

# A Personal Narrative of Involvement in Post-Traumatic Brain Injury Rehabilitation: What Can We Learn for Therapeutic Recreation Practice?

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## *Abstract*

This paper is an autoethnographic exploration of one woman's illness narrative. It provides an in-depth understanding of her lived experience of rehabilitation after sustaining a traumatic brain injury and poly-trauma. The narrative confirms the importance of providing people with self-determined choice as a primary component of rehabilitation. The voice and values of clients are integral to professional judgment. This narrative supports clients' personal choice and freedom during the rehabilitation process as a means of increasing their sense of self-determination and empowerment while improving overall health outcomes.

*Today I go past the accident site. They have closed off that service road to Jean Talon where the truck brought me down. ....Lying under that truck with its two sets of large back wheels advancing; I thought that this is the end. Nothing more, nothing less; clear and simple.*

Suzanne Lawson – Journal Entry, September 1, 1998

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## Introduction

Suzanne Lawson wrote an original manuscript early in recovery during full-time rehabilitation after sustaining a traumatic brain injury and poly-trauma<sup>1</sup>. Suzanne also wrote poetry and kept a journal throughout rehabilitation. The current paper is a collaborative research initiative that began 5 years after Suzanne's accident. The research process provided a means to autoethnographically reflect on Suzanne's original article, journal notes, and poetry writing, as well as interview data collected 4 years later. It interweaves Suzanne's narrative with an exploration of other autobiographical and scholarly writings that resonate with her experiences. Suzanne's goal in providing an account of her journey, and her involvement in documenting, researching, understanding and writing that experience, is to evoke recognition by health care professionals of the integral role that client self-determination plays in client care and rehabilitation.

We begin with a description, written by Suzanne, of the personal and professional context of her accident and the experiences that followed during rehabilitation. Following this description, we discuss how the current research came to be, elaborate on autoethnographic research methods, and explain the relevance of illness narratives as an important form of knowledge dissemination. The remainder of the paper is organized around two themes that represent the collective combination of Suzanne's original manuscript and the current research process, followed by a discussion, conclusion, and epilogue.

## Suzanne's Story

### *Fate*

*When all else fails, slit a throat.  
To cut, or not to cut?  
That is the question never pondered.  
There is no time to consider  
Whether it is nobler to draw artificial breath  
Through blood,  
Or simply let be, to die.*

*And I looked on,  
Coolly watching from above  
Apart from, yet still a part of,*

*This painful, broken, brainless body  
With its blackened pumpkin head  
And blinded racoon eyes;  
Within and yet without simultaneously.*

*Men play at gods  
When administering heroic measures.  
But it is others who must struggle  
To live with ensuing consequences.*

*Maybe this is my destiny;  
But it is a destiny much altered  
By man and by machine.  
Do humans or the gods  
Have any place  
In such a destiny?*

S.L. July 5, 2001

Written 2 1/2 years, post-accident

Until a few years ago I was working as a nurse and health educator with students at McGill University in Montreal. During my over 20-year career as a community health nurse, I have worked with diverse populations—nationally and internationally: babies, children, adolescents, young single mothers, families-at-risk, battered women, people with AIDS, the elderly, the house-bound and the dying. My pre-occupation has always been to demystify the medical system, to integrate the clients in their own care, and to share with them the tools needed for them to have control within the system and over their lives.

My hands have received babies into this world, cleansed wounds, and soothed the passage of the dying. I have worked often with underprivileged and frequently struggling populations, in the poorest areas of Maine and Montreal. I have taught pre-natal classes and conducted post-natal groups. I have worked on a Mohawk reservation and with the Cree and Inuit of Northern Quebec. I have spoken on Northern community radio and at international conferences. I have trained native

<sup>1</sup> This was quite a challenge and could not have been achieved without the guidance and support of Gilles, B., orthopedagogue (special education counselor).

interpreters about health care and supervised student peer-health education. I have trained village health workers and traditional birth attendants in rural Bangladesh. I have worked in primary health care in war-torn Burundi.

None of these experiences prepared me for my encounter with my own mortality on March 4th, 1998 and my struggle to regain all aspects of my life since living with a brain injury. I suffered my traumatic brain injury and poly-trauma as a result of a bicycle collision with a heavy truck in a major urban center with a well-equipped trauma hospital. This made available the miracles of modern technology and a highly skilled medical team who saved my life.

