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FACULTÉ DES ÉTUDES SUPÉRIEURES  
ET POSTDOCTORALES

FACULTY OF GRADUATE AND  
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Auto-Ethnography of Healing

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Creatively Rehabilitating Self-Esteem After an  
Acquired Brain Injury:  
An Auto-Ethnography of Healing

by  
Claire Smith  
University of Ottawa

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## Abstract

This participatory auto-ethnography was conducted to explore the use of creative activities to enhance the self-esteem of individuals who have sustained an acquired brain injury (ABI). There were five participants in the study, including myself as the researcher/participant. Three questions were researched: how do ABI patients feel when they have completed a creative task, how does the way ABI patients feel when they complete their creative endeavors affect the way they feel about other aspects of their lives, and, how can ABI patients learn things about themselves by doing creative activities, which will help them be more successful in other aspects of their lives?

The genre or methodology 'participatory auto-ethnography' was chosen for two reasons. Firstly, an auto-ethnography includes autobiographical writing, so the epistemological problem which can result because the researcher is from the same culture as the participants is eliminated. As the researcher, I could freely express my own experiences without fear of lessening the validity of the views of my participants. Secondly, a participatory paradigm includes alternative representation. Three were used: a short story, a play, and a pictorial representation of the data.

Data were collected in multiple forms, including participant observation, conversations with the participants, field notes, and a focus group interview. The data were analyzed, and emerging findings were triangulated. The report was written in a narrative format designed to attract readers both within and beyond the academic sphere. The findings suggest that engagement in creative activities is a positive addition to ABI rehabilitation because of its favorable impact on self-esteem. I concluded the study by highlighting areas that may benefit from further research.

**Dedication**

I wrote this thesis for my parents, Brad and Renee Smith, and for my great friend Glennis Easey. They worked together as a team during my own rehabilitation, forging ahead to guide me towards the light at the end of the tunnel. Thanks a million.

## Acknowledgements

Many people have played significant roles in this thesis journey. The thoughtful guidance given to me by my thesis advisor, Dr. Cynthia Morawski, continues to be invaluable. During the thesis process, she was encouraging and supportive when I decided to use alternative representations. Spending time with Cynthia in the past year has been a truly enjoyable and confidence building learning experience. I thank her for contributing in no small way to the rehabilitation of my own self-esteem. My committee members, Dr. Janice Ahola Sidaway and Dr. Raymond Leblanc, provided many well-considered and encouraging suggestions. I am very grateful that the thesis committee understood the appropriateness of the unusual genre I used and respected the intensely personal nature of this project.

Dr. Fran Squire taught the first M.Ed. class I took at Ottawa U. Since that time three years have passed, and she has continued to play an irreplaceable role in my academic life. Fran has read this thesis at many stages and has always been there for me to use as a sounding board. Fran's knowledgeable contributions have greatly influenced the way that this story is written.

I gratefully appreciate the informed advice I received from the staff at the site. I have learned many things about ABI rehabilitation because of their interest, enthusiasm, and admirable devotion to helping those with ABIs. I hope that this study reinforces their instincts to encourage their clients to engage in creative activities. I know that they will continue to educate me about ABI rehabilitation, as they have all done so tactfully throughout this study.

My unending gratitude goes to my family and friends, particularly to my parents. My father has been my chief editor throughout the MA program. My mother has put up with me during the whole thesis journey, especially while I was struggling to write this story. Joyce Devlin generously let me use her studio to paint the enormous pictorial representation of the data. Spending time being creative with Joyce the artist helped me decide how to use alternative representations in this thesis. To my fellow students who have become good friends: thanks, and great big hugs, for being so supportive. The shared bottles of wine have forged bonds that I hope will last beyond the MA thesis. A big thank you goes to Betty Cooper, who came to the rescue when I needed photos of the conceptual framework and the data analysis painting. So, to all my friends and family who may outwardly appear incidental in this process that was at times difficult for me because it was so personal...you are not. Thank you.

The stars of this project are the participants. Without their help and enthusiasm, I would have been unable to tell this story. So, I thank them for their time, their helpfulness, dedication and commitment, their ability to laugh with me (and also at me!), and their frank tales about their struggles. I know that they hope, as I do, that this project will help other people with acquired brain injuries.





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## Prelude

*Things didn't turn out the way they were supposed to, but what can you do? You must take life the way it comes to you and make the best of it. (p. 101)*

Yann Martel's comment in his award winning novel *Life of Pi* describes my life to date well. My life certainly didn't turn out the way I wanted it to, or expected it to. On September 13, 1997, I fell from my horse at the European Three Day Event Championships and sustained a severe closed head injury. Before that September 13, I had been an athlete; I was dedicated, motivated, tough, driven, successful, and respected. Then I fell on my head. This life-changing event caused grief, mourning, and loss.

The person I was before the fall is gone. I am very different now. I am still dedicated, motivated, and driven. My recovery would not have been possible without these qualities. However, now I am not nearly as tough. And it is a struggle to feel successful and respected. Because of my fall, I have had to carve out a new life for myself. This transformation led to a quest to contribute to the field of acquired brain injury (ABI) research. So, I returned to school and wrote this thesis.

## Introduction

This thesis is "a borderland between passion and intellect, analysis and subjectivity, ethnography and autobiography, art and life" (Behar, 1996, p. 174).

It is an auto-ethnography that explores five people's experiences with creativity as they recover from acquired brain injuries. Four of these people were recruited through the site that I had planned to use for my research. In the end, however, for logistical reasons only two of the participants used the site. I observed one of the other two participants in her home, and another in the place that she regularly receives therapy. I am the fifth participant.

This auto-ethnography explores, describes, and interprets the lived emotional experience of the five participants in the study. As suggested by Wolcott (1999), in addition to the discussing the lives of the participants I have included details of my own journey after sustaining an ABI. This strategy will allow me to study my own experience, which I hope will add depth and meaning to this thesis.

My intention is to write an introspective, evocative story that elicits reaction from its readers. I take it as a challenge to involve the readers of my thesis by, as Blumenthal (1999) coaches, "reflect[ing] the life in the data rather than squashing it" (p. 377). Ellis (1991a, 1991b) notes that an introspective work tells a story using a social process where the researcher actively recognizes, thinks about, and studies his or her own thoughts and feelings. Ellis (1991a) writes:

[By] reflecting inward as well as observing outward, we can view our own emotional experience as a legitimate sociological object of study and focus on how we feel as researchers as a way of understanding and coping with what is going on emotionally in our research. (p. 125)

Ellis' quote describes exactly how I felt when writing this thesis. Preparing the proposal didn't bother me; data collection didn't bother me (for the most part); writing in my journal was private, so it didn't bother me. I have included, in the

form of a short story, some of my thoughts and impressions as I try to get to know myself again after my injury (Ronai, 1992). Writing the story didn't bother me. The research process has been a self-reflective journey for me. Sharing thoughts from my research journey didn't bother me either. But, when I actually sat down to write this thesis and synthesize my thoughts about a topic so close to my heart, it did bother me. It was extremely hard. It was also therapeutic, revealing, and necessary. In the end the process was a source of growth and understanding, although it did increase my vulnerability, as Ellis and Bochner (2000) warned might happen. Doing this thesis has helped my own healing because, as Behar (2003) experienced, it has helped me to come "a full circle, or better, the circle widened, stretched, opened for me" (p. 342).

The most effective way to convey my ideas and thoughts about myself and my participants was to imagine this thesis as a play, where the play is an exploration undertaken to answer my research questions. To do this, I have used theatrical terms for my section headings, and written one section as the script of a play. Ideally, as Ronai (1992) remarks, readers will be able to experience, and perhaps vicariously live, the stories I tell through the medium of this text. Writing my paper in this way also allows me to distance myself from identifying personally and emotionally with the stories of my participants.

## **Director's Notes**

### ***Purpose of the study***

This thesis has been undertaken to explore the use of creative activities to enhance the self-esteem of individuals who have sustained an ABI. I also examine how bolstering the self-efficacy of ABI patients as they participate in creative activities can be a building block toward enhancing their self-esteem. This project was conceived because of the influence of creativity on my own recovery. Wolcott (2002) stresses that unique research opportunities should be pursued. So, upon my return to school, I recognized that I had a unique research opportunity which would combine creativity and ABI, so I chose to research it.

### ***Definitions of Key Terms in the Purpose Statement***

#### ***Self-esteem.***

There are many definitions of self-esteem. For the purposes of this study, I will use the one advanced by Coopersmith (1967), who said that self-esteem is:

...the evaluation which...individual[s] make and customarily maintain with regards to [themselves].... It expresses an attitude of approval or disapproval and indicates the extent to which individual[s] believe... [themselves] to be capable, significant, successful, and worthy.  
(cited in Battle, 1990, p. 25)

Coopersmith's use of the terms 'capable' and 'successful' in his definition suggests that he thinks that self-efficacy is a component of self-esteem.

Mruk (1999) notes that personality characteristics often associated with self-esteem include "increased openness to experience and possibilities that comes with being effective at dealing with the various tasks and challenges of

living successfully” (p. 87). These characteristics are also some of those associated with self-efficacy.

***Self-efficacy.***

According to Bandura (1982), self-efficacy is:

..not a fixed act or simply a matter of knowing what to do. Rather, it involves a generative capacity in which component cognitive, social, and behavioral skills must be organized into integrated courses of action to serve innumerable purposes....Perceived self-efficacy is concerned with judgments of how well one can execute courses of action required to deal with prospective situations. (p. 122)

Self-efficacy is concerned with judgments one makes about how well one can organize and execute courses of action required to deal with prospective situations which often contain many ambiguous, unpredictable, and often stressful elements. It involves a generative capability in which component cognitive, social, and behavioral skills must be organized into integrated courses of action to serve innumerable purposes. Self-efficacy also relates to the control that individuals exercise over these courses of action. Individuals' perceived self-efficacy influence whether they think self-debilitatingly or productively, optimistically or pessimistically, whether they are motivated, whether they are vulnerable to stress and depression, and what life choices they make. (Bandura, 1982, 1997; Bandura, Caprara, Barbaranelli, Pastorelli & Regalia, 2001; Bandura & Schunk, 1981; Schunk, 1983).

The above definition indicates how individuals' perceptions of their self-efficacy alter their capabilities, their optimism in their abilities, and their confidence. Self-efficacy is an especially desirable characteristic during recovery

from illness or injury, because, as Bandura (2001) explains, “daily realities are strewn with difficulties, frustrations, conflicts, impediments, failures, setbacks, inequities, and adversities... Resilient self-efficacy provides the needed staying power” (p. 21). Schunk (1983) adds that, in the face of difficulties, individuals’ self-efficacy affects their perseverance, effort expended, and choice of activities. Finally, Lightsey (1997) notes that a person who has positive self-efficacy will be more tenacious when attempting to master skills and behaviors, as well as more willing to do so. These comments show why participants’ self-efficacy would be appropriate to explore in this study, which will try to lend insight into how to help individuals during their rehabilitation from a life altering TBI.

### ***The relationship between self-efficacy and self-esteem.***

According to many theorists, an important component of self-esteem is self-efficacy (Bednar & Peterson, 1995; Branden, 1969, 2002; Mruk, 1999; Plummer, 1985; Pope, McHale & Craighead, 1988). Self-efficacy describes an individual’s capability to organize and execute courses of action when coping with situations in life that may be stressful, ambiguous and unpredictable (Bandura, 1981, 1997, 2001). The essential role of self-efficacy as an element of self-esteem is well stated by Bednar and Peterson (1995), who argue that: “The relationship of perceived self-efficacy to self-esteem is obvious. The self-evaluative processes that follow the challenge of any difficult task, interpersonal or object-oriented, are fundamental contributors to the construction of self-esteem” (p. 57).

This view is also held by Branden (1969), who describes the association between self-esteem and self-efficacy in his definition of self-esteem: "Self-esteem has two interrelated aspects: it entails a sense of personal efficacy and a sense of personal worth...It is the conviction that one is competent to live and worthy of living" (p. 110). Mruk (1999) echoes Branden's view of the importance of self-efficacy, saying: "the general idea is to help people increase their sense of self-efficacy by learning to become more successful, which, in turn, increases self-esteem" (p. 109).

Often, TBI patients' self-esteem is diminished when their self-efficacy is battered due to their compromised ability to effectively plan how to meet day-to-day challenges. The repercussions felt perpetuate when the negative self-perceptions resulting from low self-esteem lead individuals to distrust their capabilities (Bednar & Peterson, 1995). This in turn causes even more damage to individuals' self-efficacy, thereby undermining its support for their self-esteem.

Several theorists, in addition to Bednar and Peterson (1995), Branden (1967, 2002), Mruk (1999) and Coopersmith (1967), have noted the connection between self-efficacy and self-esteem. Plummer (1985) thinks that high self-esteem contributes to the likelihood of task completion and effectiveness at dealing with various tasks. This comment seems to describe self-efficacy as defined by Bandura (1997) and Schunk (1983). Notably, Pope, McHale, and Craighead (1988) describe self-efficacy as the attribute of self-esteem which enables individuals to deal effectively with life's challenges.

Bandura and Schunk (1981) comment that an improvement in individuals' self-efficacy positively affects the rate of skill acquisition and performance mastery, thereby boosting their self-esteem.

### ***Research Questions***

I will explore the following research questions in this thesis:

- a) How do individuals who have sustained Acquired Brain Injuries feel when they have completed a creative task?
- b) How does the way these individuals feel when they complete their creative endeavors affect the way they feel about other aspects of their lives?
- c) How can individuals who have sustained ABIs learn things about themselves by doing creative activities which will help them be more successful in other aspects of their lives?

### **Behind the Scenes – Before the Curtain Rises**

#### ***The Intended Audience***

Who is the audience for this auto-ethnography? As Fran Squire (2000) states, "in a research text we are not speaking just for ourselves. Considering the external voice of the audience the questions become, 'What are we doing here? Who are we writing for?'" (p. 21).

First, I will answer the question 'who are we writing for?'. I think I have several audiences. The first consists of the members of my thesis committee. Their primary task is to help me write a thesis that conforms to the guidelines set

by the University. Secondly, I am writing for the ABI community. This community includes individuals who have sustained an ABI, as well as those who are in the field of rehabilitation. This study examines only a small facet of ABI rehabilitation and its impact on the self-esteem of these individuals. But, the study offers ideas which could be used when developing educational programs for individuals who have sustained ABI's. Sitting in the audience one will also find fellow Master's students who are interested in whether my thesis has been accepted as legitimate research.

When I was planning this thesis, I had not thought more deeply about my intended audience. But, during the writing process, I have discovered that I am primarily here for my participants, to let their voices, marginalized by their positions as ABI survivors, be heard. Because I have situated myself as a participant, I am also writing for myself. And so, in answer to the question 'what am I doing here?', this thesis – somewhat surprisingly – has turned out to be a voyage of self-discovery in addition to a tale of my participants. This thesis is emergent, therefore I was able to change the genre to auto-ethnography. This is the genre I feel I can use most effectively to convey the results of my study.

### ***Planning the Play – Methodology***

#### ***A Qualitative Script***

A qualitative study is appropriate in this case because it is a study of the uniqueness of individual cases. Creswell (1998) describes my aim when I wrote

this thesis: to create a “complex narrative that takes the reader into the multiple dimensions of a problem or issue and display[s] it in all of its complexity “ (p. 5).

### ***The Choice of Auto-ethnography as the Genre for the Play***

Janesick (2000) comments: “Just as dance mirrors and adapts to life, qualitative design is adapted, changed, and redesigned as the study proceeds, due to the social realities of doing research among and with the living” (p. 395). And so, as I gathered more insight, along with more data, it became apparent to me towards the end of my data collection period that I should change the genre to auto-ethnography.

The importance of my own personal experiences in this story, as well as my own creative inclinations, led me to change the genre from a personal experience narrative to auto-ethnography. I like Wallas' (1926) model of the creative process, and I find myself spending a lot of time in the second phase he describes, called incubation. As a result, I reflected about making the change to auto-ethnography for quite a while before I decided that this was the genre to use to narrate my exploration. Eisner (1998) said that serendipitous discoveries should be pursued. Eventually, after much thought, research and incubation after serendipitously discovering the genre auto-ethnography, I decided using it would only strengthen the study.

Because auto-ethnography is a new approach, especially in this context, it warrants some special attention. Therefore, throughout this thesis, I will comment on why I used auto-ethnography to conduct this study.

The label 'auto-ethnography' is appropriate, because not only am I the researcher, but I too, have sustained an ABI. As Jenks (2002) remarks, my experiences undoubtedly have affected what I observed, what I wrote, and how others will interpret and react to what I wrote. Using auto-ethnography allows me, in my role as the researcher who has sustained an ABI, to add my own views and thoughts of the experience to enrich the story for the readers.

According to Denzin (1989), and Reed-Danahay (1997), auto-ethnography enables me to tell the story of my own life changing experience of ABI, and incorporate my story into an ethnography of my participants. Stake (1995) notes that, because I am using auto-ethnography, my personal view of ABI is co-constructed with the views of my participants. I can include my personal experiences with ABI because they help me to speak "to readers with an individual voice and that voice ...claims something like: 'Here is my truth, complete and unvarnished'" (DeVault, 1997, p. 221). DeVault maintains that the vignettes I tell will render this story easier to read, and the readers will feel that they have unique access to my personal reality. Because auto-ethnography is reflexive, I can, as Goodall (2000) states, "turn back on [myself] the lens through which we are interpreting the world" (p. 137). Neumann (1886) comments that the autobiographical writing included in auto-ethnography " shifts the observer's gaze inward toward a self as a site for interpreting cultural experience" (p. 183). I

have included autobiographical writing in the literature review as well as in one of the forms of alternative representation, a short story. It will reveal to readers why I am compelled to do this study.

Reed-Danahay (1997) notes that the term auto-ethnography : “has a double sense – referring either to the ethnography of one’s own group or to autobiographical writing that has ethnographic interest” (p. 2). I believe that the auto-ethnography I have written incorporates both these elements.

With respect to the first sense, I am writing an ethnography of my own group, individuals who have sustained an ABI. This enables me, as the researcher, to position myself within the group I am studying. Because of my background and close personal involvement with the subject under discussion, Creswell (2002) thinks that my interpretations will inevitably shape the discussion. As in the conduct of narrative inquiry, Marshall and Rossman (1999) write that in the genre auto-ethnography “there is open recognition that the researcher is collaboratively constructing the narrator’s reality, not just passively recording and reporting” (p. 122). I found that this occurred in my study. At times it was imperative to relinquish my views and understandings in order to grasp the full significance of what my participants were telling me. In other words, this re-affirmed my belief that auto-ethnography, “requires a great deal of openness and trust between participant and researcher” (p. 122).

With respect to the second sense, I have added autobiographical writing to strengthen points I am making about the group I am studying. Writing an auto-ethnography allows me to reflexively talk about my experiences. By telling my

own story, I found, as Wolcott (1999) did, that I could emphasize the importance of the recovery process. This adds ethnographic interest because it is an exploration of my life after an ABI in the culture of ABI. By adding my story in the form of a short story, Gergen and Gergen (2002) maintain that my “unique voicing – complete with colloquialisms ...and emotional expressiveness – is honored” (p.14). I admire DeVault (1997), who desires to give readers the impression that they have direct access to the author’s reality. They will see my reality through a window to a unique world, which, as Mykhalovskiy (1997) writes, has its own “social relations and experience, of human practices and activities, of embodied joys, pleasures and pains” (p. 241). Auto-ethnography is defined by Neumann (1996) as allowing the exploration of an ABI survivor’s own subjective and the cultural experience at the same time as the exploration of the subjective and cultural experiences of the participants.

This process has, for me, also had the additional effect Banister (1999) talks of: “participation in qualitative ethnographic research such as this may become a first step toward a continual process of self-discovery for the researcher as well as for the participant”(p. 6). As Tedlock (1991) pointed out, my own healing and search of self continued as I explored my own and others’ experiences in this ethnographic encounter.

### ***Experiencing and Understanding this Thesis***

According to Schwandt (1999), the most important aim of qualitative research is that the reader understands. Schwandt thinks that, when doing

qualitative research, we are losing sight of what understanding is “with all our intramural arguments about method, text, voice, representation, and the like” (p. 451). With this thesis, I do not want understanding to be lost. I agree with Squire (2000), that the goal is to not “lose the sense of immediacy and vividness emerging from my participants’ stories in a morass of academic language which would separate the kick and experience” (p. 8). When writing this thesis, my primary goal was to help the reader experience and understand the phenomenon being examined. I will start by exploring the culture of ABI. But, to understand the culture of ABI, one must first understand the meaning of culture.

### ***Understanding the Culture of ABI***

Ethnography concerns cultural exploration, so I think it is important to search for a definition of the word ‘culture’ that is meaningful for this study. Although this thesis is not an anthropological study of culture, it is an auto-ethnography of ABI. Therefore, I would like the reader to understand the distinct culture of ABI. As Fine, Weis, Weseen, & Wong (2000) note, describing the culture of ABI is the first step in connecting the voices of my participants and my own voice to the culture of ABI in this auto-ethnography.

A brief literature review of the term ‘culture’ yielded the following definitions. Harris (1999) defines the concept of culture as including thought, behavior, and other forms of socially learned ways of living. Geertz (1973) thinks that the culture individuals belong to defines the meanings that they use to understand their experiences and guide their actions. Van Maanen (1988)

comments that the knowledge that members of a given group share “is said to inform, embed, shape, and account for the routine and not-so-routine activities of the members of the culture” ( p. 3). Denzin (1992) says that culture is “the taken-for-granted and problematic webs of significance and meaning that human beings produce when they do things together...shaped by the larger meaning-making institutions of society at large” (p. 22).

For the purposes of this study, I have decided to use Wolcott’s (1999) simple and clear explanation of culture. Wolcott states that “culture is an account of particular social processes as practiced by particular people in particular settings” (p. 253). The culture I am studying is the social process of creativity as experienced by individuals who have sustained an ABI in a setting in which creative activity takes place.

What is the culture of ABI? David Blanche (1998) effectively captures how individuals feel after an ABI when he says: “I had undergone an experience that no one else had gone through or could relate to. Meeting other brain injured people made me feel part of a group; I was no longer alone” (p. 74). This describes the culture I am exploring: people who have undergone the heart wrenching, lonely, experience of enduring an ABI. Due to the social, physical, emotional, and cognitive changes the ABI forces on them, they look at the world through a unique lens. Individuals who have sustained an ABI often have experiences with meanings that are different from those encountered by the rest of society, thereby defining a distinct culture to explore. Despite my role as researcher for this study, I am from the same cultural milieu as my fellow ABI

survivor participants. Seaton (1998) describes this culture as one where individuals often “feel like outsiders in society because they cannot reintegrate into the many social roles they once played” (p. 81).

According to Crisp (2000), the culture I am studying consists of a group of people who have a “diversity of standpoints,...that collectively can be distinguished from those held by persons without disabilities” (p. 356). By letting their silenced voices be heard, and my silenced voice to speak, I have attempted to convey the experiences of the participants in this study who all belong to the culture of ABI.

### ***Building the Stage Set - Reviewing the Literature***

In order to build helpful, realistic, and meaningful connections between my thesis and the literature, I have interwoven parts of my personal story with the literature review. Using this strategy increases the validity of both my story and the literature review and makes the literature review more compelling.

### ***Theoretical Groundwork for this Study***

Carl Rogers' (1961) humanist psychology and Teresa Amabile's (1983, 1996) social psychology of creativity are used to establish the creative environment for this study. Rogers (1983) thinks that we are the architects of our own lives. Therefore, “we can discover that which is unique and precious to us, and paint that, become that” (p. 39). To use creativity to ‘build our lives’, there are three conditions that Rogers (1961) notes are necessary prerequisites to establishing a creative environment. Firstly, he thinks that it must be

psychologically safe. When individuals know that they are psychologically safe within their environment, they will feel free to play with possibilities and to toy with elements and concepts, which is Rogers' second prerequisite. This is compatible with Bandura's theory of self-efficacy. Bandura (1977, p.125) states that self-efficacy is concerned with "enhancing intensity and persistence of effort". To play with possibilities, one must have positive self-efficacy, as not all possibilities are successful, and one must be persistent in one's effort. Lastly, Rogers maintains that "openness to experience" (Davis, 1999, p. 55) stimulates creativity. This view supports Elliot Eisner's (1992, 1995, 1998) concept of experience. Eisner (1998) says we can "only appraise and interpret what we have been able to experience" (p. 17).

