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A Survey of Physical Therapists: Long Term Therapy Needs For Persons with Severe Disabilities

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Abstract

Sixty-three physical therapists participated in a survey designed to obtain their opinions regarding long-term and on-going future therapy recommendations for patients with spinal cord injuries, reflex sympathetic dystrophy, traumatic brain injuries, cerebral vascular accidents, cerebral palsy, and severe burns. Overall, therapists indicated these patients needed on-going therapy due to a loss or impairment of motor skills, ambulation skills, and loss or impairment of self-care skills. The primary reason reported for patients not returning to physical therapy for on-going treatment following their acute care was lack of insurance coverage or end of insurance benefits. This study outlines the implications for life care planners to consult with physical therapists regarding the long term on-going therapy needs of their clients, and the purpose and goal of therapy involving the six outlined diagnoses. Recommendations regarding the long-term physical therapy needs are outlined without regard to insurance coverage.

Introduction

One of the centerpieces in life care plan (LCP) development by life care planners (LCPers) is the need to consult with treating physicians and therapists regarding the long-term care needs of their clients who have had or sustained a severe disability. Standard practice for LCPers has been to consult with treating specialists (when possible) regarding the need and frequency of future evaluations, and separately with therapists for the need for future therapy (Deutsch & Raffa, 1981; Deutsch & Sawyer, 1997). Although consulting with treating specialists may be prudent, there are no studies in the literature that empirically deal with a cohort group of physical therapists' recommendations regarding long term therapy needs following acute hospitalization. Indeed, a review of the more prominent medical databases (Medline, CINAHL, eMedicine), show a plethora of studies regarding the benefits of intensive acute therapy. However, no studies were found that dealt with the benefits of extended therapy

beyond the first year post injury.

The primary objective in the present study was to explore the expert opinions of physical therapists in relation to the primary reasons why clients need to return to therapy after acute rehabilitation, common reasons why physical therapy is terminated, and, without considering insurance coverage time constraints, what physical therapists recommend long-term in regards to future evaluations and follow-up treatment. With the 1993 Daubert v. Merrill Dow Pharmaceuticals decision requiring expert witness testimony to be supported by a methodologically and validated approach, the relevance for this type of study is apparent (Daubert Ruling as cited in Field, 2000; Weed, 2009). The following literature review, albeit peripheral in nature to the present study regarding long term therapy needs, discusses related topics of interest researched in this study.

Review of the Literature

Physical therapists have previously noted the deleterious effects of cost containment as it relates to their ability to provide the services they deem necessary for optimal patient care. For example, Greenfield (2006) conducted in-depth interviews with five experienced physical therapists (with at least seven years of experience) to ascertain the nature of care in their clinical practice. Although a number of themes that evolved from this study were related to empowering patients and the ethics of caring, the therapists consistently identified the financial constraints of managed care as interfering with their ability to provide sound clinical services. In the Greenfield (2006) study, for example, one therapist stated:

> "The insurance needs constant verification…So, economically I have to figure out a way to get the patient better with the least number of visits…I give them exercises and move them along, that's what I see…more impersonal…more robotic" (p. 183).

Related studies (e.g., Demain, Wiles, Roberts, & McPherson, 2006; Phillips, Greenspan, Stringer, Stroble, & Lehtonen, 2004) have also noted that pressure from Medicare and managed care organizations to reduce costs has led to shorter lengths of stay and more rapid movement out of inpatient hospital settings. As a result, physical therapists are challenged by the insurance companies to file appeals or continue treating without reimbursement or reduce their rates for cash payments. For example, the Commission on Accreditation of Rehabilitation Facilities (CARF) states that follow-up evaluations for persons with severe disabilities are essential to detect problems caused by premature discharge from therapy (CARF, 2008). Common time points for follow-up are one, three, six, and twelve months post-discharge to maximize the potential for maintenance of achieved gains (Hall & Johnston, 1994). In addition, requirements by governing bodies such as CARF may force physical therapists to make difficult decisions under less than desirable circumstances. However, many patients do not return for follow-up due to loss of insurance coverage or depletion of therapy benefits.