The direct impact of my unprotected head on the pavement caused me to lose consciousness at the time of the collision. I regained consciousness trapped under the back double set of wheels of the truck, which dragged me forward for 10 meters destroying the flesh of my right upper arm. I was completely blind. An emergency tracheotomy was performed upon my arrival at the hospital and I was artificially ventilated in the intensive care unit for 9 days. My left (dominant) arm was completely paralysed. Blind and unable to speak, move, or even breathe on my own, I was totally dependent upon hospital personnel; however, those around me also sustained my will to live, fight for consciousness, and recovery:

[after moving from intensive care]  
On the floor my room became full of  
colour - posters, cards and flowers, and  
the messages of love that they conveyed;  
such encouragement to get literally on  
one's feet and become functional once  
more. If it is apparent that one is valued,  
one has to live up to that evaluation.  
One has to prove oneself worthy  
of such caring by others. I am convinced  
that my recovery is due in a major part  
to the active support of those around  
me. The Monday end of day nursing  
meetings were transferred to my bed-  
side where I would show off my newly  
acquired shaky walking skills. First to  
the end of the room; then accompanied  
to the end of the corridor; then to the  
elevators at the end of the visit, to  
return alone. It hurt my poor broken

*ribs to laugh, but oh, it felt so good.*  
(Journal, October, 1998)

I was physically and psychologically traumatised by this accident. Although I am no longer dependent upon others for my activities of daily living, this 'moderate' brain injury has left me with permanent lesions in the right frontal, parietal, and occipital lobes of my brain, along with a small lesion in the right caudate nucleus. Consequently, I have left hemianopsia (blindness of the left side of each eye) and an anomaly (blind spot) in my right eye. I have problems with perceptual integration, sometimes not recognizing faces even of those close to me. I become dizzy when I change my head position. My left arm and hand lack co-ordination and dexterity due to hemi-paresis. As I used to be left handed, I have needed to change dominance and learn to write with my right hand. My hand-eye co-ordination is poor. Reading and writing are laborious. My emotions are labile and unpredictable. I become stressed and panic easily. I have lost confidence in my abilities and in myself. It takes little to irritate me. I have difficulty with higher organization. My concentration is limited. I fatigue with mental and/or visual effort.

As my poem suggests, such was my state at the time of rehabilitation:

#### Brain Damage

*Through the eye of the needle  
Backwards and forwards  
I untangle  
Then rejoin  
The broken threads  
Of my torn remnants.*

*Thus, I reweave the fabric  
Of my battered being.*

*But the texture is changing,  
The same, yet so different –  
A work in progress!*

*The shape is distorted  
The material unstable,  
Quicksilver—elusive  
Forever breaking, reforming  
Constantly registering heat and cold.*

*Along the line of the fault  
The earth quakes  
The tides change  
And foul black water  
Flows from the cracks.*

*So it is with the brain.*

S.L. Nov. 25, 2000

Hemi-anopsia, hemi-negligence, and hemi-paresis made the mechanics of reading and writing difficult. Cognitively I discovered that even when I read an article more than once I was unable to pick out what was important in reference to my thesis of client involvement. 'Organic' fatigue augmented my trouble with concentration. Added to my personal challenge was the fact that my neuro-psychologist at the rehabilitation center, although validating the quality of my work, felt that I should be researching and writing on a subject in which I had less personal and emotional involvement. Then, as now, I believe writing about my own trauma and rehabilitation to be appropriate and beneficial for these very same reasons.

I met with a writing specialist weekly for help with organization and breakdown of tasks. The librarian at the rehabilitation center did the literature search for me. I also received articles from a friend. When I finally wrote, a friend of mine typed the manuscript. Two other friends in turn helped with the French translation so that the article could be shared with the center's rehabilitation practitioners to whom I presented my reflections at the end of my rehabilitation (in June of 2000). Most recently, I have also had the opportunity to share my story at two therapeutic recreation conferences (Delamere & Lawson, 2006; Lawson & Delamere, 2006).

### **Meeting Suzanne**

This section explains how the other two authors met and consequently collaborated with Suzanne in the writing of this paper. Each co-author presents their first-person recollection of these events.

I (Fern Delamere) met Suzanne socially at a community dog park during the summer of 2004. We would occasionally see each other while enjoying the company of our canine companions. As with many hidden disabilities, it was not apparent to me that Suzanne

had a brain injury. It was through circumstance that I discovered Suzanne's experience with trauma. A bike courier race was being held near the dog park. A former bike courier who sustained major injuries entered the park using his electric wheelchair, accompanied by his companion dog. I first became aware of Suzanne's accident and subsequent traumatic brain injury through our conversation and their open sharing of trauma experiences. After he left, our subsequent conversation led to Suzanne stating her desire to share her experience publicly. I validated the importance of sharing this information and suggested we collaborate on research together with the goal of publishing her personal narrative so others might also benefit. As an academic, following 8 years as a Recreation Therapist, I recognized the value Suzanne's story has in helping advance current understandings of client-centred health care. I also felt it would be useful to include Susan Hutchinson in the development of this paper. Here is how Susan explains her interest in this collaborative work.

My research has focused on how people cope with and adjust to living with a life altering injury or illness, and the role that leisure (personally meaningful and enjoyable activity/experiences in the free time context) may play in coping and adjustment (Hutchinson, Loy, Kleiber, & Datillo, 2002). Because of this research interest, Fern asked me to join her and Suzanne and on this project. However, it was not until almost a year later that I met Suzanne, just before she and Fern were going to share Suzanne's story at a large national conference. Afterwards, conference attendees, the majority of whom were therapeutic recreation practitioners, expressed how overwhelmed and appreciative they were to hear Suzanne's story. This reinforced to me how important it is for practitioners to reflect on what it means to experience a life-altering injury, and the tangible implications of this for client-centred care.

