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“Just” Words: The Perceptions of Women with Brain Injury on the
Impact of Verbal Interactions with Physicians

by

Leslie H. Allison

A THESIS

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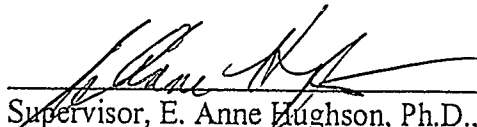
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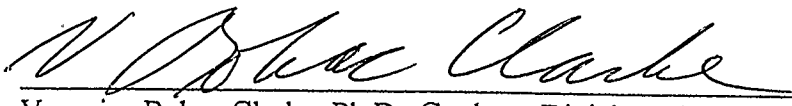
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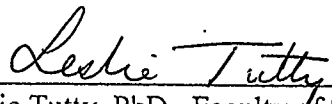
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Just" Words: The Perceptions of Women with Brain Injury on the Impact of Verbal Interactions with Physicians" submitted by Leslie H. Allison in partial fulfillment of the requirements for the degree of Master of Arts.




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ABSTRACT

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This phenomenological hermeneutic thesis contemplates suggestibility and influence.

Modeled on Moustakas' transcendental phenomenological reduction with imaginative variation methodology, I illustrated parallels with the progressive symphony, used musical terminology resonating metaphorically across disciplines, and created the "voiceprint", rooted in Cassell's (1985) paralanguage concept. The design offered lenses through which to view the question.

A three-element question with personal significance and social meaning was formulated: What are the experiences of women with brain injury in their verbal interactions with the physician? What are their personal interpretations of this discourse? Do they believe this personal interpretation of verbal interaction impacted the quality of their healing and rehabilitation?

Following the recommended three-interview process (Osborne, 1990), through open-ended questioning conversations, I explored brain injury with my co-researchers.

The literature substantiated significant elements of the co-researchers' narrative accounts, thus strengthening the trustworthiness of data. Through data analysis, implications for both physicians and brain-injured women were identified.

PREFACE

PREFACE

In the thesis that follows, I used musical expressions as metaphors, with the intention of making meanings, which were perhaps deeper, by virtue of resonating across the disciplines. Some of these musical expressions should be intrinsic, or self evident, within the specific context. In some instances, however, the parallel may not be as obvious to the reader. Therefore, in all cases, I explained the reasoning behind the particular choice of musical expression. I used these metaphors, or musical expressions, while telling the story, which was the autobiographical ground from which the research question emerged.

Paralanguage was another lens used to expand the analytical possibilities and create a richer tapestry of meanings (Cassell, 1985).

I chose as the research design transcendental phenomenological reduction (TPR), with its imaginative variation feature, which has striking similarities to the expanded musical symphony, with its progressive tonality, originating in the symphonies of Carl Nielson: here we see exemplified the assimilation of intuitive, reflective and imaginative thinking.

The TPR methodology includes the epoche process, where the researcher endeavors to lay aside all preconceived notions and approach the subject with an unbiased, receptive state of mind. This is the equivalent of a composer seeing what can be developed out of a theme, with complete coordination of thematic material, thematic

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treatment and tonality. It produces a design which is clear, logical and symmetrical. This applies to all musical language. Yet music always springs forth from the imagination.

Music is an alchemy that defies intellectual understanding. Exposed to it, any human is, for a brief time, changed, because music seems to penetrate the soul. The ancient Greeks recognized this power as well as anyone. Spartan soldiers were not permitted to listen to the flute/pan pipes or other “feminine,” and therefore weakening music, before entering battle. Due to the influence of Pythagoras, Aristides, Plato and Aristotle, the Spartans and other Greek city-states enacted laws regarding what music befitted a particular situation. Penalties including fines were exacted for breaking these laws or changing an approved music form in the slightest way (Allison, L.H., 1998, p. 27).

The influence of Pythagoras, Aristides, Plato and Aristotle have been entrenched, becoming music’s legacy in the western world: Invariant rules based on mathematical principles are always applied to music, whether in the atonality of serial, tone-row composition of Schoenberg’s School (Berg, Webern and Wellesz) or in the sonata form.

