



Information Bulletin

Use of Therapeutic Narratives in the Treatment of Neurobehavioral Disorders

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INTRODUCTION

Awareness deficits are common after brain injury. Such deficits are evidenced in a number of ways, including (1) denial that deficits exist (2) behavior that is grossly and frequently at odds with stated personal goals, including rejection of help, and (3) repeating an ineffective behavior despite negative consequences.

Awareness deficits are important setting conditions for maladaptive behaviors. They strip the individual of the ability to predict the consequences of actions, to avoid negative consequences, to learn from experience, and ultimately, to meet basic needs and attain personal goals. Awareness deficits place the individual at the mercy of their basic impulses and make them likely to repeat maladaptive behavior patterns indefinitely unless intervention is effective in altering the pattern.

Cognitively impaired individuals with challenging behaviors may not benefit from traditional counseling due to difficulties processing, integrating, retaining, and applying new information that are common after brain injury. However, it is known that

cognitively impaired individuals may be able to benefit from feedback that promotes insight and better self-control if the information is provided and reinforced repetitively in overlapping oral, written, and graphic presentations.

The term "Social Stories™" was created and trademarked by Carol Gray, an educator known for her work with autistic spectrum disorders¹. Social Stories™ are narratives written from the subject's point of view, that describe social situations that are challenging for them, including effective ways of managing such situations. The intent is to share social information that the individual may be lacking, a lack that may contribute to if not cause maladaptive social behavior. The approach is widely used with children who exhibit autistic spectrum disorders as a means of promoting the development of social skills and reducing challenging behaviors.

Presenting new information redundantly, in several modalities, and collaboratively created instructional narratives, outlines, and representational diagrams are fairly common practices in the field of brain injury rehabilitation. The purposes are typically to promote self-awareness, to facilitate disability education, or to support self-expression and self-advocacy skills. Until encountering Carol Gray's work¹, we had not thought to use a narrative approach specifically to reduce challenging behaviors.

METHOD

Narratives are constructed by speech-language pathologists, occupational therapists or social workers based on their knowledge of the subject's circumstances. The narratives include a description of the challenging behavior(s) and a suggestion for an effective way of handling difficult situations. This information is typically preceded with basic personal biographical information and selected clinical facts about the injury and rehabilitation program, in order to establish a better conceptual context for the behavioral issues.

Each narrative is individually created and designed primarily to appeal and communicate with the subject, taking into account their personality, manner of expression, differences in information processing and reading ability, personal preferences, and personal sensitivities. The narratives are created first by the clinician and subsequently reviewed and revised as necessary with the subject. All are written in the first person, from the subject's perspective, and with an attempt to convey a positive outlook toward rehabilitation and toward the individual's life in general.

The treatment procedure is simple. The individual is encouraged to read the narrative. Assistance is given so that the reading is fluent and expressive in order to emphasize meaning and facilitate comprehension. If the individual is unable to read the narrative, it is read to him or her.

While none of the clinicians have formal training in creation of therapeutic narratives, all are licensed and experienced clinicians and have been made aware of Ms. Gray's excellent public website¹ and encouraged to incorporate the guidelines for creating Social

Stories™ that are referenced there. The primary clinician typically consults with the social worker to assure accuracy of biographical information and with psychology staff if there are concerns regarding the emotional impact of particular facts.

The individual is determined to be an acceptable candidate for the approach if they accept the procedure. If and when the most challenging behaviors are stabilized, we try to establish higher degrees of internalization of the information and greater collaboration in the creation of the scripts themselves.

Deeper internalization is attempted by gradually fading text, first by eliminating more and more key words that the subject is asked to supply from memory, and then by fading the narrative altogether in favor of a detailed outline. Finally, the detailed outline is faded in favor of a key word outline, if the individual is able to wean from written word cues.

OVERVIEW OF RESULTS

Our results indicate that therapeutic narratives are a useful adjunct to the treatment of neurobehavioral disorders. Significant decreases in target behaviors; improvements in mood, acceptance of help, and increased willingness to participate in rehabilitation have been noted in virtually all subjects who were willing to cooperate with the procedure.

