	3				
158. Cycling/Hand cycling activities	<input type="checkbox"/>	(3-3)	3	3				
159. Activities for emotional well-being	<input type="checkbox"/>	(3-4)	3.5	3				
160. Exercise/Gym activities	<input type="checkbox"/>	(3-4)	3	3				
161. Fishing	<input type="checkbox"/>	(2-3)	3	2				
162. Hobbies	<input type="checkbox"/>	(3-4)	3	4				
163. Hunting	<input type="checkbox"/>	(2-3)	2	2				
164. Internet Access (email)	<input type="checkbox"/>	(3-4)	3	4				
165. Kayaking	<input type="checkbox"/>	(2-3)	2	2				
166. Watching movies	<input type="checkbox"/>	(2-3)	3	4				
167. Outward bound	<input type="checkbox"/>	(2-3)	3	2				
168. Pre-injury activities	<input type="checkbox"/>	(3-4)	3	4				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	(5) Not Sure	Interquartile Range	Median	YOUR Previous Response
169. RV-ing	<input type="checkbox"/>	(2-3)	3	3				
170. Shopping	<input type="checkbox"/>	(3-4)	3.5	4				
171. Social recreation	<input type="checkbox"/>	(3-4)	3	4				
172. Volunteering	<input type="checkbox"/>	(2-3)	3	4				
173. Support groups	<input type="checkbox"/>	(3-4)	3.5	4				
174. Transportation to go shopping	<input type="checkbox"/>	(3-4)	4	4				
175. Running errands	<input type="checkbox"/>	(3-4)	4	4				
176. Transportation to sporting events	<input type="checkbox"/>	(3-3.25)	3	4				
177. Transportation to recreation activities	<input type="checkbox"/>	(3-4)	3	4				
178. Transportation to the bank	<input type="checkbox"/>	(3-4)	3	4				
179. Transportation to church /community activities	<input type="checkbox"/>	(3-4)	3	4				
180. Transportation to the dry cleaners	<input type="checkbox"/>	(3-3.25)	3	4				
181. Driving children to school	<input type="checkbox"/>	(3-3.75)	3	4				
182. Transporation to the video store	<input type="checkbox"/>	(2-3)	3	4				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	(5) Not Sure	Interquartile Range	Median	YOUR Previous Response
183. Transportation to MD/Therapy appt.	<input type="checkbox"/>	(3.25-4)	4	4				
184. Getting take out food	<input type="checkbox"/>	(2.75-3)	3	4				
185. Transportation to the hardware store	<input type="checkbox"/>	(3-3)	3	4				
186. Getting a haircut	<input type="checkbox"/>	(3-4)	3	4				
187. Transportation to the library	<input type="checkbox"/>	(2.75-3.25)	3	4				
188. Transportation to the movies	<input type="checkbox"/>	(2.75-3)	3	4				
189. Transportatation to pay bills	<input type="checkbox"/>	(3-4)	3	4				
190. Transportation to the pharmacy	<input type="checkbox"/>	(3-4)	4	4				
191. Transportation to the post office	<input type="checkbox"/>	(3-4)	3	4				
192. Transportation to professional activities	<input type="checkbox"/>	(3-4)	4	4				
193. Transportation to restaurants	<input type="checkbox"/>	(3-3)	3	4				
194. Transportation to school	<input type="checkbox"/>	(3-4)	4	4				
195. Transporation to the theater	<input type="checkbox"/>	(3-3)	3	4				
196. Transportation to social outings	<input type="checkbox"/>	(3-4)	3	4				

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The following activities are important to consider when making recommendations for personal assistance and replacement services in a Life Care Plan:

	(1) Strongly Disagree	(2) Disagree	(3) Agree	(4) Strongly Agree	Not Sure	Interquartile Range	Median	YOUR Previous Response
197. Transportation to spontaneous events	<input type="checkbox"/>	(3-3.5)	3	4				
198. Transportation to volunteer.	<input type="checkbox"/>	(3-4)	3	4				

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Please list any comments you have in regards to the third round of this study:



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Thank You for Your Participation!

