Topics in Brain Injury and Preconference
Journal of Nurse Life Care Planning is the official peer-reviewed publication of the American Association of Nurse Life Care Planners. Articles, statements, and opinions contained herein are those of the author(s) and are not necessarily the official policy of the AANLCP® or the editors, unless expressly stated as such. The Association reserves the right to accept, reject, or alter manuscripts or advertising material submitted for publication.

The Journal of Nurse Life Care Planning is published quarterly in Spring, Summer, Winter, and Fall. Members of AANLCP® receive the Journal subscription electronically as a membership benefit. Back issues are available in electronic (PDF) format on the association website. Journal contents are also indexed at the Cumulative Index of Nursing and Allied Health Literature (CINAHL) at ebscohost.com.

Please forward all email address changes to AANLCP® marked “Journal-Notice of Address Update.”

Contents and format copyright by the American Association of Nurse Life Care Planners. All rights reserved. For permission to reprint articles, graphics, or charts from this journal, please request to AANLCP® headed “Journal-Reprint Permissions” citing the volume number, article title, author and intended reprinting purpose.

Neither the Journal nor the Association guarantees, warrants, or endorses any product or service advertised in this publication nor do they guarantee any claims made by any product or service representative.

In order to make safe and effective judgments using NANDA-I nursing diagnoses it is essential that nurses refer to the definitions and defining characteristics of the diagnoses listed in this work. Other diagnoses may be relevant depending on individual patient needs.
Editor’s Note

Welcome to the Fall 2012 issue of the Journal of Nurse Life Care Planning. Our focus is on Brain Injury. We believe that this issue will offer you insights into this topic, and we offer many resources and links. Our authors are also always willing to help; contact information for each is in the articles.

We hope to see you at the conference in beautiful Albuquerque NM on October 12-15, 2012, with a backdrop of the internationally-famous Balloon Festival. You may view the schedule, register for the conference, and find booking information for hotel rooms on the website at www.aanlcp.org/conference/.

As we go to press, our conference committee is putting together another excellent program. Of particular interest to all nurses who do life care planning will be the discussion of the revised Standards and Scope of Practice (disclaimer: I will be on that panel). Please be sure to attend, and to be present at the membership meeting for this and other important business.

Some of the presenters have offered us brief essays about topics of interest to them; you will find them beginning on page 689. Do approach them to say hello and thank them for their dedication to nurse life care planning and willingness to share their expertise with us.

Please welcome our RN CLCP colleagues, our associate members, and our sponsors and vendors. We have so much to share. Nursing is such a collaborative profession!

Cordially,

Wendie Howland

Editor, Journal of Nurse Life Care Planning

whowland@howlandhealthconsulting.com

---

American Association of Nurse Life Care Planners

3267 East 3300 South #309
Salt Lake City, UT 84109
Phone: 888-575-4047
Fax: 801-274-1535
Website: www.aanlcp.org
Email: info@aanlcp.org

2012 AANLCP Executive Board

President
Anne Sambucini RN CCM CDMS CNLCP MSC-C
President Elect
Joan Schofield BSN RN MBA CNLCP
Treasurer
Peggie Nielson RN CNLCP MSCC
Secretary
Nancy Zangmeister RN CRRN CCM CLCP CNLCP MSCC
Past President
Jackie Morris RN BSN CRRN CNLCP CLNC

The American Association of Nurse Life Care Planners promotes the unique qualities the Registered Nurse delivers to the Life Care Planning process. We support education, research, and standards related to the practice of Nurse Life Care Planning.
Information for Authors

AANLCP® invites interested nurses and allied professionals to submit article queries or manuscripts that educate and inform the Nurse Life Care Planner about current clinical practice methods, professional development, and the promotion of Nurse Life Care Planning within the medical-legal community. Submitted material must be original. Manuscripts and queries may be addressed to the Editorial Committee. Authors should use the following guidelines for articles to be considered for publication. Please note capitalization of Nurse Life Care Plan, Planning, etc.

Text
Manuscript length: 1500 – 3000 words
• Use Word© format only (.doc)
• Submit only original manuscript not under consideration by other publications
• Put the title and page number in a header on each page (using the Header feature in Word)
• Set 1-inch margins
• Use Times, Times New Roman, or Arial font, 12 point
• Use double-spacing, using the Word formatting feature
• Place author name, contact information, and article title on a separate title page, so author name can be blinded for editorial review
• Use APA style (Publication Manual of the American Psychological Association)

Art, Figures, Links
All photos, figures, and artwork should be in JPG or PDF format (JPG preferred for photos). Line art should have a minimum resolution of 1000 dpi, halftone art (photos) a minimum of 300 dpi, and combination art (line/tone) a minimum of 500 dpi. Each table, figure, photo, or art should be on a separate page, labeled to match its reference in text, with credits if needed (e.g., Table 1, Common nursing diagnoses in SCI; Figure 3, Time to endpoints by intervention, American Cancer Society, 2003)
Live links are encouraged. Please include the full URL for each.

Editing and Permissions
The author must accompany the submission with written release from:
• Any recognizable identified facility or patient/client, for the use of their name or image
• Any recognizable person in a photograph, for unrestricted use of the image
• Any copyright holder, for copyrighted materials including illustrations, photographs, tables, etc.

All authors must disclose any relationship with facilities, institutions, organizations, or companies mentioned in their work.
All accepted manuscripts are subject to editing, which may involve only minor changes of grammar, punctuation, paragraphing, etc. However, some editing may involve condensing or restructuring the narrative. Authors will be notified of extensive editing. Authors will approve the final revision for submission.
The author, not the Journal, is responsible for the views and conclusions of a published manuscript.
Submit your article as an email attachment, with document title articleName.doc, e.g., wheelchairs.doc

All manuscripts published become the property of the Journal. Manuscripts not published will be returned to the author.
Queries may be addressed to the care of the Editor at: whowland@howlandhealthconsulting.com

Manuscript Review Process
Submitted articles are peer reviewed by Nurse Life Care Planners with diverse backgrounds in life care planning, case management, rehabilitation, and the nursing profession. Acceptance is based on manuscript content, originality, suitability for the intended audience, relevance to Nurse Life Care Planning, and quality of the submitted material. If you would like to review articles for this journal, please contact the Editor.

AANLCP® Journal Committee for this issue
Shelly Kinney MSN RN CCM CNLCP
Editorial Committee Chair
Wendie Howland MN RN-BC CRRN CCM CNLCP LNCC
Journal Editor
Shelly Kinney MSN RN CCM CNLCP
Newsletter Editor

Reviewers
Barbara Bate RN CCM CNLCP LNCC MSCC
Mariann Cosby MPA MSN RN PHN CNE NE-BC LNCC CLCP CCM MSCC
Liz Holakiewicz BSN RN CCM CNLCP
Linda Husted MPH RN CNLCP LNCC CCM CDMS CRC
Barbara Malloy RN BSN CCM CLCP MSCC
Cheryl Mathis RNC CLNC CNLCP
Kathy Pouch RN-BC MSN CCM CNLCP LNCC
Victoria Powell RN CCM LNCC CNLCP MSCC CEAS
Nancy Zangmeister RN CRRN CCM CLCP MSCC CNLCP
Contributing To this Issue

Patricia Brock RN MSN, LNCC, CLCP (“From Clinical Nurse to Entrepreneur: Becoming a Life Care Planner”) has been a nurse for twenty-nine years. She began her nursing career as an Associate Degree nurse and after two years of med/surg, she worked exclusively in critical care. In 2004, she left the bedside temporarily to obtain her certifications and grow her business, HTI Legal Nurse Consulting and Life Care Planning. She is a new member of AANLCP and an active member of the Orlando chapter of the American Association of Legal Nurse Consultants and frequently performs as a nursing SOC expert. Ms. Brock is a clinical nurse educator for Daytona State College and she is currently working on her PhD in nursing.

Dan Gardner, MD (“The Protective Barrier in Head Injury”) is in the private practice of psychiatry and psychoanalysis in San Diego and Del Mar, California. He is a Distinguished Life Fellow of the American Psychiatric Association; Assistant Clinical Professor of Psychiatry, UCSD School of Medicine; Council member of the San Diego Psychiatric Society; and member of the Executive Committee of the Board of Directors, San Diego Psychoanalytic Society and Institute. He is currently Medical Director of Hidden Valley Ranch Rehabilitation Services, and he consults with other brain injury rehabilitation programs. He was formerly Medical Director of NeuroCare at Stone Mountain, a post-acute brain injury rehabilitation program in the San Diego area.