I suggest that Teresa Amabile's theories are complementary to Rogers' humanist view. In her social psychology of creativity (Amabile,1983), she explains that "particular social and environmental conditions might influence the creative behavior of individuals" (p. 5). Amabile (1996) maintains that there are three factors to consider when evaluating creative behavior. These include 1) the presence of others, 2) the imitation of observed behavior, and 3) the motivation of the individual. What is the individual's intrinsic or extrinsic approach to work? The first two factors were originally suggested to be influential by Allport (1924). Allport said that the presence and sight of others simultaneously involved in creativity increased the creativity of the individual.

After establishing a creative environment (Allport,1924; Amabile,1983, 1996; Rogers,1961), I will consider the implications of creativity on my

participants' development using Woodman and Schoenfeldt's (1989, 1990) interactionist theory of creativity. Woodman and Schoenfeldt (1990) note that "the consequences of the creative act in turn affect...the state and development of the person in a continuing feedback process as behavior unfolds over time" (p. 16).

As a grounding for the literature review, I have used an article I wrote (Smith, 2003a, OBIA Review), explaining my journey after my own injury, which led to this study being born. I have, as much as possible, broken down this article into sections and followed each section with the relevant part of the literature review.

*In September of 1997, I sustained a severe closed head injury when I fell from my horse while competing at the European Open Championships in Burghley, England, as a member of the Canadian Three Day Event Team. Three day eventing is one of the Olympic equestrian sports, consisting of dressage, cross country, and jumping. I competed as a Canadian Equestrian Team member from 1994 to 1997. As a team member, I took part in several international competitions, including the Atlanta Olympics.*

*After a head injury, one's return to emotional well-being takes much longer than recovery from the cognitive and physical trauma caused by such an injury. For a long time after the accident, I was unable to accept that life, as I had known it, was over. I spent twelve months in the hospital and in rehab. Before I was injured, when I was competing, I lived on the road, from one competition to the next and from one 'home base' to the next. So, when I left hospital, I tried to return to the old, comfortable and reassuringly familiar routine I was accustomed to. I moved to the town in North Carolina*

*where I had spent the last ten winters. I needed to be close to the world and people I knew best. I tried for a year, but I finally realized that I no longer fit in. I moved to Pennsylvania, where I tried again to make it work. Time went on. I struggled with changes, slowly becoming aware that the ABI had imposed many limitations on my old lifestyle.*

The isolation I felt in my old world typifies the social changes typically felt after an ABI. I will now discuss the effects of an ABI on one's social world.

### ***The Effect of an ABI on an Individual's Social World***

Society has long shied away from and discriminated against individuals who are socially and behaviorally different. This is mainly due to our fear of their unpredictability, whether the cause is mental illness, or homelessness, or brain injury...most people in society simply fail to understand the severity and consequences of the disability  
(Seaton, 1998, p. 77).

Seaton reaffirms my position that one of the hardest parts of head injury recovery is coming to terms with, and learning how to cope with, the reactions of others. Others react even if the individual who sustained an ABI has overcome any psychosocial deficits. These reactions understandably had a huge and negative impact on my self-esteem, and have on the self-esteem of other ABI survivors as well. They are experienced in addition to the challenge that ABI survivors already encounter when they are faced with having to overcome psychosocial deficits (Seaton, 1998).

***Psychosocial and Emotional Factors Following Head Injury***

I like Kay's (1992) definition of the primary psychosocial factors that occur after a head injury. Kay thinks that primary psychosocial factors are those: "that affect a person's ability to function after a seemingly mild injury" (cited in Sohlberg, 2000, p. 137). These changes include personality changes, a loss of the sense of self, diminished self-esteem and a change, usually a loss, in social and environmental support.

Kay (1992) notes that individuals with psychosocial problems "become embroiled in cycles of failure, frustration, loss of confidence, anxiety, avoidance, depression, and eventual isolation, social alienation and unemployment" (p. 375). Therefore, according to Prigatano (1988), patients can make less than optimal gains if emotional and intra-personal factors are not addressed during rehabilitation.

Emotional, intra-personal, social, and psychological effects are unpredictable and the response of these deficits to treatment is enormously varied. Emotional response, which depends on the intra-personal integrity and the coping style of the person with the ABI, is unpredictable during recovery (Rosenthal, Christensen, & Ross, 1998). An ABI is not only threatening to the individual's sense of physical well being, but also, as Lehr (1990) says, to "their sense of emotional and social integrity. The [self-esteem] that they have been developing over time and that is usually taken for granted is often jeopardized... by alterations in emotions and self-perception" (p. 160). Personality, emotional, temperament or psychological changes are important factors when one is:

...teaching, befriending, and in general living with children and adolescents after injury. For children and adolescents themselves, changes in psychosocial functioning cause significant emotional distress and confusion that can be difficult for them to understand and deal with.

(Lehr, 1990, p. 160)

During recovery, emotional factors, combined with motivational factors, perform an important role in the recovery of higher functioning after an ABI (Prigatano, 1988, p. 336). According to Prigatano, emotional factors “play a crucial role in adaptation and, unless they are addressed in the context of rehabilitation programs, the patient can make less than optimal gains” (p. 336).

The loss of self-esteem is a huge consequence of head injury. Seaton (1998) notes that:

After a brain injury, individuals are often much less socially integrated, and feel like outsiders in society because they cannot reintegrate into the many social roles they once played...A major challenge for caregivers after a brain injury is to find ways to reintegrate the survivor with a variety of positive social opportunities ...this helps reduce feelings of isolation; it also fosters self-esteem. ( p.82)

Psychosocial problems occurring after a head injury are generally attributed to a combination of factors, rather than to a single variable (Lehr, 1990). In fact, the “prediction of psychological and social effects after injury is much more complex and less consistent with injury characteristics than [the] prediction of cognitive effects” (Lehr, 1990, p. 155). Psychosocial consequences of an ABI are difficult to discern and then evaluate, which makes awareness among the patient, caregivers and friends of the possibility of their occurrence, very important. Personality changes in ABI patients are generally psychosocial in nature, and affect the ABI patient’s ability to develop and maintain meaningful relationships (Seaton, 1998).

There are several factors implying a higher risk of psychosocial maladaptation after an ABI. The first factor is the severity of the injury. However, the severity of the injury is only as important as the patient's awareness of his or her situation. In severe cases, an individual's functioning is compromised and they are unaware of what has happened to them (Lehr, 1990). Secondly, the pre-injury personality and behavior can have an effect on the occurrence of psychosocial disorders. Thirdly: "psychosocial disorders were most frequent in children after head injuries when a severe head injury was combined with increased psychosocial adversity" (Lehr, 1990, p. 156). In other words, those children from compromised family, home, school, or socio-economic situations were more likely to have psychosocial problems after injury.

I now write about the changes I slowly became aware of during the recovery process:

*I gradually realized, and more reluctantly accepted, the fact that restrictions had been placed on me that would not allow me to live my former life. I am incredibly lucky; I have almost no cognitive or physical deficits from the injury. The legacies I am left with are minor. My memory is not great, but it is more than functional. I used to have a never-ending supply of energy, now I need to be more selective about what I do. My balance is not as good as it used to be. These shortcomings, which cause inconsequential inconveniences to an average lifestyle, would make returning to life as an elite athlete very difficult. My sport is dangerous. The risk of incurring another head injury was too great for me to contemplate resuming competition at the international level. This was a tough reality for me to accept.*

The section above illustrates that self-awareness is another facet of head injury rehabilitation that usually needs to be addressed. An individual's self-awareness depends on feelings and emotions, which, in turn, enhance motivation. Self-awareness is necessary for optimal adaptation after injury (Prigatano, 1988).

Next, I explore how to I attempted to find a goal oriented lifestyle that will satisfy me.

*Because I am a motivated overachiever, I need to strive for goals to fuel my existence, and competing with my horses was unfortunately no longer going to fill that need. Before I was injured, my narrow and small world was incredibly focused and carefully defined. But life, as I had experienced it, was only a small portion of the whole picture available to me. Finally, I recognized this, and I went back to school. I enrolled in the M.Ed. (Counseling) program at the University of Ottawa.*

***The role of a patient's intentionality and motivation in rehabilitation.***

Prigatano(1988) says that intentionality and “ motivation [do] seem to influence the performance of actions and the acquisition of new information...one of the primary goals of...clinicians is to balance the [ABI] patient's actual capacity with salient, motivating stimuli” (p. 344). Personal awareness and self-consciousness after an ABI have:

...a lot to do with the phenomenon of intentionality. Intentionality and intention are never purely cognitive phenomena. That is, they reflect something about the emotional and motivational characteristics of the organism as well as the perceptual and attentional state. Consciousness and particularly self-consciousness emerge or diminish depending on the intactness of brain

structures that allow for attention and perception and the capacity of the organism to interpret feeling states.

(Prigatano, 1988, p. 340)

The patient's history before the injury plays an important role in his or her intentionality and self-awareness. Positive intentionality and consciousness will lead to increased motivation. Prigatano found that "when old feelings are experienced after brain injury, the individual is able to self-perceive in more realistic terms...the patient will practice the rehabilitative tasks in a more motivated manner" (p. 343).

Success and motivation play a chicken and egg game – which came first?

Seaton (1998) thinks that:

It is commonly believed that people are successful because they are motivated. Actually, people are motivated because they are successful. Only individuals who experience more successes than failures can feel good about themselves. Unfortunately, on a daily basis, most individuals with a brain injury experience many more failures than successes because of their social and cognitive deficits (p. 78).

Because ABI patients are often unsuccessful due to deficits caused by the injury, Seaton feels that their motivation is negatively affected. This highlights the importance of this thesis, which is an exploration of the effects of creativity on self-esteem. Increased self-esteem may enhance motivation because it leads to feelings of success and accomplishment.

### ***How will an individual react to a brain injury?***

An understanding of emotional factors can play a key role....but basic to this awareness is a knowledge of why the person with brain injury is reacting in such a way...an individual with a brain injury may show specific reactions because of certain stages in the recovery and rehabilitation process.

(Orto & Power, 2000, p. 38)

There are specific determinants that can forecast the reaction to brain injury. The severity and type of injury is the first factor. This factor tends to establish the personality changes that occur. These changes are the most significant concerns of families of ABI patients.

Secondly, if an individual is an independent person pre-injury, this may cause heightened feelings of depression. But, depression can be minimized "if a person can recall during post-injury those satisfactions...these memories can provide a sense of satisfaction" (Orto & Power, 2000, p.39).

A third determinant is that an ABI causes roles within a family to be quickly and often permanently changed (MacFarlene, 1999). Unpredictable behavior can cause economic and relationship changes to occur, as the emotional response and the coping style of the person with the injury are often unpredictable during recovery (Rosenthal et al., 1998). A challenge to the injured individual is the stereotypical ideas about brain injury and "unrealistic or negative expectations from family members concerning performance in the home" (Orto & Power, 2000, p.41).

The life stage that an ABI occurs at is also significant:

The different unpredictable cognitive, physical, and emotional aspects of brain injury during the indefinite post-trauma period can be quite troubling...for individuals who are accustomed to having a measure of control over many life events, such as health, career, and family life, living with the unknown and episodic occurrence of symptoms may bring continued anxiety, irritability, and impatience.

(Orto & Power, 2000, p. 41).

Therefore, as Christenson et al. (1994) point out, if patients are aware of the disruption that the ABI has caused in their lives, it may precipitate depression and cause behavioral outbursts. For individuals used to having the maximum control possible over their life events, the dependency caused by an ABI can be quite devastating. Therefore, these changes can together cause uncertainty, irritability, and anxiety in the patient's life.

Lastly, the physical location of the ABI has an effect on the outcome. However, because the brain is incredibly complex, it is almost impossible to predict the outcome. Armstrong (1991) notes that "emotional reaction is a collaboration between the left and right, superior and inferior areas of the frontal lobe, each of which stimulates and inhibits positive and negative emotions" (p.17).

I now describe the process of arriving at the topic I wanted to research for my thesis.

*Because I have a B.Sc., not a B. Ed., I had to do five extra M.Ed. courses before I started the program. While I was completing these courses, I realized two important things. Firstly, I discovered that I loved to research and write. I was surprised to find that I enjoy spending long hours reading, writing and thinking. Producing a final paper for each course was a creative task that I enjoyed. What would I write about? How would I make the paper unique? As I started each course, I found that I was looking forward to reading the requirements for the final paper. Conceiving an idea for a term paper was an outlet for my long latent creativity.*

*Secondly, I learned that individuals all understand and learn differently, and therefore express themselves most effectively in unique ways. So, in addition to producing a term paper, as my creativity resurfaced I added a creative dimension to an assignment in each course. For one course I made a video. I made papier-mache painted sculptures for others, including a globe shaped pinada. My creative and artistic side, long hidden by an obsession with, a commitment to, and a narrow focus on, sport, had re-emerged. I found that producing these creations enhanced my self-esteem and self-confidence. Despite my injury, I was still able to express myself in original ways. I felt good; my self-esteem was given a lift. My self-esteem was boosted when I had the idea of what to do for the current assignment, and then again when I completed the project.*

This experience caused me to ponder the question: How does an ABI typically affect one's feelings about one's importance in the world?

***The effect of cognitive deficits on feelings of self-esteem.***

An important component of cognitive functioning is executive function. Executive function is defined as: "those mental functions involved in formulating goals, planning how to achieve them, carrying out plans, and strategically revising those plans in response to feedback" (Lezak & Luria, cited in Ylvisaker & Debonis, 2000, p. 30). Critical components of executive function include self-awareness of strengths and weaknesses, and the ability to self-evaluate, set goals, and profit from feedback (Ylvisaker & Debonis, 2000,).

Typically, an ABI negatively alters individuals' executive function, particularly their ability to plan, organize information logically, and retain

information. Consequently, these individuals have deficiencies in insight, initiation, judgment, and problem solving. They may also have limitations “in the ability to make realistic plans, consider options, and predict the likely consequences of actions” (Seaton, 1998, p. 78). These deficits also indicate problems with self-efficacy. Because limitations with self-efficacy usually lead to repeated failures, the ABI individual can also consequently experience a loss of confidence and self-esteem.

### ***The Effects of an ABI on Self-Esteem***

After an ABI, the unseen residual effects of low self-esteem often last long after physical, emotional, and cognitive therapies have been administered, and the outside world considers the patient to be recovered. Low self-esteem can cause emotional disturbances that are often not apparent to others, except possibly to those close to the individual. Because of this, brain injury is sometimes called the ‘silent epidemic’. Emotional damage resulting from an ABI, which can include diminished self-esteem, is frequently difficult to understand and then to resolve, in part because the severity and consequences of an ABI are not fully understood by most people in society (Seaton, 1998).

### ***The Use of Creative Activities to Improve Self-Esteem***

Jennings and Minde (1993) think that creative activities help individuals to become aware of their feelings so they will eventually be able to verbalize them:

When working with art, you are both part of your artwork and outside of it. It is a process of entering and being part of it, as well as leaving it and being separate. There are many experiences in life, which are not possible

to verbalise, but often through artwork they start to take form, which later may be transformed to verbal language. (p. 114)

Therefore, as a result of engagement with art, ABI patients can learn to use past catastrophes in their lives, as well as positive experiences, to help rebuild their self-esteem. Individuals' frames of reference and connections to the world, which are intrinsic to them, can be explored by the individuals through glimpses provided by their involvement in creative activities (Tamminen, 1998). By encouraging involvement in creative activities, one can take advantage of the strength of the creative process to unlock feelings and thoughts. Several theorists (Henderson and Gladding, 1998; Johnson, 1984, 1985, 1999; McNiff, 1997) maintain that creative activities engage the senses, arouse emotions and offer alternate forms of communication in the form of art. In support of using creativity as an alternate form of communicating knowledge, Gamwell (2002) thinks that:

Through the arts, students are encouraged to find ways of interpreting and exploring knowledge in new and creative ways...students are able to become personally engaged in their work and to explore connections between concepts in creative and unique ways in a context which is emotionally and aesthetically rich. (p. 3)

During creative activities, the sense of self is discovered as the individuals' spirits are set free by the will and freedom of their participation (Aldridge, 1991). Simon (1997) notes that: "The essence of creativity lies in the joy of awareness creative activity can bring, for none can paint another's picture, shape another's sculpture, or write another's poem" (p.63). This frees the creator to feel empowered by a sense of individuality, which will hopefully help lead to improved self-esteem.

Simon (1997) also says that when “physically ill and disabled patients” engage in creative activities, it “has a beneficent effect upon the mind and body; it is visible evidence of the uniqueness of individual experience” (p. 62). When life’s experiences begin to take form, in this case using the vehicle of creative activities, they can start to be expressed. When individuals become aware of their life experiences that are brought to the surface while engaging in creative activities, they are ready to confront them, deal with them, and learn from them. According to Sacks (1986), involving people in creativity allows us to consider individuals’ possibilities and abilities, rather than focusing on their deficits. Engaging in creative activities can help people experience a greater control over their lives and thus improve their sense of self (Gladding, 1995).

I now describe how my focus changed from the counseling program to an interest in research.

*As I finished more courses, I realized that, rather than becoming a counselor, I could use my first hand experience with ABI to research how to help others who had suffered a TBI. Being creative was aiding my emotional healing, how could engaging in creativity help others as they struggled with the devastating aftermaths of their injuries? I switched to the M.A. program and decided to explore this question. My thesis will be entitled: A Narrative Inquiry Exploring How Creative Activities can Enhance the Self-Esteem of Individuals who Have Sustained a Traumatic Brain Injury.*

*I will be working with six participants as they complete creative projects. My site is associated with a head injury rehabilitation facility. At this center, clients have the opportunity to undertake projects to build their self-esteem. What these projects entail*

*depends entirely on what my participants want to do. They can choose from a wide range of options: woodworking, working with stained glass, painting, or they can choose another activity. How does it help their self-esteem to undertake a creative project from the beginning to completion? As I try to discover what the opportunity to be creative means to them, I will be working alongside them in an attempt to deepen my understanding of the desirable results of my own creativity on my emotional state.*

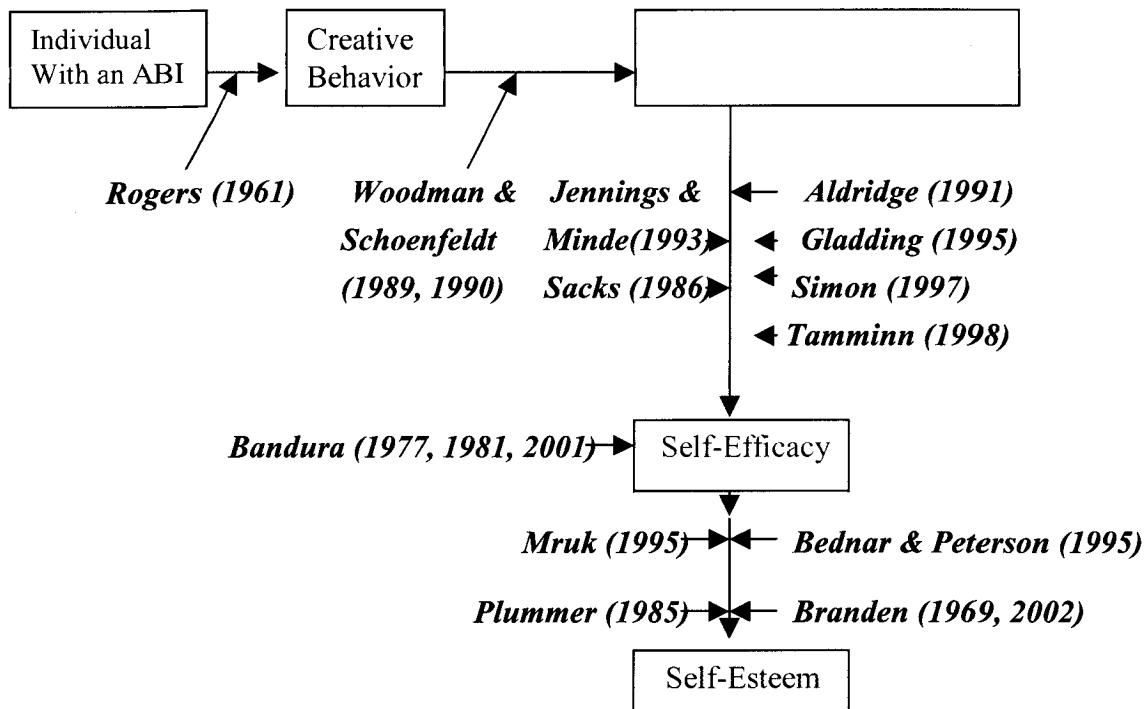
*This project gives my motivated, competitive self a goal to work towards. My energy has been successfully redirected from my competitive riding to academia. In addition to fulfilling my goal driven needs, I feel that, with my research, I can help others who have had a similar, life-altering experience. I will always be aware that I am incredibly fortunate that I have recovered sufficiently so I am able to do this. I would like to help others so they, too, are able to maximize their recovery potential.*

*I will conclude with this analogy: Sometimes the roads of our life have sharp bends. We are not always able to negotiate these hairpin turns successfully the first time. If we end up in the ditch, we may need tractors to pull us out. We may have to choose a less dangerous route. With persistence and determination though, we can make it to a destination. It may not be where we thought we were headed, but if we choose our new destination based on our needs and abilities, progressing towards it can be very, very satisfying.*

### **Synthesis of the Literature Review**

The above studies provide valuable insight into the exciting possibility of using creativity to enhance self-esteem. After serious injury, the diminished state

of this characteristic can have a devastating impact. Figure 1 shows the link between the literature and the study.



*Figure 1* The Use of Creativity to Rekindle the Self-esteem of ABI Patients

This figure demonstrates how I think creativity can be used to enhance self-esteem. The theory of Rogers (1961) is used to build an environment to encourage creativity. When ABI patients are immersed in this creative environment, which can positively influence their selves and situations in life (Woodman and Schoenfeldt, 1989, 1990), they can enhance their self-efficacy and, therefore their self-esteem. Other theorists also suggest that outcomes of creativity promote self-esteem (Aldridge, 1991; Gladding, 1995; Jennings and Minde, 1993; Sacks, 1986; Simon, 1997; Tamminn, 1998).

The literature review implies that this study may fill a gap in the literature. I feel that I have a unique 'insider' position in this study, because none of the

researchers in my literature review documented that they have personally had an ABI that they have struggled through. The epistemological positioning that the ABI I sustained places me in fortifies the choice of auto-ethnography as a very appropriate genre for this study.

Even a head injury which ultimately results in a maximal and miraculous recovery can leave the survivor with many losses. Head injury causes an enormous upheaval in one's life in terms of career and relationship expectations. I can relate to ABI survivor David Blanche's (1998) eloquently stated description of living with an ABI:

I have learned to push the albatross from in front of my legs to a place near the center of my back. But I still feel the weight of that bird. Sometimes, the albatross shifts, falls in front of my legs and trips me. A problem with this weight is that no one can see it...[But] My albatross is still there, an inescapable companion. ( p. 74)

### ***The Conceptual Framework***

My vision of this study, artistically represented to symbolize the creative nature of the study, conveys both my ideas and the artistic way I hope to represent them. I see the reader experiencing the study by looking through an imaginary digital camera submerged in the 'sea of creative potential' (Appendix A). The position of the digital camera within the sea symbolically shows that I am attempting to minimize epistemological distancing in the study. The fish in the sea symbolize the players in this study: the participants, and myself as the researcher and as a participant. My role in this study, discussed later, is very fluid; it will be continually changing.

The relationships among the players are interactive, therefore the fish representing the players are swimming, and their positions in the sea are constantly changing. As they immerse themselves in the study, the participants, the researcher, the researcher-participant and the readers of the study will compose their understandings and interpretations of the study, symbolized as digital images viewed through the camera. These images will emanate from the camera, representing the emergent nature of the study. The ones that the participants, researcher and readers are not happy with will be discarded on the spot. The remaining images will be dropped into a container so their processing, interpretation, examination and reframing can occur.

### ***The Theoretical Groundwork for the Artistic Representation***

My description of the conceptual framework shows that, as a qualitative researcher, I agree with Stake (1995) who says that qualitative research has a need for “understanding the complex interrelationships among all that exists” (p. 37). The participants, the researcher-participant, and the study’s readers’ impressions are conveyed as digital images. These images are an expression of narrative qualitative research because this study combines views from the participants’ and researcher’s lives jointly in a narrative (Creswell, 2003) as they make meaning of their experiences. Stake (1995) suggests that qualitative research searches for unexpected relationships, as well as anticipated patterns, to be uncovered during the study. This is symbolized by the swimming fish

because the positions of the fish in the sea of creativity constantly change. The digital camera is located in the sea of creative potential so the digital images can be viewed by the researcher and the participants in the sea. Before they are viewed by the readers so they can make their own interpretations of the study, the digital images will be kept and processed further, or discarded.