Case illustrations are attached.

ABOUT NORTHEAST CENTER FOR SPECIAL CARE

Northeast Center for Special Care is a 280 bed, transitional brain injury rehabilitation center devoted to the recovery, rehabilitation and community reentry of individuals with severe neurological impairments, in particular, those resulting from acquired brain and spinal cord injury. Northeast Center for Special Care is licensed as a skilled nursing facility but provides a number of specialty services that are unusual for this setting, including a ventilator-weaning program, an intensive neurobehavioral rehabilitation program, and a specialized, multi-disciplinary brain injury rehabilitation program that utilizes both traditional and alternative therapies in a therapeutic community context. More information can be obtained by visiting the Northeast Center for Special Care web site at www.northeastcenter.com

REFERENCES

1. Carol Gray's Web-site: <http://www.thegraycenter.org/socialstories.cfm>
2. Journal of Applied Behavior Analysis, Number 4, Winter 2001
Pages 425-446
3. Journal of Positive Behavior Interventions, Volume 4, Number 1, Winter 2002
Pages 53-60

CASE ILLUSTRATIONS WITH THERAPEUTIC NARRATIVES

NOTE:

Identifying information has been altered or eliminated to protect confidentiality.

#1. MD

MD is a 47 year old male who is 29 years status post brain injury resulting from an MVA. He is independently mobile in a manual wheelchair. He is semi-independent with basic Activities of Daily Living (ADL's) has poor Independent Activities of Daily Living (IADL) abilities, limited self-awareness, and no clear personal goals.

Challenging behaviors were of longstanding and included yelling, cursing, demanding cigarettes and coffee, verbal threats of violence, and occasional physical aggression. These behaviors also prevented rehabilitation efforts. One or several of these behaviors occurred on virtually a daily basis since his admission.

Prior to the use of a therapeutic narrative intervention, MD was oriented only to person, often spoke in a quasi-delusional manner, referring to staff as "God," and making other bizarre statements. He was frequently irritable and participation in general recreational activities was minimal.

It is noteworthy that MD received rehabilitation services prior to his admission. His progress in the previous setting had been limited and the long term prediction at the time he was admitted to Northeast Center for Special Care was that he would require long term care, indefinitely, notwithstanding Northeast Center for Special Care's commitment to attempt to gain HCBS Traumatic Brain Injury Waiver through the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) approval despite this.

The therapeutic narrative below was introduced in May of 2004 as part of an ongoing effort to address behavioral issues reported above. The narrative was read to D.M. at least once a day by Para-professional staff. The therapeutic narrative follows.

"My name is (Name). I was born on (Date). It is now the year 2005 and I am 48 years old.

I was born in the town of (Name), New York. My Mother's name is (Name) and my Father's name is (Name). I have a brother named (Name) and a grandfather named (Name).

When I was 18 years old, I had an accident. I was in a car and it was hit. I was badly hurt and in a coma for about a year. The most serious part of the accident was the injury

to my brain. Since then, it has been difficult for me to think clearly, to remember, and to manage things in my life.

This place is called the Northeast Center for Special Care. It is a rehabilitation center that I came to on April 8th, 2002. That's about 3 years ago. I am here for help to get my life back on track.

What I am most interested in is getting to the point where I can do things for myself. I have most difficulty with memory, which is why I am doing this exercise. The purpose of reviewing personal information about myself is to re-learn it. By the time I finish with these exercises my goal is to know more about myself than anybody else does!"

RESULT

MD's result was dramatic. His daily behaviors stopped abruptly the day after the readings began in May of 2004. The gain noted as been sustained. Target behaviors occur at the rate of less than once per month and are easily re-directed. The bizarre delusional statements are rare. He is now oriented to person and place and has established a daily activity routine. His participation in recreational activities has gradually increased and he was recently re-referred for rehabilitation services. He has been accepted by OMRDD Traumatic Brain Injury Waiver program and is awaiting availability of residential services.

