

A Survey of Speech-language Pathologists: Long-term Speech Therapy Needs for Patients within Three Neurological Conditions

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Abstract

Forty-seven speech-language pathologists (SLPs) completed a written survey designed to obtain their opinions regarding the speech-language pathology needs of patients presenting with communication deficits following traumatic brain injury, cerebrovascular accident and cerebral palsy. Results indicated that over one-half of the SLPs in the study cited the most common reason that speech therapy is stopped is due to lack of insurance coverage, not because the patient reached maximum improvement. After discharge from services, 78-92% of SLPs affirmed that their patients would have benefitted from ongoing speech-language treatment if insurance limitations were not a consideration. In many instances, therapy was recommended for several years up to lifetime follow-up. Study results demonstrate that a common reason for termination of therapy was due to insurance limits. The implications of this pilot study for life care planners pertain to consulting with SLPs regarding what the evaluation and long term speech-language pathology needs may be for patients with these three neurological disorders, without considering insurance limits.

Introduction

Life care planning is an advanced specialty practice which utilizes a standardized

methodology to determine the future medical, vocational, and comprehensive care needs of individuals with catastrophic injuries or complex health care needs. The clients' needs are assessed and recommendations are made to ensure optimum medical care and to maximize independence and quality of life. As part of the life care planning process, life care planners (LCPers) consult, when necessary, with SLPs and other members of the rehabilitation team, including but not limited to physical therapists, occupational therapists, and physicians (Deutsch, Sawyer, Jenkins, & Kitchens, 1986). Despite the fact that consultation with treating clinicians is integral to the life care planning process, there are no available empirical studies regarding speech-language pathologists' recommendations of long-term care needs following acute hospitalization.

The primary objective in the current pilot study was to examine the opinions of speech-language pathologists to determine how much therapy a client with one of the three neurological conditions of interest needs regardless of insurance limitations. Additionally, this study sought to explore prevalent reasons why speech-language therapy is terminated, and what recommendations SLPs would make in terms of future therapy for their clients without consideration of insurance coverage limitations. The need and relevance for this type of study is readily apparent in light of the 1993 *Daubert v. Merrill Dow Pharmaceuticals* decision, which stated that expert witness testimony must be supported by a methodologically sound and validated approach (*Daubert v. Merrill Dow Pharmaceuticals*, 1993). According to Weed (2010), expert testimony must be based on scientifically-validated research that can be appropriately and accurately applied to the facts of the case.

Speech-language pathologists have frequently noted the negative effects of cost limitations in provision of services deemed necessary for a patient to reach maximum medical improvement. A fairly recent roundtable interview of two speech and hearing clinicians was conducted to examine the "crisis" in health care reimbursement (American Speech Language and Hearing Association [ASHA], 2006). In this interview, both clinical experts stated dire concerns regarding dwindling third-party reimbursement and other financial constraints of managed care. The clinicians' comments included the following:

"Because of increasing costs, we've had to limit how many patients we see. On some plans, the number of [therapy] visits is capped. As costs continue to rise, the amount of reimbursement is decreasing, and as a result families are not able to stay. We're at the mercy of the claims reviewer of the third-party payer; it's frustrating because we're put into positions of having to tell families that their insurance carrier has denied claims. It's a vicious cycle" (p. 3).

Several studies (Demain, Wiles, Roberts, & McPherson, 2006; Phillips, Morrison, & Davis, 2004) have reported that pressure from Medicare and managed care organizations to reduce costs has resulted in shorter lengths of inpatient hospital stay. Additionally, according to data collected by Fox and Newacheck (1990), insurance coverage of rehabilitative therapies, including speech therapy, was considerably less prevalent than other medical supplies and services across a variety of short- and long-term care systems. Thus, speech-language pathologists and other rehabilitation professionals face numerous challenges, such as choosing whether to treat a patient who is demonstrating modest gains in therapy over another patient on a waiting list.

Unfortunately, foregoing therapeutic services deemed necessary by treating clinicians can have negative and even disastrous effects. Kane, Chen, Finch, Blewett, Burns and Moskowitz (1998) examined outcomes of 117 Medicare patients status-post stroke and 101 patients status-

post hip fractures following discharge from inpatient hospital care. Patient interviews were conducted up to one year post-discharge. Outcome measures were assessed according to functional status, re-hospitalization(s), and mortality rates. Results showed that patients with severe strokes over age 65 years who were discharged to long-term care centers had the highest mortality rates. Those discharged directly to home with no formal therapeutic care or access to rehabilitation facilities had the highest rates of re-hospitalization. Of note, those patients who were discharged to rehabilitation facilities or to home with home health care had significantly higher activity of daily living (ADL) ratings than those in nursing homes and those discharged to home without formal care (Kane et al., 1998). These results clearly indicate that post-hospital care may heavily influence patients' functional outcomes; thus, careful consideration must be given to hospital discharge decisions.

Recognizing increasing third-party payer demands for evidence of therapeutic benefit and need for more thorough documentation of tangible outcomes, ASHA developed a task force in 1994 to establish a database for functional outcomes data. This "clearinghouse" served as a central depository for such data, which could be analyzed and disseminated to clinicians and other relevant bodies as appropriate. ASHA later revised the system and developed its own outcomes measurement methodology, now known as the National Outcomes Measurement System (NOMS) (Mullen, 2004). Operating under three large umbrella components, data collection under the ASHA NOMS system began in 1998 (Mullen, 2004).