### **Illness Experiences and Autoethnography**

In this next section we describe the research context for Suzanne's personal narrative. Numerous theoretical and methodological approaches have been used to explore people's lived experiences. Proponents of narrative theory have long argued that the stories

that people tell themselves and each other are not just reflections of experience—they are constitutive of experience (Bruner, 1986; Gergen & Gergen, 1997; Polkinghorne, 1991). What people understand about their experiences become their stories and personal narratives. By extension, stories of experiences of illness or injury are also viewed as the means by which people can make sense of the disruptions they experience to their sense of self and life following a traumatic injury (Brody, 1997; Bury, 1982; Kleinman, 1988; Mattingly & Garro, 2000; Williams, 1984). Stories are said to help people affirm valued aspects of who they were in the past, and at the same time reconcile their present situation. For proponents of client-centred care, narratives are the lens to understanding clients' experiences of suffering and triumph in the context of illness or injury: "To restore the human subject at the center—the suffering, afflicted, fighting, human subject—we must deepen a case history to a narrative or tale; only then do we have a 'who' as well as a 'what,' a real person, a patient" (Sacks, 1987, viii).

Autoethnography has been utilized as a research methodology in the social sciences to explore and understand personal experience. Ellis and Bochner (2000) described autoethnography as "an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural" (p. 739). The expression of personal experience and emotion are the essence of autoethnographic writing (Ellis & Bochner). Autoethnography provides a process whereby the social and cultural features of personal experience, in this case the experience of traumatic brain injury rehabilitation, can be highlighted in a reflexive way. Reflexive ethnographies often study the researcher's experience of doing the research in conjunction with the personal narrative being explored. As such, the goal is to highlight the personal experience of Suzanne during rehabilitation, but to also acknowledge the collective narrative of this project.

### **The Research Process**

An autoethnographic method was used in this research. This article is based on Suzanne Lawson's illness narrative. As noted earlier, Suzanne wrote an original manuscript early in

recovery during full-time rehabilitation. She also wrote poetry and kept a journal throughout this period. The original manuscript forms the foundation for this article. Suzanne's poetry, journal writing, and additional interviews (conducted 4 years post accident) were used as data. They were collectively analysed and interwoven into this paper as a means of supporting key points that Suzanne made in her original manuscript.

The research process began in March 2005, when Suzanne and Fern collectively wrote an ethics proposal and submitted it to the Human Research Ethics Committee of a large Quebec University. After approval for the project was granted, unstructured informal interviews between Fern and Suzanne were conducted in July and August, 2005, and transcribed over the winter of 2006. The interviews focused on Suzanne's experience as a client and her use of various writing and leisure-based activities as a means of recovery. In addition, Suzanne shared with her co-authors (Fern and Susan) her journals (seven hand-written books filled with almost daily entries) and also the poetry she had written during rehabilitation. Here is an example quote from one interview, in which Suzanne was talking about the process and meaning of writing poetry during this time:

*SL: I don't know, but I think you've read some of my poetry? Some of it is pretty black, but just writing it gets you through, and I still write a journal. (Interview, 2005)*

The descriptions Suzanne shared during the interview process were studied closely for content that representatively supported Suzanne's personal narrative and poems written during her rehabilitation process.

The process began with Fern reading Suzanne's poems and narratives and making note of thematic materials that helped explain Suzanne's experience. In addition to Suzanne's prior reading of the brain injury and health literature, other scholarly work guided our analysis of Suzanne's writing as to the important salient points of her narrative (e.g., literature about client-centred care; illness experience). Fern also systematically analyzed transcripts from a series of interviews that she had with Suzanne. The coding of data proceeded inductively. Inductive coding involved bracketing segments relevant to understanding

Suzanne's experience of rehabilitation, and her everyday life. Through repeated meetings we shared input on our findings, stating rationale as to why one interpretation or narrative fit well over other possible interpretations or narratives. Suzanne, having lived this experience, was best positioned to make final determinations about which quotes, poems, and journal entries best represented and supported what she was trying to say. It was important to her co-authors that Suzanne played an integral role in the academic process and that she made the final decision about all narratives used. This ensured that her narrative was enhanced and her voice strong through the paper.

Richardson (2000) outlined five criteria to evaluate the quality and rigor of autoethnographic manuscripts. After completing the processes described above, we employed these criteria to assess the "trustworthiness" of the co-constructed autoethnographic account represented here. These criteria included: 1) *Substantive contribution* - Does the writing substantively contribute to our understanding of social life?; 2) *The aesthetic merit of the writing* - Does the paper succeed aesthetically and is it artistically shaped, satisfactorily complex in its writing, and not boring?; 3) *Reflexivity* - Did the author/s demonstrate how they came to write the text and how has the author's subjectivity been both the producer and production of the text?; 4) *Impact of text* - Does the text move me emotionally and/or intellectually? Has it generated new questions for me or moved me to action in some way?; and 5) *Expression of reality* - Is the text a representative embodiment of a lived experience? The following text intentionally attends to these criteria as a guideline for framing Suzanne's story. In doing so, it is hoped that this manuscript makes an academic contribution that is transformative for the reader and health care professional.