Extended sonata form has particularly striking similarities to phenomenological thesis structure, especially when we examine the “Progressive Tonality” sonata form used by composers such as Nielsen and Mahler. For this reason I intended to exploit the musical analogy and make imaginative connections.

As a spider weaves a unique, structurally sound web (plucking the strands to detect resonance and perceive location on that web), I attempted to weave a structurally sound web into the fabric of this thesis, using resonant meaning-strands: words, conversations, paralanguage, extended sonata form, and musical indications. I hoped to spin layers of meaning, making the findings transparent.

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It may be important to give further clarification of the musical analogy. Therefore a brief account tells us the sonata form has interested symphonic composers for more than 250 years. The sonata form was originally sectional and symmetrical. This form possesses great capacity for expansion and contraction, scope for inter-relations between sections, and possibility for varieties of treatment in the development and coda movements, happily submitting to departures from its inherent principles which are essentially tied to a carefully planned use of tonality. The form lends itself easily to flexibility in proportion and relation of sections and thus, to continuous and organic growth. Consequently during the Romantic and Modern periods the sonata form continued to be used and modified.

Examples of flexible and expansive late romantic or modern symphonies are those of Mahler, Carl Nielsen, Prokofiev, Shostakovich, Hindemith, Stravinsky, and the English composers: Walton, Vaughan Williams, and Tippett.

The musical analogy used in this study is a flexible, expansive, late romantic or modern symphony, which exemplifies the extended sonata form with progressive tonality.

The following paragraphs illustrate the similarity between the TPR method with imaginative variation, and the extended sonata form of the progressive tonality symphony.

Chapter one introduces and provides the autobiographical ground, the information, the thinking that lead to addressing the phenomenon, which became the research question. Possible results of this research are listed in the implications section.

PREFACE

The initial movement of the extended progressive symphony (EPS) form is the *introduction*, which is usually written for both structural and dramatic reasons. The musical equivalent of the autobiographical ground would be a “*Monothematic*” approach, that is, considering the developmental possibilities of the single theme.

The second chapter of this thesis contains the review of literature. I explained the thinking that revealed the three operationalized constructs, and then defined the constructs. I addressed the definitional issues of people with brain injury (including statistics on brain injury), patient-physician communication, psychological and social impacts (of brain injury), general psychological concerns in rehabilitation, and major psychological and social themes. I summarized the findings and explained the research approach.

This would be equivalent to the second movement in an EPS, which is an *exposition*, presenting the initial statements of musical material on which the *exposition* is based. The thematic treatment consists of complete and successive presentation of the subject matter. The leading theme is direct and concise.

The third chapter presents a particular way of viewing the TPR design (which is based on Moustakas’ (1994) TPR approach to human science inquiry), and offers a methodological explanation of the conceptual framework. In the imaginative variation component of this research design, I included analogies to the EPS form, the “voiceprint”, and use of musical metaphors. The chapter details the presentation of the individual textural descriptions and of the composite textural-structural descriptions.

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Within the EPS form, the third movement is the *development*. In exploiting the possibilities of the theme(s) of this movement, thematic “character”, treatment and tonality are totally coordinated. The thematic treatment is discursive: It can utilize dismemberment, contrapuntal elaboration, rhythmic variations, modulation, and combination of musical material or themes. The thematic character can be subject to variability. This discursive treatment proceeds to a conclusion logically rather than intuitively. The sonata form has invariant rules (just as the tone-row serial form of composition). Within Moustakas’ (1994) particular TPR design, intuition comes into play in the imaginative variation component. In music, this “imaginative variation” is the working out of possibilities of the themes in use. Beethoven used up to six themes.

The fourth chapter contains the presentation of data and reporting of the results. An explanation of approach, co-researcher histories, individual textural descriptions and composite textural-structural descriptions with summaries and examples are included.

In the EPS form, the fourth movement can be either a *transition* or a *re-transition*.

A *transition* is an incidental change of key in the course of a movement. It can serve also as a linking passage.

A *re-transition* refers to the part of the composition moving back to the original music and occurring by use of a dissonant note where one would expect a consonant note.