#2. BT

BT is a 40-year-old male admitted in November 2004. BT is fully ambulatory, independent of Activities of Daily Living and without any significant communicative or physical impairment. He sustained a brain injury as a result of encephalitis from measles in early childhood. He completed the 9th grade and then dropped out. He is single and has no family involvement.

BT has had numerous contacts with community mental health services and criminal justice throughout his life. There have been several psychiatric hospitalizations and at least 2 placements in long term care facilities prior to admission to the Northeast Center. He was admitted to Northeast Center for Special Care from a neurobehavioral program in another state. Diagnoses include intellectual impairment within the mild range of mental retardation, paranoid schizophrenia, and organic personality syndrome.

He was admitted to Northeast Center for Special Care to undergo neurobehavioral rehabilitation and to eventually return to the Community with support provided by the Office of Mental Health.

His critical barriers are considered to be behavioral dyscontrol and rejection of assistance. He has reduced self-awareness and has very poor Independent Activities of Daily Living and executive control. He is clear and consistent about wanting to return to the

Community but his behavior is highly disorganized. Conversation readily shifts off of an established topic to paranoid thoughts or, variously, to self-reassurances that "No, no one is going to hurt me. I'm going to be okay."

Behaviors included frequent threats of physical violence and menacing gestures alternating with sexual advances on female staff. There have been several incidences of physical aggression. He tends to ignore his peers for the most part and avoided all organized activities when first admitted, spending many hours each day in his room listening to music at a high volume. Primary treatments included psychopharmacology, psychotherapy, and occupational therapy to assist in developing self-awareness and self-management skills, and therapeutic recreation.

He has required a one to one staff assistant for most of his admission thus far, to provide guidance and encouragement to attend programs, and to provide supervision and re-direction. He is prompted to report to his Social Worker or staff nurse twice daily to review his behaviors and activity during the previous hours and to establish a clear plan for the remainder of the day. He took to this routine quickly and now presents himself for his appointments without prompting.

The therapeutic narrative was introduced in hopes of establishing a clear, shared reference regarding his barriers, interventions, and their relationship to his goals. He reviews the narrative with staff at least daily, sometimes several times a day.

Note the personal and optimistic tone of the narrative. When he was first admitted, BT made comments that suggested he sometimes thought he was in prison--not surprising given his history and state of confusion.

"My name is (Name). I was born on (Date). I am 40 years old. I am in a rehabilitation center in upstate New York called the Northeast Center for Special Care. We are half way between New York City and Albany. I have been here at the Northeast Center since November 5th of last year, so I've been here about (Months).

This is a place for people who have had brain injuries. I'm here because I had an injury to my brain a long time ago. I had German measles with an infection that spread to my brain when I was very young. Since then, I have had problems controlling my behavior for most of my life. I have spent quite a bit of time in hospitals because of this.

I went to school up to the 9th grade. Then I dropped out. They tell me that I must be smart because, even though I didn't finish school, I seem to know a lot of things! I remember that once I had a job delivering papers. I think I would like to have a job again some day.

The folks here at the Northeast Center for Special Care tell me they care about me and will try to do everything possible to help me get better. They say they want to help me move back closer to the City, IF that is what I want. I DO!

They also tell me they will always be honest with me. They told me that I have to work on being safe and letting others be safe too. I have to work on not threatening anyone. I have to work on controlling my temper. I know that it is unacceptable to threaten anyone. I know it is unacceptable to hit anyone. The staff here will keep everyone safe, including me.

This is not a prison. Staff will react to my behavior but they will not punish me. They will help me get control of my behavior so I can get out of here some day. They say that I have a good chance of getting out of here if I can stop threatening others and never hit anyone...for any reason.

It is a little hard for me to feel safe and to feel like anyone cares about me. I will try to trust the staff here. I will try to accept help. I know this is a fresh start. They say they won't judge me by my past. They say they know I am a good person and that they like me and will help me reach my goals. I know that I will have to do most of the work.

They tell me that I need to keep busy. I need to go to groups. If I get angry, I need to go to staff and tell them. I must not yell, threaten, or go after anyone. If I can learn to control my temper and go to staff when I am angry, then I will get better. If I can control my temper, I will have a chance to move back to the City.