Data collected for the *Adult Healthcare Component* of the ASHA NOMS National Data Report (2008) was recently released. The report summarized findings from nationwide data collected in outpatient rehabilitation settings over the most recent five years. It is thus far only available to certified ASHA members and submitting participants. The data provide information regarding numerous aspects of service delivery patterns of patients receiving SLP services (ASHA, 2008). To the current authors' knowledge, this report is the only recent available literature reporting outcomes data and issues on a large-scale basis in the field of speech-language pathology. Unfortunately, information provided in the report is limited; no interpretation of raw numbers is provided, and actual number of respondents and patients was unable to be determined (Mullen, 2004). However, according to Mullen (2004), as of 2003, the Adult NOMS database contained records of over 100,000 patients, so it is reasonable to assume that the actual participant numbers through 2008 are considerably greater.

According to the ASHA NOMS data (2008), the top five primary medical diagnoses of acute care patients receiving speech-language pathology services are cerebrovascular accident (CVA) (35%), respiratory diseases (13%), head injury (6%), hemorrhage injury (5%), and central nervous system (CNS) diseases (4%). Reported diagnoses of outpatients receiving speech-language services is somewhat similar: CVA (40.4%), head injury (9.8%), CNS diseases (7.7%), respiratory diseases (5.1%), and hemorrhage/injury (4.2%).

Disease-Specific Conditions

The following literature review will categorically examine the primary medical diagnoses of CVA, head injury, and CNS diseases as they relate to speech-language pathology service provision. The diagnoses will be discussed in the context of available data regarding therapeutic value, particularly in the long-term/chronic stages of recovery and information relevant to reimbursement issues (ASHA, 2008).

Cerebrovascular Accidents

Cerebrovascular accidents (CVAs) are a primary cause of serious, long-term disability (Miller & Spilker, 2003), and estimates of stroke incidence in the United States range from

500,000-760,000 annually (Leary & Saver, 2003; Miller & Spilker, 2003). However, that number may be even higher, as these figures most likely do not reflect incidence of non-symptomatic infarcts and hemorrhages (Leary & Saver, 2003; Miller & Spilker, 2003). Deficits in communication and swallowing abilities warranting speech-language pathology services are common after CVA. Following a stroke, patients can suffer from mild, moderate, or severe disorders in the discipline areas of cognitive-communicative disorders, aphasia, dysarthria, apraxia of speech, and/or dysphagia (Baron, 2000).

According to ASHA NOMS Adult Outpatient data (2008), the average length of stay (i.e., total time of outpatient therapy services) of stroke patients is 70.6 days. For these patients, SLPs reported that the primary reason for discharge from treatment was that patient goals were met (59.7%). Other reasons included plateau in progress (14%), discharge from facility (6.0%), medical condition changes (6.4%), and "other" (9.5%). Reasons associated with reimbursement limitations comprised 4.4% of reasons for discharge from therapy (insurance declined coverage, 1% and insurance benefits exhausted, 3.4%). Continued speech treatment was recommended by the providing clinicians in 28.8% of CVA patients, of whom the majority were returning to home (approximately 90%). It is unknown/unreported how many of those patients continued to receive therapy services (ASHA, 2008).

The amount of therapy following discharge from acute hospital care is a critical variable for maximizing functioning. Some literature indicates that little recovery from CVA should be expected after six months, however, several authors have asserted that recovery can occur in the chronic stages post stroke, even in patients who had appeared to plateau in recovery (Demain, et al., 2006; Tangeman, et al., 1990). The concept of recovery plateau after CVA continues to be a controversial topic among medical professionals (Demain, et al., 2006). "Plateau" describes a phase of recovery when functional improvements are no longer observed; it is frequently cited as a primary reason for discharging patients from therapy (Wiles, Ashburn, Payne, & Murphy, 2004). However, according to Demain, et al. (2006), recovery plateau is more complex than typically considered. These authors purported that duration and intensity of therapy play an important role in both rate and extent of recovery. They systematically challenged the notion that many other factors may be involved, such as patient's true potential, therapist values, and service provision limitations. These authors proposed that short-term therapy provision may avoid complaints of "therapy rationing," which may occur when therapy is provided in a more long-term capacity. When therapy resources are scarce, therapists must make complicated, difficult decisions such as who will be treated and for how long with what interventions. Pressures for cost containment and legal and regulatory influences are often key components in the treatment course. However, they caution that failing to acknowledge the role that service constraints play in plateau simply maintains status quo; if all patients are treated until they can no longer benefit, third-party payers are unlikely to provide additional resources (Demain, et al., 2006). In fact, in 2000, the Audit Commission, an external body that audits central government departments in England, recognized the disparity in stroke rehabilitation and urged rehabilitation professionals to accurately assess patient needs without reliance on other factors, such as staffing levels and cost limitations (Audit Commission, 2000).

Aphasia is one of the most common consequences of CVA (Salter, Jutai, Foley, Hellings, & Teasell, 2006). In the presence of mixed outcomes research, weight of scientific evidence regarding optimal intensity, duration, and time-post-CVA of speech-language service provision in this population has been questioned, particularly by third-party payers (Robey, 1998). A large-scale meta-analysis of clinical outcomes for aphasia treatment in adulthood was

conducted across 55 relevant studies published during the years 1961-1994. Results demonstrated adequate “scientific evidence to warrant the assertion that treatment for aphasic persons is effective” (Robey, 1998, p. 181). Speech-language treatment applied in the acute recovery period demonstrated the greatest positive effect on communication. In the chronic stage, recovery of skills continued and the average effect for treated individuals exceeded that for untreated individuals by a factor of 12 (Robey, 1998).