### **Major Themes of Research: Defining Experiences in Rehabilitation**

As we went back and forth between the various sources of data and our respective interpretations of what were the important stories to tell, Suzanne identified two "points" that defined what she believed was important for health care professionals to hear and understand in relation to her experience. First is the importance of continuity of self in the face of

life-altering injury. Second is the importance of client-centred care and the meaningful inclusion of clients in the decision-making aspects of their care and, therefore, their lives. In Suzanne's experiences, there was a disjuncture between the client-centred theory espoused in her rehabilitation centre and her lived experiences. These two themes are communicated through representative poems, excerpts from Suzanne's journals, the narrative she wrote during her rehabilitation, and the interviews.

### ***The Importance of Continuity of Self in the Face of Life-Altering Injury***

A narrative of illness and chronic disability, such as Suzanne's, is a salient representation of what Frank (1993) described as the "rhetoric of self-change." Autobiographical accounts of illness shed light on the disruption in self-hood and identity, but also illuminate the continuity of life. Suzanne's struggle for this continuity and reconstruction of self-hood is an important part of her narrative. Essential to this is how Suzanne's narrative informs health care practitioners how to best help clients during rehabilitation and beyond.

The following is a continuation of Suzanne's original manuscript infused with our analysis of her data. The opening words represent Suzanne's accidental "life event" (Frank, 1993), and her difficulties with shifting self-identity, whereas her prose represents her desire for continuity of life. The analysis and added scholarly references, interwoven with the original manuscript's narrative, affirm and reinforce Suzanne's experience.

*Suzanne's accidental "life event".* My accident was certainly a life event, and adjusting with the associated changes was very challenging. Because of the suddenness of the trauma, and the seeming change in the essence of self from one day to the next, it was very difficult to grasp the reality of the situation--a reality which was forever changing, at a time when my brain had a hard time adapting to any change. I had become more rigid at a time when I needed to be more flexible. I had become less adaptable at a time when I needed to adapt to all the different personalities of the various professionals involved in my care and my rehabilitation; and, most basically, I had to adapt to my diminished self. I was frightened, anxious, and angry. I could not grasp the real-

ity of the present nor envision anything for the future.

### Survival—for M.G.

*Life compounds  
That is true.  
But when one survives  
Against all odds,  
It is not merely to wither.*

*My orchid died;  
Neglect post trauma.  
Yet I guard it still  
As I myself cling to life  
Despite the little that I do.*

*Our challenge,  
Dear doktor,  
Is to discover  
How to use  
My near death,  
My fractured vision,  
My splintered brain  
For benefit  
In this, our world.*

*Dead orchid—to garbage;  
Live woman—to living!*

S.L. Nov. 30, 2000

When I reached the tertiary stage of rehabilitation—integration into the community, with an emphasis on work—I felt that who I was as a person was becoming engulfed by a medical system that seemed ignorant of what it meant to be a person who had experienced a life altering injury. Here is what I wrote in one journal entry, approximately 5 months after my injury:

*I feel that I am losing my identity to a system which saved my life and thus seems to assume that it has a right to my soul; a system made up of well meaning people who, through their professional arrogance, feel that they can control the path of their client's progress; that they understand their client's strengths and weaknesses from their few hours of professional evaluation, and that with their professional status and control of the purse strings they can impose their*

*values and dictate the life course of their client who becomes a passive patient even if no longer hooked up to the fancy lifesaving equipment of the intensive care unit. (Journal, Aug. 15, 1998)*

It seemed that I had taken a more active role in my treatment plan in intensive care on a respirator than in a program that boasted a theoretical goal of client autonomy. Ironically, I felt that I was treated more as an individual in intensive care, where I was continually consulted despite my severe limitations, than at my tertiary rehabilitation centre where I felt I was treated as just another 'brain injury'.

*During any intervention, one appreciates people introducing themselves when they approach—especially when one cannot see, one appreciates the timbre of voice and the quality of touch. Fear of the unknown and helplessness are terrifying, yet strangely these fears are easily quelled by information, however bad. When one is told how one can actively contribute to a procedure, one immediately feels better, less helpless, less passive, however minimal one's contribution is in concrete terms. (Journal, September 18, 1998)*

Part of what exacerbated my profound sense of loss of self was the loss of my role as a valued member of the health care team. For myself, I needed to find meaning in my situation and I needed to be heard by the health care professionals. In living with a traumatic brain injury, this proves particularly difficult when the nature of the injury decreases the ability to concentrate and formulate ideas. When one is easily fatigued and emotionally labile it is hard to trust oneself, let alone establish credibility with one's experienced rehabilitation team. In my own case, with the aid of critical insight from my neuropsychologist and the active support of my rehabilitation team, I was able to use my experiences of negative interactions and lack of control to constructive benefit in redeveloping my own strengths, self-control, and confidence.