Kane, et al. (1998) analyzed the outcomes of different types of hospital care for a cohort of 117 Medicare patients with strokes and 101 persons with hip fractures for up to one year following hospital discharge. Participant interviews were conducted at the time of hospital discharge and at six weeks, six months, and one year after discharge. Outcome measures were assessed based on functional status, re-hospitalization, and mortality rates. Results showed that patients over age 65 with more severe strokes who were discharged to nursing homes had the highest mortality rates. Those discharged home with no formal care or access to rehabilitation facilities had the highest re-hospitalization rates. However, those who were discharged to

rehabilitation facilities or to home with formal home health care had significantly higher activity of daily living (ADL) ratings than those in nursing homes and those discharged home with no formal care. Participants with hip fractures discharged to nursing homes had the lowest re-hospitalization rates and those discharged to home health care had the highest rates of re-hospitalization. However, those receiving post-hospital care in rehabilitation facilities and home health care had significantly higher functional improvement than those discharged to nursing homes or home with no formal care. These results suggest the choice of post-hospital care can heavily influence the course of functional outcomes for patients. Careful attention must be paid to how hospital discharge decisions are made and the financial incentives for the different types of post-hospital care. In addition, nursing home facilities frequently are understaffed with therapists to meet the demands of post-hospital care for all the patients needing therapy.

Complex Regional Pain Syndrome

Complex regional pain syndrome/CRPS (formerly known as reflex sympathetic dystrophy) is a neuropathic pain state that is difficult to understand and treat. Excruciating pain is the most common symptom for which patients with this disorder seek medical consultation and its management involves tremendous health care expenditure (Ghai, 2004). Rehabilitation is the mainstay of CRPS and treatment often involves extensive physical and occupational therapy. Unfortunately, insurance benefit limitations often preclude people with CRPS from obtaining the long-term care required to adequately treat this disorder.

Spinal Cord Injury

Persons with spinal cord injury (SCI) also have ongoing, lifetime physical therapy needs. Fortunately, some facilities recognize this. The Rehabilitation Institute of Chicago's (RIC) "Second Look" program was devised so persons with SCI can, after their acute discharge, return for a recommended "tune up" at any point in their life (Chen & Eberhardt, 2008). According to Chen and Eberhardt (2008), pressures from insurance companies and concerns relating to hospital-acquired infections limit treatment and patients are not always appropriate for admission. Some of the services offered by Second Look include updates on therapy techniques from expert clinical and medical staff. The RIC program is an innovative approach for providing the quality of long-term are most persons with SCI can benefit from without having to rely on cost-containment programs that are limited to acute rehabilitative services.

Cerebral Palsy

In contrast to SCI and cerebral vascular accidents where patients had an intact and normally functioning nervous system prior to injury, persons with cerebral palsy (CP) are generally at a disadvantage in achieving normal function of their muscles, and bones. In addition, their cardio-respiratory systems are not fully developed before the brain injury occurs. As a result, they are likely to have a lower physical starting point as well as slower progress in developing these structures (Damiano, 2006). Physical therapy and orthopedic surgery has been a strong component of the rehabilitation management of CP for decades. What is less clear is the extent to which physical therapy can alter the motor prognosis or make a clinically significant change for any given patient. Damiano proposes that traditional "packaged" forms of physical therapy for persons with CP be replaced with more focused approaches that entail intense, active hands-on training. As such, physical therapists are encouraged to optimize their limited therapy time by eliminating treatment components that only have marginal positive results and replace them with evidence-based protocols shown to

be effective in improving current and future functioning. However, extensive physical therapy follow-up to assess progress and a patient's needs is essential.

Type and Duration of Physical Therapy

Kirk-Sanchez and Roach (2001) examined the relationship between the total hours of physical and occupational therapy received by patients (mean age 72.6 years) with orthopedic problems enrolled in a comprehensive rehabilitation facility and their mobility at discharge. Mobility was assessed through self-care, transfers, locomotion, and bowel and bladder function. The average amount of therapy was 40.5 hours over an average 14-day stay. Results indicated that patients averaged a mobility score of 47.1 at the time of admission and a score of 71.6 at discharge. The results of this study provide evidence that increasing the number of hours a patient receives therapy and extending their length of stay can significantly improve orthopedic functioning and may increase the likelihood of discharge to their homes versus more expensive health care settings.