David Krych MS-CCC-SLP (“Brain Injury and Cognition: Some Practical Considerations”) is currently a VP at ReMed Recovery Care Centers and co-founded the Centre for Neuro Skills, both post-acute community-based brain injury programs. He earned a degree in communication disorders and sciences in 1979 at Southern Illinois University. He has received the Distinguished Alumnus Award from SIU for contributions to the field of brain injury rehabilitation and a lifetime achievement award from the American Congress of Rehabilitation Medicine. He has edited and contributed to books and articles on brain injury and has presented extensively in the US and abroad on a variety of brain injury topics. He is active in The American Congress of Rehabilitation Medicine; The American Speech Language and Hearing Association and The Brain Injury Association of PA.

Keith Sofka (“Technology Corner: Assistive technology for Brain Injury”) is a principal of Caragonne and Associates, Ajijic, Jalisco, MX. He has practiced the provision of assistive technology services for the past 30 years. Mr. Sofka provides consultation to hundreds of companies, schools, Government Agencies and individuals. A major focus of Mr. Sofka’s work has been to provide recommendations for and implementation of school and workplace reasonable accommodation recommendations for individuals and organizations. This work typically includes housing and commercial building access as well as transportation, mobility and completion of daily living needs as well as modifications to the individual worksite. He has also taken training and practiced in other areas of assistive technology including custom seating and positioning for individuals with severe orthopedic involvement. His work has always been focused on ways to use technology to increase the independence of the individual.

Janet Williams MSW PhD (“A New Look at Life Care Planning”) is the founder and president of Minds Matter, LLC., a provider of functional community-based therapies for individuals who have experienced a life-changing injury or event. She is also the founder and president of communityworks, inc., a Kansas-based company that supports people of all abilities who wish to live, work and play in their communities. Both companies are firmly committed to the belief that individuals with brain injuries and other disabilities can and should play an active role in making decisions related to their rehabilitation and living options.
Comfort, healing and safety from the provider you trust.

Today, our solutions reduce pulmonary complications and improve mobility in the home setting.

To learn more about our bed frames, contact www.hill-rom.com or 812-212-2563.

To learn more about The Vest® System, contact www.thevest.com or 800-426-4224.

©2012 Hill-Rom Services, Inc.
ALL RIGHTS RESERVED.
06/28/2012  ENG – US
As an internal medicine intern twenty years ago, I and other trainees evaluated a distraught artist, suffering from shortness of breath and progressive walking problems. Noting a normal physical exam and a recent emotionally traumatic breakup with his lover, I concluded that the symptoms were manifestations of an hysterical conversion reaction, rather than caused by any physical problem. What a shock I had the next day as I observed a swarm of medical personnel rushing this poor man, barely able to breathe, to the intensive care unit to be placed on a ventilator! The diagnosis: polio!

The same year I speculated that a man complaining of severe back pain and a stormy relationship with his son was symbolically expressing his disappointment, frustration, and anger with his son through the pain. That is, his son was "a pain in the back"! I changed my diagnosis, however, after seeing the bone spurs (probably pressing on nerves) in his spinal x-rays.

These two cases are examples of a common pitfall to which we all fall prey at times: the wish to find clear-cut, simple, unambiguous answers to life's complex problems. At the time I was so interested in the psychological factors in illness, that I downplayed possible physical contributors.

And so it can be in the evaluation and treatment of head injury. Pressured by constraints of time, money, and other resources, we may eagerly narrow the focus to one particular issue to explain complicated behavior. For example, depending on the perspective of the evaluator, a brain injury survivor's irritability may be attributed only to: frontal lobe bruising, neurotransmitter imbalance, inadequate sleep, poor nutrition, excessive or inadequate medication dose, relationship disappointments, lack

**Dan Gardner, MD**

As a psychiatrist and psychoanalyst, I deal with emotional, behavioral, and cognitive problems of head injury survivors and their families.

---

Dan Gardner, MD is in the private practice of psychiatry and psychoanalysis in San Diego and Del Mar, California. He is currently Medical Director of Hidden Valley Ranch Rehabilitation Services, and he consults with other brain injury rehabilitation programs. He may be contacted through his website at www.dangardnermd.com
of recreational and vocational outlets, loss of job, etc.

My point is that head injury is best viewed from a biological/psychological/social perspective: injury occurs to a person with a particular physical status, particular life experiences and coping style, and particular current relationships with individuals and organizations. As a psychiatrist and psychoanalyst, I deal with emotional, behavioral, and cognitive problems of head injury survivors and their families. Emotional problems include depression, anxiety, fears, irritability, anger, shame, guilt, etc. Behavioral difficulties include temper outbursts, sleep problems, poor initiative, passive-resistance, impulsivity, wandering, sexual inappropriateness, etc. Cognitive problems include poor judgment, forgetfulness, poor attention span, trouble with multiple tasks, planning and organizational difficulties, etc.

**The protective barrier**

I find it helpful to view the nature and severity of problems resulting from head injury as determined by a protective barrier (as discussed by neuropsychologist Thomas Kay, Ph.D.) comprised of biological, psychological, and social factors. And it is individual differences in the components of the protective barrier that explain why similar neurological insults produce inconsistent outcomes.

Various biological factors influence outcome in brain injury: for example, status of brain structures and functions, previous head injuries, age, prescription medication effects (benefits and side effects), illicit drug and alcohol use, seizures, fluid collections inside the head, metabolic or hormone imbalance, and infection (inside or outside the central nervous system).

When considering psychological factors, I try to keep in mind the following: It's not only what happens to us, but how we interpret it and how we respond to it. Our psychological vulnerability to head injury relates to past experiences and development, as well as current psychological resources. We evaluate the present in terms of our past internal psychological conflicts, relationships, and goals.

Head injury and the varying degrees of resulting dependency, loss of control, and incapacity lead to regression, i.e., revival of earlier, more childlike ways of thinking, feeling and relating to others. These are often more primitive and less reality oriented. When healthy, we are unaware of these regressive attitudes, but they are reactivated and intensified under the stress of head injury.

**Head injury-induced regression**

The regression caused by the head injury reactivates certain universal fears (as described by consultation-liaison psychiatrists James Strain, M.D. and Stanley Grossman, M.D.) that are similar to those we experience at earlier stages in our development. The ability to adapt to current worries/stresses depends on how
adequately we adapted to these stresses when we experienced them as children. The predominant fears, internal conflicts, and their degree of resolution depends on our early life experiences, e.g., nature of relationships with parents and other caretakers.

Brain injury is always followed by loss of self-esteem and unpleasant feelings, e.g., depression, anxiety, guilt, shame, helplessness, powerlessness.

Those of us who as children were not neglected, hurt, or exposed to extreme emotional or physical traumas, and whose relationship with parents was built on trust, are less likely to be affected by the fears, losses and painful feelings of their current disability. For example, a good early childhood relationship with mother allows us to have basic trust in our caretakers. A good early relationship with father leads to our ability to trust men, allow ourselves to be passive in relationships with men (e.g., comply with recommendations of male health care providers and caretakers), and respond to authority without fears of being weak.

Following is a list of the universal fears reactivated by head injury-induced regression. I have illustrated these fears with relevant case examples.

Threat to integrity of the self
Integrity of the self refers to a basic sense of well being, bodily integrity and strength, all of which are "shaken" by a brain injury.

Twenty-five year-old John denied the seriousness of his seizures and the existence of post-injury thinking or judgment problems. He boasted of his verbal abilities and of intentions to capitalize on his attractive physical appearance by becoming a male model. At the same time, he avoided social or academic contact with peers, instead preferring solitary exercise activities. The head injury-related threat to his self-integrity added to a prior sense of deep inadequacy, resulting in a defensive, grandiose attitude. The emotional pain of directly acknowledging and dealing with his deficits was intolerable, so he tenaciously clung to a defensive, hyperinflated self-image, which he could only maintain by remaining socially isolated.

