

Something More Valuable Than Life

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As members of the health delivery system we are all aware of the increasing success of medical technology. Ten or fifteen years ago, a brain stem infarct, such as mine, might well have resulted in death. Now, many of us survive the original injury requiring that a new level of medicine come to life - *rehabilitation*. In rehabilitation you work with brain damaged patients to teach them to walk and talk; to bathe, dress, and feed themselves; and sometimes even to read and write. If there are problems that you seem unable to retrain, you try to teach your patient compensation skills. You give the patient braces, slings, wheelchairs and walkers, and tools to aid them in dressing and feeding themselves. It would seem that you have helped the patient with all the functions of daily life, but we have overlooked the most tragic loss of all -- their self. We have concentrated so hard on the gross functions of daily living that we have forgotten the tiny, almost imperceptible skills that help us define our lives. They are functions we all have but rarely, if ever, pay attention to. They are skills that form our temperament, personality, and give us the abilities we need to cope with our environment as it changes. We loosely group these processes under the heading of cognition.

We tend to define cognition as the process of thinking. When this definition is broken down further, there is a tendency to get very concrete. Thinking, we say, is the ability to manipulate numbers; perform tasks in the proper order; or arrange blocks in a prescribed manner. But when you treat cognition, you treat much more than that. You are reaching much deeper. You're reaching into that part of a person that feels the world. When even just one thread which integrates one section of the brain with another becomes severed or interrupted, the whole world loses its familiarity.

Even the simple task of taking out the garbage becomes a major undertaking.

When I first started therapy in cognitive rehabilitation, I lived in a high-rise that was set up for handicapped and low income. The incinerator room was three apartments down, and just on the other side of the elevator. I knew I had to count out three dark splotches on the wall and then go past this brightly lit hole, which is what the area around the elevator looked like to me. Setting out to accomplish the task, I fortified myself by telling myself that deep inside I knew the dark splotches were doors, and I knew from experience that there really wasn't a hole in the hallway.

I would grab a bag of garbage and set out the door. But if someone had their apartment door open, it would completely confuse me and, struck with fear, I would attempt a frantic dash back to my apartment. But this involved several functions. First I had to decide *where* I was: the first door, the second door? Then I had to decide which direction to turn. And then I had to recognize the dark splotch that was *my* apartment door. Once found, I would close myself inside and try to work through the feelings of disgust, anger, confusion, fear, and frustration.

Sometimes I would make a second attempt, but more than likely I would lock the door and remain in the safety of my apartment. It was many months before I began to gain the ability to perceive and interpret correctly, making such a task easily carried out. In the meantime, psychotherapy along with the cognitive rehabilitation helped me cope with the stress created by such failures. The psychotherapy also helped foster feelings of self-worth needed to keep myself experimenting with the world.

After a head injury you experience a void separating how you *remember* the world, and how it *appears to you now*. How do you react -- according

to the way things are ingrained in your memory, or according to the input you are receiving now? This is the task you undertake; to bring the two worlds together again. We are striving to return a whole person to their highest level of functioning. In order to function well in life one must be able to correctly identify their environment, place it within the proper period of time, define the activities around them and react properly.

When you as professionals work with this type of therapy, you should not just instruct someone in the steps they need to take to mail a letter, or tricks to help them get back to a room once they leave. You should be equipping them with the processes needed to work these problems out for themselves.

When I first went grocery shopping for myself, I had not yet gained all the cognitive processes I needed to cope with the challenge, so my therapist thought of a system that would work best for me, and then he helped me through the first two times. He taught me to go down an aisle checking the shelves on the left which was the side I could see best out of, then turn around and go back up the same aisle, checking the shelves on the other side. I went through the *entire* store this way, including cat litter and baby supplies. It took a while to finish, but I was able to gain this piece of independence. Yet it was not complete. Should something throw me off my set pattern, and no one was there to help me back on the road, I would be gripped by a sudden wave of panic, anger and frustration. One time I left the store in tears, leaving a cart full of food standing in an aisle. Now the only time I leave the store in tears is after I pay the checkout person!

At this time I am able to scan two sides of an aisle at once, find what I want, and still not knock over any little old ladies. I can check the foods at the beginning of the aisle and decide if that aisle has what I'm looking for. I rarely check out diapers and baby food anymore.

