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Consensus Among Life Care Planners Regarding Activities to Consider When Recommending Personal Attendant Care Services for Individuals with Spinal Cord Injury: A Delphi Study

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Abstract. *Personal attendant care (PAC) needs often represent the single most expensive part of a life care plan (LCP). As such, life care planners should exercise care in accurately depicting the types and amount of PAC in a life care plan. The purpose of this study was to acquire benchmark data that could provide validity checks for life care planners when recommending PAC. A Delphi study was conducted with 24 life care planners to reach consensus regarding the activities to consider when recommending PAC. Consensus was reached after three rounds, resulting in 164 items that should be considered when recommending PAC. These items represented self-care, home/yard maintenance, transportation, leisure, work, and educational activities. The results of this study provide life care planners with a detailed checklist of PAC activities to utilize while working on a life care plan for individuals with spinal cord injury (SCI). This checklist, in conjunction with client interviews, review of medical records, and consultation with rehabilitation professionals, should facilitate the development of accurate prediction of PAC needs for individuals with SCI.*

Personal Attendant Care 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).

Personal attendant care 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). These types of services are provided for 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.

For many individuals with SCI, absence of assistance with such day-to day activities can lead to serious health care problems affecting 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, as individuals with SCI age, they experience a wide array of physiological and health-related changes, translating into increasing demands for PAC (Robinson-Whelen & Rintala, 2003).

Individuals who provide personal assistance to individuals with SCI are often referred to as personal care attendants (PCAs). These providers 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 expected to be 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) with specialized training. 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 (Winkler & 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). For example, Hall et al. (1999) found that individuals with high tetraplegia used more than 135 hours of paid assistance weekly. If paid personal care attendants hired from an agency were being paid $10-15 per hour, this agency provided care would amount to a range of $70,200-$105,300 per year.

Experts in Recommending PAC Services

As cited in Weed (2004), the life care plan is defined as a dynamic document based upon published standards of practice, comprehensive assessments, data analysis, and research. Further, 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. Topics that are covered under a LCP often include projected evaluations, projected therapeutic modalities, diagnostic testing/education assessment, wheelchair needs, wheelchair accessories/maintenance, aids for independent function, orthotics/prosthetics, home furnishings/accessories, drug/supply needs, home/personal/facility attendant care, future medical care-routine, transportation, health/strength maintenance, architectural renovations, potential complications, future medical care/surgical intervention, orthopedic equipment needs, and

vocational/educational needs (Weed, 1989, rev. 1993, as cited in Weed & Field, 2001).

Life care plans are frequently used in personal injury and other types of litigation and must be defensible in courts of law. In addition, PAC, often included within the Home/Facility care recommendations, comprises a substantial volume of measurable data and costs within a life care plan (Sutton, Deutsch, Weed, & Berens, 2002). As such, to prevent improper estimation of PAC needs, life care planners must often rely on objective and accurate measures of rehabilitation needs and outcomes. Winkler and Weed (2004) state that overestimating PAC needs will result in inaccurate, unjustifiable, and more expensive rehabilitation plans. They also point out that underestimating PAC needs may lead to a higher rate of complications and hospitalization, even possibly reducing life expectancy.

Because PAC is one of the costliest components of a life care plan, such recommendations are often challenged in the forensic arena (P. Deutsch, personal communication, January 24, 2002). Such recommendations most often fall under the home/personal/facility attendant care component of a life care plan. Under this category, PAC consists of recommendations based on assistance needs imposed by the onset of disability as well as replacement services or assistance related to household activity, yard, and property maintenance that were performed independently prior to the disability (H. Sawyer, personal communication, January 16, 2004).

Methods

The purpose of this study was to acquire data that could provide validity checks for life care planners when recommending PAC. The University of Florida Health Science Center Institutional Review Board (IRB-01) approved this study prior to the enrollment of participants.