Providing further evidence that aphasia treatment is efficacious in chronic aphasia patients, Moss and Nicholas (2006) reviewed 23 single-subject studies from the years 1985-2003. Patients were seen at greater than 1 year after symptom onset. On average, communication skills improved 28-47% with treatment, indicating that time post-onset did not influence treatment effectiveness. The latter and former studies’ findings directly challenged insurance companies and other payers that have denied claims for reimbursement, particularly during later stages of stroke recovery.

Traumatic Brain Injury

Traumatic brain injury (TBI) is the primary cause of trauma-related disability in the United States (Phillips et al., 2004). Approximately 1.5 to 2 million persons sustain a TBI each year (Centers for Disease Control and Prevention – National Center for Injury Prevention and Control [CDC-NCIPC] (2003), and almost 100,000 of those are permanently disabled following TBI (Phillips et al., 2004). Survivors of TBI often sustain significant cognitive, behavioral, and communication deficits warranting speech-language services. In fact, approximately 5.3 million Americans are currently living with some degree of impairment secondary to TBI (Steirwalt & Murray, 2002; Thurman, Alverson, Dunn, Guerrero, & Snizek, 1999). Numerous studies have indicated that various rehabilitation programs are effective in improving functional performance in TBI survivors (Harrick, Krefting, Johnston, Carlson, & Minnes, 1994; Mills, Nesbeda, Katz, & Alexander, 1992), however, efficacy has yet to be demonstrated through large-scale, clinical trials. Survivors of TBI are traditionally considered “high-cost users,” meaning that obtaining services and insurance coverage post-injury may be more difficult than in other patient populations (Batavia & Dejong, 2001).

According to the ASHA NOMS Adult Outpatient data (2008), the average length of stay (i.e., outpatient duration of treatment) for patients with TBI undergoing speech-language pathology services is 72.0 days. This figure is just slightly higher than length of stay of CVA patients. The primary reason provided for discharge from speech-language treatment was that goals were met (66.2% of patients). Other reasons included plateau in progress occurred (10.5%), “other” (10.2%), discharged from facility (5.7%), and patient medical condition changed (3.6%). Of note, limitations associated with reimbursement issues comprised 3.8% of reasons for discharge (insurance declined coverage, 1.2% and insurance benefits exhausted, 2.6%). Continued speech therapy services were recommended by the treating clinicians in 27.4% of patients with TBI, of whom the vast majority were returning to home (approximately 95%). It is unknown/unreported how many of those patients actually received continued therapy services (ASHA, 2008).

Hall and Johnston (1994) proposed that discharge does not represent maximum functional potential for most survivors of TBI. They maintained, “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). In a recent paper, evidence pertaining to TBI rehabilitation was systematically examined and summarized (Cullen, Chundamala, Bayley, Jutai, & Group, 2007). The review was not specific to speech-language

pathology, but rather included all interventions related to the rehabilitation of an individual with TBI. They found that although better outcomes were noted in patients receiving earlier treatment, in one study, patients receiving relatively late services demonstrated notable improvement as well (Cullen et al., 2007). Thus, follow-up after discharge becomes paramount to detect complications as a result of too-early discharge.

Recently, a systematic review of available evidence pertaining to cognitive and behavioral rehabilitation for patients with traumatic brain injury was conducted (Laatsch, Harrington, Hotz, Marcantuono, Mozzini, Walsh, 2007). These authors examined 28 relevant studies and summarized their findings across various treatment methods and approaches. General results demonstrated “improved speech and language skills following treatment” for treated patients, who were 0-19 years of age (p. 253). Additionally, the studies yielded strong support for attention and memory remediation for individuals post-TBI.

Providing additional evidence that rehabilitative therapy post-TBI is vital, a systematic review of 15 studies through 2004 was recently published (Kennedy, Coelho, Turkstra, Ylvisaker, Sohlbery, Yorkston, 2008). The studies that underwent review examined the results of intervention for executive functions following TBI. Subjects varied across studies, from young to older adults aged 1-60 years. Notably, most participants were long past the acute stages of recovery, i.e., they had chronic disabilities (only two studies included subjects who were less than one year post-injury). General results were positive, indicating strong treatment effects supporting cognitive therapy in individuals post-TBI (Kennedy et al., 2008).

Cerebral Palsy

Cerebral palsy (CP), a disorder of abnormal movement and posture control, appears early in life secondary to pre-, peri-, or postnatal central nervous system dysfunction. Approximately 10,000 babies in the United States develop CP; many require specialized medical care, social and educational services, and other assistance throughout their lives (Ashwal, et al., 2004). Most children with cerebral palsy survive to adulthood (Platt, Andrews, Young, & Quinn, 1980), and up to 70% of individuals with cerebral palsy demonstrate functional deficits in communication abilities (Hagen, Porter, & Brink, 1973). Half of individuals with CP use assistive mobility devices and almost 70% have other disabilities, specifically mental retardation (Ashwal et al., 2004). Cerebral palsy has the highest life-time costs per case of the most common congenital disorders (Grether, Cummins, & Nelson, 1992).