Thank you for your responses to the third round of this study. For completing all three rounds of this study, you will receive a certificate for 5 CEU's applicable towards your Life Care Planning Certification (CLCP) from the Commission on Health Care Certification. Once we receive your data, we will be sending you an email requesting contact information in regards to where you would like to receive your CEU certificate. Please type YOUR email address and click SEND to submit your responses. You may go back and change any responses before clicking send. If you have any questions in regards to this study please contact:

Jamie Pomeranz, Ph.D(c), CRC
Doctoral Candidate
Department of Rehabilitation Science
University of Florida
Gainesville, FL 32611
email: jpomeran@phhp.ufl.edu
Phone: 352-273-6566

BACK

Email Address:

SEND



APPENDIX H

DELPHI ROUND 3 EMAIL TO LIFE CARE PLANNING EXPERTS

Dear Participant:

Thank you for completing the first and second rounds of questioning for our study entitled "Creating a Personal Attendant Care Measure for Individuals with SCI".

The third and final round of questioning is now ready for your participation. As with Round 2, this round is considerably quick and simple to complete and should take you about 15-20 minutes to finish. This is the third and final round of questioning.

Participants will receive 5 CEU's for their Life Care Planning Certification (CLCP) for completing all three rounds of the study.

The goal of this round is to achieve consensus regarding whether or not each item listed in the questionnaire should be considered when making recommendations for personal attendant care and replacement services in a Life Care Plan. You will now have the opportunity to review consensus data from all the participants' responses to each of the items listed in the second round. You will now be instructed to review the consensus data as well as your previous answers and decide whether or not you would like to keep or change your response to each item.

A stated previously, there are no discomforts or risks to the expert by taking part in this study. The purpose of this study is to acquire benchmark data that can provide validity checks to Life Care Planners while assessing and addressing personal assistance and replacement services.

To begin the third round of this study, please click the link below or cut and paste the link into your browser. It is recommended that you use a later version of Internet Explorer or Netscape to view the survey.

http://www.phhp.ufl.edu/~jpomeran/quasksurvey/lcp3_

Please contact Jamie Pomeranz, Ph.D(c), CRC at (352) 273-6566 with any questions regarding this study.

APPENDIX I
DELPHI ROUND 3 FRIENDLY REMINDER EMAIL

Dear Participant:

A little over a week ago, an email was sent to you in regards to the third and final round of questioning for the Delphi Study involving Life Care Planners. This is a friendly reminder you still have the opportunity to complete the third round survey and advance our knowledge in this important aspect of Life Care Planning by continuing to participate in this study. This round is considerably quick and simple to complete and should take you about 15-20 minutes to finish. This is the third and final round of questioning. Participants will receive 5 CEU's towards their Life Care Planning Certification (CLCP) for completing all three rounds of the study.

The goal of this round is to achieve consensus regarding whether or not each item listed in the questionnaire should be considered when making recommendations for personal attendant care and replacement services in a Life Care Plan. You will now have the opportunity to review consensus data from all the participants' responses to each of the items listed in the second round. You will now be instructed to review the consensus data as well as your previous answers and decide whether or not you would like to keep or change your response to each item.

A stated previously, there are no discomforts or risks to the expert by taking part in this study. The purpose of this study is to acquire benchmark data that can provide validity checks to Life Care Planners while assessing and addressing personal assistance and replacement services.

To begin the third round of this study, please click the link below or cut and paste the link into your browser. It is recommended that you use a later version of Internet Explorer or Netscape to view the survey. It may take a minute for the survey to load on slower connection speeds.

<http://www.phhp.ufl.edu/~jpomeran/quasksurvey>

Please contact Jamie Pomeranz, Ph.D(c), CRC at (352) 273-6566 with any questions regarding this study.

APPENDIX J INTERVIEW GUIDE

This interview is designed so that we can develop a means for determining personal attendant care needs. You have received a consent form to sign, which indicates your consent to this interview. This interview will be recorded. You will hear questions in regards to personal attendant care. This type of care is defined as any personal assistance you need in order for you to complete tasks or activities on a daily basis.