The emergent, artistic and participant nature of this study will, I hope, be apparent to the readers. They will discover, as Eisner (2002) says, that “the work, so to speak, also speaks, and at times it is the artist [(the researcher participant)] who listens. The work in progress [will begin to look]...more like a conversation than a lecture” (p. 78). Eisner’s point is reinforced by Maxine Greene’s comment, who notes that a participatory study will: “involve readers, not only with visions of the possible, but also with the consciousness of contradiction and incompleteness that moves people to pose significant questions” (Brunner, 1994, p. xi). Therefore, further meanings can be constructed by the readers of the study and are represented by the digital images outside the sea of creative activity.

### ***Rehearsing the lines – Data collection methodology***

...life is not lived realistically, in a linear manner. It is lived through the subject’s eye, and that eye, like a camera’s, is always reflexive, nonlinear, subjective, filled with flashbacks, after-images, dream sequences, faces merging into one another,....

(Denzin, 1992, p. 27)

Denzin’s metaphorical portrayal of data collection describes my experience of data collection well. My data collection was emergent in an attempt to capture the nuances and complexities of my participants’ experiences. The

necessity for this became apparent when conversing with Valerie and Jim, two of my participants. I have described the changes I had to make with each participant in 'The Research Experience' (see Act 2 below). In all cases, however, my data was collected using participant observation (Marshall and Rossman, 1999, Tedlock, 1991, 2000), as well as informal interviews as suggested by Creswell (1998), conversations, group informal interviews, e-mails and talks with third party therapists. As my participants had special needs, I was required to use many methods to collect the data. Because of these circumstances, I dealt with epistemological issues that caused me to continually reflect on which 'self' I am. Am I a MA student? Am I a researcher? Am I a fellow ABI survivor? Am I a friend? Am I a teacher? (see Act 1, Scene 1 below).

### ***Participant Observation***

When they talk about the data collection methodology they will be using, Wolcott (1999) counsels researchers "to describe, with far more detail than is prompted by the phrase itself, precisely what they intend to do, giving specific examples of the kind of data they believe they will need and the procedures by which they intend to obtain them" (p. 45). As a neophyte researcher, I will take Wolcott's advice.

Wolcott (1999) uses the term 'experiencing' to describe data collected through participant observation. Participant observation involves the researcher "taking an active role in *asking* about what is going on" (p. 47). Because I have used participant observation as my primary data collection methodology, it

became “the filter through which everything else is screened as we make sense of all that we have observed” (p. 51). I will describe the different data collection techniques that were used, along with participant observation, in more detail in the individual stories for each participant.

I chose to use participant observation to collect data for this auto ethnography for several reasons. It allowed face-to-face interaction with the participants while I was exploring their perspectives. Therefore, I could include nonverbal behavior as data. This was important, particularly in the case of my participant Valerie, because of her considerable cognitive deficits. I will introduce her in detail in Act 2, Scene 3. It was also important, again, particularly for Valerie, that I was able to collect the data in a setting in which the participant was at ease. Jim and Diana felt very comfortable at the study site, *Creative Enterprises* (to be described later), but I talked to Valerie at a location with which she was familiar, *The Eagle’s Wing*. Because Sally does not have a car, I met with her at her apartment. In all cases, I scheduled follow-up conversations at the earliest convenience of my participants. As Marshall and Rossman (1999) mention, this is another advantage of participant observation. It allows immediate follow up conversations if they are warranted.

### ***Data Collection with Jim, Sally, and Diana***

I started by conducting interviews which were an hour to an hour and a half in length with Jim, Sally, and Diana individually. These sessions served a number of purposes. I first made sure that I had given them information letters

and that they had signed a consent form (Appendices B and C). Then, we discussed the time frame required, and chose pseudonyms to ensure their anonymity. I then collected background information, after which we talked about what they wanted to do for a creative activity (questions used to guide these conversations can be found in Appendix D). At this time, I also carefully asked questions about their self-esteem. I agree with Wolcott (1994) that the first impressions experienced during initial conversations with each participant are very important. In most cases, they formed a base and therefore a starting point for subsequent meetings.

After our first meetings, I spent approximately six weeks observing and conversing with my participants as they worked on their creative projects. At the end of this time period, I felt that it would be beneficial for the participants to meet together. So, one day, when their creative projects were almost complete, we sat in a comfortable room at *The Eagle' Wing* and chatted at length. I used the questions outlined in my proposal as a guide (Appendix E). At the close of our meeting I asked each of them to e-mail me their thoughts and impressions.

The e-mails I received after this session were revealing of the session's usefulness. Diana wrote that she "felt totally understood, accepted, supported, and encouraged". This remark was echoed by Jim, who said he learned that he didn't "have the market cornered when it comes to problems... It reinforces the fact that you are not alone...there are others going through the same process". Interestingly, Sally's feedback centered more on concrete processes. As I have realized over the course of the study, Sally tries to learn from everything she

does. She said that the meeting “provided the opportunity to validate each others’ experiences and learn from those [experiences] that were different from our own”. It is fascinating to realize in hindsight, that, although Sally talks at length about the lessons she has learned that she takes away from her sessions with me and her therapists, she seems to have trouble actually applying these lessons. Therefore, I was excited to hear from her a couple of months after I was finished data collection. She had, on her own, completed several more sets of note cards for a charity sale.

I felt this session added enormously to the quality of the data I collected. Had I chosen to do a group discussion early on, Sally, Diana, and Jim might have unconsciously let the others’ feelings and opinions influence their own. But, by holding it at the end, the group session was an affirming and positive experience for all participants. Because the interview occurred at this point in the data collection, it did not intrude on, or interfere with, each of the participants’ unique impressions and ideas.

### ***Data Collection with Valerie***

Data collection in Valerie’s case presented considerable challenges. Whereas Sally, Diana, and Jim have hidden deficits, these deficits do not prevent them from communicating fully, being aware of how they feel, and expressing what they feel. Valerie has significant impairments from her accident (see Act 2 Scene 3). Her distrust of the tape-recorder and of me taking notes meant that I had to rely on memory and copious note-taking after our sessions. Because of

her deficits, she has difficulty describing and expressing verbally how she feels after her creative experiences. My perception is that she doesn't understand how she feels, beyond her immediate reactions. Many of my interpretations are suppositions of how she feels after doing creative activities, and what she is thinking. Her occupational therapist, Terry, was extremely generous with her time, helping me understand how best to communicate with Valerie. Terry also gave me her own impressions after each session.

### ***Critiquing the Play - Data Analysis Methodology***

It is possible that we sit on a sort of giant pendulum, gently and invisibly being swung by the intellectual tides from one side to the other....the pendulum seems to point us toward a mirror in which we appear to be unclothed and turning over and over our own understandings of fieldwork for inspection. If so, we will no doubt swing back again, and in the mirror will appear others whose thought and action puzzle, instruct, and fascinate us...

(Van Maanen, 1988, p. 138)

Van Maanen concludes his clever metaphor for fieldwork analysis by stating that "there is no sovereign method for establishing fieldwork truths" (p. 138). Keeping Van Maanen's remark in mind, I based the analysis of my data on methodology outlined by Wolcott (1994, 1999, 2001a, 2001b), methodology also advocated by Creswell (1998, 2002, 2003). Wolcott (1994) discusses three ways to 'do something' with qualitative data: *description*, *analysis*, and *interpretation*, terms he defines as follows:

*Description* addresses the question, "What is going on here?" Data consist of observations made by the researcher and/or reported to the researcher by others.

*Analysis* addresses the identification of essential features and the systematic description of interrelationships among them – in short, how things work....

*Interpretation* addresses processual questions of meanings and contexts: “How does it all mean?” “What is to be made of it all?” (p. 12)

During the data collection phase of this study, I followed the suggestion made by Creswell (1998, 2002, 2003), Marshall & Rossman (1999), Merriam (2001), Rossman & Rallis (1998), and Wolcott (1994, 2001a), that data analysis should be done simultaneously with the collection of the data. Merriam echoes Wolcott when she comments that, “The final product is shaped by the data that are collected and the analysis that accompanies the entire process” (p. 162).

Rossman & Rallis (1998) suggest that the observations made during data collection may provide important leads that can be followed in other conversations with the participants. This initial analysis, coinciding with the data collection, provided fuel for the *description* (Wolcott, 1994) of the study.

To maximize the validity of my study, I triangulated the data, by drawing the data from several sources during data collection. Creswell (2002), and Miles and Huberman (1994) define triangulation of the data as meaning that independent measures show results that do not contradict each other. Creswell (1998) points out that using this strategy involves “corroborating evidence from different sources to shed light on a theme or perspective” (p. 202). Therefore, in order to bear out my findings, I obtained data by several methods. I had conversations with my participants, a group meeting with the participants, and conversations with their therapists. I also used observation, participation, field notes, reflections from the participants via e-mail, and member checking of transcribed data by the participants. So, as Miles and Huberman suggest, “the

verification process [was] largely built into data collection” (p. 267) as I proceeded.

The first step in the *analysis* phase (Wolcott, 1994) was to transcribe the data within a week of its collection. Because of time constraints, I hired someone to do the transcribing for me. However, in order to be aware of all the nuances in the data, I did replay the recordings several times each. To protect the participants, I asked the transcriber to sign a confidentiality letter (Appendix F). As Janesick (2000) recommends, once the data was transcribed it was given back to the participants to member check (Appendix G). After my participants had checked the transcripts, my job was to code the data. This task is defined by Merriam (2001) as the “formal representation of analytic thinking” (p. 155). As Wolcott (1994) points out, the goal of this stage was to “identify key factors and the relationships among them” (p. 10). Because I analysed my data by hand, I found, as Gamwell (2002) did, that I was able to identify emergent categories by reading and re-reading the transcripts, zeroing in on data that addressed the research questions. This allowed me to identify themes and discover patterns, a process Wolcott (1999) calls “the identification of regularities” (p. 256). I substantiated the themes with quotes (Merriam).

During *interpretation* (Wolcott, 1994), the most subjective phase of data analysis, I drew conclusions about what I had learned during the study (Creswell, 2002). Wolcott (2001a) maintains that interpretation invites examination of the data using sense-making, in the form of intuition, past experience, and emotion. To help me with the data interpretation, I decided to create a visual

representation. It is an all encompassing illustration (Appendix H) of the participants. By using a visual representation, Wolcott (1994, 1999) and Creswell (2002) point out that researchers can illustrate what emerged from their involvement with the participants, the uniqueness as well as the commonality of the themes, and the patterns which unfolded during analysis. As Wolcott (1994) found, creating a visual representation helped me to “to reach out for understanding or explanation beyond the limits of what can be explained with the degree of certainty usually associated with analysis” (p. 1).

### **The Play Begins**

*When I first proposed this thesis, and then prepared for data collection, I was constantly wondering what creative project I could do for the study. I reflected, I thought, and I pondered this question. Something wasn't right. I do creative things regularly. It suddenly occurred to me...this thesis would do wonders for my self-esteem! The fact that I was completing my MA is huge, and this thesis is a very creative part of it. My self-esteem will get a huge boost when I finish this from the planning required to complete the project. The positive impact on my self-esteem when I do complete it will be incredibly valuable to me.*

*What else is this thesis about for me? Firstly, it is a requirement for completion of my MA degree. When I blithely chose to explore the influence of creativity on individuals who had sustained an Acquired Brain Injury, I had no idea of the impact the study and research would have on me. But, I found that, as Behar (1996) says, for me writing this thesis has been part of my healing process: “Mourning...is not replacing the dead but*

*making a place for something else to be in relation to the past.... We bring the past to the present, we allow ourselves to experience what we have lost, and also what we are – that we are – despite this loss” (p. 175).*

### ***Act 1: The Team Behind the Scenes***

#### ***Act 1 Scene 1: A Participant Observer as the Director***

Because of my familiarity with ABI, I felt I already had the “personal involvement to achieve some level of understanding” (Wolcott, 2001a, p. 66) to share with others. This involvement validated my choice of auto-ethnography. I chose auto-ethnography as my methodology because, epistemologically, I am inextricably personally and emotionally involved with the topic of my study, although not nearly to the extent that Wolcott (2002) describes. Axiologically, because this is an auto-ethnography, I have reported my “values and biases as well as the value-laden nature of information gathered from the field” (Creswell, 1998, p. 76). Ontologically, in this postmodern study I am recounting the multiple realities presented to me by my participants to represent their diverse perspectives.

#### ***A director with many selves collecting the data.***

When doing ethnographic research, the researcher often feels an emotional connection with the subject. Therefore, as Banister (1999) effectively states, gathering data is “unavoidably an act of engagement that will inevitably implant an unpredictable dynamic into the topic of study” (p. 21). Because of my

personal closeness to the subject matter, I was more aware than I expect most researchers are of the effect of my questions on my participants when I was interviewing them. With each question I had to consider, as suggested by Karp (1996), should I ask carefully, should I prod, or should I change course if the participant appeared to become uncomfortable.

Behar (1996) notes that an auto-ethnography requires a “keen understanding of what aspects of the self are the most important filters through which one perceives the world and, more particularly, the topic being studied” (p. 13). After reading Banister (1999), I realized that the access I gained to my participants was a great influence on the data I collected. Therefore, it was crucial for me to mold my researcher self in a manner that would be useful for the study, so I could reap the greatest benefit of the time I spent with my participants (Smith, 2003b). Before spending time with each participant, as Reinharz (1997) points out, I had to think carefully about what my expectations were for the interaction we were about to have. After reading Stake (1995), I was constantly asking myself: “Do [I] have it right? [Am I] generating a comprehensive and accurate description?...[Am I] developing the interpretations [I] want?” (p.107). Fontana & Frey (2003) and Schwandt (2000) note that, to answer these questions, I had to repeatedly reassess how I should be towards the participants in my study.

As a result, in my attempt to become close to the participants during data collection, I became, according to Eisner (1981), the research instrument, clothed in a variety of selves. I was forever creating new ‘selves’ so I could reap the

maximum benefit from the time I spent collecting the data. By doing so, I strived to remain as close as possible to my participants. Pinsent Johnston, Smith, & Thompson (2003) talk of how to do research looking through the eyes of the many selves one must become to maximize the effectiveness of the research experience. I agree with Lincoln (1997), who wrote that I would have to settle on many different selves, all with frailties. That way, my story would have the most impact on readers.

Jamison (1995) hit the nail on the head when she noted that, as much as I identified with my participants, I was always, in a sense, “a zebra among horses” (p. 186). At all times I remained someone who was viewed a little differently. To minimize this, I was always mindful of how I wanted to appear to my participants: a student, a fellow ABI survivor, a therapist, a teacher, or a fellow learner. As Ronai (1992) wrote:

I supposedly have a self that is a whole, neatly divided up into parts or facets that act to fulfill the tasks of particular roles. But, in reality,...the self exists as a process in a constant state of transformation and flux... The answer changes as quickly as I can reflect on it because the situation is constantly in motion. (p. 107)

Ronai summarizes the dilemma she describes when she says: “self is fleeting” (p. 106). This describes my experience of instantaneous changes to mold my self to the research situation.

Some of the selves in which I found myself while researching were those that I normally try not to reveal to others. One of these selves is the ABI survivor self who is still dealing with the emotional baggage introduced by an enormous life change. But, I realized that by allowing myself to be an ABI survivor self, I

would be able to better relate to my participants. Lincoln (1997) suggests that including this other self would greatly increase the number of selves I could become in the infinite number of situations in which I could find myself in the field. By becoming a number of different 'selves', I show that the participants in this study are, as Ronai (1992) describes, "all processual, emergent, multivoiced entities living different situations yet sharing similar lived emotional experiences" (p. 123).

In this auto-ethnography, I had to expose the self I am, because I am not just a spectator but, as Behar (1996) states, my story is essential to the argument I am presenting. A revealing and comforting discovery for me was that the path of my life after my injury, which I had considered to be my own unique experience, was, as Shields (2003) points out, in fact very similar to the ones followed by my participants. DeVault (1997) notes that a partially autobiographical account "brings a more immediate kind of disclosure than the typical empirical study together with more intimate reasons for concern about others" (p. 223).

***Writing the script – an emotional experience.***

I felt like a filmmaker with reels of... story before me that I had to assemble using filmic principles of montage and movement... I undid necklaces of words and restrung them,... I dressed up hours of rambling talk in elegant sentences and paragraphs of prose,...I snipped at the flow of talk, stopping it sometimes for dramatic emphasis long before it had really stopped....

(Behar, 2003, p. 16)

It became my goal after data collection, as described so graphically by Behar, to work with the data to write a compelling story. After the interviews,

conversations, and chats are over, I hope I have conveyed my interpretation of the study in a way that is readable and understandable for everyone. I am attempting to offer, as Gergen and Gergen (2000) find desirable, “a greater expressive range and an opportunity to reach audiences outside the academy” (p. 1029).

As I wrote this thesis, I found myself experiencing what Ellis (1997) had experienced, that I was always rewriting, until the story moved away from getting all the details ‘right’ to an evocative tale of the lives of five people, my four participants and myself. I tried to become “involved with narrative truth...the criterion we use to decide when a certain experience has been captured to our satisfaction” (p. 129). I was continually refocusing and narrowing in on the research questions I had chosen to examine. I was constantly remembering the purpose of this quest, to answer the research questions. I agree with Slobin (1995) that writing of my own experiences at the same time as I explored these questions with the participants was the best way for me to let myself feel, see, and understand.

This research journey was an emotional experience for me and writing the autobiographical elements of this story was tough. It was difficult for me to extricate a researcher self from all my other selves because of my close emotional involvement with my participants and with the subject I was studying. As it did for Slobin (1995) in a certain sense, “writing became my freedom” (p. 498) because it allowed me time to ponder and reflect on what I had found in my research as well as on my own journey of recovery. I experienced what Ellis and

Bochner (2000) note sometimes happens with research. Although therapy was not the main objective of this research, it was a useful outcome from the writing of this study.

When I read Marianne Brandis' (2003) comment on the path and direction of her life, I found it very applicable to my continuing journey of healing. Brandis eloquently states, "the road I took need not be defined in terms of negatives, of things lacking – at least no more so than any other course of life. It has an identity and pattern of its own, and the process of shaping it continues" (p. 161). Writing this thesis has contributed to the shaping of my life and has been part of my healing. During the writing process, I appreciated Shields' (2003) comment, and I also often felt "the heat rising from the words, and the human relief of having shared a story" (p. 366).

### ***Act 1 Scene 2: The Beginnings: Introducing the Support Staff and the Site***

When I originally had the idea for this thesis last year, I spoke with Grace and Philippe, the directors of *The Eagle's Wing*, a head injury rehabilitation centre. We sat in a comfortable room at *The Eagle's Wing*, and I excitedly talked about my idea for a thesis. When I had finished my story, they looked at each other and laughed. It turned out that they were just in the process of opening a centre, to be called *Creative Enterprises* and used by their clients for creative activities.

So, in all our minds, the study was obviously meant to be! A year after that initial meeting I began the data collection for my study. As I now revisit my notes

from my conversations with the support staff, it is fascinating to see that each member of the staff places emphasis on a different rehabilitation component of *Creative Enterprises*. Grace sees the impact of participation in activities at *Creative Enterprises* rehabilitating the self-esteem of clients. Shawn, the supervisor at *Creative Enterprises*, feels that the social aspect of the site is its most valuable asset. Rob, the occupational therapist, places emphasis on the resources and tools of the facility. Because his clients have access to these resources, they can work on projects whose complexity is geared to their current abilities. This makes Rob's job helping them relearn planning skills easier.

### ***Act 1 Scene 3: Grace – A Therapist and Director of The Eagle's Wing***

I first talked to Grace, who continues to play a leading role in my own rehabilitation, and I asked her to tell the story of how she became involved in *The Eagle's Wing*. She told me how her husband had been critically injured many years ago, when her sons were preschoolers. Philippe was the psychologist assigned to ask her to sign to give permission to donate her husband's organs in the event of his death. She refused. Today, her husband still lives at home with her. Grace returned to school, and, after graduating, she and Philippe opened *The Eagle's Wing* together.

Grace explained to me that they found that many of the clients of *The Eagle's Wing* who were coming in from out of town had too much down time:

....they were just sitting around, watching TV a little too much, sitting on their hands outside of therapy time. So we needed an activity, a functional activity site to get them involved in. That combined with the rehab benefits which would be high-end, I'm going to say eye-hand coordination,

sequencing, and different things. What we realized when we really started looking into this is that just task completion in itself was a huge impact on their self-esteem and they felt much better.

So, in 2002, *Creative Enterprises* became part of *The Eagle's Wing*. The facility offers recreational and therapeutic creative activities to their clientele. *Creative Enterprises* has turned out to offer many unexpected benefits to *The Eagle's Wing's* clients. The benefits of *Creative Enterprises* will be further discussed below, but I will now introduce them with a brief discussion of Grace's impressions.

Grace sees uplifting self esteem as the biggest asset of *Creative Enterprises*. Grace emphasized that the activities at *Creative Enterprises* help the clients develop "their self-esteem, help them to feel good about themselves and what they can accomplish". As well as the emotional benefit of enhancing self esteem, she finds that the activities at *Creative Enterprises* also aid individuals with cognitive skills such as planning and sequencing. *Creative Enterprises* is beneficial to their self-efficacy, because they perceive themselves to be more capable. Hand-eye coordination is also improved by working with equipment such as the scroll saw.

Grace says that everyone is amazed at the quality of work being done. Because their clientele typically worked with their hands pre-injury, she remarked that "what was really neat about it was that it wasn't us teaching them. They were teaching us".

**Act 1 Scene 4: The Site - Creative Enterprises**

A few months after I had spoken to Grace and Philippe about my plans, Grace took me over to *Creative Enterprises*, located a short drive from *The Eagle's Wing*. It is hidden in the back of rows of warehouses and offices. We walked through the door and were greeted by the sounds of an active workshop. No one paid attention to us, everyone was intently focused on their jobs. Several clients were working on scroll saws, cutting wood into intricate designs. Others were working with bigger pieces. One was making a bookcase, which I saw later beautifully finished. A wine rack was well underway, and several rocking horses were being completed.

Grace introduced me to the clients, each one absorbed, focused and concentrating while working on a project. I then met Shawn, the supervisor of *Creative Enterprises*.

**Act 1 Scene 5: Shawn – The Supervisor at Creative Enterprises**

Shawn's job is to oversee the clients, give them guidance, and carefully ensure that everyone is safe. He describes how he ended up at *Creative Enterprises* as "a fluke of nature". He was doing work for Philippe, one of the directors of *The Eagle's Wing*, and was asked if he was interested in supervising at *Creative Enterprises*. He has been there since it opened.

At this time, most of the work done at the site is woodwork. There are scroll saws for doing detailed work, but there are several big and dangerous looking saws on the site. I asked Shawn about that. He said that he watches

carefully. I found it amazing how he seemed able to keep an eye on all the people working. Shawn noted that he's had to teach the staff in the same way as the clients. He finds that most of the clients are easier to teach because they were hurt on construction sites and similar working environments and therefore were skilled at working with their hands before they were hurt. Because of the clients' background, they are predominantly male.

Shawn describes his job as dream fulfilling. He is proud of the facility and the impression it makes on the people who come there. He sees big differences in some of the clients as they spend time at the site, citing improved self-confidence as one factor. Some clients "weren't sure if they could do it anymore, and then once they knew they could, they can do whatever they want". I asked him what he thought creativity was, and he said that "it comes not necessarily from yourself [*sic*], but it does come from ideas from other people".

Shawn sees the social aspect of Creative Enterprises as having the strongest impact on the lives of his clients. He has created an atmosphere where "you are just here having a good time and working at the same time." Everyone helps each other. He finds that "there's always somebody having thoughts, you know, I don't care who they are or every single person out here has given it a different thought at one time or another to make something a little nicer". Rob, the occupational therapist, notes that Shawn "has a tremendous rapport with the guys", which no doubt helps him create a positive atmosphere.

**Act 1 Scene 6: Rob – the Occupational Therapist**

I met Rob in Shawn's office. The walls are so thin that sitting there made it difficult to make sense of my tape recording afterwards, because we were serenaded by the sounds of saws. Several times the phone rang and Shawn came in to answer it. Rob explained that his background and experience, which involves a return to work focus, brought him to *The Eagle's Wing*. He finds hands-on therapy effective because you can "give therapy that's relevant to the client...you're focusing on the same goals that you would in a clinic but doing it in a different manner".