In addition to the type and duration of physical therapy where individuals with severe and chronic disability are discharged, the amount of therapy following discharge from acute stays is also critical for maximizing physical functioning. For example, Tangemann, Banaitis, and Williams (1990) maintain that although much of the literature indicates that little recovery from stroke can be expected after six months; new research shows that recovery can continue for several years. Hall and Johnston (1994) also purport that acute care discharge does not represent maximum functional potential for most patients with traumatic brain injury (TBI). In fact, they maintain, "The traditional goal of maximum independence at discharge is now becoming the minimum independence required before transfer to a less expensive and less intensive level of care" (p. 16). Subsequently, follow-up therapy after discharge becomes even more essential to continue progress towards maximum levels of independence. Unfortunately, research designed to examine the effects of long-term physical therapy is limited at best and without such studies, it can be expected that persons with severe disabilities will continue to receive inadequate and insufficient therapy follow-up.

It seems apparent from available research that most physical therapists' believe that patients with chronic disabling conditions need periodic evaluations and treatment for their conditions. Unfortunately, insurance coverage limitations often curb treatment that is essential towards maximizing a patient's maximum level of independence and function as well as preventing secondary complications.

Research Questions

In the present study, the following major research questions were of interest:

1. Does your facility conduct annual evaluations following initial acute care intervention for the six disabilities?
2. What are the most common reasons why patients stop therapy?
3. If not constricted by insurance benefit limitations, would physical therapists recommend ongoing periodic physical therapy for the six disabilities discussed?
4. If ongoing physical therapy is recommended for the six disabilities, on average, approximately how many sessions per year, and until what age would therapy be recommended?
5. What are the primary reasons why most patients return for physical therapy following acute rehabilitation?

Method

Participants

Participants for this study included 64 physical therapists from across the United States representing 24 states. States with the greatest representation were Alaska with 19 respondents (29.7%), followed by Minnesota with eight (12.5%), and New Hampshire with four (6.3%). The remaining 21 status had anywhere from one to three respondents. Of the 64 respondents, only 62 surveys were usable (we dropped one respondent with less than two years work experience who partially completed the survey). The other significant identifying information of respondents was years of experience, which showed 38 (59.4%) reported over 11 years of experience, eight (12.5%) indicated 8-11 years of experience, six (9.4%) noted having 5-8 years of experience, and nine (14.1%) reported 2-5 years experience. Overall, 97% reported at least two or more years experience in the field, with one individual reporting less than two years.

Procedure

The idea for the study was postulated by one of the authors who is a practicing occupational therapist and co-authored the survey instrument used. A faculty research grant was obtained along with institutional review board permission. A graduate student was hired and trained for the study purposes, regarding the procedure on how to contact and recruit therapists for the study. Various means were used to recruit potential participants by finding relevant physical therapy work settings via hardcopy yellow pages from various cities in the library, visiting clinics locally in person, having physical therapists complete the survey at conferences, and finding physical therapy clinic phone numbers from the internet yellow pages and making cold calls. Potential participants were briefed about their participation being voluntary and anonymous, and informed consent was assumed by physical therapists agreeing to participate and subsequently returning a completed survey.

With available funding, the authors set a goal of a minimum of 60 physical therapist participants. Approximately 150 physical therapists were either contacted by phone or e-mail, with a 42% (n=63) response rate overall. The method of delivery for the survey was distributed in several ways including e-mail attachment, using the online surveying program surveymonkey.com, facsimile, hand-delivered and ground mail. Respondents were provided with a return e-mail address, fax number, and self-addressed stamped envelope respectively to return their surveys. All contacts were categorized and maintained, and when potential respondents agreed to participate, they were contacted only one time thereafter for a reminder. All completed surveys were coded using Microsoft Excel software and later analyzed using Statistical Package for the Social Sciences (SPSS) 12th version. Due to the small sample size, only descriptive statistics were analyzed, therefore no higher-level analyses were conducted.

Instrument

The overall survey was designed as part of a larger study including physical therapists, occupational therapists, and speech-language pathologists. The dataset for all three disciplines was coded separately in order to investigate how each works with the various disabilities and their recommendations for future therapy. All therapists answered all the same questions except for the first which distinguished them by their job title. The survey itself was comprised of five demographic questions dealing with job title, state, years of practice, type of setting they worked in, and number of years experience working with each of the six disabilities noted here. The remaining 13 questions were either checkmark forced response (e.g., type of

insurance injured patients are covered by: ___ private insurance; ___ workers compensation; ___ Medicare); or rank order questions (e.g., rank order what are the most common reasons therapy is discontinued: __ patient not interested in continuing; __ lack of insurance coverage; __ therapist doesn't feel any more therapy can help).