Fear of separation
Especially common in people with visible, permanent, and severe disabilities is the fear of being rejected and abandoned by spouse, children, friends and other family. Often this fear becomes a reality, resulting in despair at the loss of these important relationships. In addition, earlier life experiences of emotional and physical abandonment are reactivated.

continued next page
Her slow, slurred speech and paralyzed right arm and leg, the result of a stroke and traumatic brain injury, left Sara in a dependent, incapacitated, and vulnerable position. This reactivated terror, rage and despair stemming from childhood emotional neglect and abandonment by mother while father sexually molested her. The revived feelings resulted in Sara's angry, desperate clinging to hospital staff, as well as to a deep mistrust of and fear of injury by some of her caretakers.

Fear of loss of love and approval
Jack was despondent over his incapacities: His head injury left him unable to financially support his wife and children, satisfy his wife sexually, and relate patiently to his children. The strong sense of shame and despair Jack currently felt was rooted in his early life failure to win approval from parents who unrealistically expected him as a young child to assume care for his younger sister.

Fear of loss of control of developmentally achieved functions
Control of bowel, bladder, feelings and thoughts may be impaired in brain injuries. The amount of distress over loss of control of these abilities depends on childhood experiences surrounding achievement and loss of control of these functions.

Allen was mortified at the frequent tearful outbursts that followed his head injury. He recalled being shamed by a first grade teacher for wetting his pants and chastised as a child by his parents for any expression of intense emotions.

Fear of loss of or injury to body parts
Fears of permanent disabilities may resonate with early childhood fears of injury to and loss of body parts, viewed as punishment and retaliation for desiring an exclusive sexualized relationship with one parent and associated wishes to get rid of the other parent. An injured man may unconsciously view his disability as a symbolic castration, feminization, and subsequent vulnerability to attack by other men.

To cope with a passive, weakened state, which threatened his masculinity, construction worker Bill flirted with women caretakers and boasted to his children about how bravely he endured painful diagnostic procedures.

Feelings of guilt and shame and fear of retaliation for previous transgressions
Many people view their disabilities as punishment for previous "sins" of omission or commission, e.g., being too needy, greedy, neglectful, disobedient, or hurtful to parents as a child.

Jean believed her accident and injuries were divine retribution for the ingratitude and rage she felt as a child toward her parents, who she experienced as neglectful and depriving.

Tom viewed his head and spine injuries as punishment for an accident he had caused ten years earlier. While drunk, he drove his car broadside into a police car, injuring the officers.

Personality style
In addition to reactivation of universal fears, personality style is an important psychological contributor to how we interpret and react to the deficits of head injury. Personality style can be defined as our habitual mode of relating to our own wishes and fears, as well as to other people.
Passive dependency was Tim's personality style prior to injury. He strove to find both individuals and organizations who would meet his financial, physical, and emotional needs with minimum expenditure of effort on his part. Injury-related deficits and a large financial settlement served to legitimize and reinforce these behaviors. He delighted in attention from his caretakers, but opposed their attempts to help him assume more responsibilities.

Unable to care for her children after a brain injury, Jane felt depressed, ashamed, and helpless. As the oldest of six children, Jane had been placed in the role of caretaker and surrogate mother from an early age. To cope with the frustration and disappointment of unmet dependency needs, Jane developed a Pseudo-Independent personality style, becoming a caretaker and rescuer to many people in her life. The head injury-related deficits interfered with her playing the caretaker role, and the financial gain and attention she received from compassionate rehab staff served as a major, though unconscious, obstacle to rapid recovery.

Ed was a logical, orderly, well-organized engineer with a compulsive ("Too Perfect") personality style. Post-injury anxiety about his cognitive deficits led to a compulsive preoccupation with and charting of the frequency and character of his bowel movements. This was his attempt to feel more in control of his life: if he couldn't control his thinking, he would turn his attention toward another bodily function that could be more easily mastered.

Other personality styles that influence one's response to head injury are: Histrionic (overly dramatic), Borderline (emotional instability, stormy relationships), and Narcissistic (basic low self-worth hidden by an inflated sense of self-importance).

Understanding the interplay of biological and psychological factors within a person is helpful, but incomplete, since a person exists not in a vacuum, but in a social network. Our lives are interconnected with family, friends, coworkers, as well as work, school, social, and religious organizations. The degree and nature of these connections influence the outcome after head injury.

One (unconscious) motivation of Dorothy's multiple post-injury physical and emotional setbacks was that she could only see her favorite sister while hospitalized, since Dorothy's husband had forbidden the sister to see her any other time.

continued next page
Bill, a head injured army veteran, managed to emotionally decompensate and be re-hospitalized just often enough to qualify for his Veteran's Administration disability benefits.

Phil was isolated, suspicious, and argumentative prior to his head injury, estranged from ex-wife, child and his parents. His injury-related deficits served only to magnify his premorbid suspiciousness and to widen the rift between him and his family.

Thanks to a generous financial settlement and extreme family dedication and commitment, Frank received a comprehensive, home-based rehabilitation program, which resulted in dramatically improved cognitive, emotional, and behavioral function.

It helps to keep in mind that family's response to a head injured member depends on the nature of the relationship prior to the head injury, the special psychological meanings to the family of the survivor's deficits, and the family's coping style.

Susan's husband was a devoted caretaker, bearing with little protest the emotional and physical strain of her brain injury disabilities. His unwavering involvement seemed based on his guilt about her being struck by a car after she had angrily left their car during a heated argument.

Dale's wife had always been quick to act as a caretaker, in part as a reaction to her own unmet dependency needs in childhood. Dale's disabilities led to her self-sacrificing overinvolvement with him. The increased caretaking efforts served to unconsciously defend more vigorously against her own unmet needs, which she was unable to admit to herself and others for fear of disapproval and rejection.

Pam's mother found herself emotionally reserved and irritated with Pam's incapacities and neediness. Her mother had been raised in a religious

continued next page
school where demonstration of strong emotional needs was explicitly discouraged. Therefore she could not tolerate feelings of neediness and dependency in either herself or her children.

Bill's children coped with their fears of his injury-related rage outbursts by unconsciously identifying with this behavior and reacting to his impending outbursts with verbal attacks and provocations of their own. While their pre-emptive assaults helped his children cope with a terrifying situation, it also intensified Bill's sense of inadequacy as a husband and father and his subsequent rage.

To understand and treat head injury-related disabilities effectively, it helps to look at the components of the "protective barrier" that stands between the force of impact and the brain. As one author stated, "It's not only the kind of injury that matters, but the kind of head."

References


Brain Injury and Cognition: Some Practical Considerations

David K. Krych, MS, CCC-SLP

Creating a life care plan for an individual with brain injury poses a number of challenges. Those injured are often young, have multiple disabilities, and have more complex and dynamic medical and psychosocial needs (Leskin et al., 2007). Information about recovery and prognosis is ever-changing and the predictive validity of medical and even neuropsychological testing is quite limited (Flanagan et al., 2008). Further, life care planners must rely on information from a variety of sources, all of whom speak similar, but not the same languages. This is particularly true of the concept of “cognition.”

Treatment team
Brain injury treatment teams consist of practitioners of many disciplines, including physical therapy, speech/language pathology, recreational therapy, social work, nursing, psychology, and occupational therapy. Each of these disciplines has its own specific area of expertise with methods of assessing, treating, and discussing the many physical, behavioral, and cognitive sequelae of brain injury. However, each of these disciplines must address the problem of cognitive impairment in the individuals they see, albeit with differing definitions of what exactly constitutes cognition. Psychologists describe performance on neuropsychological testing in terms of response time, memory, and speed of processing; speech pathologists talk about difficulty in problem solving tasks and tangential speech; occupational therapists look at issues associated with the reestablishment of daily routines; and physical therapists are likely to talk about safety when transferring.

Interestingly enough, treatment team members all focus on valid issues; they just reflect individual treatment biases.

David Krych is currently a VP at ReMed Recovery Care Centers and co-founded the Centre for Neuro Skills, both post-acute community-based brain injury programs. He has edited and contributed to books and articles on brain injury and has presented extensively on a variety of brain injury topics. He is active in The American Congress of Rehabilitation Medicine; The American Speech Language and Hearing Association and The Brain Injury Association of PA. He can be contacted at 16 Industrial Blvd, Paoli PA 19301, dkrych@remed.com
Interestingly enough, these are all valid issues; they just reflect individual treatment biases. The problem is that we all need a more basic hook on which to hang our understanding of cognition. Maybe the early work of Bruner (1964) framed it best when he related the process of language development to cognitive processes. He postulated that language is a way of sorting out one’s thoughts while thought is a mode of organizing perception and action.