Rob emphasized the practice in executive planning skills, such as organization and sequencing, as the most obvious benefits of *Creative Enterprises*. I think that these skills are important to Rob because of his job as an occupational therapist. To encourage his clients, Rob explores where their interests lie. He says "I don't care what project it is, whether its woodworking or whatever, it still requires planning and organizing and sequencing and things like that". *Creative Enterprises* also helps clients *believe* in their capabilities, in other words, their perceived self-efficacy (Bandura, 1982). Because of the employment difficulties that people with disabilities face, Rob feels that, as Strauser (1995) states, he can assist in their career decision making by improving their self-efficacy.

Rob agrees with Shawn about the social aspect of *Creative Enterprises*. He noted that after a head injury you become isolated. At *Creative Enterprises*, "you can be a guy again [it tends to be mostly guys]. The teasing that goes

on,...But, also just being normal. ...It's huge for a lot of these guys". The heightened self-esteem felt by the clients is also desirable for Rob: "what I hope they walk away with is self-esteem – feeling that they can do more than what they have been doing".

### ***Act 1 Scene 7: The Impact of Creative Enterprises***

From my conversations with Grace, Shawn, and Rob, it is apparent that they see an enormous benefit from *Creative Enterprises* in several areas. Firstly, working at *Creative Enterprises* has given many of the clients "a new outlook on life in terms of potential". When people are producing something, they feel good about themselves. Grace notes the tremendous impact on self-esteem "when you look at something, knowing you've produced it, knowing you have the confidence to start and finish". Her words reflect Marinelli & Orto's (1999) comment, that: "The devalued role that people with disabilities...have in our culture, combined with the frequent insensitivity of others,...[contribute] to the battered self esteem of persons with disabilities" (p. 137).

Secondly, as an occupational therapist, Rob sees an impact on the self-efficacy, and therefore on the self-esteem, of the individuals who use *Creative Enterprises*. Rob told me that he likes to have his clients "do something that's functional, at the end of the day you have something to show for it", which he feels increases their sense of pride and their self-esteem. As I explained earlier, self-efficacy is seen by many scholars as a subset of self-esteem (Bednar &

Peterson, 1995; Branden, 1969, 2002; Mruk, 1999; Plummer, 1985; Pope, McHale & Craighead, 1988).

Thirdly, the experience at *Creative Enterprises* is valuable because of the community atmosphere it harbors. A few of the clients have scroll saws at home, but “they come to *Creative Enterprises* to work because it’s social.” Grace comments that:

It’s fun to collaborate with other people and it’s fun to get feedback and it’s fun to learn from somebody else. These folks are isolated enough, like just having a brain injury itself is an isolating experience for people, so absolutely, the social aspect is just huge.

Shawn agrees with Grace. He had had no previous experience working with individuals who have sustained an ABI. The first thing he tells people is always that he is not there to judge whether or not they can go back to work. His goal is to create a:

...good atmosphere to be around. You are not being watched by anybody, you are not being watched by doctors or any other people now. You are just here having a good time and working at the same time...just to have other people to communicate with because you are stuck on your own otherwise half the time.

### ***Act 2: The Research Experience***

Act 2 describes the research experience with each of the participants. I have used subtitles to indicate the concepts being introduced. In some cases it was only necessary for these areas to be a few lines long. In other situations, the sections are much longer.

The data analysis does not take place in this section, nor do I answer my research questions. I did find, however, that this was the most appropriate place

to discuss the selves in which I placed myself in during data collection. I also analyze my own reactions as I assume these different roles. This is especially true in the case of Sally. When I spent time with Sally, I really had to pull back and re-examine the self I presented to her.

**Act 2 Scene 1: Jim's New Life**

*If one views the process of adaptation to disability as an embryonic model with milestone sequences, then adaptation embodies assessing, coping with, and gradually assimilating various changes in body, self, and person-environment interactions necessitated by the disability.*

(Livneh & Antonak, 1991, p.299)

Jim is a positive example of Livneh and Antonak's description of adjustment to disability. Jim was the first participant who volunteered to be part of this study, and was also one of the first clients of the Eagle's Wing to make use of *Creative Enterprises* when it opened. He spends one and a half hours on a bus every Wednesday just to get to the city, and then spends another half hour crossing town to get to *Creative Enterprises*. So, I went to *Creative Enterprises* on a Wednesday, eager to meet the man that everyone felt epitomized the reason it had been established. I was not disappointed. I did find that after all this data collection, when I was finally ready to write of Jim's experiences, I really had trouble knowing where to start. He has affected me with his positive outlook, his enthusiasm, his skills, and his extraordinary sense of self-efficacy. Talking to Jim and receiving his many e-mails has for me been an eye opening experience.

Jim is forty-five years old. He has bright, shining eyes with which he looks unwaveringly and penetratingly at you while he is talking. He is about five foot eight with dirty blond curly hair, and he wears a diamond earring in his left ear. At the age of forty, Jim suffered a stroke while watching television at home. He quite rightly said to me: "I have an ABI from a stroke, not an accident. But, I think it's the BI [brain injury] that matters!" He spent over six months in the hospital, and continues physiotherapy every two months. He walks with a pronounced limp. His most noticeable impairment is his speech, and it is the one at which he works the hardest.

Jim is married, but is currently not living at home. He finds his tolerance level too low to handle his sixteen year old son's loud music and his eleven year old daughter's TV shows. He has effectively and admirably dealt with this problem by moving to a bachelor apartment within easy walking distance of his house. He and his family think this arrangement works wonderfully. He maintains access to his house, eats many meals with his family, and says he probably sees more of his children now than he did before his stroke. Heinemann and Shontz (1984) would view that the fact that Jim has experienced changes in feelings, attitudes and values since his stroke and has adjusted his lifestyle accordingly as an indication that he is coping positively with these changes.

My first conversation with Jim was in Shawn's office. Jim leaned forward and gave everything he had to maximize the interview. I realized then that the problems I would encounter with my participants were probably not the usual problems researchers face. Jim was very forthcoming, thought carefully about

the questions I asked him, and contributed freely in the interview. The problem was that he is so hard to understand. It was clear to me that taping our interviews was not an option, because the taped conversations would be incomprehensible and therefore impossible to transcribe. I thought long and hard about this problem. Jim felt practicing talking was incredibly important, and when he e-mailed me after our conversation, he noted that having to talk was one of the benefits of going to *Creative Enterprises*:

Probably the biggest benefit to me was having to verbalize my idea's [sic], which in turn helped me speak a little more. At times I get too dependant on things like e-mail (sorry) or Word to help me... I can vocalize but I don't have the confidence.

In the end, I went to *Creative Enterprises* to spend time with Jim and to talk to him. To do this was vital to his self esteem and worthiness. But to gather data, I would give him questions, and he would e-mail me back, punctually, thoroughly, and thoughtfully. I used the excuse that he had time on the long bus ride home to think about what to tell me. So, Jim e-mailed me faithfully with his thoughts after his sessions at *Creative Enterprises*. I also received copious additional e-mails. The following one arrived prior to my well thought out 'questions of the week'. I had included apologies for asking yet more questions, and I had apologized for taking his time: "A day without questions from Claire would be like a day without sunshine! Sorry for the abuse of poetic liscense [sic]. Knock your socks off. Oh ya, my time isn't that valuable, the one thing I have is time". At one point, Jim caught me off guard. His prompt, well thought out e-mail

ended with: “Hope this answers some of your questions and doesn’t propagate a whole lot more”...!!

Before his stroke, Jim worked as a buyer for an electronics company. Pre-injury, Jim thought his life was going along smoothly. He had status and was respected:

I took my job very seriously. If I bought too much material it would affect the bottom line in more ways than one... People realized that in my position I could make them look bad. If I tried real hard but couldn’t find a part they spec’d in they would look bad. If I found a part that would operate better than they thought and I found it fairly easily, then they would look like a hero. As long as you tried your best respect would follow.

His strategies for dealing with the deficits from his stroke are impressive. He says that he likes “to create therapies out of everyday situations”. For example, one day a week he volunteers at a trophy shop where “having to assemble small parts, like those in trophies helps with my fine motor skills which are lacking”. He is remarkably positive, stating that he prefers “not to dwell on what I can’t do now as opposed to what I can do...When I think of what I can’t do now, it tends to bring me down, so I try to think about what I can do now”.

### ***Creative Activities.***

There was no need for me to discuss what creative activity Jim wanted to do for this study – he always had several on the go. While the glue was drying on one project, he was using a scroll saw to cut a piece for another one, or he was leafing through the magazines to see what he could make next. He would usually arrive at *Creative Enterprises* with a current project in hand. Jim often brought an

unfinished project with him for which he needed to use equipment that he didn't have at home.

***Changing my role.***

After my initial conversation with Jim, I had the opportunity of watching him work a number of times. He walks around the workshop confidently with a big smile on his face. Jim was the participant that first caused me to stop and think about the 'self' I was. I had been the researcher, carefully probing into his thoughts in the office. I continued to be the researcher as I watched him work. Then, one day, Rob, the occupational therapist, told us of the hockey pool *The Eagle's Wing* was organizing. I thought that this was a perfect opportunity to bond with Jim. So I suggested that I pay the ten dollar fee, and he could choose our players. We would split any winnings fifty – fifty. Jim's bright eyes got even brighter, and he happily retreated to a corner to choose the players for our pool.

This was a fortuitous event for me. It was the crossover between the researcher – participant relationship we had, to one where I could chat to Jim as 'one of the boys'. I was pretty pathetic. He had to explain to me exactly what was happening in the pool, prompting another flood of e-mails (Appendix I). Jim seemed to enjoy helping me understand the hockey play-offs. I was learning from him: he was heading towards the teacher role in which he would next find himself.

***The researcher as a learner.***

One day at *Creative Enterprises*, I was talking to Jim while he was using the scroll saw. I mentioned that I'd like to try it. With a big smile, he scurried off to find a scrap piece of wood. He was then seen conferring with Shawn, and then looking for a 'beginner' scroll saw pattern. The next thing I knew, I was seated in front of a saw and Jim was explaining what to do. I tried it but was only moderately good at it. At one point I asked a question, and prefaced it with: 'Jim, I have a stupid question'. He immediately retorted, in true teacher form, 'there's no such thing as a stupid question!'

Jim then tried to include me in his next project. He had me cut some shapes for him, later to be glued onto the mailbox shaped piggybank he was making. After my dismal attempt at the scroll saw, the lines weren't straight. Poor Jim. I pleaded with him not to use the piece, but he insisted, saying that where it was positioned, "no one will ever notice". I think he was trying not to hurt my feelings!

***Jim's self efficacy and planning.***

Jim has extraordinary self-efficacy and planning skills. They manifest themselves in a couple of ways. The first is in his use of compensatory strategies for dealing with the residual weaknesses left after his stroke. He says that "most tasks that are simple operations for most aren't simple for me". He has to come up with some "unusual methods of holding my project, seeing I only have one 'good' side". Things take more time because he explained that he "not only has

to think about how [he's] going to hold something steady, but what [he] need[s] to do to implement that idea".

Secondly, Jim demonstrates his understanding of planning when he notes that most things in life can be simplified and "related back to a work project...The big thing you learn is to follow a process in either case. Following a process is a transferable skill". Jim realizes that the self-efficacy he demonstrates in the shop, or, in other words, the capabilities he perceives he has (Bandura, 1982), can be transferred to other life situations. It is one of the goals of the therapists at *Creative Enterprises*, particularly of Rob as an occupational therapist, to help all the clients realize this.

Jim's planning skills and self-efficacy enable him to modify any plan. He feels great when he can change a design to better suit the person for whom he is building something. He thinks that, if "you build a plan as one book or catalogue describes it, it doesn't give you the same level of satisfaction that a plan from a book that you had to tweak will". He likes to think 'outside the box', and says that he takes "a great deal of pleasure utilizing something (sometimes with a little modification here and there) for what it wasn't designed or meant for".

***Jim's self-esteem and self confidence.***

Jim seems especially to like helping other people. One day, he recounted how he helped someone in the grocery store put things on her cart. He said:

It wasn't a big thing but I had a certain satisfaction knowing that I had probably helped her. She probably didn't know it, but she had a big role in shaping my day...Being aware that, even in a small way, helped to make someone's day a little easier is comforting to me. I don't think there are

words to describe the feeling you get when you've had a fairly traumatic or serious brain injury and then helped to make someone's day go smoother.

Grace notes that Jim is not able to express his feelings as well as he used to. So, instead, he makes things for people, saying "words cannot properly describe the feeling you get when you give (not sell) to someone. To be able to plan, build, and complete a project that is, for lack of better words, a shock to the person receiving it is very gratifying". Of his work at *Creative Enterprises*, he thinks that "Even though your self-confidence grows on the scroll saw, it has to spill into everyday living".

Jim realizes that he has changed since his stroke. He feels his stroke has allowed him to examine his feelings, and not always look for the obvious. He thinks that "giving things to people definitely affects how you feel about one's self". He makes things "mainly for others because of the reaction I think. When I do build something for myself I don't get near [sic] as excited".

### **Act 2 Scene 2: Sally's Struggle**

We may seek to present ourselves as a 'friend' or 'disinterested bystander' or 'novice', but subjects can and usually do reinterpret, transform, or reject these presentations in favor of their own.

(Chamaz & Mitchell, 1997, p.210)

With this quote, Charmaz and Mitchell have neatly summarized my research experience with Sally. I met Sally briefly at *The Eagle's Wing* Christmas party of 2002. When Grace suggested to me that Sally would be an excellent participant in this study, I happily agreed. She seemed pleasant, articulate, and easy to talk to. Because she has no car of her own, arranging transportation can

be difficult for her. So one day, I went to meet her in her apartment. She lives right downtown within walking distance of many things. I called her from my car as I parked, saying I would be right there. I went into the building and rang the bell. She buzzed to open the inside door. I took the stairs to her third floor apartment. The second I rang the door bell, the door opened. She had obviously been waiting for me behind the door!

I was more than a little surprised when I entered her tiny apartment. The small bachelor space was incredibly overcrowded. Boxes lined the walls in precarious piles. They partly blocked the windows. Sally's miscellaneous possessions overflowed out of the boxes. I was fascinated and intrigued. Sally was gracious and a perfect hostess. After asking if I had had trouble finding the place, she politely took my coat and hung it on a hanger. There was no way it could be squeezed into the packed closet, so she hung it on the doorframe. Sally offered me a chair at a four foot round wooden table which stood in the corner, covered with yet more piles of stuff.

I surreptitiously glanced at the assortment of things on the table. They were mostly papers, some neatly filed and placed in portable boxes on the table. After offering me a glass of water, Sally took the second chair at the table. She sat straight in her chair, hands folded on the table in front of her. We started talking, and I once again felt extremely lucky. Like Jim, Sally was eager to help. She maintained eye contact, and was engaged at all times. Sally asked immediately about the time commitment and made notes as I told her what the

plan was. She had no problem with meeting me once a week for an hour, especially when I was able to offer her several alternatives for meeting times.

Sally is 39, and has lived in Ottawa since 1991. She was in a car accident in 1988. At that time, she was living by herself in Toronto. She had completed a BA in psychology, and was working for a major bank as a sales representative. Because she was setting up authorization machines for Visa, she says she was “on the road during the day visiting clients....setting up my own schedule, doing my paperwork”. She said that when she stopped by the grocery store on the way home, she would “get a week’s worth of groceries, with or without a list you know, not thinking a whole lot about it. Come home, I’d make dinner. Making meals was never a challenge”.

After her accident, she spent two months in the hospital. Her physical injuries were very serious. The doctors did mention to her that, ‘by the way, you have a mild concussion.’ Sally struggled for a long time, fighting fatigue and sensory overload. She moved to Ottawa to be closer to her best friend, and enrolled in an Interior Design program at Algonquin. She lasted two years, and then quit at the same time as she was asked to leave. She was unable to keep up with the program. Sally says “I tried the school thing, I tried doing some volunteer work, and you know, I couldn’t keep up with any of them”.

It wasn’t until 1994, six years after her accident, that she was properly diagnosed. After watching a program on TV about head injury, she went to her family doctor, who arranged neuro-psychological testing. It was discovered that

she did have cognitive impairments from her accident, so then she searched for a long time to find appropriate therapy.

Sally happily answered questions, and chatted very articulately about many things. She told me that, after her accident, she had immediately noticed sensory overload. However, she was unfamiliar with the concept and therefore unable to understand what was happening. She says she “wrote it off because of course you feel sensory overload because you have been sort of sensory deprived because you’ve been inside for almost two months”. She also found she had problems with “...fatigue. And a close second to that is attention, concentration, initiation...”.

### ***Creative Activity.***

Sally and I discussed several options for her creative activity. I received the first of many beautifully formatted e-mails outlining her thoughts. She was full of ideas, but she kept coming back to working on water colour skills. So, after a lot of discussion, she decided to make a set of water colour note cards. Sally was pleased to realize that she would be able to use the techniques she was going to learn to make gifts for people in the future.

### ***Selves.***

I found that, each time I visited Sally, she would be waiting just inside the door for me. She was unfailingly polite, and provided me with much information. This, however, came at a price. I found it was yet again necessary to reach into

my grab bag of 'selves'. Sally wanted to be my friend. She not only told me a lot, but she probed and questioned. In one of her weekly notes that she faithfully sent to me, she said that she enjoyed "the social element of Claire's company".

***The wrong self – an epistemological error.***

In Sally's case I think I made a mistake identifying myself as an ABI survivor. In an effort to become closer to her, and therefore privy to more of her information, I gave her some articles to read that I had written about my own injury. To my chagrin, at our next meeting, she exclaimed "It's so nice to meet someone who is in the same situation I'm in...High functioning, without obvious impairment!" I looked at her in horror. I felt that I had completely misjudged my own situation. I had a lot of trouble concentrating for the rest of the visit and, as soon as I was in my car, I phoned Grace. Grace told me that I had experienced a typical reaction to counseling, when the client identifies with the counselor. She told me not to worry, that I was not comparable to Sally in terms of where I was in my recovery.

The incident left me questioning my judgment. Who should I be in conversations with the participants? I had obviously missed completely this time. In fact, my misjudgment carried over for the entire data collection period. I found myself standoffish, and always steering conversation back to the point where I could be in charge as the teacher of water colour techniques. I had made the wrong decision about how I should be epistemologically toward Sally. Although I

was constantly trying to be closer to my participants, I felt that she had breached our relationship.

Looking back on it now, I think that, although I expected the participants to let me be as close to them as I wanted to be, I wanted to keep them at a certain distance from me. I expected their walls to go down, but I was not prepared to lower my own. Sally had crossed the line by announcing that she was just like me. Consequently, I felt threatened by Sally because of the identification she made with me. By identifying with me, Sally had unwittingly challenged who I was. In my mind, I was to be viewed primarily as a researcher, not as an ABI survivor. However, Sally placed me as an ABI survivor. I had not expected the participants to identify with me, even though the purpose of giving them articles to read was to assure them that I was one of them. Goffman (1959) describes the scene I experienced with Sally perfectly:

When these flusterings...become perceived, the reality that is supported by the performance is likely to be further jeopardized and weakened, for these signs of nervousness in most cases are an aspect of the individual who presents a character and not an aspect of the character he projects, thus forcing upon the audience an image of the man behind the mask.  
(p. 212)

As Goffman suggests, my performance in Sally's presence was altered by Sally, and therefore, I had to reveal the real me to the audience, not the researcher 'self' I had been to this point. I was forced by Sally to let the readers see me 'behind the mask'. Although the proper and conventional place within this thesis to discuss this issue may have been in the data analysis, I feel that this predicament adds so much more weight and 'realness' to Sally's story that I have included it here.

In contrast to Sally's reaction to the articles, Jim's thoughtful comments after reading them were wonderful and very much appreciated, because he never compared our situations. He would e-mail me his version and his thoughts, and describe how it was for him. But, in Sally's case, by giving her the articles to read, I gave her reason to constantly compare our situations. At one point I felt as if she was the one conducting the interviews! When I spoke to Grace about this, she laughed and said that the speech therapist at *The Eagle's Wing* had said that she was exhausted after each visit with Sally. Sally was draining. I felt that I needed to push her away all the time. I thought that she had crossed the line between friendship and friendliness. I agree with Kirsch (1999), who points out that this caused me to closely examine my expectations of the relationships I wanted to have, not just with her, but with all my participants.

I have read and rewritten this section of the paper over and over. But, I failed to realize what was really happening until my thesis advisor pointed it out. Sally was coming to terms with her frustrations about her own injury by identifying with me. She saw me busily re-mapping my life after my injury. So I became her role model, and she identified with me as someone who has succeeded in the struggle to make a new life post-injury. By doing this, Sally could accept her own ABI and her own situation and see herself as successful. But my ABI survivor self felt completely threatened. I saw Sally as someone who had far more deficits than I, yet she put herself in the same place in which I was. It took a long time for me to realize that Sally has a deficit which, as Lehr (1990) notes, often occurs in individuals who have sustained ABI's. Sally is unaware of

what her problems really are, and how deep-seated these problems are. Sally does not have the self-awareness necessary for maximal rehabilitation after ABI (Prigatano, 1988).

### ***Teacher Self.***

To overcome the problem that occurred when Sally identified with me, I re-asserted myself and I became purely a teacher. By placing myself in the 'teacher' self position, I could always steer the conversation back to water colour techniques and away from her probing questions and constant comparisons. I would come to Sally's apartment, look at my watch, and tell her how much time we had before I had to go. I found myself being very businesslike. I stayed that way until the last couple of visits, when I finally was able to be more relaxed. This incident with Sally had shaken my confidence and caused me to realize the importance of determining the self to be in each research situation. Reinharz (1997) says I had to:

...both *bring* the self to the field and create the self in the field. The self we create *in the field* is the product of the norms of the social setting and the ways in which the 'researcher subjects' interact with the selves the researcher brings *to the field*. (p. 3)

The self I had to create was not the self I wanted to be. I felt I was not able to get as close to Sally as I wanted. I felt out of control, that she was determining the shape of our relationship, I was not.

Charmaz and Mitchell (1997) believe that "Ways of viewing the experience shape what is viewed as well as the voice of the viewer" (p. 206). My confidence in my abilities as a researcher were shaken by Sally, and, I am sure, my loss of

confidence also shaped what I viewed and how I have written about it. In Sally's case, as Fontana and Frey (2003) point out, the self in which I cast myself left a profound impression on my participant. This impression did not have the type of influence on my relationship with Sally that I had hoped for. I think that what I came away with was a more superficial contribution to my study than that which I wanted. Because of this misjudgment on my part, I did not come away with a detailed examination of my participant, which would have led to a deeper and more insightful look at Sally's self-efficacy and self-esteem.

### ***Sally's self-efficacy and planning.***

Sally was a prime candidate for self-efficacy rehabilitation in an interesting way. She did not have the self-efficacy to perceive herself executing "courses of action required to deal with prospective situations" (Bandura, 1982, p. 122). Sally was able to plan on paper (Appendix J), but she consistently bit off much more than she could chew. She would make a plan, be overwhelmed, and simply give up. Sally chose to do water colour note cards for her project. One of our first tasks was to make a schedule for Sally which broke down the process of completing the note cards into manageable bites. After she had found the supplies she needed, we planned to spend three weeks practicing water colour techniques. We then had three weeks to make the note cards.

I noticed that Sally had trouble initiating tasks. I would receive e-mails, beautifully formatted and presented (Appendix J), outlining her plans. I found, though that, unless she was prompted, the proposed tasks remained only

proposed. She notes that “perhaps I recognize that I need to have a, b, and c done but I don’t make the connection that oh, so if they have to be done for tomorrow, then I have to find some way to get them done between now and then”. It did not seem to bother Sally that she didn’t get past the planning stage with tasks.

After our initial meeting, Sally spent three meetings practicing water colour techniques, and then three making the note cards. She followed each meeting with a journal entry (Appendix K). The end results were lovely. To get there, however, I found was exhausting! Sally was still learning how to manage her changed situation many years after her accident. Crisp (1994) notes that “long term adjustment to TBI is anything but a predictable course. Many individuals were still developing their compensatory and coping strategies many years after the onset of injury” (p. 17).

### ***Sally’s self-esteem.***

Sally is extremely articulate. She is very well spoken, and thinks before she forms very informative and interesting sentences. Initially, I found I was mesmerized by her grasp of the English language. She seemed very sure of herself. But, after she cast me in the same mold as she was from, she caused me to sit back and question some of the statements she had made.