Using a phenomenological methodology, the results cannot be anticipated. Therefore, in musical terms, the results, as discussed in Chapter four, could have produced either a *transition* or a *re-transition* as the fourth movement.

PREFACE

The final chapter includes a discussion and interpretation of the results. After presenting the analysis of these data, and arriving at a synthesis of meanings and essences, I compared these data to the literature review findings, considered limitations in methodology and in findings, contemplated future possible research and drew conclusions with implications.

In the EPS the *recapitulation* is the fifth movement. There is a parallel with the final chapter, which uses both conventional procedures plus the unconventional “paralanguage” analysis (the melody of spoken language). This is equivalent to the exploitation in EPS of all possibilities of the theme, including tonal or key relationships. The *recapitulation*, which revisits the thematic material, consists of re-presentation of the themes, in a complete and successive manner. I reconsidered the findings and themes, before arriving at the synthesis of meanings and essences and drawing conclusions.

With the development of the symphony sonata form in the late romantic and modern periods, the themes can sound entirely different, over and above different orchestration and new accompaniments. This development and expansion of the symphony of late romantic and modern periods heralded a move towards greater flexibility in proportions and relations of sections. Thus, what was originally sectional and symmetrical, now has the effect of continuous and organic growth. Carl Nielsen’s first symphony (1892) began the practice of starting in one key and ending in another. The analogy to the methodology is the outcome of this research, “finished in a different key”, which could not be predicted, but was made possible using a phenomenological

PREFACE

research design. Nielsen's first symphony uses convincing tonal and structural principles, for these reasons it is named "Progressive Tonality."

The *Cadenza* can be considered equivalent to "Future Possible Studies from the Research". Before the *Cadenza*, the orchestra pauses on a 6/4 chord in the dominant key; the soloist embarks on improvisation and concludes, with the orchestra, on the previously deferred cadence. Players are expected to display virtuosity and make allusions to the thematic material of the movement.

The *Coda* is the equivalent to the conclusions in the research design. It consists of a short addendum to round off the EPS.

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Dad, thank you for sharing your wisdom. You have always been respectful, compassionate and gentle.

Kenneth, my “big” little brother, what imagination you have! Your talent for humorous story telling, antics and facial expressions lift my spirits.

Irene, my sophisticated sister, world traveled, multi-lingual, gifted scholar and author, your clever insights served as catalysts, continuously yielding “perspective”.

Kiera, you gave *everything* to assist my recovery. You are my daughter and my treasure.

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DEDICATION

DEDICATION

To my parents Helen and Walter Allison, and my daughter Kiera Allison.

Mum...

You shared your wisdom and scholarly publications, which have entered these pages, greatly enriching this thesis.

Your deep understanding and compassion, the sharing of your personal stories, your insuppressible, delicious sense of humor have obliterated the many miles between Vancouver and Calgary, allowing you to cradle me in your arms. Love and hope, which comprise your essence, have supported and uplifted me in my darkest hours.

Dad...

Thank you for your wisdom, insight, gentleness, patience, unfailing counsel and support. Your composed, logical counsel is the “calm” within the eye of my storm. *Pibroch* lives for eternity!

Kiera...

You have always been wise beyond your years: not nineteen, yet an award winning scholar, philosopher, writer, poet and multi-talented performing artist...

“Love is like a butterfly. Try to grasp it and it is destroyed.

Let it go. If it comes back it is truly yours.”

You, Kiera, have proven the truth of these words: I shall forever be in awe of your wisdom in leaving when you did. Loyalty, honesty, generosity, modesty and strength of purpose describe the essence of you. I cannot express the depth of my love for you. I shall always love you and be “with” you. *Shalom!*

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EPIGRAPH

Words have not only cognitive and affective meanings but are also capable of producing somatic sensations and of evoking a spiritual awareness that the subject may find difficult to put into language. When you speak to someone, you are speaking to the person's body. You are also simultaneously speaking to the person's emotions and thinking function as well the listener's spiritual side.