According to the ASHA NOMS Adult Outpatient data (2008), the average length of stay for the category of “other neurological diseases,” which includes central nervous system diseases, anoxia, mental disorders, encephalopathy, and presumably cerebral palsy, is 56.6 days of speech-language services. The prevalent reason for discharge from speech-language treatment was that goals were met (63.5%). Other reasons included plateau in progress occurred (12.3%), “other” (9.3%), patient medical condition changed (7.7%), and discharged from facility (5.7%). Limitations associated with reimbursement issues comprised 2.1% of reasons for discharge (insurance declined coverage, 0.5% and insurance benefits exhausted, 1.6%). Continued speech therapy services were recommended by the treating clinicians in 23.7% of patients, of whom the majority were returning to home (approximately 90%). It is unknown/unreported how many of those patients received continued therapy services (ASHA, 2008).

Though more data is slowly emerging regarding the effects of long-term speech-language therapy, the data are raw; available information is limited and often confined to specific patient populations and/or subgroups. As previously addressed, it seems apparent from the available

literature that speech-language pathologists often recommend therapy after discharge from outpatient facilities in the interest of continuation of care for their patients with chronic communication disabilities (ASHA, 2008). Unfortunately, insurance coverage limitations may often curb treatment that clinicians may deem as essential towards maximizing a patient's level of independence and function as well as preventing secondary complications.

The purpose of this current research study was to examine the opinions of speech-language pathologists with regard to their recommendations for treatment continuation long term following the post-acute care settings. In the authors' opinion, these results may augment the data reported above (ASHA, 2008), provide additional insight regarding procedures for conducting follow-up evaluations, and provide information on therapeutic recommendations from clinicians regarding the three frequently-serviced patient populations across a variety of settings. Additionally, these results will also provide critical information regarding the possible occurrence of changes in patient care plans due to insurance limitations.

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 patients with TBI, CP, and CVA?
2. What are the most common reasons why these patients stop therapy?
3. If not constricted by insurance benefits, would speech language pathologists recommend ongoing periodic speech language therapy for the three disabilities discussed?
4. If ongoing speech language therapy is recommended for the three disabilities, on average, approximately how many sessions per year, and until what age would be recommended?
5. What are the primary reasons why most of these patients return for speech language therapy following acute rehabilitation?

Method

Participants

Participants for this study included 47 speech-language pathologists (SLPs) representing 24 states across the United States. States with the greatest representation were California with 10 respondents (16%), followed by Montana with 4 (8.5%) and Tennessee with 3 (6.3%). The remaining 21 states had one or two respondents each. All 47 respondents submitted surveys. Overall, the majority of respondents had more than 10 years of experience in the field. Specifically, 34 (72%) reported over 11 years of experience, five (10.6%) indicated 8-11 years of experience, two (4%) reported having 5-8 years of experience, two others indicated 2-5 years experience, and one reported less than two years experience. In terms of the types of work settings SLPs reported working in, approximately 96% indicated home health experience, 87% had worked or were working in the schools, 85% in private clinics, 81% outpatient clinics, 70% in rehabilitation hospitals, and 68% in acute care facilities.

Procedure

The idea for the study was developed by one of the authors, a practicing occupational therapist, who co-authored the survey instrument used in the study (See Appendix A). A faculty research grant was obtained along with institutional review board permission. A graduate student was trained regarding the study purpose and assisted with data collection. Various means were used to recruit potential SLP participants including the following: locating

relevant therapy work settings via yellow pages, visiting clinics in person, recruiting at conferences, and locating phone numbers from Internet searches. Although contacting SLPs in various parts of the country was randomly selected, respondents represented a convenience sample of those deciding to participate. All potential participants expressed understanding that their participation was voluntary and anonymous.

With available funding, the authors set a goal of a minimum 60 SLPs participants from part of a larger study of 180 physical, occupational, and SLPs. Approximately 125 SLPs initially agreed to participate, however, the overall number of usable surveys returned was 47, representing a response rate of 37.6%. The survey was distributed in several ways, including e-mail attachment, fax, in person delivery, and self-addressed stamped envelope. All contacts were categorized and information was maintained according to institutional review board procedures. When potential respondents agreed to participate, they were contacted only one time thereafter as a courtesy reminder. All completed surveys were coded using Microsoft Excel software, and later analyzed using SPSS 12th version (www.spss.com). Only descriptive statistics were used in this study as the relatively small number of respondents and data collection methods did not allow for higher order analyses to be conducted.

Instrument

The study instrument was a survey designed as part of a larger study that included physical therapists, occupational therapists, and speech-language pathologists. The datasets for all three disciplines were coded separately in order to investigate how each works with the disabilities of interest and their recommendations for future treatment. In order to maintain homogeneity and consistency within the study's larger goals, all therapists were given the same survey and answered the same questions. However, data for all six disabilities (spinal cord injuries/SCI, burns, amputations, CVA, CP, and TBI) were analyzed only for the respondent groups of physical therapists and occupational therapists given that the three additional disabilities (SCI, burns, amputations) represent patient populations in which speech-language pathology services are relatively uncommon. Therefore, data for only the three disabilities of most relevance for the discipline of speech-language pathology (CVA, TBI, CP) were analyzed and will be discussed in the current paper.

The administered survey was comprised of five demographic questions requesting information regarding job title, state in which respondents primarily practiced, years of practice, types of setting in which respondents were employed, and number of years of experience working with each of the disabilities of interest. The remaining 13 questions were check-mark, forced response, or rank-order questions. Once the instrument was developed, an experienced registered occupational therapist (OT) with over 20 years direct clinical experience and work history as owner of a therapy clinic that employed both physical therapists and SLPs reviewed the survey for content validity; suggested changes were critically discussed and implemented as warranted. Although a panel of relevant experts was not formerly convened, the OT informally consulted with clinic therapists regarding survey content validity.