I WANT to control my temper. I know it will be hard but I will trust the staff and let them help me. If I get angry, I will go to the staff for help. I will not yell, threaten, or go after anyone.”

RESULT

BT has been utilizing a therapeutic narrative for only several weeks. He remains on one to one assistance but the team has begun to wean this. He has begun to establish a daily routine and looks forward to his twice-daily reviews with staff.

Fear of punishment was a dominant theme prior to the use of the therapeutic narrative. It was also difficult to re-establish rapport with him from day to day, especially after a weekend. The treatment team attributes improvements in these areas to the use of the therapeutic narrative. BT's paranoid or fearful verbalizations are rare or noted only briefly at the beginning of an interaction. Rapport is established easily and his disorganized thought process and speaking resolves quickly upon making contact with him. He is clearly recalling elements of the social story and will recite parts of it appropriately when particular issues are raised during therapeutic contacts. The admission diagnosis of schizophrenia is being re-evaluated.

#3. BJ

BJ is a 33-year-old male admitted to Northeast Center for Special Care on 1-11-01 with Traumatic Brain Injury secondary to a Motor Vehicle Accident in 1998, poor impulse control, seizure disorder, depression, mood disorder, intermittent explosive disorder, and Insulin Dependent Diabetes Mellitus IDDM.

BJ is fully ambulatory and had no significant physical disability. His issues were severe cognitive and behavioral disability.

At best BJ's cognitive processing is slow and concrete. Significant effort is needed to facilitate comprehension and he requires many, many repetitions in order to learn new information.

BJ's poor judgment and lack of understanding of his medical condition made it impossible for him to comply with a diabetic diet. Whenever his blood sugar levels were sub-optimal, his ability to process information became profoundly impaired and his irritability extreme. Until he could be stabilized medically, there was no hope of educating him regarding the importance of diet, regarding the relationship of diet to behavior, and in turn to his long term goal of being re-united with his daughters.

There was a direct correlation between verbal and physical aggression and his blood sugar levels. While staff made every attempt to try to get BJ to accept healthy alternatives, BJ is a large, powerful man who became menacing whenever anyone suggested a different choice of food or drink, no matter how deftly. Finally, instances of physical aggression qualified him for placement on a secure unit.

Placement on the secure unit provided our first real opportunity to make significant gains with BJ. It made it more difficult (although not impossible) for BJ to obtain food from peers. He could still order out but he no longer had free access to the facility's public cafe. Consequently, his blood sugar levels were more stable. With diabetic teaching he began to understand the need to limit his ordering out and blood sugar levels further stabilized.

The following current therapeutic narrative succeeded several earlier versions. It has continued to evolve BJ's understanding progressed by the speech-language pathologist, in consultation with the dietician. It is reinforced regularly as part of the formal program of diabetic teaching.

"About Me. My name is (Name). I was born in (Town) on May 23, 1971. I have 3 sisters and 2 brothers. My family owned a grocery and Laundromat. I was the clerk, cashier, and did cleanup.

I have two daughters, (Name) and (Name). I like to spend time with my daughters and the most important thing in my life is to become part of their life again.

My Accident. In 1998 I got in a car accident while I was in Alabama. I flew out of the sunroof of a truck. I was in critical condition, blood rushed out of my head. I got a head injury and was in bad shape. My family came down from (Town) to Montgomery to pray for me. I was in the hospital for a while.

Rehabilitation. I came to the Northeast Center for Special Care in 2001. My brain affects me sometimes. I didn't have control of my anger before but I think it is getting better. I also have to control my sugar by watching my diet. Sometimes I get angry and call staff names and swear at them when they suggest that I eat smaller amounts of food, or different foods. I think its because I forget that it is important for my health. I want to be a good role model for my daughters and I want to be around to watch them grow up.

My Goals. I want to get a job. I want to live on my own in (Home Town). I want to help raise my daughters.

My Plan. When I get angry I count to 15 and things get better for me. This way I don't yell at people or get into fights.

I am working on my memory by using my memory book. I need to write down what I do each day so that I remember. It is important for me to spend more time out of my room.