Dr. Eric J. Cassell, Talking with Patients Volume 1: The Theory of Doctor-Patient Communication

CHAPTER ONE: INTRODUCTION AND BACKGROUND**The Musical Introduction**

In this thesis, I drew musical parallels with transcendental phenomenological reduction methodology.

I am a soprano who has performed internationally, including Europe and the United States. I have recorded for Radio France and frequently for the Canadian Broadcasting Corporation. Two of the highlights of my performing career are my solo concert in New York's Carnegie Hall in 1984, and many performances, in the summer of 1985, with New York's Bach Aria Group. My writing on music has been published (Allison, 1998). My ability to dance classical ballet took me to France, where I was engaged to perform the role of *Venus* in a revival of Rameau's *Pygmalion*.

Another aspect of my career was interviewing "live-to-air" for a Vancouver radio station. The program was called "Women of Note"; I interviewed women who are well-known musical performers or composers.

Taking advantage of my musical training, I used musical analogies as "meaning-strands" where appropriate, throughout this thesis; this was done to resonate across the disciplines of music and social science. By using musical analogies in this way, I hoped to creatively produce richer, deeper meanings within the thesis.

This thesis takes up the study of a phenomenon I have experienced. Interpretation of this phenomenon is both examined and limited by my personal history.

Acciaccatura: A Crushing Dissonant Note Struck with a Harmonic Chord

I chose the musical indication “*Acciaccatura*” in order to convey what seemed to me an ironic situation. Crushing dissonance represents the terrifyingly chaos I felt myself to be in. The harmonic chord represents my being lucid and having cognitive ability amidst this seeming chaos.

December 2, 1999.

The surgery must be over ... I am hot.

I see the blinking message on my monitor reiterating hypnotically, second stroke, second stroke, second stroke... My heart! Did you fail me? Yes, the surgery is over.

I try to push the blankets away but cannot.

I am situated directly across from the nursing station. No curtains obscure my view. I look. Male and female nurses are seated behind computers. I cannot make eye contact. Is this how a hospital runs, with nurses hidden behind computers? Is this a bizarre time warp, with juxtaposition of values, computers before patients?

I wait for what seems to be an eternity. Finally in desperation, I try to call out. I try to speak the word, *help*. I try to bring my vocal chords together to make the sound. Nothing happens. A sickening thought ... I am mute. I have only my eyes, my look of desperation, with which to speak.

I see a clock above the nursing station, which tells me that it is 2:00 a.m. I do not allow myself sleep. I am too terrified, too thirsty, too hot. I watch helplessly while the minutes move into hours. I stare at backs of computers,

willing someone to look up and see my distress... 5:30am... still afraid to blink lest I miss the chance of catching someone's eye. *I must not fall asleep; surely someone will see the desperation in my eyes and help me.*

The nurses seem very tired. From time to time one of the staff stands, stretches, glances at the clock ... looks at the other nurses, looks everywhere but at me. I am screaming with my eyes, *Help me, please!* Nothing ...

The shift changes. My heart beats rapidly in anticipation, as the new group of nurses is given notes. Maybe now...but no one looks, no one comes. My proximity to the nursing station could not be closer, yet I feel I could not be more distant. Oh, the bitter irony. If only I could push the call buzzer.

Trapped within this body that cannot move, buried under blankets that are unbearably hot, trying desperately to catch someone's attention, terrified of falling asleep ... this is the passing of my first night.

When a female nurse finally comes at 7:30 a.m., I cannot tell her of my inability to speak. I cannot tell her I am burning hot, that I am desperately thirsty. She covers me with additional blankets! I am frantic. *Please don't do this.* I cannot push the blankets away; although I try. *Can't you understand I am too hot?* She doesn't seem to understand. She leaves. Did I make her very impatient, I wonder, in my panic?

This experience recurs with different nurses. They now tell me that if I want to continue being difficult, they are not going to go along with it. Why do they think I am being difficult?

During the entire episode just described, I was lucid, thinking, *is this the way a hospital functions?*

Con Sordino: With Mute

I chose “*Con Sordino*” because I was mute, without voice, in the physical and emotional sense; being mute I felt entirely vulnerable to the “whims” (the decisions) of the staff. I felt utterly alone.