Subjects

Life care planners (n=100) were selected from a mailing list of approximately 500 individuals who completed the MediPro Seminars LCP Certificate Program. Based on a review of the literature and in order to obtain diversity in responses, the investigators 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 subjects that are "information-rich and illuminative, that is they offer useful manifestations of the phenomenon of interest" (p. 40). This non-probability sampling technique does not assure representativeness; however, the method is often used for Delphi studies in order to select participants that can apply their knowledge to a certain problem on the basis of criteria, which are developed from the nature of the problem under investigation (Hasson, Keeney, & McKenna, 2000). The individuals selected for this study had worked for at least three years as life care planners in order to assure that they could make knowledgeable recommendations for PAC. Since the Delphi method requires a continued commitment from subjects being questioned about the same topic over multiple rounds, there is an increased potential for participant drop out (Hasson et al., 2000). Furthermore, the average response rate for health related surveys is 60% (Asch, Jedrziewski, & Christakis, 1997). This percentage is associated

with a single round survey and would be expected to decrease following two additional rounds of questioning. Therefore, to maximize the potential to obtain commitment from 24 participants across multiple rounds, the initial sample included 100 participants.

Delphi Study

A web-based Delphi technique was used to reach a consensus regarding the activities to consider when recommending PAC. The Delphi technique is a method of soliciting and combining the opinions of a group of experts. The method involves a rapid and efficient way to combine the knowledge and abilities of a diverse group 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 investigation (Williams & Webb, 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 (Linderman, 1981). 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 and is suitable for problems where there is insufficient or contradictory scientific evidence (Herdman, Rajmil, Ravens-Sieberer, Bullinger, Power, & Alonso, 2002).

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. While the development of opinion 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 & Webb, 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

The article's primary author developed a list of open-ended questions based on review of the literature, standards of practice, and preliminary data from brainstorming with LCP experts regarding significant issues to explore in developing a PAC assessment for individuals with SCI (See Appendix). In addition, demographic questions were developed to assess diversity in terms of gender, age, education and training, occupation, and experience.

The next step involved formatting the first round of questioning to be applied in a web-based format. The Quask Form Artist® software program was used to develop online forms that would be easily accessible to the participants (Quask, 2004). This web form design program enables the user to collect and analyze data through a wide range of export and statistical analysis functions. The rationale for using a web-based approach was 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 who responded from different parts of the country.

Once the initial round of questions was developed, the survey was alpha tested on four 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. The recommendations from the alpha testing were incorporated into the initial round of questions to be sent to the LCP experts.

Delphi Round 1

All 100 life care planners were contacted via email and requested to voluntarily participate in the Delphi Study. As incentive for involvement in the study, the participants were informed that they would receive five continuing education credits (CEUs) toward their life care planning certification. The investigators obtained pre-approval to provide the CEUs from the Commission on Health Care Certification. 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. Prior to completing Round 1, participants were asked to voluntarily consent to take part in the study by indicating that they understood their rights as a research participant. A friendly reminder email was sent to the experts who had not responded within two weeks following initial contact.

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 inte-

grating the processes of interpretation and focused questioning. Text records are freely edited and coded and linked with multimedia. The software enables researchers to interpret the emergence of theory resulting from qualitative inquiry (QSR International, 2002).

The software facilitated the retrieval of text records from the Quask® Web Software. Once the data was imported, this investigator coded all of the responses based on activities to consider when recommending PAC. 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" if they could not come up with an applicable rating. At the end of the survey, participants had an opportunity to respond with specific comments in regard to Round 2. Similar to Round 1, a friendly reminder email was sent to the experts who had not responded within two weeks following initial contact.

After the Round 2 questionnaires were received, they were analyzed to determine the consensus among all of the experts. For each item from Round 2, interquartile ranges were calculated as measures of dispersion of responses 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, Chan, Berven, Habeck, & Taylor, 2001). The median and interquartile ranges for each of the items were calculated using SPSS® software (SPSS, Inc., 2003).

Delphi Round 3

Following the calculation of consensus data, median and interquartile range results were sent along with a third questionnaire to the experts. The experts were presented with the same activities listed in Round 2 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. At the end of the survey, the respondents again had the opportunity to provide comments regarding Round 3 and were instructed to submit their responses once the survey was completed. Similar to previous rounds, a friendly reminder email was sent to the participants who had not responded within two weeks following initial contact.

Results

Panel Demographics

Of the 100 life care planners solicited for this study, 31 participated in Round 1. Participant experience ranged from 4 to 30 years (Mean = 11.4, SD =7.3). Participant age ranged from 36 to 65 years (Mean=49.1, SD=6.9). Additional information describing these participants is listed in Table 1. 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 existing certified life care planners (V. May, personal communication, June 2, 2006). Next, there were diverse responses to the question regarding the highest level of education attained with the

majority reporting that they had either a Bachelor's or Master's Degree. There were a few individuals who indicated that their highest level of education was a high school, technical school, or other. This may relate to the fact that an individual has three options for becoming a Registered Nurse (RN): Hospital Diploma, Associate Degree, or a Bachelors Degree and an individual, who obtains the RN credential, meets the minimum education requirement to take the life care planning certification exam (V. May, personal communication, June 2, 2006).