Once developed, an experienced occupational therapist reviewed the survey for content validity and made suggested changes. Participants were asked to consider in their responses the needs of the "typical" patient who is diagnosed as moderate-severe in each of the six disabilities, and to consider the "AMOUNT of therapy the patient needs **AND** **NOT** BASED ON WHAT INSURANCE TYPICALLY COVERS." (See Appendix A for a copy of the survey).

Results

Usable data for 62 physical therapists or a 42% response rate was analyzed. As noted earlier, demographic information indicate that over 97% of respondents had at least two or more years of experience, with approximately 60% having over 11 years experience. One therapist reported less than two years experience and only partially completed the survey. Physical therapists also reported a diverse work setting background, with the highest majority (n = 30, 46.9%) working in a clinic, followed by 26.6% working in an acute care hospital, and 21.9% working in an outpatient facility. Regarding years of experience working with one of the six specific disability groups studied, over 50% had two or more years working with persons with spinal cord injuries (SCI), 59% reported two or more years working with persons with traumatic brain injuries (TBI), 92% having worked two or more years with patients with a cerebral vascular accidents (CVA's), over 50% with two or more years of experience with severe burns, 80% with two or more years experience with those with amputations, and approximately 70% having worked with persons with cerebral palsy. Table 1 indicates a breakdown of demographic information.

Table 1

Demographic Information regarding Physical Therapists

Overall Years of Experience (n = 62)

Number of Years	# Participants	Percentage
< 2 years	1	1.6%
2 - 5 years	9	14.1%
5 - 8 years	6	9.4%
8 - 11 years	8	12.5%
> 11 years	38	59.4%

Type of Work Setting(s) (one or more settings can be marked) (n = 62)

Work Setting	# Participants	Percentage
Private clinic	30	51.6%
Home health	7	10.9%
Acute rehab hospital	17	26.6%
Outpatient freestanding clinic	14	21.9%
School district setting	3	4.7%
Extended care facility	8	12.5%
Rehabilitation facility	8	12.5%

In response to research question number one, "does your facility conduct follow-up annual evaluations following initial acute care intervention for each of the six disabilities," 59.4% reported they do not conduct annual evaluations for patients with cerebral palsy, 57.8% do not for SCI, 59.4% do not for patients with TBI's, 60.9% do not for those with amputations, 56.3% do not for CVA's, and 68.8% reported no annual follow-up evaluations for patients with severe burns. In all instances, the remaining responses showed most facilities tended to conduct one annual follow-up after acute care therapy (ranged from 9.4% for cerebral palsy and SCI, to 21.9% for CVA), but not ongoing.

Research question number two ranked what the most common reasons for physical therapy cessation were, and therapists overwhelmingly (n= 43, 68.2%) reported the number one reason therapy stops is due to a lack of insurance coverage or lack of further insurance benefits, and not because a patient had reached maximum medical improvement (MMI). The second most commonly ranked reason reported was therapists who believed their patients had plateaued or reached MMI (9, 14.3%), while the third-highest ranked reason was the patient/family moved (4, 6.3%). The remaining reasons fell lower than this and included the patient being in too poor of health to continue, or not interested in continuing (4.7% each). Table 2 outlines the most commonly ranked reasons why patients are seen for follow-up, and delineates the most common preventative reasons why patients return for long-term therapy.

Table 2

Primary Needs Addressed in Follow-Up Therapy, and Most Common Preventative Reasons for Patients Needing Long-Term Therapy

Rank Order as to Primary Needs Addressed in Follow-up Therapy

Reason	*# Participants*	*Percentage*
Routine Assessment	36	56.3%
More Therapy	30	46.9%
Wheelchair/Ambulation Needs	18	28.1%
Self-Care/ADL Needs	9	14.0%
Caregiver Training	9	14.0%
New Equipment/Training Needs	7	11.0%
Home Program Review	2	3.10%

Most Important Impact of Long-Term Treatment is to Prevent:

Reason	*# Participants*	*Percentage*
Due to Loss of ADL Skills	54	84.4%
Loss of Ambulation Skills	54	84.4%
Prevent Need for More Attendant Care	34	53.1%
Prevent the Need for Surgery	32	50.0%
Prevent Premature Death	25	39.1%
Tx Makes No Difference	4	6.3%

Note: - ADL abbreviated for activities of daily living.
- Tx abbreviated for therapy/treatment
- Numbers overlap, therefore do not add up to 100%

Research question number three "If not constricted by insurance premium limits, would therapists recommend ongoing periodic physical therapy for each of the six disabilities," required a yes/no response. For SCI, 58 or 90.6% reported yes, 89.1% for HI said yes, 92.2%

for CVA responded yes, 82.8% reported yes for persons with cerebral palsy, 75% reported yes for those with severe burns, and 71.9% reported ongoing physical therapy would benefit persons with RSD. Therapists were also given the option of "not applicable" if they had no experience or opinion.

