



THE HIGH COST OF A BUMP ON THE HEAD

INTRODUCTION

We all know that the results of a “bump on the head” may range anywhere from a slight headache to major alterations in the physical, cognitive, emotional, and vocational status of an individual. Likewise, the cost in terms of dollars and cents may range from the price of a bottle of Tylenol to literally millions of dollars. To adequately address the topic “The High Cost of a Bump on the Head”, one might spend as little as three minutes or as much as a lifetime for the issues to be understood. I have, therefore, chosen to narrow the topic to include three major issues: 1) First, I will review cost in terms of the loss experienced by the family and the person with a head injury; 2) Second, I will review cost in terms of replacing or restoring that which was lost; 3) Third, I will review how economics defines and drives the rehabilitation process—for better or for worse. Through examining these three issues, I hope that we will better understand the difficulty in assigning a monetary value to intrinsic needs, such as the need for self-esteem, the need to be loved, and the need to be productive. I also hope that we will have a better understanding of why rehabilitation should emphasize an individual’s residual strengths as well as their deficits. Ultimately, it is my goal that each of us will leave this presentation with the awareness that as consumers and/or providers of rehabilitation, we are not buying or selling products. Rather, we are united in a process that incorporates a whole person, their past, present, and future, into a rehabilitation plan that minimizes the barriers and creates possibilities for a quality of life after head injury. I will conclude my talk by showing you a videotape of a conversation I had with a gentleman who is twelve (12) years post-head injury. The gentleman, whose name is Tom, will tell you what it has been like to live with a head injury and about the high cost of a bump on the head to him personally. I think his experience will touch you and will help bring this topic, “The High Cost Of A Bump On The Head”, home for all of us.

LOSS + RESTORATION = COST?

At this time, let’s examine the first two issues: 1) cost in terms of loss; and 2) cost in terms of how much money is required to restore the loss. In order for you to have an appreciation of the issues, I will ask you to do an exercise. This exercise has two components. First, I would like for you to think about the skills you possess, and quickly identify one skill that is most important to you. Please identify this skill by name and write it on a piece of paper. Examples might include, writing skills, accounting skills, skills for successfully working with people, public speaking

skills, musical skills, etc. After you have written down a skill, I would like for you to identify the amount of money for which you would sell this skill. Keep in mind that once you sell it, you may never repossess the skill in its original form. It is possible to purchase an altered version, but not the original skill. Please write this amount of money beside the name of the skill.

For the second part of this exercise, please close your eyes and imagine yourself. Identify one personal quality or aspect that you feel really makes you yourself. Examples may include integrity, honesty, sense of humour, warmth, curiosity, or an investigative nature. Please identify that one personal aspect that makes you who you are and write this down on your piece of paper. This should not be a skill, rather a personal or human quality. Beside it, please write an amount of money for which you would sell this quality, however, for the purpose of the exercise, please assign a monetary value to the quality and write it down.

How many of you assigned a greater value to Number 1 (your skill) than to Number 2 (the personal quality)? Please look around the room. There are not many hands up at this point. Now, how many of you assigned a greater value to Number 2 (the personal quality) than to Number 1 (your skill)? Please look around the room, and you will see by the show of hands, most of you assigned a greater value to your personal quality than you assigned to your personal skill.

Based upon this response, we might assume that most of you would feel a greater loss should you have to give up your personal quality than if you were to lose your most valued skill. My guess is that there is an intimate relationship between the personal quality by which you define yourself and your most valued skill. Your personal quality is the style by which you perform your skill. It is your personal trademark or insignia. Many other people possess the same skill that you possess, however, you are known by the manner in which you carry out this skill more than by the skill itself. This personal style or quality is what I refer to as “the kernel of truth” about an individual. There is a kernel of truth about each of us—it is that salient feature which makes us who we are individually, and separates us from all other people.

Given that each of us possesses a kernel of truth, we must ask ourselves an important question, “Does the kernel of truth about an individual change following a traumatic brain injury?” Often I have heard it said about a person with a head injury that he or she died in the accident, and that following injury there is a new individual in place of the old person. The persons with head injuries with whom I have had the opportunity to know through our work together have not felt or believed that they died in their accidents. On the contrary, they have felt that who they are in the present is basically who they were before their head injury. The expression of themselves may be different, their behaviour and personality may well have changed due to disruptions in their cognitive systems. Certainly their skills in many areas have been altered or lost but who they are and what they believe—their “kernel of truth”—was not altered with the onset of a head injury. In rehabilitation, we pay hundreds of dollars to buy back skills and abilities. Yet we pay nothing, especially in time or attention, to what was not lost. I believe that in rehabilitation, dollars and time should be given toward replenishing lost skills, but not to the exclusion of focusing on the “kernel of truth” about each individual. As rehabilitationists, our job is to bring the “person” from behind their physical and cognitive barriers. In doing so, we help put the person with a head injury back in touch with him or herself. When this reunion occurs, rehabilitation is in progress and in process.