In addition to education, participants held multiple credentials. This sample included 29 (93.6%) individuals who currently hold the Certified Life Care Planner (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 a Certified Case Manager (CCM). Thirteen individuals selected 'other' as a credential. Due to feedback from some of the participants, a large percentage of those who selected 'other' may have held the Licensed Nurse Consultant Certified (LNCC) credential.

Table 1. Panel Demographics

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

The experts identified 198 activities they consider when making PAC recommendations for individuals with SCI. Participants were asked to respond to a series of questions about what kinds of activities might require PAC within the general areas of activities of daily living (ADLs), housekeeping, home/yard maintenance, transportation, leisure activities and work/education. Tables 2 through 8 contain samples of items that life care planners agreed should be considered when recommending PAC from each of these six categories.

Delphi Round 2

For the second round of the Delphi, 25 of the original 31 participants responded and indicated their level of agreement with whether each of the 198 items identified from Round 1 should be considered when making PAC recommendations for individuals with SCI. The median (Med Δ) and interquartile ranges (IQR) were calculated for the items. The interquartile range is the distance between the first and third quartiles (middle 50%) of responses to the items, which were measured using the following Likert scale: 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 since after Round 2, 173 of the 198 items resulted in interquartile range of 1 or below. In other words, respondents demonstrated a high level of agreement for 87 percent of the activities.

Delphi Round 3

For the third round of the Delphi, 25 participants reconsidered their level of agreement with whether each of the 198 items should be considered when making PAC recommendations for individuals with SCI. As with the previous round, median and interquartile ranges were calculated 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 that in Round 3 a greater consensus had been achieved among a 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. In other words, enough participants changed their response to these three items on the third round to warrant a final median of less than 3.0 (agree). These three items along with the rest of the 34 items appear to be related to home maintenance type activities.

Table 2. Sample of Activities of Daily Living

Activities of Daily Living (ADLs)						
	Round 2 (N=25)			Round 3 (N=25)		
Activity	Med.	IQR*		Med.	IQR*	Med. Δ **
Bowel/Bladder Mgmt.	4.00	4.00 - 4.00		4.00	4.00 - 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
Hygiene	4.00	4.00 - 4.00		4.00	4.00 - 4.00	0
Teeth Brushing	4.00	3.50 - 4.00		4.00	4.00 - 4.00	0
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

*IQR=Interquartile Range

**Median Change

Table 3. Sample of Housekeeping Activities

Housekeeping						
	Round 2 (N=25)			Round 3 (N=25)		
Activity	Med.	IQR*		Med.	IQR*	Med. Δ **
Clean up after meals	3.00	3.00 - 3.50		3.00	3.00 - 3.00	0
Clean dishes	3.00	3.00 - 4.00		3.00	3.00 - 3.00	0
Clear cobwebs	3.00	2.00 - 3.00		3.00	3.00 - 3.00	0
Dusting	3.00	3.00 - 3.00		3.00	3.00 - 3.00	0
Grocery management	4.00	3.00 - 4.00		3.00	3.00 - 4.00	-1.00
Ironing	3.00	2.25 - 3.00		3.00	2.25 - 3.00	0
Maintain clothing	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
Mopping floors	3.00	3.00 - 4.00		3.00	3.00 - 3.00	0
Sweeping with a broom	3.00	3.00 - 4.00		3.00	3.00 - 3.00	0

*IQR=Interquartile Range

**Median Change

Table 4. Sample of Home/Yard Maintenance Activities

Home/Yard Maintenance						
	Round 2 (N=25)			Round 3 (N=25)		
Activity	Med.	IQR*		Med.	IQR*	Med. Δ **
Taking out the garbage	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Garden management	3.00	2.00 -	3.00	3.00	2.00 - 3.00	0
Lawn mowing	3.00	3.00 -	3.00	3.00	3.00 - 3.00	0
Leaf blowing	3.00	2.00 -	3.00	3.00	3.00 - 3.00	0
Changing light bulbs	3.00	3.00 -	3.00	3.00	3.00 - 3.00	0
Outdoor repairs	3.00	2.00 -	3.00	3.00	2.00 - 3.00	0
Snow management	3.00	3.00 -	3.00	3.00	3.00 - 3.00	0
Using a string trimmer	3.00	2.00 -	3.00	3.00	2.00 - 3.00	0
Raking	3.00	2.00 -	3.00	3.00	2.00 - 3.00	0
Watering garden/grass	3.00	2.00 -	3.00	3.00	2.00 - 3.00	0