One of the things she talked about was the improvement in her self-esteem after her accident. I wondered about that at the time. When I went back to read my notes, I realized that she was depending on other people to make her

feel worthwhile. She considered her self-esteem was increased when she received praise from other people. According to Coopersmith (1967), self-esteem is internal, but Sally looks for external validation. She says that "it's funny that it takes something like [a head injury] to have existing skills suddenly recognized".

Another time, she said almost the same thing:

..what was taken for granted or expected before now suddenly, you do something and uhm, it's like my intelligence and my abilities to articulate didn't change a lot. But all of a sudden, you're so articulate...all of a sudden somebody's recognizing and validating a skill that I have. Or an ability that I have and telling me that it's good. And since I know I had it before, it's like, oh, well I didn't realize that that was such a big deal.

Sally feels that skills she has always had are now recognized. This seems more important to her than how she feels inside about herself:

....suddenly my powers of observation and perception and analysis get complimented or acknowledged...It's only when you're injured that you start getting recognition for the things that you are doing...I don't know that I'm any more articulate now than I used to be but people now regularly tell me how articulate I am.

I feel that this project really has helped Sally's self-esteem. After I finished guiding Sally through the completion of her note cards, I was thrilled to get a call from her saying that she had completed ten sets of cards for a charity booth at a local fair. I was delighted that she had continued on, and she noted when she called how good it felt to have completed so many note cards. In her usual gracious way, she thanked me for helping her find this outlet for her creativity, and initiating the process for her. I am pleased that she has made progress with her trouble with initiating tasks. I also think that, unlike the examples above, the heightened self-esteem she feels now comes from within her.

**Act 2 Scene 3: Valerie's Journey**

*A painter takes the sun and makes it into a yellow spot. An artist takes a yellow spot and makes it into a sun.*

(Picasso, cited in Eisner, 1998, p. 9)

Valerie made yellow spots into suns, as described so eloquently by Picasso. Including Valerie as a participant in this study provided a real contrast to the other participants, who are much higher functioning. Initially I was reluctant to use Valerie because of this disparity. But I quickly realized that, as a participant in this study, Valerie was valuable because she was very different from the other participants due to her cognitive impairments. I met with Valerie at *The Eagle's Wing* because her therapist, Terry, felt that to change the setting to *Creative Enterprises* would be too disruptive for her. The introduction of me as a new person for her to relate to was disruptive enough.

**Background.**

Valerie is 43 years old, and has lived in Canada for twenty years. She met her husband when he flew to his native country to find a bride. He had taken two weeks off from his job as a landscape architect. It was an arranged marriage, but Valerie told me that it took her only ten days to decide to marry him. Of Valerie's marriage, Terry told me that:

...even if it was an arranged marriage, I think they really did grow to love each other...there are numerous photographs of them together and they make a gorgeous couple.....I don't want to pry, but her eyes light up when

she talks about him...she expresses great pride and happiness in their life together.

Before her accident, Valerie wore many clothes traditional to her native land and spent a lot of time doing her hair. Valerie was proud of her appearance, and she told me that she used to do a lot of shopping.

After coming to Canada to be with her new husband, Valerie worked in a factory as a supervisor. At the time of her accident, Valerie was going to school in the evening. She was just finishing getting a diploma in the computer field, and she was applying for jobs. Terry told me that "She'd done all her studies while she was working full time. She was very responsible and she had moved up through the ranks at her work so she was more or less in a position of supervision." Five years ago, when she went to check on something, her hair got caught in a conveyor belt, and she was pulled into the belt. Her physical injuries were horrific to see because she had been literally 'scalped', so only these injuries were noticed and treated. After a short stay in the hospital, she was sent home.

### ***Therapeutic background.***

Terry only started working with Valerie two years ago. Terry notes that Valerie is very different now than when she started therapy: "When she started here, she'd never look anyone in the eye, she'd spend most of her therapy time looking at the ground and making one word answers." Terry added that "all that information I've given you about her job? I didn't get that until I was working with her for more than a year".

When I met Valerie, she was sitting in the waiting area at *The Eagle's Wing*. I went over to introduce myself to her. She answered me in monosyllables, continuously playing with the cord on the hood of her sweatshirt. After catching my eye, she quickly looked away, winding the cord nervously around her head. She would wrap it around her hand, unwind it, and then put it over the top of her head, pulling it from side to side.

I tried to follow my instincts, so I said very little, and waited until her caregiver, Mary Lou, was free. I spoke to Mary Lou without Valerie present. She told me how she thought Valerie would relate best to me. She had spoken to Valerie about my study, and it turned out that Valerie did not want to be tape recorded. Despite this drawback, and full of confidence that I could handle the situation, I met with Mary Lou and Valerie.

The first meeting was an eye-opener for me, and also a much needed reality check for me about the needs of a severely head injured individual. I confidently picked up my clipboard, and started questioning Valerie. In her soft, quiet voice, Mary Lou intervened. Catching my eye, she broke down all the information I had just thrown at Valerie into short segments for her. Picking up on Mary Lou's cues, I slowed down and lowered my voice. Valerie then shared a lot of information with me, prompted by Mary Lou. She talked in constant streams that were hard to understand, all the while wrapping the cord of her sweatshirt around her head. I wrote furiously. Valerie asked Mary Lou constantly "Why is she writing? What is she writing?"

I left the meeting frustrated. Not only had I had a lot of trouble understanding Valerie, but she obviously distrusted me. Despite these feelings, Mary Lou confided in me that she was surprised and pleased that Valerie had been so forthcoming. All the same, I wondered whether she would fit into my study. She was severely impaired, distrusting, hard to understand, and she seemed unable to decipher her own thoughts for me. She did not fit the mold of the participant I had envisioned: communicative, helpful, and willing, the mold into which all the other participants had fit. When I spoke to Terry about this, she told me to wait, she felt that Valerie would be a valuable addition. I was very worried about her reluctance to be taped and her wariness of my note taking. Terry spoke to her privately before our second meeting, but Valerie was adamant: no tape recorder. The compromise Terry reached was that she would take notes while I was talking to Valerie. I then made copious notes after each session with Valerie.

### ***Creative activities.***

Because of Valerie's severe deficits, it confused her to be given too many choices. Therefore, we chose what activities she would do. We thought she might enjoy doing a variety of things, so we planned a different activity each week. In the end, we only did two activities, decorating picture frames and painting flower pots. She seemed to really like decorating these items so we did not complicate matters or confuse her by changing to new activities.

**Selves.**

In Valerie's case, there was no point asking her how she felt, what she thought, or her reasons for doing things. The input I gained from Valerie's participation contributed nothing to my data on self-efficacy, because Valerie had no sense of feeling capable of dealing with a prospective situation (Bandura, 1982). In addition, Valerie has little idea how to organize, plan, or in what order to do things. Cognitively, this will always be beyond her. On the other hand, I inferred that she derives tremendous pleasure and increased self-esteem from completing a creative project.

Analyzing her feelings, thoughts and reasons for doing things was only possible with the help of her therapist Terry. With Valerie, I had to be a therapist self and an observer self. But, I was also a learner self. I learned a lot from my interactions with her about how and why therapists do what they do. Terry was very generous with her time. She sat with us, silently doing other work while I interacted with Valerie and assumed the role of therapist. Terry would quietly interrupt only when I needed help. After each session, she would tell me how she thought I had managed.

Terry's most valuable input for me was helping me to understand how to relate to individuals with slowed cognitive processing. My natural inclination is to jump into situations quickly and to expect people to be mentally agile. Terry taught me to slow down and speak softly. I learnt not to confuse Valerie with too many options. Terry wrote in her notes to me:

You need to realize that Valerie processes information a little slower. So, for example, when you ask her if she likes something...you need to stop

long enough for her to think about her response. If you push too fast – she will just answer impulsively or stop listening.

She advised me to give Valerie two choices, rather than throwing a confusing array of information at her. When I made the mistake of overwhelming her, two things would happen. Valerie tended to rush things and be impulsive. It was easy to get sucked into her “impulsivity and need for speed”. My loud and quick talking, giving her a variety of choices, fed into this way of being. Instead, she needed to be encouraged to slow down and take her time.

The second thing that would happen is that Valerie would clam up. She would stop interacting, and retreat back to a place Terry had finally coaxed her out of, a place that felt safe to her. My learner self eventually turned into a therapist self, a completely new role for me. This self allowed me to also be an observer self, so I could try to answer my research questions by watching Valerie and interpreting her feelings.

### ***Valerie's self-esteem.***

Terry commented that Valerie “has wonderful ideas of colour and shape; she just needs prompting or a variety of suggestions from which she can pick a topic or which she can use as a spring board”. Valerie shows a real knack for choosing colours. Terry thinks that “instinctively [Valerie] makes good choices and we need to listen and respect her choices better”.

In the end, Valerie painted about six flower pots. When she had completed art previously, she had proudly hung it on the walls at *The Eagle's Wing*. Every time she arrived there, she would check that her art was still displayed. Since my

sessions with Valerie, I have seen her flower pots displayed at *The Eagle's Wing*. This is very important to her and I have no doubt she checks on how everything looks each time she visits the facility.

### ***Concluding thoughts.***

I'm glad that I was talked into persevering with Valerie. Working with Valerie taught me about interacting with severely impaired ABI patients. Terry guided me, teaching me how to interact with Valerie, and giving me pointers after our meetings each week on how I could improve. I don't think that Valerie ever completely understood what I was doing there. However, she did open up and would chat and laugh becoming less wary as I slowly figured out how best to relate to her. After our final session, I said good bye, and Mary Lou prompted her to say good bye, mentioning that I wouldn't be back. Valerie waved goodbye. I heard her ask Terry and Mary Lee what my name was when I left.....

### **Act 2 Scene 4: Diana's Experience**

*I think I tried to be who I was for a long time, I used to write tests and say, how shall I answer? Like I was, or like I am now? Like I feel right now or how I used to feel? You know, how do you answer? Like I could be two...its hard to decide what is your identity now, when you know something's different, but for forty years I've been this.....*

Diana's comment mirrors the identity crisis that most people who sustain an ABI face. At 49, Diana is attractive and well groomed. During our initial meeting, we discussed what she wanted to do for her creative activity. Diana expressed interest in stained glass and felt it would add a "component of learning" to the study for her. Not knowing anything about stained glass myself, it would be a learning experience for both of us. Luckily Rob, the occupational therapist, was experienced with stained glass and was eager for an excuse to work more with it. So, I arranged to meet Diana and Rob once a week at *Creative Enterprises*. Diana was happy to be helpful to my study. Although she was very busy, she said that once she committed to something she stuck to it and, as a result, she faithfully came every Thursday morning to *Creative Enterprises*.

In 1994, at the age of forty, Diana was in a car accident. At the time, she was a single parent of two daughters, age twelve and fifteen. She was working in a nursing home as the director of care. Because she was not quite qualified for her job, she was taking courses in senior management for long-term care. She was half way through the courses and doing very well. She was busy and she loved her independence. Diana was very driven, and says she was "a real type A". Her identity was formed by her job, not by the fact that she was a mother. She describes herself as being very self-motivated, and did her work to please herself more than to please other people.

After the accident, Diana was in the hospital for seven and a half weeks. Six months after her accident, she went back to work. She says "it was way too early. All I can describe it as being a stranger in a strange land." There were a lot

of things she should have remembered that she couldn't remember. About a year after her accident, she was finally sent to a neurologist by her insurance company. The neurologist gave her a booklet about brain injury to read:

I read through it and I started to cry because everything was me. It all made sense. I thought 'ohhhh'. I never thought I was going crazy or anything, but I thought things were a little different for sure. But I didn't have a lot of insight, so I didn't really see myself. I just knew things were different.

But, Diana didn't accept that she had a head injury for a long time. She says that she really "wasn't aware that she had problems":

I didn't acknowledge it. ..How do you cook? ...I used to say 'ok, this chicken looks good. Do I have chicken? No. ok. Buy chicken....I'd cook it, again with a few mistakes, like does glass go in the oven or does glass go on the element? I couldn't remember a few things, like, was the handle hot, or was the pan hot? And I'd pick up the pan, drop it on the floor....a few things like that. Not a lot, but a few. I'd remember there was a place to touch on the pan, but not remember where it was.

At the time of her accident, Diana had just been dating Bob, now her husband, for three months. She hid most of her deficits from him as long as she could. She would keep going all weekend to keep up with him, and then sleep all week to recover. She says she "tried to be normal, I didn't want to be handicapped....and I didn't want him to see it". She feels the relationship survived because "we didn't have a big history". They had been casually dating when she was hurt, and the accident helped him realize that he didn't want to lose her.

Last year, Bob thought the couple needed marriage counseling. Because Diana felt that a lot of their problems were due to her head injury, they went to *The Eagle's Wing* for counseling. Diana also had some personal counseling then,

and says “I didn’t realize I was as unhappy as I was”. Now, she feels more comfortable telling Bob things that he wasn’t previously aware of, like her debilitating fatigue. She thinks that “we live a pretty normal life, and he accepts the fact that I sleep in the afternoons. He doesn’t give me a hard time. He really understands that....we do pretty well I think...without, always alluding to brain injury”.

### ***Deficits.***

Diana’s deficits from her ABI are not at all obvious. The first deficit she talked about was her trouble with procrastination, or getting started with something. She says that “this could be from starting a project to picking something up off the floor...I spend more time avoiding doing it than actually doing it”. Planning, which used to be automatic, is not automatic anymore. She has to make things happen, and says everything is “a little more work, a little more effort”. She gets “tired thinking of all the steps”, so she finds herself procrastinating to avoid starting a process. Often, she finds that things are “overwhelming, it’s just too much stuff”.

Diana’s self-esteem has improved since she started going to *The Eagle’s Wing*. When she first went, her self-esteem was almost non-existent, but now she says she is more accepting of herself. Diana also feels her self-confidence is not as good as it once was. After establishing a sense of self, she feels that being injured at a certain age is:

...almost like starting from scratch....bit by bit you realize you lost who you used to be....putting that new person together and feeling good about it

when there's lots of failures in that new person... definitely my self-confidence is not as good, definitely my ego is very fragile.

For a long time after her accident, Diana isolated herself from people, but she is now enjoying them more. She and Bob socialize a lot, but she says that the friendships she makes are more social friendships than close friendships. She says she used to have a lot closer friendships, but now it is different. For the longest time she didn't trust herself to "get close to people and carry on conversations". Now, she says that life is a bit more normal and she has made a few friends at her gym. Diana describes the changes:

I used to be very emotional, very heart to heart, and now, like...I'm a little cooler, a little standoffish, which I never used to be.... Totally different in that way. I pulled back a bit more...it's not a protective thing, it just is....I feel real [*sic*] different, like I feel I'm a fraud sometimes, because I look...I'm the same person, my injury was such that I hid most of it....I think the person that really knows is [Bob].

Diana noted that her activities at *Creative Enterprises* added a social aspect to her life. She has met new people and feels comfortable around them, which has been difficult for her during the last few years.

I think that Diana is also challenged by sensory overload. She told me that she finds it confusing to work with another person. Diana notes that she thinks that "this is due to added input which doesn't make it easier to decide on something – it just adds more to consider". When she works on her own, there is "no distraction and I can concentrate easier". She prefers not to be doing something else while she is socializing.

**Planning.**

Diana saw her stained glass project as an opportunity to plan and break down a task into steps. She felt she was able to “visualize each step and not feel overwhelmed, by taking one step at a time”. Diana tends “to shy away from planning...and organizing...if somebody else will do it, I’m perfectly happy”.

**Self-esteem.**

The stained glass she learned for her creative activity “took the mystery out of learning a new skill”. A huge step for Diana was that she felt accomplished after the study, and said “how rewarding it is, to finish what you set out to do is, is a really nice feeling”. She says that she appreciates everything she accomplishes, and feels very good when she finishes a project, even if it’s not perfect. The stained glass project has helped her to “gain confidence ...and [she has an] increased sense of pride” in herself.

**Selves.**

During the time I spent with Diana, our relationship was clear. We were both learning about stained glass, and she was helping me by being a participant in my study. My conversations with Diana allowed me to be, as Wolcott (2001a) points out, “a listener able to play an active role, thereby making a more effective speaker out of the person talking” (p. 111). Wolcott adds that: “An interview ought to be a satisfactory experience for listener and speaker alike” (p. 111). The time I spent with Diana was rewarding. At no time did I experience the confusion I was feeling during the same time period with Sally. Diana appears to be busy. Thursdays was the only time she had to spend at *Creative Enterprises*. She

spends time at the gym three mornings a week. With her reduced energy level, she tries to schedule one activity a day. I became the Thursday activity.

Diana shared personal stories with me, but I always felt that our relationship was well defined, in contrast to my relationship with Sally. She was professional in her conversations with me. We would laugh and joke while working together, but I sensed an air of detachment, that she was 'one step removed' in her interactions with me. This was a firsthand example of the feeling that Diana had described to me that she has experienced since her accident.

Because I knew nothing about stained glass, Rob became our teacher. As well as observing Diana and conversing with her, I was given jobs to do by Rob as I learned about stained glass. He was primarily teaching Diana, but I was never allowed to sit and do nothing. I was always cutting glass to fit and foiling the edges of the glass before soldering. As we worked together, the three of us chatted and laughed. The time we spent together was not only a learning experience, but it was fun socially for Diana.

### ***Act 2 Scene 5: A short story - The Long Tunnel***

#### ***Situating this alternative representation.***

As I was collecting my data for this study, I slowly realized that, epistemologically, it was going to be very difficult for me to create any sort of distance from the participants by bracketing my own experiences. By the term bracketing, I mean setting aside my own "preconceived experiences to best understand the experiences of participants in the study" (Moustakas, 1994, cited

in Creswell, 1998, p. 235). The participants' experiences are too intertwined with my own. As I recounted above, this was brought home to me when I was talking to Sally, and she pronounced, to my dismay, that I was just like her. I didn't want to impinge on the study's validity by recounting my horror when I found myself in that position. However, I felt that it was important to the integrity of the study to include that episode.

It became apparent to me that, to establish validity for research purposes, I had to define my researcher role in a way that would allow me to be part of the study as a participant. Although my experiences were not like Sally's, they were equally valid and, therefore, I needed to express them. I realized that, by changing my methodology to auto-ethnography, I would be able to bracket my own experiences but still recount them without smothering or compromising my participants' equally valid and unique voices. By using the methodology 'auto-ethnography', I became 'one of them' and I was able to be an equal voice in the study without overshadowing, influencing, or coloring the voices of the participants. Therefore, I have included my own story in two forms, as a previously published article (Smith, 2003a), and as a short story.

This study uses three alternate forms of representation: a pictorial representation of the themes discovered in the data collected, a play in Act 3, and this short story. The story is an abstract and also metaphorical representation recounting my personal experiences following head injury. Although it is written as a story, the facts are all true.

**Author's note.**

...I cannot imagine initiating a study in which I had no personal feelings, felt no interest or concern for the humans whose lives touched mine, or failed to find in those concerns a vital source of inspiration and energy. Neutrality is another of those topics we must be able to address without having to embrace.

(Wolcott, 2001a, p. 166)

As Wolcott suggests, planning, researching, and now writing up this study has been a long searched for 'vital source of inspiration and energy', something I craved after my ABI. This story is a description of this search.

**The Long Tunnel.**

*I struggled to my feet. It was pitch black. I was in a tunnel. I had no idea why I was there. The footing was deep, uneven, and very, very heavy. I groped the wall, staggering and losing my balance. I could hear voices coming from behind a door. I could barely see the door. I felt along the wall for the knob. I struggled with the door. I couldn't open it. A man wearing a white coat finally opened the door. He was a doctor. He stepped aside. I entered, weaving from side to side. The doctor steadied me. I leaned on him. Everyone stopped talking. They looked at me. I saw my parents. My mother took my arm. Some of the other faces were familiar. I don't know who they were. I was confused. I stayed in the room. Everyone started talking again. They were talking through me. I was tired. I felt invisible. Finally, someone said it was time to leave. I was led out the door.*

*The door closed behind me as I headed down the hall. The hall was just like a tunnel. At the end, I could make out a pinprick of light. I inched towards the light, groping my way along the wall. This time I was walking on rough*

*cobblestones. Before long, I felt another door knob. I managed to open this door, but it required an extra hard turn and the door stuck. Finally though, I got it open. The room was not as dark as the previous room. I could make out the soft shadows of people in the mist. The people all rushed over to help me. I did nothing. They fed me, and there was a special person there to look after me. I spent a lot of time leafing through magazines. I didn't have the patience or the memory to read books anymore. They let me spend lots of time doing exercises. I really liked spending time that way. I learned later that what I was doing was called physiotherapy. I couldn't find my way across the room by myself. There was always someone there to lead me. I was taken to talk to one person, and then the next. It was great; I had to do nothing. I really didn't understand why I was kept in this room.*

*When it was time to leave, I wondered why I had to go. I felt secure and happy there. I was finally finding my own way around. All the people who had helped me waved goodbye. I stepped out the door, and started to make my way through the tunnel. There was more light now, it was soft, but glowing. The tunnel was like a beach, the footing was warm and solid, but like the sand when the tide is at its highest, it could also be shifting and uneven. All the same, I felt secure and stable most of the time. I found the next door; it was easy to open. I walked into a room that was bright, warm and welcoming. I felt that the colour was returning to my life.*

*This room was fun! I played games and did neat exercises. Someone called Grace listened to me, which was a novel experience for me. She quietly*

*offered suggestions that would make my journey along the tunnel easier. I discovered that I no longer needed to be dependent on other people; in this room I relearned how to solve problems for myself. It was empowering. It was sad to leave this room, but finally I knew that it was time to move on. I went out the door, and into the tunnel.*

*The tunnel was brighter now. It reminded me a bit of a misty summer morning when you know the haze will burn off. I walked down the center of the tunnel for the first time because I could see where I was going and my balance was good enough to walk without support. The footing was much better. It reminded me of walking on the cobblestones of an old village street in Europe. The next door was open, and I saw people I had known before my accident. They welcomed me with open arms. I was happy to be there. I spent time with my horses, and I fell into the life I was familiar with. Initially, I embraced it. Before long though, I sensed that it wasn't for me. My friends in this room were from a different life; it was a life that I finally reluctantly realized that I could not go back to. It was impossible for the people from this room to understand or relate to my new life and the experiences that had brought me to where I was now. As far as I was concerned, they were living in my past, and I had moved on. My life had irrevocably changed. It seemed to take me forever to recognize this fundamental but heart wrenching difference, and longer still to remove myself from the room. For a long time, I kept moving between this room and the next one. I always left the door open when I went to explore the next room. I was avoiding having to choose between them.*

*Eventually, feeling that it was the right thing to do rather than intellectually making the decision, I resolutely walked out of the room I was familiar with for the last time. I closed the door behind me. It was very sad and hard because it contained the life I had known so well, but I had made my decision. I headed down the tunnel, which, by this point, was bathed in light. The surface now was hard packed gravel. It would be perfect in all conditions but extreme weather. I made my way towards the next door. The sign on it read 'Scholarly Pursuits – Always Open', and underneath it, another sign said 'Welcome'. I gave the door a light push to open it. Upon entering the room, I felt comfortable and confident. My father was there, waiting for me. The self doubt I had felt since my injury dissipated. When I saw the challenges, goals, and paths that awaited me, I knew I would stay.*

### **Act 3: The Conceptual Framework in Action**

#### **Act 3 Scene 1: Message From the Director**

##### **Introduction.**

...of all our cognitive capacities, imagination is the one that permits us to give credence to alternative realities. It allows us to break with the taken for granted, to set aside familiar distinctions and definitions.

(Greene, 1995, p. 3)

I am using Wolcott's (1994) system of describing, analyzing and interpreting the data to lend credence to this study's findings. I will use my imagination to convey my interpretations in original ways. The next section, which describes (Wolcott) the group interview at the end of the study, is presented in the form of a play. This is in keeping with the theme I have used all

along for section headings. After the play is over, I will discuss the themes I have found after analyzing the data accumulated during this study. By interpreting the data I will answer the research questions. I will then revisit the purpose of the study to see whether it has been addressed.

***Background information.***

The actors in the play are three of my participants, Diana, Sally, and Jim. I will appear in my role as the researcher. Valerie is not a member of the cast, because she was not at the group interview. The number of people present at the interview would have been confusing for her, and the sensory overload she would probably experience would cause her to withdraw completely. So, the information she provided to the study was obtained in sessions with her and her therapist Terry. I could then observe her reactions, her expressions, and her emotions without causing her discomfort.