Unfortunately, rehabilitation often focuses on what is missing or what has been lost rather than what is present within an individual. This deficit-oriented approach to treatment is economically encouraged when the rationale for funding rehabilitation services is based upon fixing the dysfunctional piece of the puzzle. This approach is most obvious in the acute phase of rehabilitation where the goal is to restore physical and cognitive functions in order to return the patient to a reasonable state of self-care. When this goal has been met, discharge is usually deemed

appropriate and the patient leaves the hospital setting. We now have a person who can walk, talk, toilet, dress and feed themselves, but to what end and for what purpose? This state is much like being “all dressed up with no place to go.” Rehabilitation must focus on the whole person not just their missing parts or deficits. It must be a blend of an individual’s strengths, weaknesses, and their personal qualities. It must take into consideration the individual’s value system which is culturally bound. Rehabilitation must be tailor-made and individualized to fit a person’s unique blend of characteristics. Rehabilitation cannot be a factory-like process. A one-for-all and all-for-one approach is certain to fail, although this approach is certain to be least expensive.

At this point, I would like to describe the components and cost involved in a client-oriented (as compared to a deficit-oriented) approach to rehabilitation.

COMPONENTS OF CLIENT-ORIENTED REHABILITATION

The key elements in a client-oriented rehabilitation approach are as much attitudinal as they are technical in nature. First, we will review the attitudes involved in this approach.

ATTITUDES

- 1) The focus of rehabilitation is on the person rather than a series of treatment procedures.
- 2) The rehabilitation plan must take into consideration the client’s background. For example, teaching a male client to cook and clean or a female client to balance the chequebook may not be an appropriate role expectation within some cultures. To make the assumption that these are characteristics of “independent living skills” may be an inaccurate assumption.
- 3) Within the rehabilitation relationship, the professional staff is the guest in the client’s life. The client is not the object or subject of the professional’s career.
- 4) The client’s family wears many hats. They are a part of the treating team, they are a part of therapy, and forever they are case managers. The family is also the link point between the client’s past, present, and future. The best laid plans for rehabilitation must be made with the family, not for the family, instead of, or in spite of the family.
- 5) The rehabilitation plan is produced from input by the client, the family, and the professionals. All parties must be updated and informed as the rehabilitation plans progress.
- 6) Of critical importance in the success of the rehabilitation plan is identifying the essence, or the “kernel of truth” about the client. Without this information, rehabilitation becomes focused on the client’s parts, i.e. their skills and behaviours, rather than who they are as a person. Treating the parts instead of the whole is like watering the leaves of a plant instead of its roots.

In combination with the attitudes that I just reviewed, the following logistics should be incorporated into a client-oriented rehabilitation approach.

LOGISTICS

- 1) Following the hospital-based rehabilitation phase, continued efforts at rehabilitation should occur within an environment that most closely approximates the targeted discharge environment. If possible, it should utilize real life, natural settings.
- 2) The rehabilitation plan must be customized and tailored to the client’s strengths and limitations in the areas of: neuropsychological and cognitive functions; psychological reaction to the injury; pre- and post-

injury personality factors; physiological function; pre-and post-injury vocational preferences; recreation opportunities, and hobbies; and family support systems.

- 3) Therapy tools and therapy content should be age-appropriate and meaningful to the client. Therapy which utilizes devices or tools not likely to be found in the client's natural environment should begin with an explanation to the client about the purpose and value of the therapy.
- 4) Training procedures should gradually move from the treatment environment into real life situations.
- 5) Therapies must be blended through specific goals and objectives which are carried out in a total therapeutic milieu instead of isolated therapy sessions.

ECONOMICS

A comprehensive client-centred rehabilitation plan is likely to be based on cost per day rather than cost per unit of treatment. The actual sum of money may not differ drastically; however, the expected outcome differs tremendously. The expected outcome for a unit of treatment is to improve functioning within a treatment session. The expected outcome in a more comprehensive model is to improve functioning within the client's life space. The difference, for example, is between improving memory by increasing the number of words recalled on a word list versus improving one's ability to successfully grocery shop by teaching compensation strategies for memory deficits, such as how to plan ahead and to utilize a shopping list.

The cost for client-centred rehabilitation in which the whole person is addressed, at least within the community re-entry program I had the opportunity to direct, averaged about \$345 per day. This cost covered all individualized, group, and community-based therapies; initial assessment and follow-up assessment in all areas of rehabilitation, an initial neurological evaluation and follow-up neurological monitoring; recreational activities; vocational work stations, both on-site and off-site; job coaching; 24-hour supervision commensurate with individual needs; room and board (including food); and transportation. In comparison, a cost per unit of individual therapy delivered by a speech, physical, or occupational therapist averages between \$65 and \$95 per hour. Four therapies per day at this rate would be equivalent to the daily rate for the services previously mentioned.