Question four was a follow-up to question number three, and more specifically

"If ongoing physical therapy is recommended for the six disabilities, on average, approximately how many sessions per year, and for how many years would therapy be recommended for"(if insurance was once again not a consideration). Respondents had an opportunity in this question to essentially fill in the blank regarding an estimated number of sessions and years respectively. For this reason, the approximate number of sessions was collapsed for each disability to be more meaningful. Table 3 indicates the specific breakdown of each disability, and the most highly ranked frequency and duration of physical therapy reported. A non-response to this question was interpreted as the physical therapist will likely not having much or any prior experience working with a specific population.

Table 3

Research Question #4: Would Patients Benefit from Long-Term Physical Therapy; if so, How Many Treatment Sessions per Year and for How Many Years?

Disability Type	*# Sessions per Year*	*n / %*	*# of Years*
SCI Tetraplegia	n/a	17/26.6%	50+ - 60.9%
	2 - 12	26/41.3%	
	13 – 50	10/15.9%	
	51 +	10/15.9%	
Paraplegia	n/a	17/26.6%	50+ - 55%
	2 – 12	29/46%	
	13 – 50	11/17.5%	
	51 +	6/9.5%	
TBI Mild	n/a	19/29.7%	50+ - 28.1%
	2 – 12	30/47.6%	
	13 – 50	13/20.6%	
Moderate	n/a	20/31.3%	50+ - 31.3%
	2 – 12	23/36.5%	
	13 – 50	10/15.9%	
	51 +	7/11%	
Severe	n/a	19/29.7%	50+ - 42.2%
	2 – 12	24/38.1%	
	13 -50	9/14.3%	
	51 +	9/14.3%	
CVA (ambulatory)	n/a	14/21.9%	50+ - 34.4%
	2 – 12	27/42.8%	
	13 – 50	9/14.3%	
	51 +	7/11%	
CVA (wheelchair user)	n/a	13/20.3%	50+ - 43.8%
	2 – 12	27/42.8%	
	13 – 50	7/11%	
	51 +	10/15.9%	

Table 3 (continued)

Research Question #4: Would Patients Benefit from Long-Term Physical Therapy; if so, How Many Sessions per Year and for How Many Years?

Disability Type	# Sessions per Year	n / %	# of Years
Cerebral Palsy (under 21)	n/a	24/37.5%	50+ - 34.4%
	2 -12	18/28.5%	
	13 - 50	5/7.9%	
	51 +	15/23.8%	
Cerebral Palsy (over 21)	n/a	25/39.1%	50+ - 51.6%
	2 – 12	18/28.5%	
	13 – 50	9/14.3%	
	51 +	6/9.5%	
Severe Burn (ambulatory)	n/a	27/42.2%	
	2 – 12	17/27%	
	13 – 50	4/6.3%	
	51 +	10/15.9%	
Severe Burn (wheelchair user)	n/a	26/40.6%	50+ - 35.9%
	2 – 12	20/31.7%	
	13 – 50	4/6.3%	
	51 +	11/17.5%	
Reflex Sympathetic Dystrophy	n/a	25/39.1%	
	2 – 12	16/25.4%	
	13 – 50	9/14.3%	
	51 +	8/12.7%	

Note: SCI abbreviated for spinal cord injury. TBI abbreviated for traumatic brain injury. CVA abbreviated for cerebral vascular accident.