In providing responses to the survey, participants were asked to consider the functional capabilities of the "typical" patients who are diagnosed as moderate-severe in each of the disabilities of interest, and consider the "amount of therapy the patient needs and not based on what insurance typically covers." (See Appendix A for actual survey instrument). The authors did not want to be too prescriptive in defining the severity of the disability, and the use of the term "typical" was designed to indicate there were no co-morbid contraindications or dually diagnosed conditions.

Results

As previously noted, usable data was compiled for 47 SLPs out of the sample of 125 contacted, for an overall 37.6% response rate. Over 70% of the respondents had 11 or more years of work experience in a variety of clinical settings.

In response to research question number one, "Does your facility conduct follow-up annual evaluations following initial acute care intervention for patients with TBI, CP, and CVA?" 32% of clinicians reported they conducted follow-up 1-3 year evaluations for persons with CVAs, 44.6% for patients with TBI, and 27.6% for persons with CP. A small minority of SLPs reported performing follow-up annual evaluations beyond three years for all three groups. Over forty percent of SLPs (44.6%) reported the question was not applicable for patients with CP, 34% reported not applicable for patients with TBI, and 36% reported not applicable for patients with CVAs. It was unclear to investigators as to whether SLPs reporting "not applicable" meant they did not perform follow-up annual evaluations beyond three years, or they simply did not work in a setting that annually provided follow-up.

With regard to research question number two, "What are the most common reasons why these patients stop therapy?" over one-half of the respondents (n= 25, 53%) indicated the number one reason that therapy stops is due to 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 that patients stopped coming to therapy was that a plateau or MMI had been reached (n=12, 25.5%); the third-highest ranked reason was that the patient was not interested in returning (n=6, 12.7%). The remaining reasons fell lower than this and included the patient moving or health status being too poor to continue. Table 1 outlines the most commonly ranked reasons why patients stop coming for SLP for speech-language services and also delineates the most common preventative reasons SLPs see patients return for long-term therapy.

Table 1

Most Common Reasons Why Patients Stop Coming for Treatment
(Research Question #2)

<u><i>Reason</i></u>	<u><i>n</i></u>	<u><i>Percentage</i></u>
1. Lack of insurance coverage	25	53.2%
2. Patient has plateaued/MMI	12	25.5%
3. Patient loses interest	6	12.8%
4. Patient moves/out of area	2	4.3%
5. Patient is in poor health*	1	2.1%

*Poor health was deemed to mean the individual was physically not healthy enough to return for treatment.

Research question number three, "If not constricted by insurance benefits, would speech language pathologists recommend ongoing periodic speech language therapy for the three disabilities discussed?" required a yes/no response. For patients with TBI and CVAs, 43 out of 47 (91.5%) of SLPs reported yes, these patient groups would benefit from ongoing therapy, and 37 (78.7%) reported that persons with CP would benefit from ongoing periodic speech-

language therapy. Therapists were also given the option of selecting "not applicable" if they had no experience or opinion; one SLP reported 'no' across the board for all three disabilities. The remaining minority of SLPs did not answer the question (3 or (6.4%) for TBI, 6.4% for CVA, and 7 (14.9%) for CP).

Question four was a more specific follow-up to question number three and stated, "If ongoing speech language therapy is recommended for the three disabilities, on average, approximately how many sessions per year, and until what age would be recommended?" if insurance was once again not a consideration. For this question, respondents had an opportunity to fill in the blank regarding an estimated number of recommended sessions and years, respectively. To allow more meaningful interpretation, the approximate number of sessions recommended by SLPs was collapsed for each disability. Table 2 indicates the specific breakdown of each disability and the most highly ranked frequencies and durations of speech-language therapy sessions that were reported. A non-response to this question was interpreted by the authors to mean that the SLP has insufficient experience and/or knowledge working with specific populations in these circumstances.

Table 2

Would Patients Benefit from Long-Term Speech Therapy? If so, How Many Sessions per Year? (Research Question #4)

<u><i>Disability Type</i></u>		<u><i># Sessions per Year</i></u>	<u><i>n / %</i></u>
TBI	mild	n/a	20/42.6%
		1 – 12	11/23.4 %
		13 – 50	7/14.9 %
		51-156	9/19.1%
	moderate	n/a	19/40.4%
		1 – 12	10/21.2 %
		13 – 50	6/12.8 %
		51 – 156	12/25.5%
	severe	n/a	18/38.3%
		1 – 12	12/25.5%
		13 -50	4/8.5%
		51 -260	13/27.6%
CVA (ambulatory)		n/a	27/57.4%
		1 – 12	8/17%
		13 – 50	5/10.6%
		51 -200	7/14.9%
CVA (wheelchair user)		n/a	27/57.4%
		1 – 12	8/17%
		13 – 50	4/8.5%
		51 -260	8/17%
Cerebral Palsy (under 21)		n/a	21/44.7%
		1 -12	6/12.7%
		13 - 50	5/10.6%
		51 - 260	15/32%
Cerebral Palsy (over 21)		n/a	20/42.5%
		1 – 12	12/25.5%
		13 – 50	5/10.6%
		51 - 260	7/14.9%

Note: CVA abbreviated for cerebral vascular accident.

TBI abbreviated for traumatic brain injury.

Re: column “# Sessions per Year” - SLPs filled in the blank, therefore no consistency regarding why some SLPs had a maximum of 200 sessions versus those who placed a maximum of 260 sessions per year.