My hearing was, and is, very acute. I was extremely aware of even the murmured conversations, held at the foot of my bed. The medical staff were speaking about me and making assumptions. I had no voice with which to interject. I was without articulated language. I could not correct assumptions; the information was imprisoned within me. My words screamed silently. I felt enclosed within a glass cage, without voice. Without the ability to sign, I was bereft of all forms of communication. I felt helpless. I felt panic.

I had been both ballerina and athlete. I was elated whenever outdoors, hiking, backpacking on the West Coast Trail or mountain climbing. Being a soprano working in the operatic field necessitated understanding three languages in addition to English. I regularly interviewed over the radio.

I loved words. I loved using words. I loved speaking. I loved conversing. I had always taken speaking for granted. What cruel, ironic sleight-of-hand stole this from me?

So many losses: it seemed to me that I had lost my life. Was I in Hell?

Was Persephone more fortunate, having only half of every year to spend with Hades, in the underworld of Hell?

That was how my journey began... a journey into unknown territory without compass or map. I had to find my way alone, in darkness. No one could show me the way.

How would I perform the feat of climbing a sheer glass wall? I faced that sheer glass wall innumerable times...without hand or foot holds, rope, climbing irons, ice pick or crampons. I did not know if this ascent would be possible, nor how long it would take.

A cappella: Sung Alone, Without Accompaniment

My choice of "*A cappella*" was provoked by the fact that I am a soprano.

As the accompanist, pianist or orchestra is considered to be supporting the singer or instrumentalist, therefore *without accompaniment* equates to being unsupported. *Without Accompaniment* also alludes to my solitude, isolation and loneliness. When my voice began to return, I was singing alone.

"*A cappella*" is the most challenging type of singing, or playing. I felt that I was undergoing the supreme challenge of my life.

My surgery to remove a brain tumor occurred on December 2nd of 1999.

My neurosurgeon and I anticipated a positive outcome and discharge about eight days later. However, damage was sustained to my brain during the surgery.

I spent over two weeks in the neurological trauma unit, waiting for a bed on the rehabilitation ward. This rehabilitation ward housed patients recovering from spinal chord injury, stroke and brain injury.

I did not sleep through the night for the entire duration of my stay in hospital. This was due to noise (the room doors were never shut), the nurses speaking full voice, room mates with varying serious hourly needs requiring interventions by the nurses, cries of pain from other patients and the lights being on all night in the corridors. Blood samples were routinely taken by 6:30 a.m. Room lights were switched on full and laboratory staff tightly tied the rubber tourniquet to find a vein and take blood samples (I always had six samples taken). During blood-sample collections I felt like a stuck pig. The schedule of treatments, examinations, blood tests made sleeping thorough a night impossible. This sleep deprivation situation was exacerbated whenever the physiotherapists reminded me that rest and sleep were of the greatest importance in the recovery process. Many times I felt as if the hospital was deliberately conspiring to drive me mad.

I was surprised by the choice of words used by most physicians and most nurses when speaking to patients. The following words were spoken to me many times by nurses: “try to use your good arm, the bad arm isn’t strong anymore.” Was my arm “bad”? What did “bad” mean? Was it a moral issue? Had my arm performed a morally unacceptable act? Was it rotten, a spoilt apple? I didn’t understand this at all. It made no sense to me that my arm was suddenly “bad”.

I overheard a doctor telling my roommate that she would never walk again. I also overheard other pronouncements by doctors: "...he will be on medication for the rest of his life and will need 24 hour care." "She's not going to get any further than this. She'll just have to learn to make the best of what function she still has." This last statement was spoken about a patient, to a nurse and family members, in the patient's presence. Hospital ward privacy seems to involve no more than drawing a curtain around a roommate's bed; the curtains obviously were not sound proof. Is this ritual drawing of the shroud, privacy? I recognized both the nurse and husband of my second roommate before the doctor arrived and the ritual drawing of the curtain took place. Of course I heard every word.

I once overheard these words: "...you can never really predict the outcome... what will heal first, nor how much healing the body will accomplish. I have seen some miracles."