At first glance this may seem to be overly simplistic, but in fact these few words go a long way to helping us discover some common understanding and appreciation for what our brains do to make sense of the world. Because, in the final analysis, that is exactly what cognition is: making sense of the world. So, if as Bruner suggests, our first task is to organize; how do we go about doing this?

Attention
Recent research makes a compelling argument that the place to begin when trying to understand cognition is in the human ability to attend. Without attention to our environment, we cannot organize it. Stuss and colleagues (2002) looked at individuals who had sustained lesions in various regions of the frontal lobe of the brain and discovered that rather than a generic functional system, as researchers and practitioners had thought, there were different functions or processes associated with specific frontal brain regions that contribute in different ways to perform even a very simple task. One reason that this research is important is that the occurrence of frontal lobe involvement in brain injury is well-documented, so problems associated with different frontal lobe syndromes would be expected (Levin & Kraus, 1994; Hofman et al., 2002).

From a clinical standpoint, clinicians often translate attentional deficits into other terms. For example, a person who is unable to maintain attention to an ongoing task may be referred to as “distractible.” Those unable to persist with an activity might be described as “having difficulty with concentration.” Unfortunately, clinicians often fail to determine whether the issue is an inability to attend per se or to selectively filter conflicting distractors. Likewise, someone who is unable to shift attention from one activity to another may be described as “perseverative.” Again all of these terms are in some way correct, but what do clinicians do about it and how does this matter to life care planners?

Environment
First, activities need to be developed in such a way as to be easily manipulated from both a stimulus presentation and an environmental standpoint (Ashley & Krych, 1995). In other words, clinicians should start with activities that are concrete, in an environment that is quiet and visually simple and move up from there to more complex tasks in the presence of visual and auditory distracters; and fi-

continued next page
nally move to activities that require a shift in attention. Using measures of specifics such as response time (how long it took to complete a task), the amount of cueing needed to complete the task, or overall accuracy allows a measurable yardstick to be used. As long as the complexity of the task is described in terms of the environment (in a quiet room versus a situation with distractors present) there can be a fairly good measure of progress in terms of increasing attentional skills.

Too often practitioners are subjective in clinical comments such as, “He’s less distractible now.” In fact, more important data are, “What is he doing now, how well is he doing it, and what is the environment that he is doing it in?” Otherwise, understanding the individual’s functional performance is not possible. Without an in-depth understanding of an individual’s cognitive issues, there is no way to appreciate the breadth of difficulties an individual will face across his or her lifetime.

**Categorization**

The next building block in the development of cognition has been recognized by researchers for a significant period of time. It has been studied not only in its relationship to cognitive process in brain injury, (Lamberts & Shapiro, 2002; Constantinidou et al., 2001 & 2005, Coltheart, 2001) but also in language development (Farah & McClelland, 1991; Knowlton & Squire, 1993; Vygotski, 1986). It is categorization.

Constantinidou and Kreimer (2004) showed that after brain injury, subjects were unable to extract and use attributes such as color, shape, size, composition, texture, detail and function to either spontaneously describe objects or to create categories, either basic or abstract. In other words, people might be able to identify an object by name, but could not categorize them across the features described above and could not move into higher levels of abstract idea formation. This is an important finding when we remember how often we, in our everyday lives, automatically categorize things in our environment and make decisions based on that ability.

**An example:** Once, when I was interviewing a gentleman who survived a brain injury, and his wife, the topic turned to his safety around the house. His wife indicated that her husband seemed fine in the hospital but now did “strange things” that made him unsafe, particularly in the kitchen and in his workshop.

*continued next page*
The rush to define the cognitive problem might lead one to suggest that this person had “poor judgment” or was “unsafe” for kitchen or leisure activity in his workshop, or maybe he was “impulsive.” While those descriptions may be accurate in terms of the outcome of an event, the problem is that the descriptions don’t tell the why of the story.

His wife went on to describe how he had attempted to drive nails into concrete, cut metal with his circular saw and put popcorn in the oven to stay warm in a Tupperware bowl. The outcome of these behaviors is apparent: the individual is unsafe when left alone. However, his cognitive problem actually has to do with category boundaries. In each of these situations, he missed an important categorical feature, and consequently he made bad decisions.

In her writings, Constantinidou has suggested a hierarchical approach to categorical training to encompass not only the feature aspect of categorization (color, shape, construction, etc.) but also the idea of cognitive distance. Cognitive distance relates to the idea that real objects are easier to mentally represent, organize and manipulate than are photographs, line drawings, or written or spoken words. From a practical standpoint, improving judgment and safety requires hands-on experience in the real world with real things. Describing the problem conceptually doesn’t yield a treatment plan or determine functional abilities. Clinical focus without practical environmental experience does not do the job.

**Distributed Cognition**

Similarly, the concept of distributed cognition provides another way of looking at the complex and synergistic qualities of cognition and the interplay of the environment. Distributed cognition relies on the principle that learning and knowledge are not confined to an individual but are distributed across individuals and environments.

The unit of analysis in distributed cognition is the sum of functional activity at hand, the environment in which complex behavior emerges, and the resources involved, not the specific skill or component of cognition being measured (Duff et al., 2012). Therefore, clinicians must use real world (or close to real world) activities to assess potential problem areas like attention, memory, or problem-solving. This results in a more complete picture that allows us to see where and why breakdowns occur.

Without this level of understanding, important decisions about the long-term needs of individuals with brain injuries, such as return to work, cannot be made.

**Functional Cognition**

Other researchers have pointed to the development of functional cognitive constructs across the brain injury continuum. Donovan and colleagues (2011) are developing a computer adaptive measure of

*continued next page*
functional cognition for TBI. Their hope is that this project will result in an efficient, precise and ecologically valid measure of six identified functional cognitive constructs: attention, memory, processing speed, executive functioning, social communication, and emotional management that can also be used to predict functional outcomes. To date, the project has worked to specify these constructs to capture the full range of cognitive deficits associated with traumatic brain injury.

**Cognitive Rehabilitation**

Another consideration life care planners will often face is how to make decisions about the utilization of cognitive remediation or cognitive rehabilitation therapy. To date, there is limited evidence of the efficacy of cognitive rehabilitation therapy (CRT). In part, this is due to methodological shortcomings of the research, the variety of ways in which CRT is performed, and the fact that there are no uniform guidelines or standards for practice (Koehler et al, 2011). To this end, the American Congress of Rehabilitation Medicine has created *The Cognitive Rehabilitation Manual: Translating Evidence-Based Recommendations into Practice* as well as a two-day training for CRT practitioners. The goal of this significant compilation is to provide guidance in evidence-based CRT techniques for use in everyday clinical practice. The publication and training could be very valuable to the life care planner that works extensively with brain injury.

**Implications for Planning**

For now, when evaluating functional deficits and resulting lifelong needs of an individual, nurse life care planners must rely on information from a variety of perspectives, disjointed and not reliably predictive. While future developments in medical diagnostics like functional MRI (fMRI), computerized testing, and evidence-based CRT are forthcoming, determining how an individual’s cognitive deficits will manifest in real life is best done in real life.

Life care planners must therefore plan for and insist that some resources are reserved for treatment in the home, on the job, and in functional activities that will be required of individuals long term. They must resist a rush to assume that an individual’s functional capacity will appear the same across increasing demands. Life care planners might also request information from practitioners in formats that assist in the long-term planning for their clients. Questions to consider

---

*continued next page*
might include: What issues do you anticipate on the job, in the home, in life roles as a result of this individual’s cognitive profile?

Life care planners might also include reserving resources for environmental and technological adaptations for cognitive shortfalls. These compensatory devices might include older favorites like medical alert systems, newer devices such as tablets, smartphones, and “apps,” and newly-imagined adaptations like “smart houses.”