1. What is your specific level of Spinal Cord Injury?
2. What is your age if less than 89?
3. How old were you when your injury occurred?
4. In regards to personal hygiene, for what activities currently or in the past have you needed a personal care attendant?
5. In regards to hobbies and leisure, for what activities currently or in the past have you needed a personal care attendant?
6. In regards to household chores, home maintenance, and yard work, for what activities currently or in the past have you needed a personal care attendant?
7. In regards to work or education, for what activities currently or in the past have you needed a personal care attendant?
8. What person acts as your personal care attendant (private hire, spouse, nurse, son, daughter, etc.)?

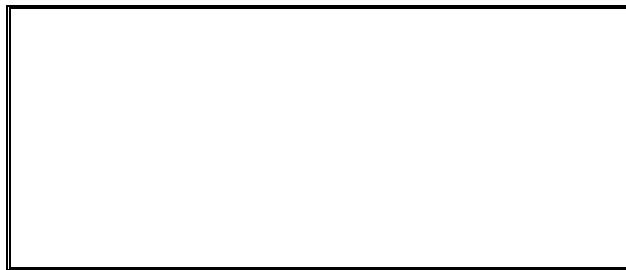
9. How many hours in a typical day do you require a personal care attendant?
10. Are there any activities for which you don't receive assistance from a personal care attendant that you feel you do need assistance?
11. How did you obtain your personal care attendant?
12. Tell me about any situations, in which you might require, more personal attendant care?
13. Tell me about any situations that might result in you requiring less personal attendant care?
14. How has your living environment affected your need for personal attendant care?
15. Where did you get the funding to support a personal care attendant?
16. How has the aging process affected your need for a personal care attendant?
17. What do you feel should be considered when assessing an individual with a spinal cord injury's need for personal attendant care.
18. Do you have assistive technology or assistive devices that have replaced your need for personal attendant care?
19. What additional activities that require a personal care attendant, do you feel could be replaced by assistive devices?
20. Is there any issue we have not discussed that might impact your need for personal attendant care?

Thank you for participating in this interview. The information you have provided will help us determine the specific personal attendant care needs for individuals with spinal cord injuries

APPENDIX K
CONSENT FORM FOR VETERAN PARTICPANTS

IRB# 266-2004

Informed Consent to Participate in Research



You are being asked to take part in a research study. This form provides you with information about the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Your participation is entirely voluntary. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. If you choose not to participate in this study you will not be penalized or lose any benefits that you would otherwise be entitled to.

1. Name of Participant ("Study Subject")

2. Title of Research Study

Creating Personal Attendant Care Measure for Individuals with Spinal Cord Injury

3. Principal Investigator and Telephone Number(s)

Jamie Pomeranz, Ph.D., CRC. jpomeran@hp.ufl.edu 352-273-6566

4. Source of Funding or Other Material Support

This study is funded by the Department of Veterans' Affairs (VA) Pre-Doctoral Associated Health Rehabilitation Research Fellowship Program.

5. What is the purpose of this research study?

The purpose of this study is to develop an instrument to determine the broad range of personal attendant care (PAC) services needed by individuals with SCI. By using such assessments, consumers, health care professionals, and policy makers will be better informed about the personal attendant care needs of individuals with spinal cord injuries

6. What will be done if you take part in this research study?

You will be asked questions about your disability and your ability to perform daily life activities. These questions will directly relate the need for personal assistance. This session will be audio taped and last for approximately 1 hour.

7. What are the possible discomforts and risks?

There is a possibility that you may feel uncomfortable because the questions may be about challenges you face in performing your daily activities. You may refuse to answer any question you do not want to answer and you may withdraw from the study at any time without consequences of any kind. If you wish to discuss the information above or any other discomforts you may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

Throughout the study, the researcher will notify you of new information that may become available and might affect your decision to remain in the study.

If you wish to discuss the information above or any discomforts you may experience, you may ask questions now or call the Principal Investigator or contact person listed on the front page of this form.

8a. What are the possible benefits to you?