This interview was conducted so I could ask my participants as a group the questions listed in the interview guide of the research proposal. I decided to present this interview as a play so I, as the researcher, could show more effectively the relationship I had with my participants, as well as sharing their responses to some of the interview questions. However, after listening to a recording of the focus group interview on which the play is based over and over again, it suddenly occurred to me that there are two other surprising, fascinating, and satisfying outcomes of including this interview in the form of a play. The first is that it is the portrayal of the conceptual framework in action. Therefore, along

with the normal comments found in a play script, I have added director's notes at the end which tie together the play and the conceptual framework.

Secondly, this play incorporates the theories of Erving Goffman (1959, 2001). Goffman (1959) wrote that:

A character staged in a theatre is not in some ways real, nor does it have the same kind of real consequences as does the thoroughly contrived character performed by a confidence man; but the successful staging of either of these types of false figures involves the use of real techniques – the same techniques by which everyday persons sustain their real social situations.

(p. 255)

Throughout the play I have noted where Goffman's theory is evident. I have explained Goffman's theory more in the next section.

### ***Act 3 Scene 2: Acting Out Selves: Dramaturgy and Symbolic Interactionist***

#### ***Theory***

*In analyzing the self...there will be a team of persons whose activity on stage in conjunction with available props will constitute the scene from which the performed character's self will emerge... The self is a product of all these arrangements, and in all of its parts bears the marks of this genesis.*

(Goffman, 2001, p. 181)

I originally wrote this play to show the selves I became during the data collection phase of this study. I was not aware of the dramaturgic approach to social interactions when I thought that a play would provide an appropriate 'stage' for showing the selves I was during this study. However, unbeknownst to me, Erving Goffman (1959, 2001) had already studied the 'play' metaphor in life.

Dramaturgy is defined as a:

...situational-based examination of interactions which focuses on social behaviors as the product of encounters between people and groups rather than the frameworks for such encounters. [The dramaturgic approach maintains that] theatre and ordinary experience share significant ...elements.

(“Encyclopedia of Sociology, Volume 5”, 2000, p. 386).

Dramaturgical analysis, according to the *Encyclopedia of Sociology, Vol. 5* (2000), considers “the individual engaged in social interaction to be an ‘actor’ who can, and will, change his or her performance ‘roles’ as situations demand” (p. 386).

As described by the *Encyclopedia of Sociology* (2000), Goffman uses dramaturgy to illustrate that daily behaviors are similar to the performances of actors on a stage. Goffman’s work was brought to my attention after I wrote the play. Before I heard of Goffman, I had already noted the impressions of reality that I perceive the participants have, as well as those that they are trying to arouse among the other participants. I used the play to reveal this added layer of interaction among the participants to the reader, and I now I have added director’s notes to point out where I think that Goffman’s theory is evident.

According to the *Encyclopedia of Sociology* (2000), dramaturgy “provides a framework of theatrical metaphors for looking at social relationships and in doing so focuses on the underlying, shared, and often unspoken assumptions that function in social life” (p. 387). In the vein of Goffman (2001), I try to illustrate in the play what I see as “the ‘true’ or ‘real’ attitudes, beliefs, and emotions of the individual, [which] can be ascertained only indirectly, through his avowals or through what appears to be involuntary, expressive behavior” (p. 175). Because

the readers of this play are unfamiliar with the participants, by showing the actions and perceived emotions of the participants in italics, I allow readers to “apply their previous experience with individuals roughly similar to the one before them” (p. 175).

Symbolic interaction theory is also evident in the play. This theory suggests that:

...self reflects society and organizes behavior...that addresses the nature of human action and interaction and the relationship between society and the person....Interaction is ‘symbolic’, that is, conducted in terms of the meanings persons develop in the course of their interdependent conduct.

(“International Encyclopedia of Sociology”, 1995, p. 3095)

Throughout the process of data collection, of which the play illustrates a focus group interview, I am very conscious of the ‘self’ I am at any given time. This process is called ‘role making’ by symbolic interactionists. The changes I make in my ‘self’ are an attempt to maximize the quality of the data I collect. It is evident from reading the play, that, at any point the ‘self’ I am is not only the role I place myself in, but also how I perceive myself to be viewed by those I am interacting with (“International Encyclopedia of Sociology”, 1995).

A process called role taking also takes place within the play, because I try to see the world through the participants’ eyes. When interacting with the participants, I try to put myself “in the place of those people to see the world as they do, using prior experience with them, know of the social categories in which they are located, and symbolic cues available in interaction” (“International Encyclopedia of Sociology”, 1999, p. 3097).

**Act 3 Scene 3: The Play – The Conceptual Framework in Action**

**Setting:** *A comfortable meeting room at The Eagle’s Wing. Claire has pushed all the chairs and the sofa together so the microphone on the tape recorder will pick everything up. Everyone is on time, and, as always, eager to help. Diana and Sally have met, but Jim has not previously met them. Sally, in her polite way, takes the initiative and introduces herself. The other introductions follow, and soon Claire and the participants are all talking and laughing. Claire is in her role of researcher.*

**Claire:** Okay, guys, are you all set? So, the first question is: **“Do you like to learn?”**

**Diana:** Are we not doing them in order?

**Claire:** This is the order. Oh, sorry. The order changed a little. Sorry.

**Diana:** *[giggling]* So the first question is: Are you flexible?

*[Everyone giggles. They are all relaxed. Claire is looking suspiciously at her tape recorder. Claire realizes that Diana is viewing her in the role of ‘friend’, someone she can tease.]*

**Claire:** I’m going to have to stop in a few minutes and make sure this thing is working. OK, so, if you’re flexible *[laughter]*, the first question is: **Do you like to learn?**

**Jim and Sally:** *[together]* yes

**Diana:** *[looks shyly at the others]* Well, I feel differently....Ummm, I'm afraid to learn. I'm afraid to tackle new learning. When I was doing the foiling step of my stained glass project with Rob, I had to find a different way, a way that made sense to me.

**Jim:** That's what I mean about creating your own therapy. That's what you're doing in reality. It may not be the right way, but it's the way you're comfortable with.

**Sally:** Not only are you getting all this new information, but you're having to figure out how to learn it.

**Diana:** What works for one person doesn't work for another.

*[Nods of agreement from everyone]*

**Claire:** **How do you feel that your creative experience has affected your learning in general?**

**Diana:** Positive. It took me a while to see that. But you get a positive result and it was totally new learning, and, umm, it was great! I know it's possible whereas before I would have shied away. It gave me the idea that I could learn something new.

**Jim:** *[nodding enthusiastically]* It opens a lot of doors for you.

**Sally:** This experience has said to me, what else can you do here? As you learn one new thing, you sort of master it; that builds your confidence, then something will generate out of that.

*[ Sally knows what I am studying; at times I think she is just showing me what I want to know, as illustrated by the above comment. Goffman (2001) reaffirms*

*my thoughts when he says that “when an individual appears in the presence of others, there will usually be some reason for him to mobilize his activity so that it will convey an impression to others which is in his best interest to convey” (p. 177)]*

**Jim:** It’s kind of like a snowball effect.

**Diana:** What I find about new learning is that, one thing that would really help is to take notes, with the different steps. Like I found with the stained glass, there’s certain things you have to do before other things, just to write it down would have helped. So this activity helped me figure out and practice learning in general, and remind me of strategies I can use.

**Sally:** *[looking happy]* It’s nice to have something so concrete, that there’s a start, a middle, and an end. You end up with something you can see and for me that’s so nice because the rest of my life is so elusive; there’s never really an end result.

**Diana:** *[smiling and nodding in agreement]* Yes, all your energy goes towards the mundane...just getting through the day and not screwing up too badly. I think this type of endeavor gives you joy. I think consciously we have to put more joy in our lives because there’s a lot more on the opposite end.

*[Goffman (2001): although Diana was reserved in her commentary to me about her creative project, her expression and enthusiasm during this group interview or focus group (the ‘play’) relates her true feelings of pride and happiness.]*

**Claire:** *[Claire changes to her role of novice researcher].* Ok, the first break! Sit tight while I check the tape recorder. *[She rewinds the tape and*

*confirms the recorder is working*]. Great! You guys are amazing. Keep talking!

The next question is: **How do you think sensory overload affects you?**

**Diana:** *[her voice sounding truthful and honest]* I know you think my instant decision-making is due to sensory overload, but I don't really like group work and having to work things out with people, and like you Claire, I'm very strong minded and I know what I want. And so the two of us together are kind of cute....sorry Claire! *[giggling]*

*[Claire laughs, and is reminded of how insightful and observant of others she found Diana to be. She makes a mental note to record yet again the easy and relaxed nature of the relationships she had with her participants.]*

**Diana:** So I find group work difficult at the best of times, but now I just don't like too much information and I'll come to a conclusion quickly just to get rid of the dilemma. I just stop listening....

**Jim:** *[leaning forward, agrees]* Sometimes I'm in the bus and I hear 4 or 5 walkmans. Don't bother saying anything to me, I'll never retain it.

**Sally:** *[appearing to reflect on what the others have said]*. I finally realized that the difficulties I have with planning and with the feeling of being overwhelmed, it's not just because I'm too tired, its because my head doesn't know where to start anymore. Too much stuff. Then that prevents me from being able to make a decision to pick a place to start, so I can decide what to do next. But, it occurred to me that by doing these kinds of projects, it might actually help me learn how to manage sensory overload.

*[The level of enthusiasm and cooperation continues to grow. Everyone is trying to talk at once and is leaning forward in their chairs]*

**Claire:** How do you believe you are at managing the day to day events and activities in your life?

**Sally:** With the proper rehab, I'm learning to do things more efficiently and effectively as my skills improve. I can apply what I've learned from the creative process to the challenges of daily life. *[Goffman (2001) : Sally really believes that she can apply what she has learned to other activities. Claire is not sure that Sally can do this...]*

**Jim:** I think the biggest thing is that I've learnt to be adaptable. I've had no choice in the matter.

**Diana:** I rely on my husband, Bob, for a lot of things, like written material that comes in the mail. I get very overwhelmed if there's too much stuff going on. Everyday stuff is hard, like my mother-in-law is coming with a friend for the weekend. All of a sudden I have to figure out where they'll sleep, what I'll cook, what I'll do..... *[Diana sighs. Claire notes the evidence of sensory overload, Goffman (2001)'s theory about real emotion being visible in involuntary expressive behavior is evidenced in her sigh]*

**Claire:** Ok, thanks guys. Moving on to the next question, **what do you think creativity is? How does your involvement in creative activities influence the way you think about other aspects of your life?**

**Sally:** Well, I'm starting to see the bigger implications and recognizing that I need to build some structure that gives me a time context, then I'll keep moving towards it.

**Diana:** *[with a thoughtful expression on her face]* I can really see that skill falling into other aspects of your life. It helped me to learn to manage things in smaller bites. This time for me, the focus was not on the finished product, but on the learning, the doing. I learned to take one step at a time. I think a lot of my hesitancy to go forward with something is that it is just too much. Everything can be accomplished one step at a time and you can identify each step.

**Claire:** Oh oh, we're losing him *[Jim's eyes are closing]*

*[Laughter]*

**Jim:** Time for a nap! I was off in Nevernever Land. OK.....I think when you do things creatively they tend to flow into your day to day life automatically. I have a grocery store analogy. If they don't have what I need in the store, then I'll have to be flexible and adaptable, and think of something else. That was really hard at first.

**Diana:** That's just what I was just going to say. Creativity equates with flexibility.

**Claire:** **Can you talk about your self-esteem? How is it different from your self-esteem pre-injury?**

**Sally:** *[jumping in quickly]* Pre-injury, I didn't recognize my skills and abilities. I had very low self-esteem. It took almost six years for my injury to get

diagnosed, so, in order to keep going through all that time, I discovered that I'm a lot more capable, a lot stronger, a lot more determined and tenacious than I ever knew I was. I often marvel at the irony that it takes sustaining a brain injury to gain your self-esteem and self-confidence.

**Diana:** When I had my injury, my self-esteem took a nose dive because I think I lost my sense of self. I mean, you do lose your sense of self because you end up being a different person. I bet we all did the same thing, look in a mirror and say, who is that, looking back? And it's a stranger.

*[Claire nods in agreement with Diana's last remark. She feels herself moving into the role of fellow ABI survivor.]*

**Sally:** You're re-defining yourself, not only for yourself, but who you are within your family, who you are to your friends.

**Diana:** I'm not who I used to be. I'm more persistent to succeed because I have to be. It's more important to succeed now because it's harder. And I'm gonna make sure I do.

**Claire: How has your involvement in creative activities affected your self-esteem?**

**Diana:** Well, for me it's reinforcement that I can do well, and I can learn a new thing, that I can accomplish something, so it helps my self-esteem. It's the fact that I've completed something, rather than what the finished product is.

**Sally:** You get this little boost inside because you've completed whatever it is.

**Jim:** Your creative life and your day to day life are a bit intertwined. I know I'm hard to understand, but I'll ask a question in a store as opposed to walking around without asking.

*[Claire notes that how important it is for Jim to practice his speaking skills.]*

**Claire:** Are there any other connections that you can make between your creative activity and other aspects of your life?

*[ Claire sees Jim surreptitiously looking at his watch. She knows the interview is cutting into his precious time at Creative Enterprises]*

*[Goffman(2001): Jim has given his time for this interview, but his 'real' emotion is evidenced with his "involuntary expressive behavior" – wanting to return to the workshop].*

**Sally:** I have difficulty planning. So, I can apply what I've learned through this creative activity to other activities. It's another resource I have to pull out.

**Diana:** I've become more passive than I ever used to be and that passiveness results from, you know, being unsure and letting other people take the lead, or being too tired to make a decision. I found that doing the stained glass though, was **my** project, **my** colours, and **I will make the decision!** It gave me a little bit of strength.

**Sally:** It's something you can have control of, because you've been out of control for so long.

**Claire:** *[In the role of thankful researcher!]* That's it folks! You have all been so helpful! Thank you so much. Jim, I'm really sorry I had to drag you away from *Creative Enterprises*. A double thanks to you! You can all look forward to

getting an e-mail from me with more thoughts and questions. Do you all want to come for lunch? My treat. [*Diana and Sally nod enthusiastically. Jim wants to head back to the workshop.*]

### **Act 3 Scene 4: Director's Notes**

*It was an unexpected surprise to find that the meeting that this play is based on demonstrated how neatly this study fit the conceptual framework. To start with, in my conceptual framework, the positioning of the researcher, within the sea of creative potential, shows the minimal epistemological distance, and close relationships I wanted to have as the researcher with my participants. The comfortable, open interaction illustrated in the play is an example of the positive rapport I had with each of the participants and our epistemological closeness during the study.*

*Secondly, the conceptual framework indicates that my role, as the researcher, is constantly changing, as metaphorically shown by the swimming fish in the framework. When I started the study, I was struck by how fluid my role as researcher had to be, so I highlighted the changes in my 'self' in the research experience section of this study. In the play, I have only a few roles, of friend, researcher, and fellow ABI survivor, but the small changes I had to make when talking to the participants are shown in the play.*

*Thirdly, the play demonstrates that, by using Carl Rogers' (1961) humanist psychology, I was successful in my attempt to establish a creative environment within the sea of creative potential. This is expressed by my*

*participants' remarks during the play, their ease and comfort in the play, as well as by the creative activities they undertook for this study. Within the creative environment, my participants felt they were psychologically safe. They were also free to play with possibilities and they were inspired to be open to new experiences. Two of my participants, Diana and Sally, undertook to do activities with which they had no prior experience.*

*Part of the conceptual framework, Woodman & Schoenfeldt's (1989, 1990) interactionist theory, becomes clear early on in the play, in all three participants present. The 'snowball effect' mentioned by Jim is evidence of the creative act influencing "the state and development of the person in a feedback process over time" (Woodman & Schoenfeldt, 1990, p. 16). Woodman and Schoenfeldt's theory is also reflected in the answers given to the last two questions. These comments indicate that the completion of a creative project has helped my participants' self-esteem, self-confidence, and sense of control over their lives.*

*Lastly, the snapshots spilling from the camera in the sea of creative potential show my different views, which I have indicated by italicized comments in the play, and also show the views of my participants. The snapshots, some kept, some discarded, symbolize the multiple voices of post-modernity (Guba & Lincoln, 2000). They truly reflect the multiple perspectives of this study. These perspectives were also demonstrated in the play, by giving all the 'actors' equal voice.*

### ***Act 4: Finale - The Four Major Themes***

#### ***Act 4 Scene 1: Introduction***

The analysis of the data produced four major themes which appeared repeatedly in the conversations with the participants, my field notes, and my own experiences working with the participants. The themes highlight the participants

- 1) changed friendships and relationships after sustaining an ABI,
- 2) problems with planning and procrastination,
- 3) sensory overload issues, and
- 4) heightened self-esteem after engaging in creative activities.

I will now comment on these themes. The analysis protocol I used to arrive at these themes was outlined in the section entitled "Critiquing the Play". The first three themes exist in the literature. The fourth theme provides new commentary on possibilities for ABI rehabilitation. My interpretation (Wolcott, 1994) of the data will be revisited in the conclusion, when I answer the research questions.

#### ***Act 4 Scene 2: A Changed Social World***

Winslade (1998) notes that an ABI can cause obvious and debilitating physical, mental, and emotional deficits", but some, "such as social isolation, take their own insidious toll" (p. 77). These deficits can contribute to changes in the 'self' that an individual was before sustaining an ABI. One of the major hurdles the ABI survivor must overcome is that, not only must you learn about the 'new you', but you must also learn to accept how people around you react to your

injury. William James' quote: "No more fiendish punishment could be devised than that one should be turned loose in society and remain absolutely unnoticed by all its members" (cited in Seaton, 1998, p. 76), is applicable to people who have sustained a head injury. They often face isolation and loneliness, feelings that have been experienced by all of my participants. Gronwall, Wrightson and Waddell (1999) maintain that loneliness is "one of the saddest secondary effects of head-injury (p. 146). Social interaction with others is important. William James pointed out that relationships with others often facilitates progress as well as helping one to know oneself better (cited in Gardner, 1983).

Along with loneliness, two of my participants, Diana and Valerie, experienced social interaction difficulties. Newton and Johnson (1985) define 'social interaction difficulties' as "the difficulties experienced and/or perceived by the person engaged in interaction with others" (p. 226). Interestingly, and fitting to this study, Newton and Johnson found that, along with social performance and social anxiety, self-esteem is one of the variables to be considered when counseling individuals with problems in social interaction.

The original site for the study was *Creative Enterprises*. Although only two of my participants used *Creative Enterprises*, I will briefly describe Shaun's and Grace's feelings about the social benefits it offers. I will then explore the social worlds of my participants.

***The atmosphere at Creative Enterprises.***

Shaun, the supervisor at *Creative Enterprises*, thinks that one of its greatest benefits is that there are people there “just to communicate with because you are stuck on your own otherwise half the time”. So, he tries to make a “good atmosphere to be around. You are not being watched by anybody, you are not being watched by doctors or any other people”. This atmosphere has a positive impact on the social world of ABI survivors.

Grace comments that *Creative Enterprises* can be a vehicle for clients who are fairly confident in their creative skills, but shy socially. *Creative Enterprises* attempts to fulfill a need, which is aptly expressed by Crisp (1993), as helping “persons with TBI to participate in interpersonal relationships and to adapt to specific social settings” (p. 403). As outlined in the conceptual framework and in the play, *Creative Enterprises* offers the prerequisites to encourage the creative atmosphere recommended by Rogers (1961), a psychologically safe environment, the ability to play with possibilities, and openness to experience.

Grace questions whether creativity paves the way for social interaction or whether social interaction sets the stage for creativity. *Creative Enterprises’* atmosphere promotes either option. Despite Grace’s comment, I realize that, in qualitative research, things are never seen as straight forward or black and white, and comparisons to quantitative research, as this ‘cause and effect’ statement suggests, cannot be made. Creswell (1998) explains that “Qualitative inquiry represents a legitimate mode of social and human science exploration without

apology or comparisons to quantitative research". It is likely that the creative atmosphere at *Creative Enterprises* is only one factor promoting creativity at this site, and the resulting creativity has many outcomes along with increased social interaction.

***Diana.***

I was surprised to learn from my conversations with Diana that she felt her isolation was self imposed, not brought on by other people. Most ABI survivors find that, as Seaton (1998) notes, people avoid them because the people are afraid of the changes they'll find. However, Diana says she withdrew because she felt that her friends thought she was the same person she was before her accident. They didn't understand when she told them that she wasn't. She tried to tell her best friends that "who you're talking to is not who you used to talk to". Diana told me that, for a long time after her accident, she isolated herself from people, because "I feel real different, like I feel like a fraud sometimes, because I look like the same person". When describing his life after an ABI, Blanche (1998) indicates that he feels the same way. He explains that "as a result of this accident, my old self died and was replaced by a new self" (p. 71).

Initially, Diana didn't trust herself to get close to people and carry on conversations, although she finds that it is becoming easier. Diana and Bob have a big social life, but she commented that "it's not close people, you know, it's more social friends. I used to have more close friends....that's very different now". Diana appears to have social interaction difficulties, as defined by Newton

and Johnson (1985). These difficulties concern the reconciliation between self and environment. In Diana's case, the environment she is distancing herself from is her social environment. I feel Diana is just starting to come to terms with her new self in her old environment. Although she does not actively seek out friends, Diana finds that she is beginning to enjoy people more. She was surprised at her reaction when, at the gym:

I'll smile and say hi, and that's as far as it goes, and then they're saying well, why don't you come for coffee...all of a sudden life is a bit more normal...and I like that! I'm making a few friends at the gym, like lady friends, and that's nice.

Diana thinks her involvement in this study has "added a new dimension" to her life, by "adding a social aspect". She was happy to say that one of the outcomes of the study for her was the "social skills, working with you and Rob...meeting new people, feeling comfortable with new people...It's important for me to feel comfortable with new people. That's been really difficult in the last years". Diana feels that the stained glass project has given her another dimension that will benefit her social life, because she will have "more common denominators" to share with other people.

Although Diana likes the fact that this project has allowed her to develop a skill which may help her socially, she doesn't normally like the collaboration that working with other people involves, saying "I find it really difficult. I...my mind is not too flexible". As a result, during her stained glass project, she was sometimes too quick to make decisions. She would feel "overwhelmed by a simple colour decision" so she would "opt out, letting others decide". It confused her to work with another person, finding it easier "just to socialize rather than doing

something at the same time". These statements are evidence of sensory overload, which I will explore further in a later section.

*Jim.*

After reading the statement 'Head injury scares people', Jim's comment (via e-mail, as always!), was:

I've seen people cross the street to avoid me...I've made some pretty dramatic changes and I'm not sure other's [*sic*] around me recognize that. One of the rules of healing is not to worship your former self. 'You've' done this (if you've healed properly) and I'm not sure those around you know this.

Although I'm sure he is often lonely, Jim understands the reaction of other people. He wrote to me that head injury "is not only a learning curve for you, but those around you have to 'adapt' also".

He summarizes his feelings about people's understanding of head injury when he says: "how can you expect to understand some one's injury when they don't"? Karpman, Wolfe, and Vargo (1985), as well as Newton and Johnston (1985) point out that head injury often causes friendships to be lost. But, Jim thinks that if people were "friends before the injury and now they aren't, were they truly significant? Were they really friends?...you tend to find out who your friends really are."

I think that Jim's statement bears some consideration. It struck a chord with me when I think of the number of friends I have lost since my injury. I believe that most friendships, based on common interests, may not survive ABI. After a head injury, things are different. Interests have changed because the individual

who has sustained the ABI can no longer take part, or because the individual has changed. Therefore, old friendships can fade and dissolve or be much less significant than they were pre-injury. Very special friends, where the friendship transcends to a deeper level, may still be friends. However, most of us are lucky if we have one or two of these friends.

Jim's Wednesday visits every week to *Creative Enterprises* are times when he can spend social time with other people. He told me: "I very much look forward to the weekly interaction at *Creative Enterprises*. I spend time in my shop but 90% of the time I'm alone". Seaton (1998) writes that, after a brain injury, individuals often cannot re-assume the roles they once had, professionally or socially. Jim feels that *Creative Enterprises* has "certainly helped me socially", and says that some of his time at *Creative Enterprises* "definitely fills a job void. It provides me with some social contact that everyone needs".