Overall, between 20% - 27% (20% for working with paraplegia, 27% for working with persons with tetraplegia) did not respond to the question regarding tetraplegia or paraplegia; however, 41% of therapists believe those with tetraplegia should receive anywhere between 2 to 12 physical therapy sessions per year, and 60.9% indicated life-long treatment. Numbers were similar for persons with paraplegia; 46% of therapists recommended 2 to 12 sessions per year, and over 57% recommended life-long treatment. For persons with TBI, frequencies were determined for mild, moderate and severe head injury. Summarizing, almost a third of therapists across-the-board did not respond, while between 41.2% and 47.6% of those who did respond recommended between one to 12 sessions per year, and a range between 28.1% to 42.2% believe physical therapy should continue post injury through life-expectancy. Individuals with cerebral vascular accidents were differentiated by ambulatory versus non-ambulatory (wheelchair required). Approximately 20% of physical therapists for both levels of severity did not respond, while approximately 50% of both groups indicated between one and 12 sessions per year. Forty four percent of the therapists indicated individuals who had CVA's and used a wheelchair should have physical therapy for life, and 34.4% of therapists working with ambulatory CVAs indicated the same. Cerebral palsy was sub-classified for those under 21 years of age, and those over 21. For both groups, approximately 38% of therapists did not respond, while 30% to 36% of therapists who work with this population (under 21 and over 21 respectively) indicated 1 to 12 sessions per year were appropriate. Roughly 34% of the

therapists working with younger individuals recommended ongoing treatment through life expectancy, while 51.6% indicated life-long treatment for persons with cerebral palsy over 21. Patients with severe burns were sub- classified into non-ambulatory versus ambulatory. Approximately 41% of physical therapists did not respond, and approximately 35% for both levels of severity responded that 1 to 12 therapy sessions per year was appropriate, and only 23.4% indicated life-long treatment with therapy for ambulatory burn patients, whereas 35.9% of non-ambulatory burn patients were recommended life-long physical therapy. Reflex sympathetic dystrophy (CRPS) was treated as one category with 39% not responding, approximately 33% indicating one to 12 sessions of physical therapy per year was needed, and 20% indicating life-long therapy.

The last research question number five focused on ranking the primary reasons why patients returned for therapy following discharge. Therapist answering this question also stated that patients needed to return for routine assessments and additional therapy. The number one ranked reason (n= 36, 56.3%) was for a routine assessment. The second-highest rating (n= 30, 46.9%), was for additional physical therapy, and the third ranked need was for wheelchairs/ambulation needs (n=18, 28.1%). Approximately 20% did not respond. Table 2 provides a more definitive breakdown of all recommended therapies.

Discussion

Life care planners have typically consulted with treating physical therapists (where appropriate and available) regarding recommendations concerning future therapy needs for their clients. What has not been fully understood, however, is the framework from which therapists (physical, occupational, speech language) generally provide their future care opinions: whether their opinion is based on what their patients would really benefit from, or whether their therapy opinion and recommendations are constrained by what they are aware of regarding what the insurance benefits of the patient are. Our co-author's experience as an occupational therapist in private practice, having employed physical, occupational, and speech language therapists over the years, is of the opinion that many therapists actually have insurance benefit limitations influence their long-term therapy recommendations. If this is indeed the case, it would behoove Life Care Planners to preface their requests from physical therapists for future therapy recommendations as to what they perceive their patients will benefit from regardless of insurance limitations. This study clearly indicates that a majority of physical therapists in this sample believe that clients with the six disabilities described here would indeed continue to therapeutically benefit from ongoing assessments, and further physical therapy sessions for years into the future. As noted by our findings, in many instances, physical therapy is often recommended for life expectancy for many disabilities. (See Table 3). Physiatrists who also make such recommendations may also be influenced or biased by the same insurance benefit limitations framework. Synonymous with the "chicken or the egg" causality dilemma, "Do physicians and physical therapists give their recommendations primarily based on what the insurance benefit limitations are, or are they giving recommendations based on the patient's actual needs?" Insurance companies categorize patients into diagnostic related groups (DRG) that restrict therapy visits to a limited number of visits depending on the diagnosis. Given the freedom to prescribe treatment based on actual patient needs, ongoing therapy can assist the patient in acquiring and maintaining their maximum independence levels. Although most insurance companies, including Medicare with its yearly monetary therapy caps (which is $1,840 in 2009), renew their benefits yearly as a monetary or number of therapy visits per year. The usual number of therapy visits allowed by

private insurance companies for therapy can vary from 4-24 or more per year. Frequently additional therapy following an acute episode, often must be documented as an exacerbation of the prior diagnosis. With severe disabilities, some of the complications could have been prevented if adequate therapy was performed at the onset or on a routine basis.

Ongoing evaluations and therapy was further supported in this study when a majority of physical therapist participants cited the most common reasons why patients stop coming for therapy is not due to having reached maximum medical improvement (MMI), but instead due to a lack of insurance or insurance benefit exhaustion. Additionally, when patients are seen for follow-up, the most commonly ranked reasons included the need for routine assessments and additional therapy due to a loss of self-care and/or ambulation skills. Indeed, when therapists were asked whether patients with the six disabilities noted should otherwise be provided additional therapy if insurance was not an issue, the vast majority indicated affirmatively.