You will not directly benefit from participation in this study.

8b. What are the possible benefits to others?

By participating in this study, you will be helping to develop an assessment to better inform consumers, health care professionals, and policy makers about the personal attendant care needs of individuals with spinal cord injuries

9. If you choose to take part in this research study, will it cost you anything?

No

Costs for routine medical care procedures that are not being done only for the study will be charged to you or your insurance. These costs may not be charged if you are a veteran and you are being treated at the North Florida/South Georgia Veterans Health System (NF/SG VHS).

10. Will you receive compensation for taking part in this research study?

Yes. \$50.00

11. What if you are injured because of the study?

If you experience an injury that is directly caused by this study, only professional consultative care that you receive at the University of Florida Health Science Center will be provided without charge. However, hospital expenses will have to be paid by you or your insurance provider. No other compensation is offered.

You will not have to pay hospital expenses if you are being treated at the North Florida/South Georgia Veterans Health System (NF/SG VHS) and experience any physical injury during participation in a Veterans Health System-approved study.

12. What other options or treatments are available if you do not want to be in this study?

There are no other options or treatments available to you. Participation in this study is entirely voluntary. You are free to refuse to be in the study, and your refusal will not influence current or future health care you receive at this institution.

13a. Can you withdraw from this research study?

You are free to withdraw your consent and to stop participating in this research study at any time. If you do withdraw your consent, there will be no penalty, and you will not lose any benefits you are entitled to.

If you decide to withdraw your consent to participate in this research study for any

reason, you should contact Jamie Pomeranz at (352) 273-6566

If you have any questions regarding your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

13b. If you withdraw, can information about you still be used and/or collected?

No

13c. Can the Principal Investigator withdraw you from this research study?

You may be withdrawn from the study without your consent for the following reasons:

If you do not meet the eligibility criteria.

14. How will your privacy and the confidentiality of your research records be protected?

Authorized persons from the University of Florida, the hospital or clinic (if any) involved in this research, and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of them to the extent permitted by law. Otherwise, your research records will not be released without your consent unless required by law or a court order.

If the results of this research are published or presented at scientific meetings, your identity will not be disclosed.

15. How will the researcher(s) benefit from your being in this study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator may benefit if the results of this study are presented at scientific meetings or in scientific journals.

16. Signatures

As a representative of this study, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how privacy will be protected:

Signature of Person Obtaining Consent

Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how your privacy will be protected.

You have received a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

Signature of Person Consenting

Date

VA regulations require a witness for all of the signatures provided above.

Signature of Witness

Date

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BIOGRAPHICAL SKETCH

Jamie L. Pomeranz, MHS, CRC is a doctoral candidate in the rehabilitation science doctoral program at the University of Florida College of Public Health and Health Professions (Gainesville, FL). Mr. Pomeranz received master's degrees in rehabilitation counseling and exercise and sports science from the University of Florida in 1998 and 2000 respectively. Mr. Pomeranz also received a Bachelor of Science degree in nutrition and fitness from Florida State University in 1995. Accomplishments during Mr. Pomeranz's doctoral student career include being a recipient of a 2003-2004 Department of Veterans Affairs (VA) Pre-Doctoral Associated Health Rehabilitation Research Fellowship, which allowed him to conduct his dissertation studies at the Rehabilitation Outcome Research Center (RORC) at the North Florida/South Georgia Veterans Affairs Medical Center (Gainesville, FL); recipient of the 2004 John Muthard Award for excellence in research from the University of Florida College of Public Health and Health Professions, Department of Rehabilitation Counseling; and recipient of grant funding from the Foundation for Life Care Planning Research to fund his doctoral dissertation. Mr. Pomeranz has been working with individuals with disabilities for over 10 years in areas of physical rehabilitation, case management and research. While completing the requirements for his doctoral degree, Mr. Pomeranz worked as a research assistant for Dr. Craig Velozo in the Department of Occupational Therapy at the University of Florida. Additionally, throughout his doctoral training, Mr. Pomeranz was selected to present at various conferences including the 2004 ACRM-ASNR Joint Conference.