Brainline.org at www.brainline.org is one resource for such new technology. Recently they listed a number of “life-changing” apps for individuals with brain injury:

http://www.brainline.org/content/2011/05/23-lifechanging-iphone-ipad-apps-for-people-with-brain-injur y.html and also provide great guidance on assistive technology resources:
http://www.brainline.org/content/2011/06/assistive-technol ogy_pageall.html . The American Speech and Hearing Association also lists a number of apps for individuals with brain injuries at

The Real World
Across severity levels, the reality is that the true nature of potential cognitive limitations will not truly manifest until an individual with a brain injury is out of the rehabilitation hospital and faced with the demands of everyday life. Like the gentleman described previously, the person may get along well in a controlled environment but may struggle at home. Even the best cognitive remediation for individuals

continued next page
early on may not reproduce demands to which they will be exposed in the future. Often it is not until the individual fails to return to work or school or reintegration back into the role as parent or provider that the true effect of cognitive problems becomes apparent. The successful businessperson who can no longer divide attention between a variety of important work activities or the parent who melts Tupperware in the oven may not have the benefit of continued treatment if resources have already been spent or if problems were not recognized in time to be included in long-term plans for recovery. Unfortunately, individuals often go straight from a hospital outpatient-based environment to home. They never get the opportunity to fail at everyday living and have the advantage of the clinical eye as it happens. The nurse life care planner is in a unique position to complete a thorough clinical assessment and determine how the individual may be affected in a personal environment rather than simply seeing how someone functions in the shelter of a hospital.

In short, there is no substitute for the real world when it comes to observing, assessing and defining the extent of cognitive deficits in brain injury regardless of the defined severity of injury. The nurse life care planner has an especially important role when it comes to making sure that real life analysis is part of the long term plan. Real world assessment is not only essential in determining the long-term needs of a person with a brain injury, but also adds credibility of the nurse life care planner’s identification of cognitive needs and resulting rehabilitation recommendations.

References


*Moon over Vineyard Haven, Martha’s Vineyard MA*  
photo by Linda Husted
A New Look at Life Care Planning
After Brain Injury

Janet M. Williams, MSW, PhD

“Life care planning” has industry specific connotations within the context of medical care, long term financial settlements and disability. If you think about the meaning of these words in a lay context, aren’t we all “life care planning” in some form or another every day? I do life care planning when I put money away for college for my young children, my parents did life care planning when they downsized to a ranch style house before they needed it. Anyone who takes a long view of where they want to be in the future is life care planning. Life care planning, in essence, starts with where we want to end up. What do I want for my life, what would my children or parents want for their own lives?

In the field of brain injury, the event and subsequent medical and rehabilitation challenges often overshadow the question of what a person wants. Take Joe, for example. He was in a car wreck six months ago. He was in a coma for two months and has slowly begun to resume regular routines. His OT, PT, cognitive and speech therapists work with him more than 30 hours a week. He has one-to-one attendant care and is relearning how to walk, speak, and get the best possible

Janet Williams is the founder and president of Minds Matter, LLC., a provider of functional community-based therapies for individuals who have experienced a life-changing injury or event. She is also the founder and president of communityworks, inc., a Kansas-based company that supports people of all abilities who wish to live, work and play in their communities. She can be contacted at "Dr. Janet Williams"

<janetw@communityworksinc.com>
rehabilitation a thousand miles from his family’s home. The intoxicated driver who hit Joe was working and driving a company car at the time of the wreck. He admitted he was drinking and Joe’s attorney has six witnesses and the blood alcohol test to prove it. Add in that it is a Fortune 500 company and everyone involved realizes there is a way to have Joe get the best treatment available.

Where is Joe in all of this? His mother is now surrounded by attorneys, experts, medical staff and people wanting the best for him, while Joe participates in rehab. He is able to move from specialized program to specialized program in the quest to get the best care. The people closest to Joe start to realize he is profoundly unhappy, and his unhappiness becomes labeled as depression. Finally, in desperation, his mother says, “Joe you are getting the best possible treatment to get better, what more could you want?” Joe looks at her and says, “Mom, I want to go home.”

How can Joe and his Mom get home without compromising the expert care he needs? The best way to do that is to move Joe to the center of the decision making about his own life. When individuals are at the center of every decision and interaction related to their rehabilitation, they are far more likely to thrive and live rewarding lives in their communities. Principles that guide person-centered decisions regarding rehabilitation include the following (Table 1):

### Table 1. Principles that guide person-centered decisions

*Williams, 2012*

- Everyone, regardless of abilities, has the right to create a place in the community.
- All people have the right to fully control every aspect of their lives and environment.
- When individuals and therapists collaborate on goal setting, outcomes are optimized.
- When therapists coach, support, and consult with individuals and families, consumers gain confidence and respond to challenges with creative solutions.
- Regular routines minimize cognitive challenges and help individuals develop strategies that facilitate independence.
- It’s essential to teach individuals how to make connections and build relationships.
- It’s essential to teach skills that individuals need to live fully after a life-changing injury or event.
- There’s value in helping individuals discover enjoyable experiences that make their lives more meaningful.
- Coaching and consulting are important vehicles that create new possibilities for people living with disabilities.

continued next page
reach their goals. In addition, our communities become stronger when we support everyone to remain in familiar settings. The approach is also the fiscally responsible choice; it is far more cost-effective to provide home and community supports for individuals who have had a brain injury. When compared to the cost of care and rehabilitation in hospitals, nursing homes and long-term care institutions, a community-based model saves thousands of dollars.

All people have the right to fully control their lives and environment. When individuals and therapists collaborate on goal setting, outcomes are optimized. Each contact made with individuals and their families focuses specifically on needs and priorities they have expressed. It may be as simple as a trip to the grocery store or developing a strategy for managing the laundry.

At times, needs are more complex. Perhaps the individual needs assistance working up a household budget or launching a job search. In the midst of responding to needs and goals there are abundant opportunities for relearning. In most situations, learning is embraced as a new tool for living because it’s happening in a meaningful setting and context. Individuals aren’t merely learning in a generic institutional setting; they’re learning skills that promote their personal independence and success and they’re applying what they’ve learned to real world situations.

When therapists coach, support, and consult effectively, individuals and their families gain confidence and respond to challenges with creative solutions. Far too often, an individual is expected to “transition” back into the community abruptly and with little preparation. Quite literally, transition to real community life occurs during the car ride home from a rehabilitation facility. Not surprisingly, individuals are not prepared to navigate the demands of living in the real world because they’ve been living in a structured and institutional setting. That’s why immediate collaboration with therapists is critical. With coaching and support from professional therapists, individuals are able to transition successfully to life at home and in the community. Progress toward recovery takes time and thoughtful planning. Appropriate home modifications and step-by-step goal setting makes it possible for individuals to adjust and begin experiencing success. Partner-

continued next page
ship with dedicated therapists is the key that unlocks new possibilities.

It’s essential to teach individuals how to make connections and build relationships. Connections count. No matter where individuals are in the recovery journey, the ability to create reliable support systems and connections to resources is vital. A strong network consisting of friends, family, neighbors and professionals empowers individuals to pursue their goals and achieve independence.

It’s essential to teach skills that individuals need to live fully after a life-changing injury or event. There’s value in helping individuals discover enjoyable experiences that make their lives more meaningful. When therapists collaborate with individuals in familiar settings, it’s possible to minimize barriers and maximize opportunities. Therapy is more successful when it happens at home where skills can be applied to daily routines.

Serious consideration and implementation of these proven principles can make it possible for more people living with TBI – people like Joe – to live their life, their way: engaged in their communities and the things they want to accomplish. Effective use of settlement and other resources is making it possible for people who are affected by TBI to chart their own courses and create their own futures.

Nursing Diagnoses to Consider NANDA-I Nursing Diagnosis, 2012-2014

- **Chronic Low Self-Esteem**: Long–standing negative self–evaluating/feelings about self or self-capabilities (Domain 6, Self-Perception; Class 2: Self-Esteem)
- **Post Trauma Syndrome**: Sustained maladaptive response to a traumatic, overwhelming event (Domain 9, Coping/Stress Tolerance; Class 1: Post Trauma Responses)
- **Relocation Stress Syndrome**: Physiological and/or psychosocial disturbance following transfer from one environment to another (Domain 9, Coping/Stress Tolerance; Class 1: Post Trauma Responses)
- **Ineffective Activity Planning**  Inability to prepare for set of actions fixed in time and under certain conditions (Domain 9, Coping/Stress tolerance; Class 2, Coping Responses)
Assistive Technology for Brain Injury

Keith Sofka ATP (retired)

Developing assistive technology (AT) recommendations for individuals with a brain injury is usually more demanding than for any other type of disability.