The question that must be asked and objectively assessed in order to know which cost is most appropriate is, "What does the person with a head injury need in order to continue their progress toward rehabilitation? If the answer to that question is that they need a unit of speech therapy three times a week to continue their language development, then 3 units of speech therapy is appropriate. If they need a comprehensive therapeutic environment in which to address cognitive, psychological, physical, vocational assets and liabilities, then community-based residential treatment is more appropriate.

Unfortunately, what often happens is that funding sources do not recognize the need for continued comprehensive rehabilitation after the initial medical and acute phase of rehabilitation has been completed. Often the family finds themselves looking for a comprehensive program when their funding will only pay for units of specialized therapy. I can give you numerous examples of clients whose funding source was willing to pay for unlimited units of speech or physical therapy but would not fund for our community re-entry program. Follow-up on those particular clients revealed that they were not able to make a successful community reintegration and role adaptation. Let me be more specific by giving you an example of such a person who found himself in this situation. This individual's name is Tom.

Tom was referred to our program about a year and a half ago by his mother. At the point of referral, Tom was twelve (12) years post the onset of a traumatic head injury. Tom sustained a head injury from a motor vehicle accident and was comatose for approximately 3 months. Tom was involved in hospital-based rehabilitation, both

as an in-patient and out-patient for a period of about 3 years. In July, 1986, Tom was evaluated by our team of professionals who found him to be a perfect candidate for community-based residential therapy. His strengths were in the areas of general cognitive functioning, physical functioning, and he was particularly adept at interpersonal relationships. Tom's primary area of need was for vocational direction. Tom had not worked competitively since his head injury. However, he felt convinced that he possessed vocational potential. This was substantiated by our vocational evaluation. Tom's insurance funding, however, would not pay for a comprehensive community re-entry program with a vocational focus, although they agreed to pay for unlimited amounts of speech therapy. Other than a slight problem with dysarthria, Tom really did not require speech therapy in order to continue his rehabilitation. Rather, he required a program to help him identify and develop vocational direction. The amount of money the insurance company had already allocated toward Tom's rehabilitation was astronomical. Tom is a good example of a client who is "all dressed up but with no place to go". To end his rehabilitation at this point in his recovery is a waste of human potential. Fortunately, Tom was admitted into our community re-entry program on a scholarship basis. I felt sure that within 6-9 months, Tom will be qualified for some type of work within the competitive labour market.

At this time, I would like to share with you a videotape of a conversation between Tom and myself. In listening to Tom and I talk, I would like for you to focus on what you see as "the kernel of truth" about Tom. At the same time, I would like for you to consider his potential for continued rehabilitation. As you listen to Tom, I think you will also hear what life has been like for him as a person living with a head injury.

VIDEO-TAPED CONVERSATION

NANCY: I understand that you are here at Community Re-entry Services of Lynn in order to further your rehabilitation. Would you please review with me the goals that you hope to accomplish while you are in this program.

TOM: The reason I am in this program is because I actually hope to become more independent, such as hold down a job, live in my own place, things of that nature. You know, live in, like, my own apartment. Right now, I live in a housing project for the elderly. It's okay for now, but it kind of gets to be a drag after a while. I hope to have a place of my own which better fits my needs.

NANCY: So, you want to have your own apartment and live alone?

TOM: Well, yeah, I would like to have my own apartment and if I live alone or if I live with somebody else doesn't really matter. I would just like to be more independent.

NANCY: And you hope to be able to find some kind of work, Tom?

TOM: Yes.

NANCY: What kind of activities or hobbies do you enjoy doing?

TOM: Ever since I've had my head injury, I really get in to photography. I enjoy going to the baseball games and taking photographs of sports and things like that.

NANCY: So you enjoy taking pictures?

TOM: Yeah, I used to, before my head injury, I used to play sports, but after my accident, I have not been able to play sports, so, the second best thing for me is to be able to take pictures of the different plays in the game. I enjoy taking pictures by myself.

NANCY: Is this interest in photography one that you had before your injury?

TOM: Not really, see my interest before my accident was more in playing the sport not in observing it, or taking pictures of it.

NANCY: I see.

TOM: And now that I can no longer play, I don't want to become completely "out of the picture", so to speak, because I still enjoy seeing the baseball games, soccer games, and basketball games. So, instead, I go and take pictures.

NANCY: It sounds like photography allows you to still participate to some degree in sports.

TOM: Yeah, to a degree, 'cause I can show my friends and I can say, Hey, "look at this catch Jim Ray made!" or, "Look at this move that Larry Bird made!" or something of that sort.