For purposes of this study and for ease of reporting data, the category of patients status-post CVA was separated into non-ambulatory (i.e., use a wheelchair) and ambulatory (i.e., not use a wheelchair). For non-ambulatory patients status-post CVA, there was a diverse range of responses regarding number of recommended sessions per year, and for how many years into the future. The most frequently rated number of sessions per year were 12 sessions (n=4, 8.5%) and 100 sessions (n=4, 8.5%). The most frequent numbers of years recommended for continued SLP services were five years (n=7, 14.9%), two years (n=5, 10.6%), and one year (n=4, 8.5%). For ambulatory patients status-post CVA, the most frequently rated number of recommended yearly SLP sessions was 12 (n=3, 6.4%), followed by two sessions (n=2, 4.3%), 50 sessions (n=2, 4.3%), 100 sessions (n=2, 4.3%), and 156 (n=2, 4.3%) sessions per year. The most frequent numbers of years recommended for continued SLP services were two years (n=6, 12.8%), one year (n=5, 10.6%), and five years (n=4, 8.5%).

For patients with TBI, frequencies were determined for patients who sustained mild, moderate or severe head injury. For purposes of this study, the authors presumed the SLP respondents had familiarity with and an understanding of the categories of mild, moderate and severe TBI and were available to respondents to provide clarification if needed. In fact, no surveys were returned from any respondents that appeared confused or requested clarification of the categories. Summarizing the responses, between 38-42% of SLPs reported that no more therapy sessions would be warranted at the mild, moderate or severe levels of TBI. There was substantial variation thereafter regarding the recommended number of sessions persons with TBI would benefit from, ranging from one session per year to 260 sessions per year for 50 or more years (i.e., for the remainder of the patient's life). For mild injuries, the next most-frequently reported responses were 1, 2 and 50 sessions per year, each endorsed by three SLPs (6% for each category). The range of expected additional years of therapy for patients with mild head injury varied with the largest percentage (n= 21, 44.7%) indicating no ongoing SLP was required, followed by one and two years (n=7, 14.9%; n=5, 10.6%) to five years (n=8, 17%). For moderate brain injury, the highest-ranked number of recommended sessions per year was five (10.6%), followed by 12 and 156 sessions per year, each endorsed by three SLPs (6% for each category). For moderate brain injuries, almost half of respondents (n= 20, 42.6%) reported no additional therapy was needed. Among those SLPs who did endorse ongoing treatment, the top three highest-ranked ranges of years were five years (n=6, 12.8%), two years (n=5, 10.6%), and 10 years and life expectancy, each endorsed by four SLPs (8.5% each category). For patients with severe TBI, 19 (40.4%) indicated no additional treatment needed, and among those maximally endorsed sessions per year were 100 sessions (n=6, 12.8%) and 12 sessions (n=4, 8.5%). The most frequently endorsed length of treatment for persons with severe TBI was life long (n=8, 17%), followed by seven SLPs each endorsing five or 10 years (n=7, 14.9%). Again, complete details are found in Table 2 where the ranges have been collapsed for easier interpretation.

Finally, the most frequently endorsed number of sessions per year reported by SLPs for persons with CP was no sessions (21 or 44.7%). Among those endorsing sessions, six (12.8%) reported 100 sessions per year, followed by three SLPs each endorsing one visit (n=3, 6.4%) and 52 visits (n=3, 6.4%) per year. The maximum numbers of years of SLP services for patients with CP most frequently endorsed by the survey respondents included 50 years (n=9, 19.1%), 10 years (n=4, 8.5%), and three SLPs each endorsed 20 and 21 years (n=3, 6.4%, for each).

The fifth and final research question focused on ranking the primary reasons why clients return for SLP services following discharge. The number one ranked reason was for more therapy (n= 27, 57.4%). The second-highest rating indicated return for additional self-care training for activities of daily living (n= 7, 14.9%), and the third-highest ranked item was return for caregiver training (n=4, 8.5%). There were varying degrees of non-response from SLPs across all ratings, ranging from three (6.4%) to 19 (40.4%), with a mean of ten (22.7%). Again, a non-response for an item (i.e., the item was left blank) was interpreted by the authors to mean that the SLP either had insufficient experience with the select populations or did not feel the option deserved a rank. Table 3 presents a breakdown rank order of respondents' reasons why patients return for SLP after acute care rehabilitation.

Table 3

Most Commonly Ranked Reasons Why Patients Are Seen for Follow-up, and Most Common Preventative Reasons Why Patients Return for Long-Term Therapy.
Rank Order as to Reasons Why Patients Return for Follow-Up (N=47)

<u>Reason</u>	<u># Participants</u>	<u>Percentage</u>
Need for More Therapy	27	57.4 %
Self-Care/ADL Needs	7	14.9%
Caregiver Training	4	8.5%
Home Program Review	3	6.4%
Routine Assessment	2	4.3%
New Equipment Needs	2	4.3%
Wheelchair/Ambulation Needs	1	2.1%

Most Important Reasons for Long-Term Treatment

<u>Reason</u>	<u># Participants</u>	<u>Percentage</u>
Loss of Self-Care Skills	38	80.9%
Loss of Ambulation Skills	23	48.9%
Prevent Need for Attendant Care	22	46.8%
Avoid Institutionalization	17	36.2%
Prevent the Need for Surgery	15	31.9%
Prevent Premature Death	14	29.8%
Tx Makes No Difference	2	4.3%

Note: ADL abbreviated for activities of daily living.