*IQR=Interquartile Range

**Median Change

Table 5. Sample of Work/Education Activities

Work/Education Activities						
	Round 2 (N=25)			Round 3 (N=25)		
Activity	Med.	IQR*		Med.	IQR*	Med. Δ **
Carrying work/ school supplies	3.00	3.00 -	3.50	3.00	3.00 - 3.00	0
Test taking	3.00	2.75 -	4.00	3.00	3.00 - 4.00	0
Typing reports	3.00	2.75 -	3.00	3.00	3.00 - 3.00	0
Dictate reports/letters/ notes/etc.	3.00	3.00 -	3.25	3.00	3.00 - 3.00	0
Fax/Copy/Sort/ File activities	3.00	3.00 -	3.00	3.00	3.00 - 3.00	0
Work/School related lifting	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Note taking	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Work/School preparation	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Transcribing	3.00	3.00 -	3.00	3.00	3.00 - 3.00	0
Homework	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0

*IQR=Interquartile Range

**Median Change

Table 6. Sample of Leisure Activities

Leisure Activities						
	Round 2 (N=25)			Round 3 (N=25)		
Activity	Med.	IQR*		Med.	IQR*	Med. Δ **
Annual recreation camps	3.00	3.00 -	3.75	3.00	3.00 - 3.00	0
Camping	3.00	2.00 -	3.00	3.00	2.00 - 3.00	-
Church/Comm. activities	3.00	3.00 -	3.75	3.00	3.00 - 3.75	0
Wheelchair rec. programs	3.00	3.00 -	3.75	3.00	3.00 - 4.00	0
Exercise/Gym activities	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Fishing	3.00	2.00 -	3.00	3.00	2.00 - 3.00	0
Hobbies	3.00	3.00 -	4.00	3.00	3.00 - 3.75	0
Hunting	2.00	2.00 -	3.00	3.00	2.00 - 3.00	+1.0
Internet Access/email	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Watching movies	3.00	2.00 -	3.00	3.00	2.00 - 3.00	0

*IQR=Interquartile Range

**Median Change

Table 7. Sample of Transportation Activities

Transportation Activities						
	Round 2 (N=25)			Round 3 (N=25)		
Activity	Med.	IQR*		Med.	IQR*	Med. Δ **
Running errands	4.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Sporting Events	3.00	3.00 -	3.25	3.00	3.00 - 3.00	0
Recreation	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Bank	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Church/Comm.	3.00	3.00 -	4.00	3.00	3.00 - 4.00	0
Dry Cleaning	3.00	3.00 -	3.25	3.00	3.00 - 3.75	0
Driving children to school	3.00	3.00 -	3.75	3.00	3.00 - 3.00	0
Video store	3.00	2.00 -	3.00	3.00	2.00 - 3.00	0
Movies (transport.)	3.00	2.75 -	3.00	3.00	3.00 - 3.00	0
Restaurants (transport.)	3.00	3.00 -	3.00	3.00	3.00 - 3.00	0

*IQR=Interquartile Range

**Median Change

Table 8. Items with a Median below 3.

Activity	Round 2 (N=25) Med.	IQR*	Round 3 (N=25) Med.	IQR*	Med. Δ **
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

*IQR=Interquartile Range

**Median Change

Discussion

Of the 100 life care planners invited to participate in this project, 25 completed all three rounds of the Delphi study. There was strong agreement that professionals completing a life care plan should consider at least 164 of the 198 generated activities when recommending PAC for individuals with SCI. The activities generated were comprehensive and 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 Functional Independence Measure (FIM) (Granger, Hamilton, & Sherwin, 1986), the Minimum Data Set (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 assessed by other instruments typically used for predicting PAC.