It’s important to resist the tendency to generalize about the technology needs of any individual with disabilities – the sample size is always n=1. It is particularly important to keep this in mind when evaluating someone with a brain injury.

As always, in AT evaluation the cause of the disability is not as important as the obstacles involved. Individuals should have reached maximum medical improvement before final recommendations are developed. A person with brain injury may have all of the needs of someone with a high spinal cord injury, plus speech difficulties, memory problems, vision changes, disinhibition or other behavioral problems, as well as many other obstacles.

Any or all of these may be intermittent. If so, it is important to evaluate the individual at different times and in different settings. A team of the people closest to the individual, including other providers, will help identify the person’s range of abilities.

Trials with devices or strategies while the person is still in rehabilitation is very important. There are usually issues related to learning new information and consistent teaching, training and reinforcement are crucial for the successful implementation of AT.

Family and other care givers should be involved in this training process so the information can be reinforced after the individual returns home. However, significant changes in abilities

Keith Sofka has practiced the provision of assistive technology services for the past 30 years. Mr. Sofka provides consultation to hundreds of companies, schools, government agencies and individuals. He can be contacted at ksofka@gmail.com
and needs occur with therapy, sometimes in very short periods of time. Functional improvements may not plateau for several years. So it can be very easy to over-prescribe AT and end up with many abandoned devices.

Most often for individuals with severe brain injury, AT is sought to assist with memory loss issues. Accommodations should start with the simplest devices, a pen and tablet with lots of reinforcement can work wonders for some. Electronic devices like tablet computers might be a good goal, but care must be taken to assure that the individual will not be overwhelmed by the technology. A trial period with consistent training and reinforcement should be part of the AT recommendations.

Consider these factors:

- Can the person physically access and manipulate the device?
- Can the person see the device well enough to use it?
- Does the individual have the ability to integrate the device into routine, e.g., carrying it from place to place?
- Is the device effective for the obstacle(s) in question?
- Will the individual remember to use it?

This final point may be the most difficult. Some individuals will always have difficulty integrating AT in their lives. Electronic devices can set alarms and even spoken messages at certain times, but unfortunately, even this level of assistance may not be enough for some individuals.

**Summary**

Here are some key points for life care planners to consider as they make decisions about life care plan provisions. Collaborative evaluations with other specialties will be helpful.

- Evaluate extent of short-term memory with other providers to determine if the person can learn to use the device
- Evaluate what problems need to be solved with using a device
- Add AT provider time in the LCP to observe use of the device on a daily basis
- Make sure extensive training and on-going support in use of the device are part of the LCP
- Include training to ensure familiarity with the device for family members

*continued next page*
There’s An App For That

There are thousands of applications for iPad and Android tablet computers. Some are more useful than others for brain injured persons. Here are some links to websites with pertinent information.

http://www.brainline.org/content/2011/05/23-lifechanging-iphone-ipad-apps-for-people-with-brain-injury.html

You can probably spend a few hours on the Brainline.org site. It has PDF files to download that list the most useful iPad and Android Apps as well as articles about AT for people with brain injury.

http://www.tbistafftraining.info/SmartPhones/SmartPhones1.html

This is a good site for learning the basics about AT Apps and brain injury.

http://id4theweb.com/appreviews/

Making Cognitive Connections page on AppReviews, a centralized location for individuals with cognitive challenges and professionals who work with them to post reviews of apps they find particularly useful for work, home, and school.
Cognitive problems are almost universally cited as the biggest challenge brain injured people face. No matter what the cause -- trauma, a complication of surgery, an unfortunate residual of resuscitation efforts, vascular disease, malignancy, “chemo brain,” autism, or other condition -- the inability to use one’s brain to organize and make sense of one’s life is distressing for all involved. This latest offering in the Making Cognitive Connections series is designed both to help the reader master built-in Apple iOS 5 apps to organize life and to recognize and appreciate the parallel cognitive skills involved in each of them.

The author has taught in an acquired brain injury program for over 25 years. This book, chock-full of technology-based compensation strategies for brain injury survivors, is a result of her self-described passion for teaching and fascination with computers. Written with input from her students, its intent is to teach technology while becoming aware of the cognitive skills involved in learning the technology, e.g., attention to detail, planning, and critical thinking. These become transferrable skills for other areas of life. For example, remembering the steps necessary to record an appointment is practice for storing and recalling information, events, or procedures.

In workbook form, the book begins with a tour of the basics -- basic controls for sound, appearance, and folders, using wi-fi, notifications, alerts and alarms, setting the clock, and the calendar. These last two account for fully one quarter of the content, which would come as no surprise to anyone living with the effects of brain injury. Text in a neat sans-serif font and screen shots with considerable white space make it easy to read. Worksheets follow step-by-step instructions.

For example, after the lesson on using the Timer function, the learner is given a few examples, then:

Organize Your Life: Using iOS5 on the iPad, iPhone, and iPod Touch
Michelle Ranae Wild MA
ID4theWeb, Laguna Hills CA
ISBN-13 978-0-9816670-5-8
ISBN-10 0-981-6670-5-81

Wendie Howland is the Editor of the Journal of Nurse Life Care Planning. She is the owner and principal of Howland Health Consulting, Inc., providing life care planning for plaintiff and defense, case management, and editing for health professionals. She may be reached at whowland@howlandhealthconsulting.com
Then the learner is asked to:

Count down 45 minutes for a gym workout
Read for 30 minutes
Count down an amount of time before you have to go someplace.

A student could use the appointment schedule to set a weekly class schedule: “Create a Repeating Appointment” is clearly described.

Alerts can help with planning:

What are appropriate alert times for you to:
   a) Get to a doctor appointment
   b) Get to the gym for a fitness class
   c) Buy a present for your mother’s birthday?

For someone with fine-motor difficulties, the voice-control app “Siri” can be a great help.

Siri allows you to create, search or add to existing notes in the Notes app by speaking.

To interact with the Contacts app using Siri:
   1. Press and hold the Home button until “What can I help you with?” and a microphone appear on the screen.
   2. Siri will understand a number of verbal commands, such as:
      a) Note that I bought lunch at Ruby’s
      b) Note to follow up with Jan
      c) Search for Meds note.

Sections on Maps can help with wayfinding; the connectivity that everyone craves is addressed by clear sections on Mail, Camera, iTunes, Phone, and FaceTime.

Many people find technical manuals frustrating. This workbook is different: It is deliberately structured to be a learning tool for persons living with cognitive challenges. This book can be purchased online at http://id4theweb.com/iOS5_book.php
Asking a compelling and searchable clinical question about adults with acquired brain injury, cognitive rehabilitation effectiveness, and resultant quality of life (QOL) requires skill and forethought. Melnyk and Fineout-Overholt, 2011 (p. 26) described the PICOT format as one way to think about this: Population, Intervention, Comparison, Outcome, and Time or duration of achievement. This model helped form the evidence-based practice question presented here: “In adults with acquired brain injury (ABI), how does patient-focused cognitive rehabilitation affect quality of life post injury, compared to alternative or absent intervention?”

Two quantitative research studies show positive results for patient-centered cognitive rehabilitation and quality of life after acquired brain injury. Both studies validate practice intervention decisions contained herein that include concepts of (a) considerations for quality of life, (b) community reintegration, and (c) individual coping styles. All three concepts concern nurse life care planners with regard to the impact of decisions made about future medical care provisions for individuals with ABI. In accord with the International Association of Life Care Planners (IALCP) philosophical overview and goals, the life care plan is a working document that provides valid and timely information. The plan can serve as a lifelong guide to assist the injured persons health care service delivery in a managed format (IALCP, 2008).

Cognitive Rehabilitation

Purpose Wolters, Stapert, Brands, and Van Heugten (2010), investigated coping styles of individuals with ABI who participate in cognitive rehabilitation versus existing data from questionnaires and scales that measure known problem-focused evidence-based practice questions guiding a nurse life care planner practice intervention.