My therapist helped me to cope with the stress and frustration of dealing with a hostile world. He helped me to get myself to face it daily and not crawl into a hole. All the while giving me the exercises necessary to gain the skills that would once again put me back in the mainstream of life. It would have done no good to gain the processes needed had I not had the support and encouragement to test them.

Your patient will need you too. They will need a sympathetic ear and your support and reassurance. It is necessary for them to hear your observations of their progress as well as your encouragement and even a good scolding every now and then. You are offering these people something more valuable than life. You are offering them the "ability" to live.

The computer is a new and valuable tool whose full value has yet to be tapped. But remember, the effectiveness of a tool is only as good as the craftsman using it. The computer will not cure your patient. *You* will not cure your patient. But you and the computer together can offer a therapy that will result in a better quality of life. It may be difficult for you to understand just what changes to look for and how to look for them. This is internal stuff we're talking about. It won't be as obvious as a walking gait, a movement in the hand, or even a change in speech pattern. If it is hard for you to define and detect, remember your patient is having an even harder time. These are feelings, thoughts, and perceptions we're dealing with. The head injured person has already had their world disrupted once. They know they cannot react in life like they used to, just as they know they cannot walk or talk, or see as they once did. Now we offer them an alternative for straightening out these disabilities, but for your patient it is just another disruption, and can sometimes be seen in a negative way. This is a time when your presence is of utmost importance.

During one program I worked on in the early days of my therapy, one of the blocks in the program became smaller at a certain point. When I first started working on the program, I did not notice the change in size. When I did notice, I couldn't believe my eyes! In my mind, during all the months I had been working, that block had never changed sizes. I knew it had been that way because I had seen it that way. But now it was different and I *knew* it was different - I saw it with my own eyes! How did I account for this change? In my case, I decided my therapist was trying to play a trick on me and had somehow switched programs. The next time we met, I let him know what I thought about that! He had a hard time convincing me of his innocence. He calmed me, and once my anger had subsided, he explained that this was a good sign; I was now noticing something I never had before. It

was a good sign, but I needed his reasons and explanation.

It's hard to sit behind the computer. It is hard to understand that anything can be accomplished by running a block through a maze. At first the challenge is simply to accomplish the task, but your patient can feel real dumb when presented with a task that they know would have been easy at one time and now proves otherwise. They may need a boost in spirits from you. As one goes through the rehabilitation process, a person gets used to being able to *see* their improvement. They walk again, dress themselves, and see a limp hand move. The other professionals on the team have geared the patient to expect observable improvements. Now they are in cognitive rehabilitation and the improvement happens on a smaller scale, one that requires the sophistication of a computer to measure. You will have to be able to give them a convincing answer when they ask, "When am I going to get better?" It will take many hours of work and a lot of reassurance to get your patient to the point where they see and feel the difference.

You will need to be watchful for the small changes in behavior and attitude that take place, and be ready to point these things out when your patient becomes discouraged. When I first began this therapy, my therapist said I could call anytime I needed help. I took full advantage of this privilege, calling 14-15 times a day, starting at 7:30 a.m. until 10:00 p.m. My therapist answered each call as promptly as possible, treating me with patience and kindness. He never criticized me or showed impatience when he answered the same question for the tenth time in the same day. He made me feel like I was worth something, which encouraged me to stay at my programs. If he thought I was worth some of his time, then maybe I was okay, and this

therapy was worth some of my time. In the beginning, if I had to leave a message for my therapist to call me back, I would sit directly in front of the phone with my chin on my knees. After a while, I got so I would go in the other room and do something else while waiting. As I lost my impulsiveness and began to gain self confidence, I decided to try and curb my phone calls. I put a sign on my telephone dial that said, "WAIT 5 MIN". When I got the urge to call, I would see the sign, and for five minutes I would try to distract myself. If I was successful, then my therapist would be spared, but if in five minutes I still had a strong urge to call, I would. Once I had mastered five minutes, I tried for ten. I continued until I was able to master the feat for twenty minutes. I figured that was enough control for anyone!

Having lost my impulsiveness gave me the control I needed to accomplish this task, but had my feelings of self doubt and my fears, confusion, and lack of confidence not been addressed, the cognitive abilities which the computer programs retrained, would have been of little value.

Today I live a complete and full life because my therapy was complete.