Items to be excluded

The participants not only reached consensus on the items that should be considered when recommending PAC for individuals with SCI in a life care plan, but also reached considerable agreement regarding what activities should not be considered when making such recommendations. Specifically, there was consensus that 34 items, most of which related to home 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. One possible reason for the exclusion of the items could be the female gender bias among participants. Eighty-seven percent of the participants were female. 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 LCP. A second reason for the exclusion of maintenance activities could be that a majority of the life care planning participants were nurses (77.4%) and by training, may be primarily concerned with personal assistance for self-care activities. A third reason might have been that participants may have decided that maintenance activities should not necessitate the need for PAC because the individual would have likely hired someone to perform the activity whether or not they had a SCI. Finally, there is a possibility that some participants may have thought that these tasks would come under a different life care planning heading such as home maintenance and yard care. Further interviews of life care planners may elucidate their reasons for excluding maintenance activities.

Limitations

A limitation of the study 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 (McBride, Pates, Ramadan, & McGowan, 2003; Hasson et al, 2000; Rowe & Wright, 1999; Rowe & Wright, 1996; Sniezek, 1990; Spinelli, 1983; Rohrbaugh, 1979), it is possible that the participants were unfamiliar with these measures of central tendency. While a detailed example was provided on how to interpret this information, it is still possible that these measures may have been confusing.

Implications for Life Care Planners

Personal attendant care needs can represent the single most expensive part of a LCP for individuals with high level SCIs. As such, life care planners should exercise care when attempting to accurately estimate the types and amount of PAC in a life care plan (Weed & Winkler, 2004). The 164 activities identified from this study could serve as a checklist for life care planners when trying to accurately capture the PAC needs of a client and to predict the number of PAC hours for inclusion in a LCP. The checklist might be used in a variety of ways at the discretion of the life care planner. For example, a life care planner could use the checklist as a starting point to begin researching the PAC needs of a client and could review the checklist with the client prior to initial development of the LCP. A checklist could also be reviewed following completion of a LCP as a means for ensuring that all of the client's PAC needs have been assessed.

In addition to clinical practice, the results from this study can be used as an educational tool for professionals being trained to become life care planners. Individuals enrolled in LCP training programs are exposed to many service requirements for people with catastrophic disabilities. As stated earlier, life care planners must utilize available research to support their recommendations. A study such as this one can serve, not only as a guide to understanding the PAC needs for individuals with SCI, but also as support for PAC recommendations in a life care plan.

Conclusion

Consideration of the 164 activities identified in this study, in conjunction with client interviews, review of medical records, and consultation with rehabilitation professionals involved in a case, should aid life care planners in reliably predicting the life long PAC needs of individuals with SCI. In addition, activities resulting from this study could provide empirical evidence for life care planners when defending PAC recommendations in a forensic capacity.

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References

Asch, D.A., Jedrziewski, M.K., & Christakis, N.A. (1997). Response rates to mail surveys published in medical journals. *Journal of Clinical Epidemiology, 50,* 1129-1136.

Blackwell, T.L., Krause, J.S., Winkler, T., & Stiens, S.A. (2001). *Spinal cord injury desk reference.* New York: Demos Medical Publishing.

Currier, K.E., Chan, F., Berven, N.L., Habeck, R.V., & Taylor, D.W. (2001). Functions and knowledge domains for disability management practice. *Rehabilitation Counseling Bulletin, 44,* 133-143.

Dautel, P.J., & Frieden, L. (1999). *Consumer choice and control: Personal attendant services and supports in America. Report of the National Blue Ribbon Panel on Personal Assistance Services.* Houston, TX: ILRU Program.

Granger, C.V., Hamilton, B.B., & Sherwin, F.S. (1986). *Guide for use of the Uniform Data Set for medical rehabilitation.* Buffalo, NY: Buffalo General Hospital.

Hall, K.M., Knudsen, S.T., Wright, J., Charlifue, S.W., Graves, D.E., & Werner, P. (1999). Follow-up study of individuals with high tetraplegia (C1-C4) 14 to 24 years postinjury. *Archives of Physical Medicine and Rehabilitation, 80,* 1507-1513.

Harvey, C., Wilson, S.E., Greene, C.G., Berkowitz, M., & Stripling, T.E. (1992). New estimates of the direct costs of traumatic spinal cord injuries: Results of a nationwide survey. *Paraplegia, 30,* 834-50.

Hasson, F., Keeney, S., & McKenna, H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing, 32,* 1008-1015.