A fundamental part of how I defined myself was associated with my previous work as a health care professional. I defined myself—and my sense of competence and compassion—in this role. As noted earlier, before my accident,

working as a community health nurse, my priority over many years had been to involve my clients in their care, to the maximum degree that they were willing and able. I saw my job as listening to their needs and concerns, sharing knowledge, tools and expertise with them, pointing out their rights, and demystifying the medical system. Together we would work out and decide upon a plan of action that made sense for them. I saw myself as a resource person rather than someone who could tell others what to do and how to live their lives. Knowledge is power, and sharing whatever knowledge one has with others gives them a sense of power and control over their lives. As a health care professional I learned from the populations and individuals with whom I worked and I made use of this knowledge with other clients. Hopefully, I gave them some tools that allowed them to take control of their own health by using available resources and being as autonomous as possible.

*I have attempted to demystify the system, to share with my clients whatever knowledge and skills that I possess and to help them develop ways by which to have more control over their health and their lives - even if their way is not my way! I have no right to impose my values upon others just because as a health care professional I am in a position of power. (Journal, August 15, 1998)*

These basic beliefs influenced how I felt as a patient in rehabilitation process.

### ***The Disjuncture Between Theoretical Beliefs and Suzanne's Reality of Client-Centred Care***

When I arrived at the L.B. Rehabilitation Center, 5 months after my accident, I was shocked and angry to find that well-meaning professionals planned to set my goals and that I was expected to passively adjust to their system. I did need their expertise, and although I received much practical help for which I am truly grateful, I felt totally invalidated as an individual. Decisions were made for me, not by me. It seemed to be assumed that the professional staff 'knew' what was 'best' for me. The system became more important than the individual.

*What to do with the rest of one's life following a head injury. It is humiliating to be victim to the judgments of young professionals who are secure that they know how another should live, should work, what tires them, what is difficult, what is dangerous. I feel that I am rendered totally impotent. Decisions are made by others—I am incidental. (Journal, August 24<sup>th</sup>, 1998)*

For example, when I attended L.B. Rehabilitation Center, one staff member could promote or refuse a service such as physical fitness and neuromotor training, even if it had been part of my treatment plan at the previous rehabilitation centre. It was assumed that home visits would be wanted (because the physical effort would be less for me if I did not have to transport myself there), without first verifying with me, and without acknowledging the fact that the only part of my body not harmed by the accident was my legs. Physical activity was the only thing that did not augment my tiredness and that made me feel "normal." Yet this fact seemed irrelevant to those "in charge" of me and my treatment plan.

*S.L.: Well, there was definitely one big thing—they changed my physical rehab plan from one facility to the next. They would not let me go to the gym at the second rehab centre that I went to, even though I had been doing this at my previous rehab. They said I couldn't go to the gym and I was in full-time rehab????!!! (Interview, July 11, 2005)*

It was also assumed that I would not wish to be present when the team discussed their goals for me with the automobile insurance agent. I felt like I was an unwanted spoke interfering with the smooth running of the wheel of rehabilitation.

I acknowledge that many of those feelings were fuelled by a conflict of personalities and by my own discomfort at being in a position of weakness and dependence upon the system. Later I was given a copy of the Code of Ethics of the Rehabilitation Center that placed the client at the centre of her rehabilitation plan. From my experience, there was something missing between the theory and the practice. I found with time that the more that I insisted



upon being involved in every aspect of my rehabilitation plan the greater became my credibility with the rehabilitation team. However, when the members of this team changed, it was necessary to reassert my demands for active involvement.

Throughout the entire process there seemed to be a general assumption by health and social service personnel that clients must learn to accept their limitations.

*Seven months have now passed since the accident. Seven long months, seven short months—an eternity and no time at all. I cannot accept my disabilities. I feel that if I work hard enough, then I shall overcome them.* (Journal, October 5<sup>th</sup>, 1998)

Research has shown that those clients who refused to accept their situation and who kept searching for options achieve increased control over their lives (Lord & Farlow, 1990). Lord and Farlow observed that health care workers tend to see their clients in terms of their problems, which makes it difficult for clients to break free of the system's definition of them. Lord and Farlow's observations resonated with my own experiences. They noted that health and social service workers rarely realise the deep dependency fostered by the system and its resulting negative impact upon clients, who become passive victims. I personally felt as powerless in the system as I had felt when I was literally trapped under the rotating wheels of the truck—even after years of experience demystifying the system and helping my own clients take control of their own lives.

### Discussion

At the time of her original search of the traumatic brain injury literature, Suzanne found many articles discussing clients' lack of motivation, but none examining client's involvement in their rehabilitation plan. Suzanne discovered, however, that this was not the case in the health promotion literature. She also theorized that the literature from other disciplines has pertinent application to post-traumatic brain injury rehabilitation. In fact, health psychology and sociology literature related to empowerment, patient self-determination, and illness narratives reinforce Suzanne's experience of living with traumatic brain injury. Our observations are relevant for multiple

health and rehabilitation settings and contexts, although we have suggested specific implications for therapeutic recreation practice.