Animando: Becoming Animated

I chose "*Animando*" to suggest revival, a "coming back to life"; with this re-birth and revival, I was *becoming animated*, motivated and outspoken.

There were four treatment modalities to which I was assigned: physiotherapy, occupational therapy, speech and recreational therapy.

Therapies took place five days out of seven, with the exception of dreaded long weekends.

Before any and all therapies I was required to wait for a porter to take me from my room down to the location of the appropriate therapy. Since porters were scarce and overworked, I memorized the routes the first day. Having successfully done that, I knew my way. Getting to therapy was physically taxing because my wheelchair was difficult to turn; I had to use my right hand to turn the wheel rim and my right foot to push myself along. This had a major advantage however: I could assure I was early, while my fellow patients were often late, robbing them of precious therapy time. The porters left me alone. Perhaps because they were understaffed and overworked, they were glad to be relieved of some responsibility. Thus I gained a modicum of freedom and independence.

I required two physiotherapists at all times to help me stand and attempt a shuffling walk. My “walking” was terrifying. After only three weeks of lying in bed the muscles on the left side of my body had atrophied. The situation was made even more challenging because of the damage to my nervous system. My balance was compromised, and I had constantly to contend with spasms.

On the ward, handrails were situated at wheelchair level all along both sides of all corridors. I was instructed by the physiotherapy staff to practice weight bearing by using these handrails for standing and balancing. I persisted with this, getting a little stronger, from which I gained some gratification.

My leg felt as if it weighed hundreds of pounds and I was still contending with spasms. I finally consented to having a leg brace. Even given that support,

and walking with a cane, I still experienced the spasms. I was told pressure on the ball or the sole of my foot caused these spasms.

I had a single twenty-minute session held just outside the hospital, negotiating stepping on and off the curb, crossing two streets, walking on irregular paving stones which always caught the ball of my left foot (I could not clear any surface), walking on the grass underneath pine trees which brushed my face because I had to keep my eyes focused on the irregular grass surface. I was then pronounced ready for discharge. I was advised to limit my exercise to thirty minutes a day, but to continue walking. "Walking"? I could hardly describe what I was doing upon discharge as walking.

Occupational therapy was more weighted towards learning to live as a handicapped person than exercising my arm and hand. I was told early on, that because I wasn't having as much return as other patients, I would have to settle for fewer treatments. Why? Should I interpret this to mean I was not a "star performer"?

It was inconceivable to me that I would never regain my speaking ability, thus, speech therapy was extraordinarily important. I always arrived early and waited in the hallway. I spent this time vocalizing. I did this in order to thoroughly warm up my vocal chords. As I had been a professional singer I knew all the tricks. My light humming and vocalizing attracted much attention. I would see a therapist's head pop around the corner. "Was that you singing? You have a beautiful voice." I always answered "No!" and was guaranteed a look of

bewilderment. I found this tactic amusing and enjoyed my little joke with staff. Singing was a link with my past. This was something I could still do, something that gave me a sense of identity in this strange place.

Two separate segments of the brain control vocal sounds: one segment generates speaking; the other is responsible for singing. Thus I was able to sing, but my speaking ability was affected.

My speech, when it started to return, was severely impeded by dysarthria and aphasia.

[Dysarthria is a] disorder of speech and voice production due to damage to the brain cells controlling the muscles needed to produce speech and voice, leaving those muscles weak and paralyzed. [Aphasia is a] partial or total loss of ability to communicate with others through the use of language. Aphasic impairment includes expression by means of speech, writing, and gestures, of reception of the thoughts of others through their spoken, written, or gestural language. Calculation and telling time may also be impaired (Broida, 1979, pp.127-128).

It was alarming to me that I could not read; I did not recognize myself. My eyes went in retrograde motion, in other words, backwards, and I could not focus on one line. Whenever I was asked to read aloud I could feel myself going into panic mode. I was ashamed: I was acutely aware of the difference between my fluent thought and my faltering speech. I diagnosed myself as having a severe case of verbal diarrhea. Perhaps regaining my identity was tied to regaining clarity of speech and a rich vocabulary.