Patricia Brock MSN RN LNCC CLCP CNLCP

Patricia Brock left the bedside in 2004 to obtain her certifications and grow her business: HTI Legal Nurse Consulting and Life Care Planning. She is an active member of the Orlando chapter of the American Association of Legal Nurse Consultants and frequently performs as a nursing SOC expert. Ms. Brock is a clinical nurse educator for Daytona State College and is pursuing her PhD in nursing. She can be contacted at 1379 East Lansdowne Avenue, Orange City, FL 32763.
coping styles. The effects of changes in coping styles, QOL, and implications for cognitive rehabilitation provide insight and emphasize the need for inclusion of patient-focused outpatient rehabilitation programs in life care plans prepared for the ABI population.

**Importance** A significant health problem in The Netherlands, ABI accounts for one to 1.7 incidents per thousand of population yearly. Poor psychosocial adjustment and adaptation to negative effects and reduced goals resulting from a new reality demands a problem-focused rehabilitation process to help ABI patients with adjustment and coping skills to enhance their QOL.

**Design, Population, Sample, and Ethics** The prospective longitudinal study includes patients referred to an outpatient cognitive rehabilitation program by physicians or psychologists between 2000 and 2008. Inclusion criteria: (a) confirmed ABI by data or physician, (b) minimum age of 17 years, (c) presence of cognitive, behavior, or emotional symptoms interfering with activities of daily living (ADLs), and the ability to speak and understand the Dutch language. Excluded patients exhibited primary behavioral or psychiatric problems such as (a) severe aphasia, (b) degenerative brain disease, (c) personality disorders, or (d) substance abuse (Wolters, Stapert, Brands, & Van Heugten, 2010).

One hundred forty-one patients met inclusion criteria and received questionnaires by mail. The final sample consisted of 110 participants, a response rate of 78%. Final participants completed the Stroke-Adapted Sickness Impact Profile, the Life Satisfaction Questionnaire, and signed the consent form upon receipt of the information packet. The Medical Ethics Committee of Maastricht University Medical Center and the Research Committee of the Rehabilitation Centre Blixembosch approved the study (Wolters, et al.).

**Data Analysis** Participants grouped by education participated in four one-sample t-tests. Subsequent t-tests, dummy-coded gender assignment, assumptions of the regression analysis, and two linear regression analyses used SPSS software. Comparing the baseline scores of the instruments with SPSS analysis indicate the dependent variables, predictors, and differences demonstrated in the study conclusions (Wolters, et al.).

Two quantitative research studies show positive results for patient-centered cognitive rehabilitation and quality of life after acquired brain injury.
**Strengths and Weaknesses**  Five strengths of the study indicate (1) it is the first to explore changes in coping styles related to ABI with a prospective longitudinal design, (2) the high response rate of 78%, (3) no strict inclusion and exclusion criteria inhibited a broad spectrum of heterogeneous population encountered in regular clinical practice, (4) the rehabilitation program reflected current practices, and (5) QOL. Three noted study limitations include (1) injury characteristics not included in regression models, (2) QOL not measured at the start of rehabilitation, and (3) other influences such as mood impairments could influence use of coping styles and QOL. (Wolters, et al.).

**Results**  The researchers hypothesized patients reliance on problem-focused coping styles would increase and less emotion-focused coping styles post rehabilitation would enable participants to experience an enhanced QOL. However, the study result indicates scientific evidence lacked support for that hypothesis. The promise seen in this inquiry indicates individual coping styles are amenable to cognitive rehabilitation. In addition, learning to use problem-focused coping styles may be *assumed* to increase an ABI individual’s QOL.

**Virtual Reality-Based Community Living Skills Training Program**

**Purpose**  A newly developed virtual reality (VR) based rehabilitation training program for people with ABI attempts to improve the capacity to process and use information to enhance functioning in everyday life (Yip & Man, 2009). This study contributes to the applicability of the nurse life care planner premise that each plan includes options for independence of the injured person in the least restrictive setting with improved QOL as a foundational outcome (IALCP, 2008).

**Importance**  This small pilot study serves the purpose of information collection and experience prior to conducting a large-scale randomized control trial (RCT). Although lacking statistical significance, positive training effect indicates a measure of positive outcome. The VR community living skills training software called Virtools seems valuable and should undergo evaluation as well prior to or during another investigation of ABI and VR rehabilitation techniques (Yip & Man, 2009).

**Design, Population, Sample, and Ethics**  A small sample of subjects, one with ABI and three with stroke participated in a pre-and post-quasi experimental design study of the effects of VR rehabilitation on ABI. Convenience sampling accomplished recruitment from a local rehabilitation center. Inclusion criteria demanded (a) stroke or ABI, (b) medical stability, and (c) subjective complaints of cognitive deficits impeding community integration. Exclusion criteria included (a) attention span fewer than three minutes, (b) severe visual deficits, (c) pre-or post-morbid mental retardation or other "continued next page"
neurological disorder such as epilepsy, and (d) previous VR-based training (Yip & Man, 2009).

Virtools software program, a 3-D environment comparable to traditional gaming methods, includes a programmable joystick, 32-inch monitor, and stereo speakers to deliver the training modules. Content such as travelling by bus, shopping, using a public telephone, and meeting a friend at a pre-determined destination require subjects to navigate the virtual environment in a safe and appropriate manner. A subsequent task requires participants to search for a nearby store, shop for items on a checklist, and check out before leaving. Other instruments used for testing include a self-efficacy questionnaire, the Neurobehavioural Cognitive Status Examination-Chinese Version, and the Lawton Instrumental Activities of Daily Living Scale – Chinese version (Yip & Man, 2009).

Ethical approval, granted by the Ethical Committee of the Hong Kong Polytechnic University prior to the face-to-face interview, explained the purpose and explored the subjects’ suitability for the study. The participants provided written consent two weeks before assessment and VR training. Baseline measures taken prior to treatment underwent comparison directly following the final training session (Yip & Man, 2009).

**Data Analysis**  Memory deficit hindered functioning in community living to a greater extent than any other cognitive complaint. Despite a similar pattern of cognitive deficits, and a similar pattern of construction deficits among the four participants, improvement noted on individual construct and memory function established a positive training effect. Improvement in transferability of skills from VR to the real environment demonstrated a range from 15.6 to 50% improved. Global cognitive ability and level of independence show enhancement that remain constant after ten training sessions (Yip & Man, 2009). Three of the four subjects showed dramatic improvement in memory, and all four had improvement in construction and independence, thus providing a small and preliminary measure of validation for the inclusion of VR in a life care plan for ABI.

**Strengths and Weaknesses**  The strengths of the study lie in the impressions from the small sample of ABI participants’ motivation and enhanced self-
efficacy. The small sample of four cases, statistical significance, and generalization to the ABI population demonstrate the weakness of the study. In addition, the monitor size could present a confounding variable with regard to subjects’ performance. Finally, the researchers in this pilot study performed as raters of the outcome measures, raising the question of rater bias (Yip & Man, 2009).

Results  Four ABI subjects, successfully recruited for this study completed ten sessions of VR-based community living skills training. Each improved in cognitive ability and self-efficacy while demonstrating transfer of learned skills to the genuine environment. The positive changes seen in the ABI subjects require a follow-up RCT (Yip & Man, 2009).

Conclusion  Assumptions do not qualify in testimony that attempts to defend inclusion of items in a life care plan. Each item must be defensible within a reasonable degree of scientific basis. The Wolters et al. (2010) study did not directly address community re-integration, which is always a patient goal, even if limited in capacity when creating a life care plan. The Yip and Man (2009) study did not directly address QOL, which arguably is subjective. Both articles potentially assist a life care planner to choose an appropriate method of cognitive rehabilitation for a client with ABI. Validation and support based on results from both studies, combined with scientific evidence from additional research, may provide a defensible foundation for patient-centered community reintegration, recognition of individual coping styles, and enhanced QOL.

References


There’s An App (or a Website) For That!

This is a list of websites for brain injury resources contributed by several AANLCP members. Thanks to Shelly Kinney and Linda Husted for your willingness to share!

All links were functional as of the date of publication. AANLCP and the JNLCP cannot be responsible for dropped, broken, or missing links.