Jim relates a lot of the improvements that he has seen and felt in himself socially during his time at *Creative Enterprises* to his improvement in speech. Grace explained that when he first came, he was pretty shy. As he got more comfortable there, he felt more accepted and more willing to try talking. So, in fact, although Jim did not express it as such to me, Grace's feeling is that as his self-confidence grew, he talked more. From what Jim has told me, he sees the opposite, his self-confidence has grown because he is talking more.

**Sally.**

Although Sally's family lives 2 hours away, she has stayed here. Because she is familiar with the rehabilitation available here, it is easier for her to stay and try to develop her own life the best that she can. Sally has regular contact with her family by phone and through her frequent visits, and they are very supportive, an experience that Karpman, Wolfe, and Vargo (1985) noted was shared by most individuals in their study who had sustained an ABI. However, Sally misses the daily contact with people that she had when she was working. Because of sensory overload, self-efficacy, and planning issues which will be discussed later, it is more difficult than it used to be for her to "make an effort to go anywhere else". She feels that she is "lucky in one sense that I enjoy my own company and I'm quite capable of entertaining myself".

Although Sally doesn't recognize, or perhaps admit her loneliness, I felt she was lonely. In one of her e-mails to me in which she described our recent session, she noted that she "Enjoyed the social element of Claire's company". She welcomed and was very open to my feedback on her work. She wrote that she "appreciated Claire's enthusiasm" about her water colour work. She enjoyed the social aspect when I took Diana and her to lunch after the group interview. Always polite, I received an e-mail after the lunch thanking me.

**Valerie.**

When Valerie first came to *The Eagle's Wing*, she didn't talk to anyone. Her injury had caused her to experience psychological problems: fear of others,

and fear of being out in crowds and around other people. Cancelliere (n.d.) notes that chronic impairments in social skills are commonly found after a severe ABI. According to her therapist Terry, Valerie knows “she has huge deficits and she doesn’t like to appear at a disadvantage”. Trust of others is an important issue and a contributing factor to Valerie’s social deficits. Terry comments that when someone has “such severe deficits, you really do have to trust a lot of people that they’re going to do the right thing for you”. Valerie’s distrust of others became apparent when I wanted to use a tape recorder during our sessions. Valerie clearly stated to Terry that:

I’m not sure where that tape is going to be, and I’m worried that if I say something on that tape because I make mistakes, or because I’m not always clear, or I don’t have a good memory, I may say something that’s not good for me to say.

So, that was the answer. She was not even comfortable when I made notes during our conversations. Therefore, for my data, I resorted to my own memory, field notes I made as soon as possible after our sessions, and Terry’s notes.

Valerie came to *The Eagle’s Wing* very shy and quiet. As she became more comfortable, she started talking more. At times, during our sessions, she was chatty and giggling. The creative activities we did together seemed to help her be more comfortable because they gave us all something to talk about.

### ***Act 4 Scene 3: Problems with Planning***

Making a plan and then carrying it out are experienced differently by all four participants. Diana’s and Sally’s deficits manifest themselves as self-efficacy problems. Diana procrastinates. Diana has the ability to plan a task using her

cognitive, behavioral, and social skills, but she has trouble believing that she can carry out the task, although she constantly tells herself to do it.

Sally does not seem to procrastinate, but she appears to be lacking the step that links intellectually understanding a task and planning how to carry it out in the abstract, to actually doing something about it. Unlike Diana, she is not that bothered if something does not get done. Later on, I will describe in detail why I feel Sally's problems are executive function problems. Both of these participants experience lowered self-esteem because of these deficits.

Valerie's cognitive impairments prevent her from being able to plan. She does not appear to be aware of procrastination or self-efficacy. Jim's planning and self efficacy is extraordinary, as I will recount later.

***Diana.***

When she was asked what she might learn from this project, Diana said she hoped "to improve my ability to be able to start a task, i.e. not to procrastinate for no good reason". Diana told me she was very good at procrastinating, stating:

I'm not very good at starting something...and this could be from starting a project to picking something up off the floor. You know, I spend more time avoiding doing it than I spend actually doing it...we used to put things on the stairs to bring up, and I'd pass them...I'd think 'Why am I doing this? Why don't I bring them up? Next time I will....and on it goes...then I just get frustrated and think 'just pick the stupid things up'!

Since her injury, Diana finds that she's had to make a concerted effort to make things happen. She finds that it's "the starting...that's really difficult". Stoler and Hill (1998) note that this characteristic points to executive function problems.

Diana added that she hoped that completing her stained glass project would ease her inclination to procrastinate.

Diana knows that this is in part due to the fact that she is easily overwhelmed. According to Diana, “planning, which used to be automatic, is not automatic anymore. You have to plan a little more...and it’s a little more work, a little more effort”. She hopes that this project helped her learn how to break things down into manageable chunks by teaching her “to visualize each step and not to feel overwhelmed”. Diana’s problem of feeling overwhelmed will be further addressed in the section on sensory overload. Diana is hopeful that she will learn how to better manage her time.

As the researcher participant and fellow learner about stained glass techniques, I was very interested in Diana’s reaction one day when everything was going wrong. Halfway through the session, Rob had broken a couple of pieces of glass. He was frustrated and wanted to stop. Diana wanted to keep going! Rob looked at me, shrugged, and said ‘Great, but I’m not touching anymore glass!’ Diana’s self-efficacy was blossoming. As Bandura (1994) said:

People’s beliefs in their personal efficacy influence what courses of action they choose to pursue, how much effort they will invest in activities, how long they will persevere in the face of obstacles and failure experiences, and their resiliency following setbacks.

(p. 65)

It seems that Diana was not feeling as frustrated as Rob, or, for that matter overwhelmed, so I think that, despite the setbacks of that particular day, her persistence in the face of obstacles, an element of self-efficacy, was improving.

Diana's final words during our conversation about planning were that "All in all, I have to remind myself to take this one step at a time". Rob was a real help in that respect. He was there weekly to teach Diana and me stained glass techniques, step by step. Diana remarked that finishing this project, because the reward is the finished product, "will get me more inclined to, to not procrastinate about doing things....maybe it will have a fallout in other areas".

***Jim.***

Most things in life can be simplified and related back to a work project! The big thing about it...is you learn (either subconsciously or consciously) to follow a process....Following a process is a transferable skill. Future employers (if they're on the ball!) will see that. You may think that working at Wendy's doesn't add to your resume. You think 'Gee, I can flip burgers, but future employers look at the fact that you can follow a process in order to 'flip that burger' and that skill is definitely transferable to any job.

As always, after receiving a round of questions, Jim thoughtfully e-mailed me. Applying the above statement to *Creative Enterprises*, he said that working there teaches you "that there must be a 'process' for most things, both in life and in woodworking projects, that must be followed in order to achieve success at what you set out to do". It is obvious from his words that Jim understands exactly what self-efficacy is (Bandura, 1977, 1981, 2001), what the role of *Creative Enterprises* is, and why it was opened. Jim has no problems with self-efficacy, planning, or sequencing. He does not procrastinate. Jim perceives that he can complete the plans he makes. He described his typical day at *Creative Enterprises*, saying that "Every week I work on multiple projects, generally I try to focus on one project and work on others, while I'm waiting for things to happen

that I can't control, like glue drying...". All the same, Jim feels that planning is more difficult than it used to be. He feels he has "a very shallow energy pool, so thinking tends to use up a lot of energy". Because of his stroke, Jim maintains that "most tasks, even simple operations for most, aren't that simple for me". Jim has had to develop his own unique system for doing some routine tasks, and come up "with some unusual methods of holding my project", because since his stroke, only one side of his body works properly.

Jim is not satisfied if his project is made strictly from a published design.

He always 'tweaks' or modifies his project to suit whomever he is giving it to:

I will at times, look at a pattern that I particularly like and say "if I take off this, that and this and maybe add this, that and this, maybe I could make this instead of what it was designed for....That's what I like to say is "thinking outside the box". Just about anyone can build a 'box' but the difficulty is building the 'box' for something else!

Jim proudly told me that "as a rule I will look at a plan and say to myself 'ya [sic], that's what it's for, but what can I use it for with some slight modifications". He gets the most pleasure when he can change plans and utilize them for something they weren't designed for. He is proud of the uniqueness of his work and, as Simon (1997) writes, relishes the sense of individuality it brings him.

### **Sally.**

Probably the biggest challenge is the difficulty in making plans. Just not having the energy....because everything you think about requires more time and effort because all the information is being moved around by the back roads instead of the highway.

Sally thinks that one of her major deficits is her inability to make plans. I found, however, that her deficit actually lies in her inability to initiate the plans

she makes. Planning and organizing eat up more time than actually doing something. Sally commented that the trouble she has planning her life makes it difficult to plan activities too. Doing a creative project for this study was beneficial to her because it allowed her to practice the skill of determining what steps were necessary to complete a project, however minor the project or the step. She found it helpful when I gave her questions to answer, because the questions gave her clues about what I was studying. By answering the questions, she told me that she could figure out “the bigger picture of what [you were] doing, rather than just the art portion of it,... I found it to be really valuable”.

For Sally, this study really was about planning and self-efficacy. Her executive function capacity, those functions helping her to formulate goals, plan how to achieve them, carry them out, and alter them should it be required (Ylvisaker & Debonis, 2000), are compromised. From her participation in this study, Sally learned that the “process of planning and doing a creative project step-by-step can be applied to planning and doing daily life tasks”. She recognized that she had to learn to “identify the steps required and the sequence of the steps and then...how those kinds of skills can be translated into life skills”.

Because Sally is quickly overwhelmed, she feels unable to plan because “my head doesn’t know where to start”. She knows, however, that “virtually everything you do ...requires more than one step”, so it has become easy for her to procrastinate. One morning Terry cancelled her appointment with Sally at Sally’s apartment:

...all of a sudden the morning is freed up because Terry couldn’t come...that’s what I planned on doing. So now I have this time, what

needs to be done?....And what tends to happen is by the time I get that figured out that block of time that I had that I was trying to figure out how to fill, well it has been filled with trying to figure out how to fill it ....

Sally hopes that this study has helped her planning skills, because she says “[I] don’t know how to plan properly/realistically to get things done – don’t know how to break down tasks into manageable steps/ track them/ schedule steps in an appropriate timeframe because I don’t know how to develop/ track/ schedule a timeline”. Sally did learn how to make a more realistic plan during the course of the study, one that she could actually initiate because the task was broken down into manageable steps.

***Valerie.***

Valerie’s cognitive impairments are severe enough that issues of planning and self-efficacy are beyond her. She has no concept of time, and had to be guided through the steps each time we painted flower pots. I felt she was a valuable addition to the study because of the contrast she was to the other participants. I did lots of things to help her, things that she simply was unable to do on her own. I washed flower pots, mixed paint colours, and cleaned up. She worked with Terry and me on the project, and we had to suggest what the next step was (an example: why don’t you draw the design with a pencil?). I had to help her constantly, for example, telling her that the paint was too thickly applied, or that she needed to rinse her brush before using the next colour.

**Act 4 Scene 4: Slow Down the World: Sensory Overload Issues**

Diana, Sally, Valerie, and to a much lesser extent, Jim, all have problems with sensory overload. Stoler and Hill (1998) maintain that sensory overload is caused by mental fatigue, which often occurs when the brain has to cope with a multitude of incoming information after an ABI.

***Diana.***

Diana is very thankful that she has Bob to help her navigate life and thinks that if she had to “deal with everything on my own I would be totally overwhelmed”. She is afraid that she would “just cop out...it would be so hard”. She leans on Bob in many ways that are not apparent to other people, and remarked to me that “If I was totally on my own, I’d be terrified”. Sometimes, she thinks there is just “Too much stuff...like you just blank, you stop listening, like yah, yah, yah”. When there is too much sensory information, Diana relies on Bob to help her, so, according to Bandura, Adams, Hardy and Powell (1980), her self-perception of her efficacy is low when she is faced with sensory overload.

Diana’s sensory overload issues tie back into her planning and procrastination problems, discussed earlier. She finds it helpful to break things up into pieces that she can manage and, after thinking about her issues, she felt her procrastination was the result of her “hesitancy to go forward into something” that she feels is just too much. To overcome the sensory overload she faces, she wishes she “could break it down in my head, ...or on paper, whatever I had to do...I realize that its just one step at a time but I just see the whole”. She

remarked that “The hardest part of starting the stained glass project was being able to visualize all the steps involved”. Diana’s stained glass project helped her realize that “everything can be accomplished one step at a time and you can identify each step”.

***Jim.***

Jim’s issues with sensory overload are not obvious, but he told me that when he’s on the bus on his way home from *Creative Enterprises*, “sometimes I hear four or five walkmans....don’t bother saying anything to me then!” He also mentioned that he finds he makes more sense “when I’ve had the opportunity to think of what I want to say. My info retrieval rate isn’t what it once was!” This indicates that his cognitive processing may be slower than before he had his stroke.

Although he experiences sensory overload, Jim finds his physical problems are more limiting. These problems sometimes require him to use inventive and creative techniques to do everyday things. He told me that completing projects sometimes took longer because he “not only [thought] about how [he’s] going to hold something steady, but what [he] need to do to implement that idea”.

***Sally.***

I’m just thinking about the whole issue of sensory overload....It occurred to me that it is such a big part of my life, ...I think that by doing these kinds of projects, it might actually help us to learn how to manage that sensory overload....by just trying to make decisions, you know, about what colour

to use, about what to make....That in itself can get overloading, so how do we manage that bulk of information to make a choice?

As the quote above indicates, Sally is very aware of sensory overload and how it affects her. Sally first became aware of sensory overload when she was discharged from the hospital after her accident. She was stuck by “how much more noticeable the traffic was and all the lights and everything”. Stoler and Hill (1998) found that the areas of oversensitivity Sally noticed, hearing and sight, are those commonly affected when sensory overload is experienced. But, understandably, Sally wrote it off, thinking she had “been sort of sensory deprived because [she’d] been inside for two months”.

However, sensory overload issues have turned out to be a big part of Sally’s life. To explain it to me, she broke it down into three parts. Firstly, she “can be very easily distracted”, so she knows that she “needs to be concentrating” on what she is doing. Talking to me and answering my questions while she was painting caused her to lose thoughts easily as she tried “to switch between tasks”. She commented that she finds that “just trying to divide my attention...is a real challenge”. Her sustained attention, or, as it is explained by Stoler and Hill (1998), “the ability to focus and concentrate on a task or thought for a period of time while filtering out other information from your body or from the environment” (p. 141), is not what it used to be.

Secondly, sensory overload comes into play because there was “so much new info to take in and process all at once”, so, working at her project, which involved water colours, was tiring because it was a new skill for her. She is also affected by the “amount and the speed at which new information comes at” her.

She knows that the optimal way for her to learn is to have new information “delivered in manageable pieces at a slow pace”.

Thirdly, she found exploring all the options available to her in relation to the project she was undertaking was exhausting. Sally finds that she can't encode new information fast enough, so it is frustrating and difficult for her to retrieve this information later. She added that “my brain can generate information faster than it can process it”. Sally commented after our first session, that she was “really tired by the time the session was finished”. Happily, she added that although she was exhausted, she was also exhilarated.

At one point, when I was working with her, Sally noted that when she painted she was able to relax and “everything else just shuts off and goes away”. This comment added fuel to my feeling that sensory overload can perhaps be helped by counseling ABI patients to concentrate on only one thing at a time. Goldberg (1997) maintains that the arts can be used to encourage concentration and contemplation, a concept endorsed by Terry. Sally knows that she should “take the time to do something creative for my own enjoyment in order just to recharge myself”, but she added that she finds that “daily stuff takes up all the time and energy I have available”. For instance, if she is going away for a night, because of her increased fatigue, throwing the things she needs in a bag takes a lot more effort than it used to.

**Valerie.**

Sensory overload is a huge issue for Valerie. During my sessions with her and Terry I learned a lot about working with severely impaired ABI patients. I have shared most of this information in the section on Valerie's creative experiences.

Because Valerie's communication skills are limited, Terry explained that "it is at times difficult for her to voice the fact she does not like her choices. Instead she just says OK, and picks something to make peace". When used by Valerie, this strategy reduces the sensory overload she has to experience because she does not consider all the choices she is offered. By acting impulsively, she does not have to think about her options and rushes to make decisions. When Valerie is flooded by too much information, she either acts impulsively or clams up. Terry told me that when Valerie feels overwhelmed, "her desire to do things quickly interferes with her ability to turn out a well finished product". Terry cautioned me to give Valerie time to think and comment on each subject before I switched ideas.

Valerie also has physical sensory overload issues. She has a great deal of difficulty with visual overload, meaning that she is very sensitive to lighting, especially fluorescent lighting. Stoler & Hill (1998) note that this is a sensory overload problem faced by many ABI patients. If the room is too bright, or if Valerie is working with colours that are too vibrant, she is uncomfortable. She is also bothered by a hair dryer that is too loud, and she doesn't like her scalp to be touched.

**Act 4 Scene 5: I Made This! Rehabilitating Self-Esteem**

Grace summarized not only the impact of *Creative Enterprises*, but the impact of creativity in general when she told me:

*[Creative Enterprises]* helps their self-esteem, it helps them feel good about themselves and what they can accomplish...they just feel so good about what they're producing. There's a lot of different aspects to it but I think the self-esteem, feeling good about yourself, looking at something, knowing you've produced it, knowing you have the confidence to start and finish and discovering new potential areas.

My participants all used different words to describe how they felt after completing their creative projects, but there were some words that they all used to explain their experiences. Diana's main impression was the "totally new learning she had experienced and the "increased sense of pride in herself" that her project had given her. Jim, Diana, and Sally all used the words "increased self-esteem" and "feeling self-confident". Sally felt the experience was "rewarding and encouraging". Valerie's feelings are manifested in her pride when her artwork is displayed. These comments made by the participants highlight that their creative experiences let them "experience accomplishment", a result that Goldberg (1997) thinks that art brings to those that engage in it.

***Diana.***

It took Diana a while to acknowledge the influence that creating her stained glass door had had on her. Before completing the project she wrote to me that she thought completing it would have little effect on her life. Right at the beginning, Diana had told me that she was afraid to learn. However, during the group meeting, she said that her creative project had affected her desire to learn

in a positive way, because it was “totally new learning...it was great!” Because she completed the project, it helped her to gain “confidence in my abilities, especially in new learning”. Diana feels that it was “the completion rather than the finished product” that was important for her. She felt a huge accomplishment when she had finished her stained glass door. Importantly, this achievement reinforced that she was capable of learning something new. Strauser (1995) echoes Bandura (1977) when he writes that “cognitive events are induced and altered most readily by the experience of mastery arising from effective performance” (p. 7).

Another important benefit of creative activity for Diana was that it gave her joy. She thinks that consciously “we have to put more of that in our lives because there’s a lot more on the opposite end”. Aldridge (1991) makes note of the heightened sense of self that individuals discover as they experience freedom when participating in creative activities. Diana also feels an “increased sense of pride in herself”. She notes that although she felt proud looking at her clean windows, “other people do not see this as as big an accomplishment as I do”. She followed this remark by saying “a creative project is more accepted and acknowledged by others even though the same ‘work’ goes into each”. Her self-esteem is externally validated when someone praises her work.

*Jim.*

I was yet again floored by Jim’s amazing insight when he e-mailed to me his thought that, even if you’re not injured, “you as a person strive to continually

get better and if you accept anything below that you're defeated". At the time I marveled, and continue to marvel, at his acceptance of his injury.

Jim derives enormous pleasure from helping others:

I've tried to make it a goal of mine to help where I can....in the case of the short lady in the supermarket, maybe getting her that can that she couldn't reach enabled her to bake a BD cake for her granddaughter, in which case it would have been worth it. Often I'll help someone I don't know or even know and think "how did that act influence their day?" You have to think of something when you're on that long bus ride!

Jim relates virtually everything to his workshop. When asked how he is now compared to pre-injury, he commented that "before my injury I may have been too superficial and I'll always look at my injury as the 'tool' that allowed me to 'fix' that little problem (at least I think!)"

Having the chance to talk, and feeling the self-confidence to try, are definitely the biggest advantages Jim sees of his time at *Creative Enterprises*. He says proudly: "When I'm at *Creative Enterprises* and HAVE to verbalize my ideas I often say things that I never dreamed I could say". With lots of wisdom, he remarks that "An increase in self-confidence to me means realizing you did the best you can and understandably it's still not understood". I have no hesitation in saying that Jim's self-confidence comes from within himself. If he is not understood, he accepts that "it's not my fault; it's the stroke's fault".

Jim has learnt not to take it personally if someone does not understand him, showing that he has good internal locus of control, or, in other words, that he is in control of his own life and behavior. Julian Rotter's locus of control refers to the fact that "People who generally believe that they can control their own fate will behave differently in many (but not all) situations from people who typically

believe that their destiny is controlled by luck, chance, or powerful others” (Feist & Feist, 1998, p. 359). The concept of locus of control is a general indicator of to what extent people feel that they have control over their own lives. For example, students with an external locus of control will think that they did well on a test because the test was easy and it was their ‘lucky day’. Students with a strong internal locus of control will attribute their good test results on working hard to prepare for it and making sure they understood all the material.

Jim feels that his experiences at *Creative Enterprises* have increased his self-esteem because of the “things that I will do or at least attempt to do”. He adds that this then “by osmosis, spills into my life in other forms”. If you are given the chance to “build things that you never dreamed of...that can’t help but increase your self-confidence and self-esteem, and in turn benefit you as a person in your everyday life”.

In conclusion, Jim understands his injury, his former life, and his current life. He knows that his creative tasks have helped him make enormous strides in his recovery. The following thought, arriving by e-mail as usual, summarizes his feelings about the influence of creativity on his healing:

The body will do amazing things if the mind allows it. When you’ve had a brain injury and survived this is probably near the top of the hurdles you [will ever] have to get over. This is a slow process, as you well know....I tend to believe that you can learn a great deal about the ‘new you’ after you’ve completed a creative task.

**Sally.**

It took almost six years to get it [the head injury] diagnosed....the ensuing however many years to get the right kind of rehabilitation...in order to

keep going through that time, I discovered that I'm a lot more capable, a lot stronger, a lot more determined and tenacious than I ever knew I was....I often marvel at the irony that it takes sustaining a brain injury to gain your self-esteem and self-confidence.

I question whether Sally's concept of her self-esteem comes from within, or whether it is bolstered by comments from other people. I think that Sally's perception of herself is not built from inside her, but from the comments and compliments of others. Revealingly, she told me that before she was injured, nobody had "run around looking and saying...you do that really well or you do the other thing really well".

By whatever means Sally judges her self-esteem, she was delighted to have the chance to "see I can do something I didn't know I could do. I wonder what else I can do...it's exciting and satisfying". Several times, Sally mentioned that she was happy with what she was accomplishing, and proud of the cards she had made. She found the exercise of making the note cards "rewarding and encouraging". The happiness and pride she felt "fueled my energy and confidence to do, or at least to try to do, other tasks". This is an example of Woodman and Schoenfeldts'(1989, 1990) interactionist theory. As it was for Diana and Jim, the outcome of the study was positive for Sally. She noted that "the confidence that comes from a successful project can carry over into confidence to do other tasks in daily life that had previously been uncomfortable to do". This increased confidence and control over her life will, over time, lead to an increased sense of self (Gladding, 1995).

**Valerie.**

Completing art work is very valuable for Valerie. Terry has seen major changes in her in the past year. Falconer (2000) maintains that “even individuals who sustain severe head injuries continue to recover old skills and learn new skills throughout their lives when appropriate learning strategies and environments are provided” (p.1). Falconer’s findings are validated because Valerie is now communicating with others. She appears to be having fun; she chattered away when we were painting flowerpots together. When she has finished making something, Valerie tries to give it away, either to Terry for her children, or to one of the people in the office, because she is very proud of her work.

As Sacks (1986) pointed out, the beauty of Valerie’s artwork lies in its knack of letting others focus on her abilities, not her deficits. At *The Eagle’s Wing*, her artwork is displayed throughout the office. Each time she comes, Valerie looks around carefully, checking to see that her things are still displayed. The staff at *The Eagle’s Wing* recognize how important this is to Valerie. When I was last there, there were at least four flowerpots on display in the sitting area.