NANCY: Sports are important to you?

TOM: Yeah. They're important, I find a great deal of enjoyment in them.

NANCY: I understand you've had a head injury, Tom.

TOM: Yes.

NANCY: Can you tell me a little bit about when this happened and how it changed you?

TOM: Well, it happened in 1975, in February. I was in an automobile accident, and as a result of it, I couldn't speak for five months. When I began to speak, I spoke slowly and used to string together all my sounds. I also was not able to walk for a while. But after several years of being in rehabilitation, I started to get better. But my injury did change me and my life in a way, 'cause some of my friends could not deal with me after my head injury. They didn't quite say, "Hey, Tom, we can't deal with you", they just quit being my friends. That is where you find out who your true friends are. Those that couldn't take the heat, got out of the kitchen.

NANCY: Tom, you have mentioned how you are different since your head injury. Is there anything about you that did not change after your head injury?

TOM: Some of my interests have not changed. I have always had an interest in sports you see, but before I used to play sports and I wasn't that good of a player but I never did admit that to myself. Now I can't play sports so I use them as a hobby. Another thing that hasn't changed about me is that I have always been the kind of person who likes other people. I am the kind of person who cheers someone on when they are sick, or down, or in trouble. But I really never realized this about myself before my injury. Since my injury, I am even better able to relate to somebody who's in trouble. I can relate in a more true way. Someone may say, "Hey, this stinks, not being able to walk", if they have a broken leg or something. And I can say to them in truth, "Yeah, I can relate to not being able to walk" or "I can relate to not being able to talk" or mow the lawn or do a number of things that people take for granted."

NANCY: So you've always been the kind of person who is interested in others and interested in how they are doing.

TOM: Yeah, I feel pretty much that way. Even before my accident, I was a very active person. I used to be a jack-of-all-trades in my neighbourhood. I used to mow lawns, shovel driveways, deliver newspapers. There was this one man on my paper route who had a heart attack. I used to work it so that my paper route ended with his house last. I would take the paper into his home so that I could go in and talk to him for a few minutes. We would talk about sports, the weather, you know, anything he wanted to talk about. I always felt that my talking to him every day made him feel better. And I was always interested in how he was doing and if he was getting better.

NANCY: You seem like a very personable kind of person, Tom.

TOM: Thank you.

NANCY: I suspect you've always been that way.

TOM: I think so. You know, it's something you don't really think about. These are my strong qualities, like being personable and being interested in other people. Those are the kinds of things you kind of take for granted about yourself, until you have something like a head injury.

NANCY: You know, Tom if there were two qualities about yourself on which you place the highest value, what would those two qualities be?

TOM: I guess it would be the way that I get along with other people. I just enjoy being with people. You know, interacting with them and being helpful. Yeah, I guess that's it. It's my way of getting along with other people.

END OF VIDEOTAPE.

From this video, I hope you have been able to see the "kernel of truth" about Tom. I hope you were also able to recognize his potential for continued change and recovery. Tom is the perfect example of somebody whose rehabilitation was put on hold because of economics.

Fortunately, through the opportunity given him to participate in a client-centred community re-entry program, Tom will be able to work on his goals of living independently and working. I have absolutely no doubt that he will meet these two goals—and I would venture to say that both will be met within nine (9) months.

SUMMARY

At this time, I would like to summarize by reviewing the major points that I have tried to make throughout this presentation.

- 1) Rehabilitation is a value-laden business, and one which is economically driven.
- 2) The degree to which there is a match between rehabilitation needs and the ability to purchase or obtain appropriate services to meet the needs, rehabilitation can continue and progress will be made for the person with a head injury. On the other hand, a mismatch between needs and services may be as much a barrier to recovery and toward role reintegration as having no services available at all.

- 3) A major tool in the rehabilitation process is the “essence” of an individual, the inner core that makes a person who they are and is not lost as a result of a head injury. In rehabilitation, the focus should be on bringing out this “kernel of truth” from behind cognitive and physical barriers. Focusing on the barriers without focusing on what lies behind them is to rehabilitate the “parts” rather than “the whole person”.
- 4) The cost of rehabilitation is exceedingly high. The cost as defined by loss to the victim and their family following a traumatic head injury is immeasurable. But the greatest loss is that of human potential wasted because it is not appropriately channelled or directed. Unfortunately, this is the situation that exists when rehabilitation services stop before the person with a head injury stops recovering, adjusting, or changing. Hopefully, this is a life-long process.

What is the cost of a bump on the head? Is it the meagre few dollars it takes to buy a bottle of Tylenol. Or is it the hundreds and thousands of dollars to fix limbs, restore functioning, and rebuild skills? The greatest cost, according to those with whom I have worked, is to go through life having gained the identity of being “head injured” and having lost the identity of who you are as a person.

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