Recommendations for Life Care Planners

There are several notable implications from this study that life care planners may find useful in consulting with physical therapists regarding clients with any of these six disabilities. First, the life care planner should ask the provider or therapist to make recommendations for future care/therapy for their patient regardless of insurance restrictions. Second, there should be a discussion of the prognosis of function if the future therapy recommendations were not carried out. This could be made part of the complications area of a life care plan. The discussion should outline the purpose of continued therapy (routine assessments, upgrade exercises, caretaker training, a change or modification of orthotics, or to measure for new equipment). As noted earlier, patients generally return because they have lost some of the skills or the gains they made while in rehabilitation. There is now some empirical validation from a cohort of 62 physical therapists who participated in the study regarding the benefits of ongoing physical therapy recommendations for treatment for extended periods of time up to life expectancy. Finally, life care planners are reminded to follow the practice of asking specific long-term therapy questions, prefacing questions for therapists to provide recommendations based on what they perceive the patient/client will need, not based on the usual insurance limits.

Limitations

There are several limitations to this study. First, is the somewhat low response rate of 42% and the fact that caution should be taken in generalizing our findings to all physical therapists. The small sample size also limited performing higher-level analyses and did not provide for adequate power. Although we contacted random physical therapists/clinics across all 50 states for participation, the search for participants was limited to those found on the Internet and in the yellow pages of city phone books, making this sample somewhat of a convenience sample. Second, our survey consisted of either checkmark or fill in the blank format, and did not allow for elaboration on responses which may have clarified some responses by gathering some further qualitative information. A third limitation was that although this was a pilot survey, we used one of the authors who is an occupational therapist to review the questions for content validity. At least one or more physical therapists reviewing the survey may have strengthened its validity. Finally, although having covered six common severe disabilities in which life care plans are developed, future research is recommended to explore other disabilities such as blindness, brachial plexus injuries, amputation and other severe type injuries.

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Appendix A: Survey

Quantifying Long Term Therapy Needs for Catastrophic Patients

Thank you for agreeing to participate in this important study designed to obtain your expert opinion regarding the long-term therapeutic treatment needs of persons with various catastrophic injuries. In responding to questions, please answer under the assumption that these disabilities represent the functional capabilities of the "typical" moderately-severe patient with such a disability, as well as the AMOUNT of therapy the patient needs AND NOT BASED ON WHAT INSURANCE TYPICALLY COVERS. Once again thank you for your time. Please e-mail your responses to Dr. Irmo Marini at HYPERLINK "mailto:irmom@hotmail.com" irmom@hotmail.com or fax to (956) 380-6499. Phone the same number with questions.

Circle your Title: PT OT Speech Therapist *State you are in?* _____

How many years have you been in practice: _____ years

What type of setting(s) do you work in:

_____ Private Clinic
_____ Home Health
_____ Acute Rehab/Hospital
_____ Out-patient free-standing
_____ School district
_____ Extended Care Facility
_____ Rehabilitation Facility
_____ Facility with specialty in treating_____

How many years experience do you have working with persons who have:

Spinal Cord_____ years Head Injuries _____ yrs CVA_____ yrs
Burns_____ yrs Amputations _____yrs Cerebral Palsy _____ yrs

What kind of physician refers catastrophically disabled patients to your facility:

____ Physiatrists _____ Orthopedists _____ PCP _____ Neurologists _____

Does your facility do yearly follow-up evaluations with catastrophic patients?
_____ Yes _____ No ____ Depends on Disability

Does your facility do follow-up assessments with the following type of patient following the initial acute care intervention (please circle correct number) or with this and similar questions following, if you do not believe these services are applicable for your discipline, simply check "n/a."