Tx abbreviated for therapy/treatment

Multiple responses provided therefore numbers overlap and do not add up to 100%

Discussion

Life care planners consult with SLPs, when warranted, regarding recommendations for current and future speech-language therapy needs for their clients. However, the basis from which rehabilitation therapists (physical, occupational, and speech-language) generally provide their opinions regarding future care is not well understood. It is not known how frequently therapists provide their recommendations for future therapy services based on patient need, or if their recommendations are based on their knowledge of existing insurance benefit limits. A co-author of this paper who has experience as an occupational therapist in a private practice employing physical, occupational, and speech-language pathologists, is of the opinion that therapists often will make their recommendations for therapy based on their knowledge of insurance benefit limitations. In fact, the reality may be that it appears that insurance benefit limitations may have become the framework from which many medical professionals operate. Many private insurers and health care professionals appear to use Medicare benefit limitations as their standard (Advance for Physical Therapists and PT Assistants, 2009a, 2009b; Gasquoin & Jordan, 2009). Before starting treatment in a clinic, therapists know how many visits are authorized from insurance companies. Some insurance companies authorize a set number of visits per year, while other companies set a limit on dollars per year they will pay for therapy. A substantial problem with using insurance benefits as a guideline for therapy recommendations is that reimbursement caps change yearly due to cuts mandated in the Balanced Budget Act of 1997 (R. L. Phillips, Jr. et al., 2004). Currently, the 2009 Medicare reimbursement cap for physical and speech language therapy combined is \$1,840 (Centers for Medicare and Medicaid Services, 2009; Medicare Interactive, 2009). The unfortunate result of this therapy cap is rationing of therapy; if a patient needs both physical therapy and speech therapy, the two disciplines must decide how much of each type of therapy the patient will receive. When limitations are set on number of therapy visits per year, or dollar amount to be reimbursed per year, an individual's specific needs may not be held paramount. Additionally, potential long-term effect(s) of receiving inadequate therapy are not considered. Such unfortunate effects may include patients not reaching their maximum potential or independence levels. This may result in more costly, unintended consequences such as patients needing percutaneous gastrostomy surgery for non-oral feeding due to unsafe swallowing, or even not being able to return to work due to inadequate communication skills.

Of the respondents who participated in the current study, it appears a majority of the SLPs who participated in the survey suggest that clients presenting with the three disabilities of interest (TBI, CVA, and CP) would continue to benefit from ongoing speech-language pathology evaluations and possible treatment for years into the future if insurance limitations were not a consideration. Over 90% of clinicians who participated in this survey reported that patients' status-post TBI and CVA would benefit from ongoing therapy if not constrained by insurance limits, and over 78% reported that patients with CP would benefit from additional services. Emerging data from an ongoing nation-wide study indicates a similar concern regarding continued therapeutic services; however, study results appear to highlight an important chasm between what therapists are recommending for treatment and what is actually occurring, possibility due to insurance restrictions (ASHA, 2008).

According to the aforementioned ASHA survey, following discharge from an outpatient facility, ongoing speech therapy was recommended by providing SLPs for approximately 30% of their CVA and TBI patients and approximately 25% of their patients with CP (ASHA, 2008). When examining the disparity in percentages between the ASHA study and the current study, it is critical to consider the differences in methodology and SLP respondents in the current study versus the aforementioned ASHA study. Most importantly, the clinicians in the 2008 ASHA

study were asked to report what services had been recommended for their real-life clients; insurance benefits/limitations did not appear to be queried or considered. In the current survey, the percentages of SLPs who would recommend continued services are considerably higher than what was reported in the 2008 ASHA study (78-90% versus 25-30%, respectively). It is, therefore, possible that this discrepancy reflects a disheartening scenario of actual recommendations based on perceived patient need versus knowledge of insurance benefit limitations. Additionally, the current study sampled 47 clinicians across all work settings (e.g., acute care hospitals, outpatient clinics, rehabilitation hospitals, private practice, home health, and schools).

As noted by the findings in our current study, in many cases, for patients with moderate to severe speech-language impairments, speech-language therapy was recommended long term up to life expectancy, depending on the disability and its severity, if insurance limitations were not a consideration (see Table 3). In fact, after ruling out the non-response rate (38%) for patients with severe TBI, the most frequently endorsed length of treatment was over 50 years or life expectancy (17%), with 100 or more sessions per year being the most frequently selected number of sessions endorsed by 25.5% of the respondents. Consistent with these results, other studies have shown that continued speech-language therapy is often perceived as beneficial and recommended long term post-acute for maximum recovery (Moss & Nicholas, 2006; Robey, 1998). Numerous studies have supported these later recommendations and have demonstrated ongoing, cumulative gains for patients receiving continued speech-language therapy in the post-acute stages of their impairment (Cullen, et al., 2007; Miller, et al., 2006; Moss & Nicholas, 2006; Robey, 1998).

Unfortunately, limitations in insurance benefits may thwart treatment that is essential to maximizing a patient's recovery and preventing secondary complications. In fact, Fox and Newacheck (1990) reported that insurance coverage of rehabilitation therapies, including speech-language therapy, was actually less than other medical supplies and services across a variety of care facilities. A consequence is that therapists may be forced into situations involving choices that may not reflect what is most beneficial for their patients, such as choosing continuation of treatment for a slowly progressing patient versus serving another patient on a waiting list. Patient factors, professional code of practice, and personal values affect clinical judgments. However, there may be a delicate balance between what the SLP considers best for their patient while operating within legal frameworks and cost-containment measures. Health care professionals are forced to examine the causality dilemma if therapy recommendations are based primarily on the patient's actual needs or influenced by pressure from third-party payers to reduce costs. For example, insurance companies categorize patients into diagnostic related groups (DRGs) that restrict therapy visits to a limited number of visits depending on the diagnosis.