I need help with my diet. I need reminders to help me choose the right foods, because sometimes I don't understand it. I am working on eating what is on my tray and choosing good foods like fruits, vegetables, and diet drinks and snacks. Instead of trying to order 3 sandwiches at a time I am working on ordering 1.

I know that I can do all of this, so that I can go back to (Home Town) and be near my family."

RESULT

While on the secure neurobehavioral unit BJ became able to recite the relationship between diet, behavior, and personal goals without prompting. He worked intensively with his speech-language pathologist to fully internalize this information until he was able to make a formal presentation to the treatment team as a demonstration of his gains. As a result of his work his behavior fully stabilized and he was transferred off the secure unit to an open neurobehavioral unit.

With the exception of a brief period of de-stabilization after he was transferred off of the secure unit, BJ has maintained his diabetic stability and has remained behaviorally stable as well.

BJ is much more aware of the importance of diet for his long term goals. While he frequently begins by asking for something off of his diet, he now accepts suggestions and

recommendations more readily and sometimes explains without being asked why it is so important to make healthy choices. On occasions where he remains resistive, he is asked to review his therapeutic narrative first and then asked to reconsider. This typically works to change his mind toward a healthy food choice.

BJ's goal of community reentry has begun to motivate his everyday actions rather than being a vague wish unrelated to his daily behavior. He is currently under active consideration for community placement by the New York State Department of Health Home and Community Based Services Medicaid Waiver Program for Individuals with Traumatic Brain Injury and we are hopeful that he will be accepted and placed before long.

#4. BW

BW is a 58 year old man admitted to the Northeast Center in 2005 with problems including Traumatic Brain Injury secondary to fall in August of 2004, an old Left Cerebrovascular Accident CVA with Right Hemiparesis, s/p rib fractures, life long seizure disorder, ataxia with unsteady gait, long and short term memory problems, severely reduced initiative and mood, hip fracture, s/p vagal stimulator implant, dementia, and hypertension.

He presented as disoriented, adynamic, and with depression upon admission. He frequently refused his therapies (all three services had been ordered). In fact, he denied needing any help at all, tended to self isolate, spoke little, but rarely mentioned discharge or initiated on any topic. A therapeutic narrative intervention was initiated virtually upon admission.

BW's narrative is reviewed with him daily in therapy. He requires assistance to read it due to aphasia and visual impairment. It is read with him for approximately 30 minutes each day.

"My name is (Name). I was born on (Date). I am the oldest of 7 kids. I have 3 brothers and 3 sisters. I was married to my wife (Name) for 25 years before she died. We have 1 son, Christopher. I have done all types of labor work. I worked in a paper mill factory years ago. I have had a seizure disorder my whole life, since I was 3 years old. I am always hoping to find a doctor who can cure me. I was living alone in (Town) last August 2004 when I had a seizure and a fall, which caused a head injury. Now I am having trouble with walking, using my right hand, and my memory.

I went to (Name) Rehabilitation Hospital in (City) to begin rehabilitation. Now I am at the Northeast Center for Special Care in Lake Katrine, NY to continue my rehabilitation.

My goals are to get myself better, and live on my own.

I go to Occupational Therapy, Physical Therapy, and Speech therapy on a regular basis. In Occupational Therapy, I am working on getting dressed, cleaned up, and getting in and out of my wheelchair safely. In Physical Therapy, I am working on walking. In speech, I am working on my word finding and my memory. I sometimes need reminders about where I am and what I am doing here at Northeast Center. I live on (Name) unit."

RESULT

Overall improvement was noted after approximately 3-4 weeks. He has shown remarkable gains in recall of orientation information. He is now able to name the place, town, and reason for his stay with no more than an initial sound cue and without referring to the script. He is aware of having memory difficulties and he demonstrates awareness of facts concerning familiar people, everyday therapies, and his goals.

Perhaps most importantly, he no longer resists rehabilitation and therapy.

The narrative approach is being extended to the issue of wheelchair safety although the changes made recently are not reflected above. Occupational Therapy is already reporting significant improvement with wheelchair safety, e.g., using the brakes.