### *Empowerment and Patient Self-Determination*

Much of the emphasis in the health psychology literature is directed towards the popularized concept of "empowerment," i.e., clients feeling and objectively having personal power within their present situation and, by extrapolation, over their lives (Rissel, Perry, & Finnegan, 1996; Zimmerman, Israel, Schulz, & Checkoway, 1992; Zimmerman, 1995; Zimmerman & Rappoport, 1988; Zimmerman & Warschausky, 1998). The concept of empowerment "integrates perceptions of personal control, participation with others to achieve goals, and a critical awareness of the factors that hinder or enhance one's efforts to exert control in one's life" (Zimmerman & Warschausky, p. 4). Empowerment theory is based on the belief that empowerment is ecologically embedded (Perkins & Zimmerman, 1995). That is, empowerment is influenced by the interactions between individual characteristics and features of social settings and the broader socio-political context in which these actions and interactions occur.

Although the concept of empowerment has long been theoretically associated with rehabilitation services (Zimmerman & Rappoport, 1988; Zimmerman & Warschausky, 1998) there has been less attention to how patients in a medically-oriented rehabilitation context can gain power in this context, or be empowered by other health care professionals. We suggest that in order for clients to have control over their lives, even when all aspects of their lives have been disrupted by injury, they need meaningful opportunities to experience choice and make decisions if they are to be empowered as part of the rehabilitation process. In Suzanne's narrative, this is accomplished by involving clients in their plan of treatment—not just in theoretical principle, but instead in actual practice. Rehabilitation, therefore, becomes a collaborative endeavour that fosters potential for client empowerment and more positive outcomes.

Because the concepts of recreation and leisure are based on principles of personal choice and self-determination, the facilitation

of a range of individual or group opportunities for people to make choices and express preferences can directly contribute to personal empowerment. Recreation participation opportunities are particularly important in a rehabilitation environment, where opportunities for other choices and decisions are more limited. Opportunities to exercise some choice can help people feel more in control of their situation which can, in turn, contribute to personal empowerment; however, in order to make informed decisions, clients need access to information. For some, this may mean learning about therapeutic recreation and the ways it can contribute to one's rehabilitation goals; for others it may mean being fully informed of the opportunities for recreation that are available to them within their room, rehabilitation hospital, or surrounding area.

Curtis (1998), a vocational rehabilitation counsellor, suggested that rehabilitation should incorporate values of self-control, independence, self-determination, self-reliance, freedom, responsibility and self-actualisation—in other words, empowerment. Curtis sees empowerment as the ability to act on choice; however, one has no ability to act upon choice until these choices are known. From Suzanne's perspective, as a patient in a rehabilitation centre, one often has no idea as to the range of choices for that are available. This leads to feelings of impotence and insecurity.

Such feelings are similar to those voiced by the mothers of the chronically ill children in a study by Gibson (1995) of their process of empowerment. As with Suzanne, the process for these women to move from being recipients of the system to participants within the system involved discovering reality; a period of critical reflection, followed by taking charge and holding on. Like Suzanne, the women in this study needed information and they needed to be heard. They needed to vent feelings rather than to be evaluated and reassured. Also similar to Suzanne, the mother's uncertainty led to a quest for information and empowerment through knowledge. Developing and employing knowledge led to the mother's competence and confidence to make their voices heard by those in power. Similar to Suzanne's case, they were no longer subordinate to the health care system, but started to interact effectively with it.

### *Client-Centred Practices in Health Care*

Although there has been a recent theoretical movement towards client-centred care, the responsibility for initiating and directing the therapeutic relationship remains with the health care professional (Lindsey & Hartrick, 1996). From Suzanne's experience, previously as a provider and then as a recipient of services, both client and practitioner tend to tacitly fall into the habitual roles of the traditional medical model—even if intellectually critical of it. Often, both client and professional want the professional to have all the answers and to be able to heal the injury.

Lindsey and Hartrick (1996) argued that the power to define health needs and problems belongs to those experiencing them. They recommended a shift from the traditional 'top-down' model where services are provided to passive recipients, to a 'bottom-up' approach where the client-expert engages in a synergistic process with the health care professional. It is difficult, however, for professionals to give up a controlling role in a paternalistic system where clients' dependency benefits the personnel (Sakaly, 2003). In addition, it is difficult for a client who needs services not to feel at the mercy of the service provider. While medical expertise and guidance is both indispensable and often reassuring it can also be overwhelming to the patient and intensify one's sense of alienation.

A client-centered approach operates from a self-determined perspective whereby client's perspectives and goals are the primary directive for treatment as opposed to goals determined only by the medical team (DeHope & Finegan, 1999). A client-centered approach involves sharing information, negotiating care, and giving each individual the tools necessary to feel healthy within the constraints of illness or disability. Empowerment within the context of rehabilitation enables the client to be a participatory member of a multidisciplinary team rather than a mere recipient of interventions by that team. As it relates to therapeutic recreation practice, a client-centered approach is reflected in all aspects of the treatment process, from assessment to goal-setting and making decisions about leisure-based projects or activities that will be utilized to accomplish goals. It also implies that the client has a right to refuse

participation in any aspect of therapeutic recreation treatment or programming.