Results of this study indicated that the most commonly ranked reasons for patients returning for SLP services following acute or post-acute care discharge were the need for more therapy, additional self-care training for activities of daily living, and caregiver training, respectively in order of ranking. Over half of clinicians (n=27) indicated that the number one reason their patients return after being discharged is for additional therapy services. As previously discussed, when therapists were asked whether patients with the three disabilities of interest in this study should otherwise be provided additional therapy if insurance limitations were not an issue, the vast majority responded affirmatively (n= 43 or 91.5% for TBI; n= 43 or 91.5% for CVA; and n=37 or 78.7% for CP). When considered in tandem, these two concepts provide clear justification, based on this study's results, for ongoing speech-language evaluations and therapy continuation in certain patient populations and clinical settings.

Over one-half of the SLP participants cited the most common reason why patients stop coming for therapy is not due to having reached maximum medical improvement, but instead due to a lack of insurance coverage or insurance benefit exhaustion ($n=25$, 53.2%). In comparison, limited emerging data from an ongoing national study found that the numbers of SLPs who cited insurance limitations as the primary reason for discharge from outpatient facilities were considerably lower, ranging from 2% for patients with CP, to approximately 4% for patients with TBI and post-CVA (ASHA, 2008). However, it is important to note that the current study surveyed SLPs working across all possible settings, from medical facilities to schools, versus the aforementioned ASHA survey which included outpatient clinics only. It is not known if the levels of constraint that may be felt by clinicians due to insurance limitations varies according to types of therapeutic setting. Thus, it is possible that clinicians working in facilities other than outpatient clinics may feel differing degrees of limitation due to variances in insurance coverage. Additionally, the aforementioned ASHA survey did not report what numbers of clinicians may have considered insurance restrictions to be additional factors, secondary or tertiary for instance, in their patients' discharge from therapy. Regardless, it remains clear that, based on this study, some SLPs serving particular patient populations have had to juggle with bridging the gap between best practice recommendations and limitations in insurance coverage.

Recommendations for Life Care Planners

There are several notable implications that LCPers may find useful in consulting with SLPs regarding clients with any of the three disabilities of interest in this study. First, the life care planner should request that the providers or therapists make recommendations for future therapy for their patients without consideration of any insurance or funding restrictions or limitations. Second, there should be a discussion of the prognosis of function and/or communication impairment if the future therapy recommended were not realized (called Potential Complications in the LCP). The discussion should outline the purpose(s) of continued therapy (e.g., diagnostic treatment, upgrading levels of communication and/or swallowing skills, caregiver training, equipment training, modification in diet levels or communication methods, or to assess for higher-level modifications). As noted earlier, patients generally return to therapy because of needing additional therapy. This study has provided some additional empirical validation from a cohort of 47 SLPs regarding the benefits of ongoing speech-language therapy for extended periods of time within the three diagnostic groups studied (CVA, TBI, and CP). Finally, life care planners are reminded to follow the practice of asking specific long-term therapy questions to SLPs, prefacing questions to provide recommendations based on what therapy duration and frequency clinicians perceive the patient needs, not based on existing insurance benefit limitations.

Limitations

There are several limitations to this study. First, the response rate of approximately 38% (47 of those who initially agreed to participate) is somewhat low and is lower than the initial minimum recruitment goal of 60 clinicians. Thus, caution should be taken in generalizing these findings to all SLPs. The small sample size also did not provide for adequate statistical power and limited the ability to perform higher-level analyses. Although random clinicians/clinics across all 50 states were contacted for participation, the search for participants was limited to those found on the Internet and in the yellow pages of city telephone books, making this sample somewhat of a convenience sample. Second, this survey

consisted of either checkmark or fill-in-the-blank format, and did not allow for response elaboration, which may have provided additional clarification and/or further qualitative information. For example, although patient age likely has an impact on recommending SLP frequency and duration, the study did not differentiate between age. Another limitation pertains to not knowing the depth of expertise among the SLP respondents regarding whether their long-term therapy recommendations are actually influenced by insurance limits or whether it is the SLP's lack of sufficient documentation or appropriate clinical judgment in making the case for the actual SLP recommendations deemed beneficial for the patient. Finally, one of the authors, an occupational therapist, reviewed the questions for content validity. Although this was a pilot survey, at least one or more speech-language pathologists acting as reviewers of the survey may have strengthened its validity. It is recommended that future research explore other diagnostic groups and disabilities that commonly result in communication and/or swallowing disorders, such as congenital/developmental disorders and syndromes, respiratory diseases, dementia and other degenerative neurological diseases, and head and neck cancer. It is also recommended that potential differences in insurance coverage and limitations as they pertain to certain patient diagnoses and treatment settings be examined in future studies.

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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 irmom@hotmail.com or fax to (956) 380-6499.

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:

_____ Psychiatrists _____ 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 _____ need for family/caregiver training
 _____ wheelchair/ambulation needs _____ self-care/independent ADL needs
 _____ new equipment or orthotic training _____ home program review
 _____ routine assessment/no needs

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

_____ loss of ambulation skills _____ prevent need for more surgery
 _____ loss of self-care skills _____ premature death
 _____ early institutionalization _____ need for more attendant care in home
 _____ it wouldn’t make a difference

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 -NOT WHAT INSURANCE TYPICALLY COVERS.

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