### **The Conclusion**

#### ***What Do I Think and What Did I Find: Answering the Research Questions***

Throughout my data analysis, I tried to remain flexible, so I didn’t, as Rossman and Rallis (1998) advise, “hide the unusual, the serendipitous – the paradox that can lead to insights” (p. 174) that could be found in my data. The

result of this flexibility was the discovery, within the data, of countless nuances, an infinite number of revelations, and massive amounts of self-reflective insight. By *analyzing* the data (Wolcott, 1994), I reduced my findings into the four major themes discussed in the previous section. I will now *interpret* the data (Wolcott), to answer the following research questions, posed at the beginning of the thesis:

- a) How do individuals who have sustained an ABI feel when they have completed a creative task?
- b) How does the way these individuals feel when they complete their creative tasks affect the way they feel about other aspects of their lives?
- c) How can individuals who have sustained an ABI, learn things about themselves by doing creative activities which will help them be more successful in other aspects of their lives?

***a) How do ABI patients feel when they have completed a creative task?***

Accomplished, energized, self-confident, capable of learning, unique, happy, talented, having the momentum to start another task, positive about myself, sense of pride, satisfied.....pretty darn good!

These are some of the words used by my participants to describe how they felt after completing a creative task. These words could be used to illustrate the experience of any of my participants, although only Jim and Sally used most of these words. Diana was a little more restrained in her comments when relaying her thoughts. I am certain that she felt the same way as Jim and Sally, because she said that making her stained glass was a positive experience, and “anything you do positive” enhances self-esteem. We can only speculate what

Valerie's experience was by interpreting her responses. My understanding of her reactions is that these words describe her feelings also.

Jim, who derives so much pleasure from giving his woodworking projects away, told me that "there is a certain satisfaction, I think, from making anything with your own hands and giving (as opposed to selling) it to someone". Sally has "a great sense of pride and accomplishment" after completing a creative task. She got a "little boost inside" when she completed something. Diana told me that she realized that she could "learn a new thing, that I could accomplish something, so it helps my self-esteem".

***b) How does the way ABI patients feel when they complete their creative tasks affect the way they feel about other aspects of their lives?***

Jim wrote to me that "the satisfaction you get from completing a project and also doing it well gives you the confidence to cross other 'hurdles' in life". Diana's comment was that she limited the 'hurdles' she would cross to her creativity. She implies that completing her creative project would only help her complete other creative projects. Interestingly though, she then told me that completing a creative task gave her the "momentum to start another task". Sally said that she had the confidence "to do other tasks".

The above are all examples of Woodman and Schoenfeldt's (1989, 1990) interactionist theory, which is part of the conceptual framework. According to interactionist theory, the participants experience a feedback effect from their creativity which positively impacts other parts of their lives. Jim, Sally, and Diana

all experienced increased pride and confidence which they felt would carry over to other parts of their lives.

***c) How can ABI patients learn things about themselves by doing creative activities which will help them be more successful in other aspects of their lives?***

***i) Self-efficacy.***

Bandura (1995) and Feist and Feist (1998) define self-efficacy as involving a generative capability in which component cognitive, social and behavioral skills must be organized into integrated courses of action to serve innumerable purposes. I am certain that the creative projects Sally and Diana completed were beneficial to their self-efficacy. Jim came to the study with high self-efficacy. Valerie's cognitive deficits are sufficiently severe that she has very little concept of self-efficacy.

***Diana.***

Diana thought that "the process of planning a creative project had helped me in the planning of other creative projects". She added, though, that she didn't "think the process has spilled into other areas of my life". On the other hand, Diana did think that this creative project had helped her:

...to learn to manage things in smaller bites....I learned to take one step at a time. I think a lot of my hesitancy to go forward with something is it is just too much. Everything can be accomplished one step at a time and you can identify each step.

Diana's remark indicates that her project helped her self-efficacy. As Feist and Feist (1998) point out, she seems to have realized that, by breaking a project that she is planning down into small steps, she will have the self-efficacy to perform the task.

***Jim.***

I don't think that Jim has any trouble with self-efficacy, but he can see how involvement in, and completion of, creative projects can be beneficial to one's self-efficacy and planning. Jim told me several times how he thought that planning and completing creative projects can help self-efficacy in other parts of life. He commented that: "Planning a project from an idea to the finished thing can help you in many ways. It can be something in life as simple as getting the right groceries to making certain you have the proper meds and enough of them".

***Sally.***

Sally felt that doing creative activities would help her and, with prompts, she would be "able to make clear plans and follow a timeline". In addition, she felt that she could "generate solutions to problems ...[if she uses the] creative process of breaking problem down into manageable pieces/steps and deal with them one at a time".

Sally's deficits are partially manifested as self-efficacy problems. Sally has compromised self-efficacy, because she does not feel she can organize and integrate her skills to initiate tasks. According to Mruk (1999), improving one's

self-efficacy will lead to improved self-esteem. Mruk thinks that “the general idea is to help people increase their sense of self-efficacy by learning to become more successful, which, in turn, increases self-esteem” (p. 109).

I have several thoughts about Sally. Throughout the course of the study, she has impressed me with her references to the ‘life lessons’ that she takes away from an exercise. For example, she noted that during the group interview, it was “valuable to review and reinforce what we have learned/gained from this project so we can stay aware of the lessons learned and how we can apply them to our daily lives”. Another time, she talks about her inability “to develop a timeline”. She mentions that it is “important to be aware of this and find solutions because these are issues that affect many areas of daily life”. Once, she wrote that I kept her “focused on moving [the] project forward in manageable pieces because I don’t yet think to define and schedule next steps to ensure project keeps moving towards completion”. Sally has told me that she has to be aware of “the need for developing steps” and the “need for planning ahead”. When I first asked her whether doing the creative project would help her in other ways in addition to teaching her water colour skills, her response was that she wasn’t “sure yet because [she was] just starting to recognize the life lessons from the project steps”. She wrote that it “will be interesting to see if and how the skills transfer from one area to another”.

Sally is complicated and complex, and therefore she was hard work to have as a participant in this study. She is delightful, polite, articulate, and gracious, yet she presents some serious hidden deficits from her head injury. As

my data collection and analysis went along, I was more and more certain that things were not at all as they seemed to be on the surface. My feelings were confirmed by Grace, who told me that part of the reason Sally had trouble obtaining essential rehabilitation for so long was that her deficits are so concealed. According to Grace, for a long time therapists did not understand Sally's deficits. When she tried to access therapy, she seemed fine. Grace explained to me that Sally intellectualizes everything. I have experienced her intellectualization while I was involved with her in this study, and it is summarized above. Sally's overriding deficit is that she can't take an abstract concept and apply it to herself. On her own, she is unable to integrate what she has learnt and use it in her day-to-day life. Her deficits are so obscure that they only became apparent to me when I had spent quite a bit of time with her.

Sally's deficits point to executive function problems. Executive functions include planning, organizing, initiating, making sound judgments, and understanding (Stoler & Hill, 1998). Executive function skills are defined by Osborn (1998) as "The ability to organize thoughts and work, to create plans and successfully execute them, to manage the administrative functions of one's life" (p. 237).

Sally seems to have little trouble with the first stage, planning, as indicated by her well thought out e-mails (Appendix J). However, from her comments, she does not seem to recognize her ability to do this. Stoler and Hill (1998) describe that planning is "the first step in organized daily living – you must decide what it is you want to do before you can determine how to accomplish it" (p. 160). They

explain the second step, organization as “the ability to determine how your daily plans are going to be accomplished” (p. 161). The next step is initiation, which is “the ability to carry out the tasks you have set for yourself – the ability to translate thoughts into activity” (p. 161). Sally’s main difficulty lies in her inability to initiate a task, after planning and organizing it. Processing information, which is defined as integrating new sensory information with old knowledge (Stoler & Hill), is something else that Sally finds challenging. However, processing information does not present the debilitating deficits to Sally that her problems moving from the planning stage of an activity to its initiation do.

My hope is that planning the completing of a creative task will help Sally in this respect. Ideally, she will not only be able to plan, but she will also be able to continue on and carry out her plans. By improving her self-efficacy, or her belief she can successfully complete a project, her self-esteem will improve. Therefore, I was pleased to hear that Sally was going the next step and had made several note card sets of her own accord.

***Valerie.***

Valerie presents huge cognitive deficits that appear not to allow her to realize benefits to her self-efficacy from creative activities. Valerie has no concept of self-efficacy. In addition, she is not capable of planning, let alone executing a plan. The benefits from creative activity for Valerie are highlighted in the next section.

***ii) Other benefits seen from engaging in creativity.***

***Valerie.***

Aesthetic experiences lend themselves to teaching and learning in at least five ways: (1) perception: an awareness of one's surroundings and actions; (2) concentration: a tool for exploration through actively stopping, listening, seeing, feeling; (3) imagination: a journey of the mind to new places; (4) contemplation: an opportunity to question and search; (5) action: our questions and searches are pursued.

(Goldberg, 1996, p. 157)

As Goldberg (1996) suggests, the creative process offers several benefits to Valerie. When I was slow with my suggestions and spoke softly and quietly, it helped her learn to perceive what she was doing, and concentrate on it. She is also learning contemplation; Terry commented to me that "Valerie enjoys the process, the discussion". Contemplation will help her natural tendency to rush through things. Creative activities were therapy for her perceptual skills. By decorating the flower pots, Valerie practiced spacing her designs and coordinating the colours she used.

Valerie is noticeably proud of her creations. She checks that they are still displayed, and she gives them away. When I learned how to be around Valerie, I could relinquish my preconceived concepts of how something should be, and appreciate the basic benefits that are derived from creative involvement, the enjoyment of creating, the pleasure of giving, and the pride of seeing something that you created on display. The satisfaction that Valerie appears to feel after being creative reminds me of a child's immediate emotions. If only we could all feel the pleasure of creation, without fearing the judgment of others as well as

inflicting critical self-judgment on ourselves, we would all derive a lot of benefit from creativity.

***Jim.***

The benefits of the creative experience for Jim are enormous. In addition to those benefits I have already discussed, Jim thinks that engaging in creativity has helped him cognitively. He wrote that “I seem to be a little more forward-thinking than before. That is, I think of problems that I may get into (proactive) before they happen (reactive)”. I think that this is more evidence of his enormous self-efficacy; he is confident that he has the ability to build something (Feist & Feist, 1998), and he can foresee potential problems and plan accordingly.

***Was The Purpose of The Study Fulfilled?***

The purpose of this study was to explore the use of creative activities to enhance the self-esteem of individuals who have sustained an Acquired Brain Injury (ABI). I have examined how bolstering their self-efficacy by engagement in creative activities can be a building block toward enhancing self-esteem. In two of my participants, Diana and Sally, it became evident during the study that creative activities definitely helped their self-efficacy and self-esteem. Jim’s self-efficacy was already astounding, but by talking to him, it is obvious that his self-esteem is also heightened. I have no doubt that Valerie also feels increased self-esteem. The benefits of including Valerie in this study were not apparent to me initially. However, despite her severe cognitive deficits, I believe that she feels

enormous pride and satisfaction, and therefore heightened self-esteem, from her creative endeavors.

***Possibly an Encore....***

The following ideas present possibilities for future research:

- 1) How can creative involvement, in the severely compromised individual, like Valerie, be used to establish a sense of self-efficacy, planning, order, and task completion in minor, everyday tasks, such as cooking and housework?
  
- 2) Sensory overload (Stoler & Hill, 1998) presents a huge problem for individuals who have sustained an Acquired Brain Injury. Goldberg (1997) thinks that “the arts can promote or awaken perceptions and imagination while at the same time providing a tool of concentration and contemplation” (p. 150). How can the impact of sensory overload be reduced by teaching coping skills, concentration, and focusing strategies, using creative activities as a vehicle?
  
- 3) How can heightened self-esteem, attained by engagement in creative activities, be used, by individuals who have sustained as ABI in tangible and concrete ways, such as seeking employment, or engaging in a more active lifestyle or volunteer work?

### ***Limitations of This Study***

As the researcher, I feel that the benefits from this small study outweigh its limitations. However, as Creswell (2002) points out, there are several reasons for pointing out a study's weaknesses. Weaknesses are useful in the future for researchers who chose to undertake similar studies. In addition, awareness of limitations may indicate to what extent the research may be generalized to other situations.

I am a researcher who has sustained an ABI, so I can be painted as 'one of them'. This can in some ways be advantageous. I am an insider and therefore I have an insider's perspective. On the other hand, as much as I have tried to remain an observer, I did have to switch 'selves' to maximize my interaction with the participants. I hope my epistemological closeness does not colour the study unduly. I think it is only an advantage, but there may be people who think differently.

Another important limitation to this study is the question: What were my participants like before their ABIs? This limitation is huge and unchangeable. It might be that some of the changes attributed to ABI were there all along. It is impossible to verify this.

### ***Final Thoughts***

Two of this thesis' participants, Diana and Sally, started their creative involvement when they became participants in this study. Working with Diana and Sally allowed me to involve them, and then write their stories "like a potter, in

whose hands something new is formed” (Wolcott, 2001a, p.203). This quote metaphorically describes Diana’s and Sally’s creative endeavours as well as describing the process I went through writing about their experiences.

Jim and Valerie, on the other hand, have done creative projects before. Working with them allowed me to write, by carving “away like a sculptor, to reveal in fine detail what was there all along” (Wolcott, 2001a, p. 203). This quote aptly describes Jim’s thorough, thoughtful, and insightful examination of his self-efficacy and self-esteem for this study. Although Valerie was cognitively unable to express more than her immediate feelings, I feel that this quote also captures the process of including Valerie as a participant. When I interacted with her, I had to carefully expose the parts of her that derive so many positive outcomes from creativity, without causing her distrust, confusion, or sensory overload. I was extremely fortunate to have such a range of experience and cognitive abilities in my participants.

This study is directed to contributing new knowledge to ABI research. The results show that engaging in creative activities had a positive impact on the five participants. My findings indicate that, as Mruk (1999) suggests, when individuals become more successful due to increased self-efficacy, their self-esteem is also improved.

This study offers a unique perspective, because, while I am the researcher, I am from the same distinct culture as my participants. To take full advantage of the insight that could be gained from this perspective, I used auto-ethnography as my methodology. This allowed me to include my own story as a

basis for the literature review. My story also appears in the form of a short story, as one of the study's alternative representations. Significantly, I found that the study had a very important, but unforeseen result, because it positively impacted my own self-esteem. As I alluded to in the short story 'The Long Tunnel', returning to school and then writing this thesis has been instrumental in the re-establishment of my own self-esteem. Because this thesis is an auto-ethnography, I was able to use the process of writing it as an important tool in the process of creating my own 'new self' as I re-establish my identity after my injury (Greene, 1995). I also feel better having written this auto-ethnography, because, as Isak Dineson, the author of 'Out of Africa', wrote, "All sorrows can be borne if we put them in a story or tell a story about them" (cited in Monk Kidd, 2002, p. 8).

I have tried to remember that a qualitative study describes and interprets "what is"; it is not a "pronouncement of what ought to be" (Wolcott, 2001b, p. 121). Therefore, the interpretations I have made are specific to the situation and the study. My hope is that this exploration will make an interesting, useful, and concrete contribution to the field of ABI research and to the background knowledge of therapists striving to maximize the recovery of their patients.

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Artistic Representation of the Conceptual Framework





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## Appendix C

### Consent Letter Given to Participants

I, Claire Smith, am a M.A. student at the University of Ottawa working under the supervision of Cynthia Morawski, Ed. D. For my thesis, I would like to interview and work with TBI (traumatic brain injury) participants. I would like to ask for your participation in this study. To agree to do so, please sign this consent form. This is necessary because whenever a research project is undertaken with human participants, the written consent of the participants must be obtained.

The purpose of this research study, which is my thesis for the M.A. program, is to explore how the involvement in creativity helps traumatic brain injury (TBI) patients improve their self-efficacy en route to regaining their self-esteem. I hope that, in part as a result of this study, involvement in creative activities will come to be regarded as an integral part of TBI (traumatic brain injury) rehabilitation.

Your participation will be in the form of informal talks during a six-week period when I am part of the team and an observer at (Creative Enterprises), a workshop associated with (The Eagle's Wing). All informal talks will take place during your regular visits to (Creative Enterprises), or, if you prefer, in your home. As a result, there will be no additional time commitment required from you. Depending on your availability during the six week period of the study, I would like to spend an hour, once a week, talking with you. The talks will be audio-taped.

You will be given copies of the transcribed interviews, and you will be asked to verify your responses, adding, deleting and changing information as you see fit. You are invited to ask any questions you may have concerning the research being conducted. When the final study is released, you will be given a copy to keep if you would like one.

I, \_\_\_\_\_, am interested in collaborating in this research project and I certify that I understand the nature of the research as described above.

I would like a copy of the study results when the study is complete.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

## Guiding Questions for the First Conversations with Participants

1. How do you feel about the tape recorder? Do you think it will affect what you say?  
(Explain why I need it...)

### 2. Background

Name, age, living situation

Tell me about your life before your injury...family, job....

How have your living arrangements, job changed...

When was your injury?

Tell me about what happened after your injury – how long in hospital, rehab, what kind of rehab

Do you have ongoing rehab or support now? Describe....

How is your life different now? – family, friends, job etc

What can't you do now that you used to do. Why can't you do those things – cognitive, memory, physical

Describe how these changes affect the way you feel about yourself

Do you know what self-efficacy is ( the capability to plan, organize and execute courses of action when coping with situations in life).

How are your planning abilities? Changed from how they used to be?

Do you like to plan projects, trips, the day, the week, or do you make plans for next winter?

How is your self-esteem? (The conviction that one is competent to live and worthy of living)

Ask it again ...How do you feel about yourself compared to pre-injury?

### 3. Creative Activities.

What would you like to try??? (painting, woodworking, stained glass, flower arranging)

Do you get excited at the prospect of having a project to do from start to finish? Do you have any projects of any kind that you are working on now?

Are you going to make something for yourself? If not, who are you going to make something for? Why did you choose that person?

How often would you like to work on your projects

Would you do it more if you had more time

Does it matter how 'artistic' you think you are...

Can I talk to you while you are working, or would you prefer to talk to me afterwards?  
...lets think of a schedule now.....

Keep a journal after doing creative activities, how you feel before and after, how is your self-esteem generally...

Guiding Questions for the Group Meeting of Participants

To be discussed at group meeting with other participants.

[Start off by saying that if I ask a question that you don't feel comfortable answering, please say so...

Does anyone have any time constraints?]

**1. Do you like to learn?**

- a. Describe yourself as a learner.**
- b. How do you feel your creative experiences affect your desire to learn in general?**
- c. What is your understanding of what creativity is? If someone asked you to define creativity, what would you say?**

**2. What types of creative activities do you enjoy? What is it about these creative activities that you enjoy?**

**3. What do you believe about your own creative abilities?**

**4. What do you believe about your abilities in general when managing day to day events and activities in your life? Why do you think you have these feelings?**

**5. How does your involvement in creative activities influence the way you think or feel about yourself about other aspects of your life?**

**Does it matter to you how good or talented you perceive yourself to be, or is it more important to you how it makes you feel to engage in these activities?**

**Explain....**

**6. What have you learned about life skills from your involvement in creative activities?**

**7. How do you think your life skills have changed since you started your involvement in creative activities?**

**Do you think you'll be able to use these skills in your life?**

**8. Are you interested in learning the creative skills, and/or doing creative activities for relaxation, accomplishment? Elaborate....**

**9. Are there any types of creative activities that make you feel bad about yourself?**

**Do you know why this happens?**

**10. Tell me about your (self-esteem, self-confidence, sense of self, self-efficacy)...tell me how you feel about yourself...good, bad, uncertain?.....**

- 11. How are these characteristics (self-esteem, self-confidence, sense of self, self-efficacy) different from the feelings you had pre-injury? Tell me about each one...**
  
- 12. How do you think that your involvement in creative activities affects your confidence, self-esteem etc?**
  
- 13. What factors resulting from your accident do you think precipitated these changes?**
  
- 14. Are there any connections that you can make between your creative activities and other aspects of your life?**



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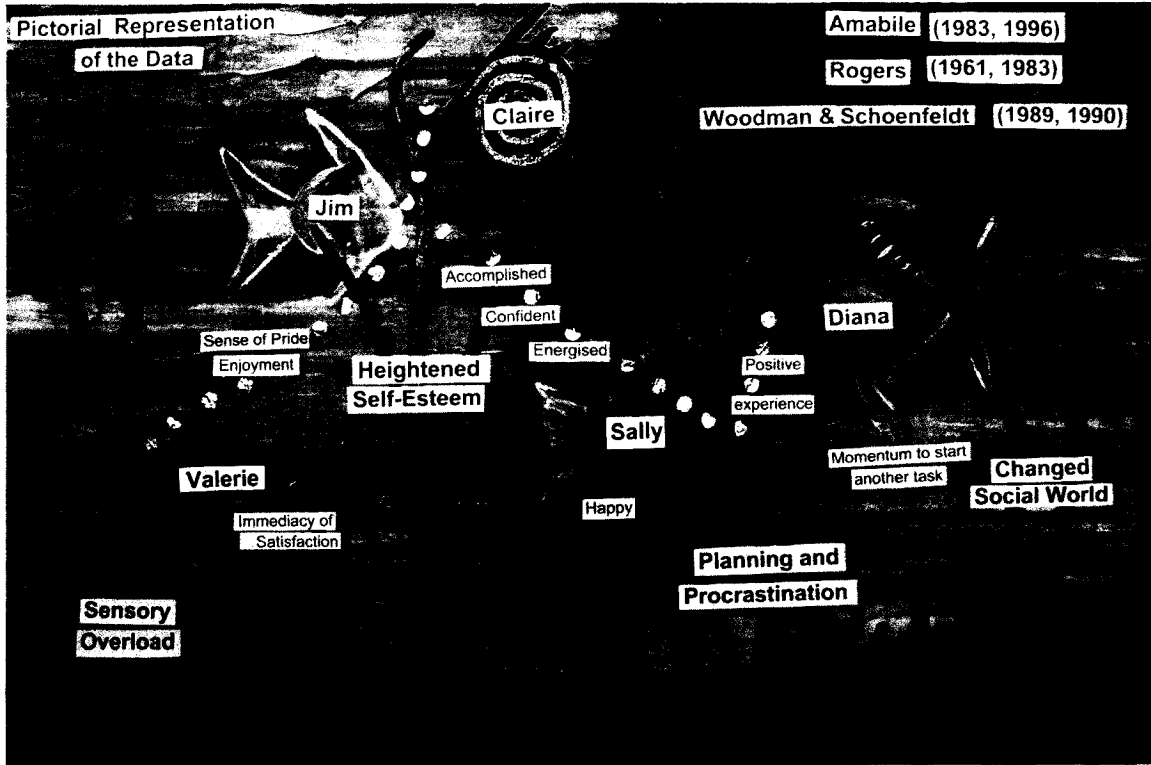
## Appendix F

### Confidentiality Letter for Transcription

I, \_\_\_\_\_ am transcribing data collected by Claire Smith for her M.A. thesis. I realize that the information I am transcribing is confidential, and I will not divulge this information to others.

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Appendix H - Pictorial Representation of Data Analysis



Sally's Plan for The Session

## **Claire Smith – Creativity Study**

**Date:** .....

### **Homework:**

- E-mail files and new journal & questions
- Paint mat
- Assemble cards
- Edit transcript

### **Topics:**

- Return transcript
- Get Answer sheet from Wed – copy notes & return
- Design Problem – unhappy with the way card looks (card too white against watercolour paper?) – how to tear edges cleanly (especially for small sizes) – how to solve?
- Position images on cards (see templates)
- Attach images to cards
- Package cards – measure cards & envelopes for size of container
  - find & buy container (\$ Store / LC/ Party Store/Wallaces/etc)
  - buy ribbon to match cards
- Samples & Pictures for Claire

### **Next Meeting / Homework:**

### **Summary:**

Sally's Journal Entry

## **Creativity Journal**

**Date:     , 2003**

- Really enjoyed today's session – fun/relaxing
- Easier to manage – less sensory overload because fewer elements to work with for cutting and pasting images on cards – less fatiguing
- Enjoy social element of Claire's company
- Glad that Claire was able to reassure me that contrast between white card stock and ivory colour of watercolour paper wasn't as bad as I thought it was – important to have someone to confer with to help resolve design issues when can't see solution/options on own
- Appreciated Claire's enthusiasm about how cards look and her suggestion of the possibility of using them as fundraising tools for the Wings of Phoenix program – presents some very exciting possibilities of using something I enjoy doing to contribute to worthwhile causes in a way that I can manage – product is of benefit to others and process is beneficial to me (the definition of a win-win situation!)
- Process of putting cards together can together nicely – old art supplies I kept after design program at Algonquin have come in really handy – like painting , process is very relaxing and completely clears my head – a lot of fun  
    Quite pleased with how well cards are turning out – rewarding / encouraging