Several general principles that facilitate empowerment can be applied to clients living with brain injury (DeHope & Finegan, 1999; Lord & Farlow, 1990; Sakalys, 2003). First, clients must be able to identify their problems and plan solutions in consultation with health-care professionals but based on the client's own experience. Second, workers need to listen to clients and to believe in their capabilities. In cases of post-traumatic brain injury this is extremely important, as one often has difficulty knowing and believing in one's own capabilities. Third, people need a sense of being valued in order to participate and to take responsibility. The process of intervention, not just the outcome, is important in order for clients to feel in control, which in turn decreases their level of stress, and gives them the freedom to make decisions - having a positive impact on their lives. All these principles are easily accommodated in a therapeutic recreation program that emphasizes client strengths and interests in the assessment, goal-setting, and treatment process.

As a patient or client ("politically correct" semantics do not change one's actual position in the system) one feels very vulnerable; the caregiver, who plans the intervention, is in the position of power in the system (Krouse & Roberts, 1989; Roberts & Krouse, 1988). From Suzanne's perspective as a client, one feels helpless and thus one has a tendency to always try to please one's practitioners. What can be done to shift this balance of power? In their examination of the active negotiation process in nurse/client relationships, Krouse and Roberts found that the client's participation is influenced by the nurses' (health care professionals') behaviour. They noted that rather than the traditional attitude where the professional dominates, an equalisation of the client/nurse relationship must occur in order to return control to the client and thus decrease the client's feelings of helplessness.

The three levels of dependence/independence in the nurse/client relationship delineated by Orem (1985) also apply well to those living with traumatic brain injury. The first level, "wholly compensatory," as in emergency, life threatening and intensive care situations, defines a client totally dependent upon profes-

sionals. The second, "partially compensatory," calls for guidance and co-operation; and the third, "supportive-educative," requires mutual participation and places increased responsibility for care in the control of the client. As Krouse and Roberts (1989) pointed out, professional behaviour influences this process and, for interpersonal, cultural and social reasons, not every provider and client can work together.

Practitioner values, while somewhat elusive, must be recognized as unwittingly influencing intervention and understandably cannot be kept out of the therapeutic relationship (Curtis, 1988). Clients, however, need to be able to voice their desires and to set goals based on their own values rather than upon those of the worker. Responsible professionals need to share their 'educated' views and opinions with their clients, and at the same time help them recognise their own values and avoid incorporating the professional's values as their own. As it relates to therapeutic recreation practice, Carter, Van Anandel and Robb (2003) suggested that, in order for therapeutic recreation practitioners to establish effective therapeutic alliances with their clients, they need to be self-aware of their motives or needs for being a helper, as well as being aware of their own personal values and biases. Hutchinson (in press) noted that there is a greater chance for the therapeutic recreation process to result in positive change when practitioners intentionally try to define and frame their work with clients in ways that are consistent with clients' world-views and values. This includes understanding clients' views of themselves, leisure, and rehabilitation.

As Curtis (1988) pointed out, the therapeutic relationship must be based on integrity and trust, recognizing and respecting individuality. From Suzanne's experience as a client living with a brain injury, it was very important for her trust and security to know some of the values of her therapeutic team, whether or not they correspond with her own. The willingness of the practitioners working with Suzanne to share of themselves allowed her to re-establish her own individuality within the rehabilitation process. For rehabilitation to be effective, clients must be involved in decision-making, and their right to make life choices must be honoured. When workers differentiate their

personal values from those of the client, they give the client the opportunity to re-establish and explore their own values and to make their own decisions upon which they can act. Understanding the capacity of values to influence clients can increase the effectiveness of interventions and decrease the risk of hidden persuasion. From Suzanne's experiences, the more she knew about members of her rehabilitation team, even in terms of their limitations, the more secure she felt in the relationship.

### ***Illness Narratives as an Integral Part of the Healing Process***

What does it mean to live with ongoing limitations associated with a life-altering injury? Lindsey (1996) developed the concept of "health within illness" to suggest that, for clients to gain self-knowledge and to feel in control, irrespective of their medical condition, emphasis needs to be directed to the health-illness experience of the individual rather than to that of their pathology. From the perspective of the care provider, actively listening to the client's experience can lead to increased client awareness, empowering the client to make choices, then to act upon these choices—owning and taking responsibility for them. Lindsey concluded that to promote health effectively, within the context of chronic illness/disability, a collaborative relationship is needed; the client then becomes a partner with the health care professional, who takes on the role of facilitator and resource person.

The other side of an illness experience is helping clients to understand and explore how their past and present are both part of shaping their future, even in the context of a life altering injury. Suzanne's journal writing became a way to both rediscover and reclaim glimpses of her self during the rehabilitation process. Suzanne's experiences of journaling and poetry writing throughout the rehabilitation process supports the therapeutic value of writing illness narratives (Sakalys, 2003). Therapeutic recreation practitioners can facilitate and support self exploration and personal reflection in a myriad of ways, from ensuring clients have access to supplies (e.g., painting or writing supplies, adaptive equipment), providing skills training (e.g., incorporating different forms of poetry or art, computer use), and creating

environments for people to feel they have the safety and comfort to explore their own feelings and thoughts (e.g., a private space).