Health Care Financing Administration (1998). *Minimum Data Set,* 2.0. Washington, D.C.: U.S. Government Printing Office.

Herdman, M., Rajmil, L., Ravens-Sieberer, U., Bullinger, M., Power, M., & Alonso, J. (2002). Expert consensus in the development of a European health-related quality of life measure for children and adolescents: A Delphi study. *Acta Paediatr, 91,* 1385-1390.

Kennedy, J. (1997). Personal assistance benefits and federal health care reforms: Who is eligible on the basis of ADL assistance criteria? *Journal of Rehabilitation, 63,* 40-45.

Linderman, C. (1981). *Priorities within the health care system: A Delphi study.* Kansas City, KS: American Nurses Association.

Mahoney, F.I., & Barthel, D. (1965). Functional evaluation: The Barthel Index. *Maryland State Medical Journal, 14,* 56-61.

McBride, A.J., Pates, R., Ramadan, R., & McGowan, C. (2003). Delphi survey of experts' opinions on strategies used by community pharmacists to reduce over-the-counter drug misuse. *Addiction, 98,* 487-97.

National Spinal Cord Injury Statistical Center (2003). *Spinal cord injury facts and figures at a glance.* Birmingham, AL: University of Alabama.

Patton, M.Q. (2002). *Qualitative evaluation and research methods.* (3rd ed.). London: Sage Publications.

QSR International (2002). NVivo [Computer software]. Melbourne: QSR International.

Quask (2004). Quask Form Artist Version 3.5 (Rev. 16) [Computer software]. London: Quask.

Robinson-Whelen, S., & Rintala, D.H. (2003). Informal care providers for veterans with SCI: Who are they and how are they doing? *Journal of Rehabilitation Research Development, 40*, 511-516.

Rohrbaugh, J. (1979). Improving the quality of group judgment: Social judgment analysis and the Delphi technique. *Organizational Behavior and Human Performance, 24*, 73-92.

Rowe, G., & Wright, G. (1999). The Delphi technique as a forecasting tool: Issues and analysis. *International Journal of Forecasting, 15*, 353-375.

Rowe, G., & Wright, G. (1996). The impact on task characteristics on the performance of structured group forecasting techniques: Issues and analysis. *International Journal of Forecasting, 12*, 73-89.

Sniezek, J.A. (1990). A comparison of techniques for judgment forecasting by groups with common information. *Group and Organizational studies, 15*, 5-19.

Spinelli, T. (1983). The Delphi decision-making process. *Journal of Psychology, 113*, 73-80.

SPSS Inc. (2003). SPSS 12.0 for Windows [Computer software]. Chicago: SPSS, Inc.

Sutton, A., Deutsch, P.M., Weed, R.O., & Berens, D.E. (2002). Reliability of life care plans: A comparison of original and updated plans. *Journal of Life Care Planning, 1*, 187-194.

Weed, R. (2004). Life care planning: Past, present, and future. In R. Weed (Ed.). *Life care planning and case management handbook* (2nd ed., pp.1-13). Winter Park, FL: CRC Press.

Weed, R.O, & Field, T.F. (2001). *Rehabilitation consultant's handbook.* Athens, GA: Elliott & Fitzpatrick, Inc.

Winkler, T., & Weed, R.O. (2004). Life care planning for spinal cord injury. In R. Weed (Ed.). *Life care planning and case management handbook* (2nd ed., pp. 483-539). Winter Park, FL: CRC Press.

Weitzenkamp, D.A., Whiteneck, G.G., & Lammertse, D.P. (2002). Predictors of personal care assistance for people with spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 83*, 1399-1405.

Williams, P.L., & Webb, C. (1994). The Delphi technique: A methodological discussion. *Journal of Advanced Nursing, 19*, 180-186.

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Appendix

Authors' Note: The Appendix includes questions from the first round of the Delphi study only. The second and third round questionnaires are not included as they are based on responses to the first round of questions. The lead author is developing a detailed checklist for a future publication that includes all the items identified from this current study.

Delphi Questions Round 1

1. 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)?

2. 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?

3. 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.

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

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

6. Please list all specific activities related to transportation you consider when recommending services in a Life Care Plan.

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

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

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

10. 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 rec-

ommendations, 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"

a. ADL's
b. Housekeeping
c. Home/Yard Maintenance
d. Transportation
e. Work
f. Education/Training
g. Leisure