Association of Rehabilitation Nursing STANDARDS OF CARE
http://www.rehabnurse.org/sites/content/index.html#section3

Webinars from BTF (Brain Trauma Foundation)  https://www.braintrauma.org/tbi-faqs/recorded-webinars/

Webinar: Aging with Traumatic Brain Injury, also by Dr. Flanagan:  
http://www.braintrauma.org/june-2011-webinar/

Concussion checklist:  http://www.braintrauma.org/concussion-checklist

The Model Systems Knowledge Translation Center has excellent information on SCI, TBI, and Burns. The link to the TBI Model Systems is:  http://www.msktc.org/tbi


DCOE monthly webinar schedule. CEUs are available:

Video on the value of diffusion tenser imaging in blast brain injury

Web link for Washington University at St. Louis lab for Neurosciences, TBI research ongoing, Dr. David Brody:  http://dbbs.wustl.edu/faculty/Pages/faculty_bio.aspx?SID=6064

Articles on military brain injury
OR  http://tinyurl.com/9gqm5vs

Heads Up! Concussion Information for Physicians

Heads Up to Clinicians: Updated Mild Traumatic Brain Injury Guideline for Adults
http://www.cdc.gov/concussion/HeadsUp/clinicians_guide.html

Assessing Outcomes in Children

Making Cognitive Connections, an online resource for anyone interested in cognitive remediation.  
http://id4theweb.com/
Pricing Data

DRG, APC, etc...

ahd.com

American Hospital Directory, Inc. provides a wide array of online hospital information and profile data for over 6,000 hospitals in the United States. AANLCP* members are eligible for a 10% discount off the single-user annual subscription cost to AHD.com. Please visit us at www.ahd.com or our booth at the AANCLP* conference to take advantage of this special offer.
In graduate school, I had my eye on the prize: a career in professional voice, coaching TV anchors, singers, announcers, and cheerleaders. No little kids, no drool, no sitting on floors. I intended to make buckets of money and wear dry clean-only clothes. Needless to say, I won a different prize. We lived in Dallas at the time, and upon graduation, there was exactly one job left open: working with infants/toddlers in a home program through the school district. In fact, for most of the last twenty-four years, I have been sitting on floors with small drooly patients. And I am in love.

It strikes me that so often circumstances fall apart, hopes shatter, and dreams do not materialize. And in their place, an opportunity appears that far exceeds the original plan. So many examples, but one has impacted my career more than I ever could have imagined. In the midst of a divorce, years ago, I began to do home health therapy as an add-on way to build a private practice. No real allure, just extra income. Little did I realize what a proving ground home health would become.

Our pediatric team was stunning, and each week became a symposium in patient care, functional management, rare syndromes, g-tubes, j-tubes, and tracheotomies. The OTs and PTs readily explained positioning needs, splinting, utensil grasp, and anti-gravity movement. The nurses thoroughly described the child’s latest surgery, medication, or genetic profile. The social workers helped us understand family loss, anger, grief, and worry.

I would not be the same SLP without this unexpected journey into medical fragility. And I could not possibly pay for this priceless experience. Gradually, with more or less kicking and screaming, I have come to view initial disappointments truly as open windows, and patiently wait for the next great thing. Like presenting at AANLCP!
Our Lifecare Management business revolves around clients and outcomes. We pioneered our Surround Care™ model, under which every client is “surrounded” with the precise types of care most suited to their circumstances, to bring about the greatest possible healing, wellness, independence and quality of life.

Some of the earlier parts of my career found me in the hospice realm. It was here that I gained an appreciation, really a passion, for the concept of “slow medicine.” In many instances, quality of life is most enhanced by a slower, more thoughtful approach to treatment. Rather than rushing toward the next procedure, the newest clinical trial, the latest therapeutic regimen, we need to take a breath and consider the patient – the person – at the center of it all.

As clinicians, we need to understand what it is this person values, what facets of life are most important to them. We need to weigh whether continued or accelerated treatment will restore a client to the life they love, or will perhaps merely prolong a bed-bound existence in a skilled nursing environment.

We often work with our clients to identify and illuminate their core wishes where life sustaining treatments are concerned. Several states are developing programs called POLST – Physician Orders for Life Sustaining Treatment – wherein patients document their wishes in a variety of treatment scenarios and make these wishes known to their doctors. Physicians are then able to put orders in the patient’s chart that reflect expressly stated treatment wishes. POLST documents fill in gaps in our understanding of a person’s overall perspective on end-of-life care, and point the way for service providers and family members as they grapple with options.

Shay Jacobson, RN, MA, NMG
“Beyond Catastrophe: Opportunities for Life Care Planning With Special Needs and Aging Populations”

As the founder/owner of Lifecare Innovations, I have at least a hundred issues on my desk at any given moment – client concerns, payroll, business development, accounts receivable, personnel matters, all key components that create and sustain a successful business.

It’s important to balance the harder edges of business with our passions. Mine happens to be animals and their unique and unmistakable ability to transform a room, a day, a mood or
a client. Our Animal Assisted Therapy program has been a wonderful venture for both the clients we serve and for our staff, many of whom have had their dogs certified as Therapy Dogs and have themselves become Certified Handlers. I have been a Certified Handler for 11 years and have owned six therapy dogs.

The dogs transform our office and are even more transformational in the field. Clients, no matter their status, recognize and respond to the presence of a dog. A client may be non-verbal, equipped with failing sensory abilities, unable to walk, but still attuned to the comforting pressure of a dog resting its head in their lap. Somehow, dogs and clients communicate. Somehow, dogs bring back childhood memories and the tangible love of pets remembered from long ago.

Many studies point to fewer doctor’s visits, less medication use, and decreased stress among the medically fragile when dogs are introduced to their environments. Pain, boredom and anxiety all seem to melt away in the company of an affectionate animal. It’s a simple formula. The touch, the attention, the easy interaction brings forth the part of us that rises above illness and pain and medical history and knows only this moment, this particular piece of time.

On Animal Assisted Therapy days, tails wag, clients smile, and our business is leavened with passion.

Linda Nelson MEd CCM CLCP MSCC

“Spinal Cord Injury and Aging: Applying Evidence-based Research”

How very fortuitous to receive a request for some comments within three hours of visiting by phone with another life care planner 2000 miles away. We both work from home and enjoy many common threads in our businesses. We met at a conference in Mexico that has provided the most incredible networking and friendships and we talked about some of the cases we’ve been working on and the devastation of some of the injuries. I’ve often thought of my life as having been constantly magical, despite no sweepstakes winnings, no home on a lovely tropical island, no glittering awards proving that I’m nothing less than incredible, and, actually, with probably my fair share of trials and tribulations over the years. My work is part of my magic – I truly love what it brings to me and what I can do for those I work with.
Gould & Lamb
Provides Solutions for Your MSA Challenges

We are dedicated to superior customer service by delivering quality cost containment and compliance products to the global insurance market.

Gould & Lamb’s Services

- Medicare Secondary Payer Compliance
- Mandatory Insurer Reporting
- Conditional Payments
- Allocations
  - Workers’ Compensation
  - Liability / Auto No-Fault
- Post Settlement Account Administration
  - Self Administration Support
  - Professional Administration Support
- Cost Containment
  - Future Medical Cost Projection
  - Prescription Drug Management Program

- Liability Life Care Planning

Gould & Lamb
The Global Leader in Compliance

101 Riverfront Blvd., Suite 100
Bradenton, Florida 34205
www.gouldandlamb.com
1-866-MSA-FILE

©2011 Gould & Lamb
Information for Advertisers
Any submission electronically with photos, art, and text is acceptable. Advertisers can submit any ad in a high-resolution PDF or JPEG. PDF format is preferred. We reserve the right to reject any advertising deemed to be in poor taste, libelous, or otherwise unacceptable. Please submit any ad for consideration to the Editor, Wendie A. Howland MN RN-BC CRRN CCM CNLCP LNCC whowland@howlandhealthconsulting.com

Rates
Quarter page, $100 per appearance
Half page, $190 per appearance
Full page, $375 per appearance
Submit copy 3 weeks before publish date, invoiced and paid before publishing. Mail checks payable to AANLCP to AANLCP, 3267 East 3300 South #309 Salt Lake City, UT 84109