However, Suzanne's experiences also emphasize the importance of reclaiming one's self through active involvement in decision-making throughout the rehabilitation process. Clients living with brain injury tend to underestimate the importance of their own contribution to their rehabilitation; the therapeutic team frequently interprets clients' hopes as being a defensive denial and lack of awareness of their present situation (Pössl & Cramon, 1996). These different perspectives often arise because the client's reference is pre-brain injury, whereas the professional's reference is just from the time of admission. Pössl and Cramon maintain, however, that the clients' 'subjective' perspective regarding treatment and outcome deserves more attention. There is limited data on how brain injury clients describe their experiences; usually studied are physical activities of daily living along with cognition/communication tests. Pössl and Cramon conclude that it is necessary to listen to clients and to stress their competences rather than their failures.

Suzanne reflected that examining her thoughts and feelings, during a time when she was evolving in her own adaptation to living with a brain injury, placed her in a unique position of *living her research*. At the same time it raises the question as to whether one can, or should be, "objective" under such circumstances. The whole question of subjectivity/objectivity is fascinating, especially as it relates to illness narratives such as Suzanne's. While the medical system is changing, it is still predominately based on objectivity and a traditional medical model approach to health. As Sakalys (2003) aptly states, "by defining health, illness, care, and patienthood in terms of disease, medical metanarratives suppress subjectivity and the uniqueness of the experience, dominating and objectifying the person who is the patient" (p. 230). Suffice it to say that as human beings we are never totally objective in any situation and that we always see things to a lesser or greater degree from the position of the sum total of our personal, educational, and professional life experience.

## Conclusion

This co-constructed autoethnography began with Suzanne's personal desire to augment her cognitive abilities post traumatic brain injury. She wanted to find out what she could and could not do in terms of concentration and conceptualization. She wanted to see where her difficulties lay and to hopefully, with professional help, find some ways to overcome them. Her writing also served as a link between her past experiences as a health care provider and her present experiences as a health care consumer; however, it evolved to become a vehicle for communicating about the importance of client-centred care in post-traumatic brain injury rehabilitation and, more generally, user empowerment within the health care system.

Although Suzanne held on to values of personal empowerment against all odds during the rehabilitation process, she also reflects here, in this conclusion, on how the research process affirmed her beliefs: Finding support for my experiences in the general literature on health, health promotion, and rehabilitation increased my confidence in my new role as a client—as health care professionals we receive years of training; as a client following a trauma we receive none. All people are unique; whether increased involvement leads to increased motivation and empowerment for all of us living with brain injury remains to be seen. Being a health care worker prior to my accident makes involvement in my rehabilitation a natural continuation of my way of life. What helps others become more involved in their own rehabilitation and if this involvement, as I would contest, is something that motivates and empowers, requires further investigation.

## Lament

*Out of the biting chill of winter morn air  
The greasy spoon waitress nurtures with care.  
Oh, but that those professionals of  
rehabilitation  
Would forget about paltry punitive  
correction.  
Rather than wanting a social norm to  
recover,  
They could listen to clients caught in their  
lair.*

*So much should they learn and discover,  
Therewith enhance skills and knowledge to  
share.*

S.L. Jan. 30, 2001

## Le Retour

*Returning to the present I see naught  
Yet in that nothingness, all is pure  
This present is not the present of before.  
My ancient dreams and memories have  
faded  
Into the receding wall that cuts across my  
soul.  
Now life begins anew.*

*Returning to the present  
I wonder, no longer wandering,  
Where have I been dwelling  
These past four years and more?*

*The struggle is over; I have lost the tug of  
war  
Between what was and what will be.  
Thus have I won the right of return to the  
present  
A present that I know not, but shall discover  
As I embark upon this journey  
Ere half my life is spent—and more!*

*Returning to the present  
I am enrobed in the cool breeze of evening  
Turning into night before the break of dawn.  
My knees are locked together as a child  
bawling  
Before fearfully taking those tentative first  
steps  
Towards the brave new world of an  
unknown present  
Of venturing into the to be discovered here  
and now.*

*I have stumbled reluctantly  
Through that valley of the shadow of death  
And I feared all good and all evil.  
I have seen no end and dreamed of no new  
beginning  
Yet, despite myself, I have been reborn  
Far from the madding crowd of memories of  
my life before;*

*A life which, in retrospect, prepared me  
adequately  
In my inadequacy to return to the present.*

*Now I smell the rain  
Before a new storm breaks  
Before tomorrow's robin calls.  
Returning to the present, I see nothing  
And, thus, see all.*

S.L. Sept. 5, 2002

### **Suzanne's Epilogue**

Ten years have passed; now all of this seems history. My deficits remain; but I have learned to live relatively peaceful with them, integrating them into my being and managing to enjoy a life which is still rich and active. It is not my previous life. Most people live once; I have had the opportunity to live twice. I am supplementing, or, should I say, complementing my pre-accident/ brain injury life with my present life. I do not know at what point I stopped mourning what I was to simply become what I now am. I know that many factors, some of which are discussed in this paper played their role.

Is not recreation about being and becoming? Each of us be and become in our own time and in our own way—with a little help from our friends and our therapists!

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