Cerebral Palsy	- 1 x year;	2 x year;	3 x year;	4 x year;	5 or more X yr __ n/a
Spinal Cord Inj	- 1 x year;	2 x year;	3 x year;	4 x year;	5 or more X yr __ n/a
Severe Head Inj	- 1 x year;	2 x year;	3 x year;	4 x year;	5 or more X yr __ n/a
Amputation	- 1 x year;	2 x year;	3 x year;	4 x year;	5 or more X yr __ n/a
Cerebrovascular	- 1 x year;	2 x year;	3 x year;	4 x year;	5 or more X yr __ n/a
Severe Burns	- 1 x year;	2 x year;	3 x year;	4 x year;	5 or more X yr __ n/a

For how many years does your facility "typically" perform follow-up assessments with the following type of patient: (please circle)

Cerebral Palsy	- 1-3 years	4-6 years	7-9 years	10+ years	Lifetime ___ n/a
Spinal Cord Inj	- 1-3 years	4-6 years	7-9 years	10+ years	Lifetime ___ n/a
Severe Head Inj	- 1-3 years	4-6 years	7-9 years	10+ years	Lifetime ___ n/a
Amputation	- 1-3 years	4-6 years	7-9 years	10+ years	Lifetime ___ n/a
Cerebrovascular	- 1-3 years	4-6 years	7-9 years	10+ years	Lifetime ___ n/a
Severe Burns	- 1-3 years	4-6 years	7-9 years	10+ years	Lifetime ___ n/a

What is the most common reasons long-term care is discontinued for patients with a catastrophic disability: (RANK ORDER – 1= most common; 5 = least common)

_____Patient/family not interested in continuing
_____Lack of insurance coverage
_____Patient moves away/loses contact
_____Patient's health deteriorates and therapy is no longer appropriate
_____Therapist doesn't feel anymore therapy can help

Types of insurance your catastrophically injured patients are covered by:

_____Private Ins_____ Worker's Comp _____ Medicare
_____Medi-cal _____ Cash Pay _____Lawsuit/Trust
_____Other (type)_____

What is the "average" length of time in minutes of a therapy session at your facility?

_____20 minutes _____30 minutes _____45 minutes
_____60 minutes _____90 minutes _____ 120 minutes

What is the average cost of 1 session of therapy in your discipline at your facility?
$_____ for _____minutes

When a patient with a catastrophic disability is seen for long term follow-up at your facility what are the primarily needs typically addressed (RANK 1=most common, etc)

_____need for additional therapy
_____wheelchair/ambulation needs
_____new equipment or orthotic training
_____routine assessment/no needs
_____need for family/caregiver training
_____self-care/independent ADL needs
_____home program review

The most important impact that long-term therapy/treatment has are to prevent: (Check all that apply)

_____loss of ambulation skills
_____loss of self-care skills
_____early institutionalization
_____it wouldn't make a difference
_____prevent need for more surgery
_____premature death
_____need for more attendant care in home

What is the most common reasons long-term extended therapy follow-up care is discontinued for a catastrophically injury/chronically impaired patient:

_____Patient/family not interested in continuing
_____Lack of insurance coverage
_____Patient feels he/she have achieved therapy goals
_____Patient moves away/loses contact
_____Patient's health deteriorates and therapy is no longer appropriate
_____Physician does not write a prescription for more therapy when needed
_____Therapist determines patient will no longer benefit from more therapy
_____Other_____

PLEASE ANSWER THE FOLLOWING QUESTIONS BASED ON WHAT YOU BELIEVE THE PATIENT NEEDS -<u>NOT WHAT INSURANCE TYPICALLY COVERS</u>.

If you were to recommend long-term or life-time therapy/treatment for the following diagnoses, what would the frequency and duration of therapy be:

Spinal Cord Injury	Quad	_____year for _____years or lifetime
	Para	_____year for _____years or lifetime
Brain Injury	Mild	_____year for _____years or lifetime
	Moderate	_____year for _____years or lifetime
	Severe	_____year for _____years or lifetime
CVA	Wheelchair	_____year for _____years or lifetime
	Ambulatory	_____year for _____years or lifetime
Cerebral Palsy	below age 21	_____year for _____years or lifetime
	above age 22	_____year for _____years or lifetime
Severely Burn	non-ambulatory	_____year for _____years or lifetime
	Ambulatory	_____year for _____years or lifetime
Reflex Sympathetic	Dystrophy (RSD)	_____year for _____years or lifetime

If money and insurance coverage were not an issue, do you believe more therapy should be administered or provided to persons with:

Spinal Cord Injury	_____yes	_____no	____ n/a
Severe Brain Injury	_____yes	_____no	____ n/a
CVA	_____yes	_____no	____ n/a
Cerebral Palsy	_____yes	_____no	____ n/a
Severe Burns	_____yes	_____no	____ n/a
RSD	_____yes	_____no	____ n/a