I wanted to test my cognitive abilities. Therefore, a few days before discharge, with my therapist's permission, I held a fictional thesis defense of

Dabrowski's Theory of Positive Disintegration. I memorized my "cue cards". I spoke softly, nervously and with some physical difficulty for half an hour and then opened the floor for questions. "The floor" consisted of a dozen speech therapists, a social worker, other interested therapists and three personal friends.

I felt exhilarated as there were so many questions and I was able to answer every one of them thinking on my feet, as it were. We went eighty-five minutes overtime. I think I regained my sense of dignity and self-respect that day. Immediately after I was discharged, I re-enrolled in university.

I wondered if the challenges of graduate school reading might prompt my brain to create new neural pathways. Perhaps this is happening; I now read easily and with comprehension. My vocabulary is returning. I see a "forgotten" word and my brain reclaims it.

If the brain is the master organ, can it not repair at least some damage to the body? If we do not comprehend fully how the human brain operates, then how can we make definitive prognoses? I suspected that my brain had the capacity to cortically reorganize itself. Much later I learned more by reading articles by Psychologist Edward Taub of the University of Alabama at Birmingham. Taub works in the area of brain plasticity and constraint induced therapy. He truly believes his theory: the brain can repair damage to the body. His research shows that constraint induced therapy can bring about cortical reorganization.

Cacophony: Of the utmost dissonance, usually used in the derogatory sense

I used “*Cacophony*”, for I felt surrounded in a cacophony of *dissonant* words, phrases and experiences. This “*Cacophony*” included patients who were expressing their frustration with the hospital system.

Was I imagining a stifling atmosphere of lethargy, despondency and misery on our ward? Initially I made a practice of eating each meal at a different table. In many cases, vocal patients confided their frustrations with the hospital system. Feelings of despair and hopelessness were frequently expressed:

There is nothing I can do, they [the nurses] won’t give me more painkillers and I can’t sleep for the pain. I have to wait ‘til they finally speak with the doctor, sometimes one whole day more of excruciating pain...[another patient stated] I can’t stand the food any longer, I won’t eat this slop.

I was extremely saddened by non-communicative patients weeping at their tables, some being spoon-fed by a nurse.

Was my eating each meal at a different table upsetting the seating status quo? Every other patient sat in the same place, with the same meal mates, and so I was always usurping someone else’s spot.

Two male patients had uncanny senses of humor. I finally gave up my attempt to be sociable with others and sat solely with them. The three of us laughed a great deal. The nurses named us “the party table” and were drawn to our enjoyment and laughter. This was the only laughter that ever occurred on that ward while I was a patient there. One and then the other of these two friends were discharged from the hospital. This saddened me immensely.

Why did I find myself retreating to my room? Did I relish the quietness and solitude? During these times I surrounded myself with music: Bach, Mozart, Berg, Rachmaninoff...was this my connection with myself?

***Cuivré*: Brassy – Indicating to a Brass Player to play with a Harsh, Blaring Tone**

My choice of “*Cuivré*” was provoked by the *harsh* experience of my hospitalization.

My last roommate was also my longest. This elderly woman, “Gerty”, had suffered a stroke and ensuing damage to the brain tissue. She was unable to speak.

Gerty’s plight engaged my compassion and I endeavored at all times to help her as much as I could.

Because Gerty could not speak, she was initially situated in a private room directly across from the nursing station. When she was moved to my room two weeks after I arrived on the ward, Gerty whined loudly like an animal in pain. These episodes occurred three or four times a night, every night. After a few nights of having been awakened from sleep by Gerty’s screams, I realized that I would have to help.

Initially, I assisted Gerty by pressing my own call button and telling the nursing station (by virtue of my returning speech) that Gerty needed help. Then I realized that I could calm her further by telling her to push her night alarm button and the nurses would come. Gerty would scream and I would awaken and say,

“Gerty, just push your call bell and the nurses will come. You can do it, Gerty, it’s right beside you – just push it.” Her urgency became my urgency. We were connected. When she finally responded three or four nights later and pushed the call bell, I rejoiced. I felt proud of being instrumental in vastly reducing Gerty’s fear by helping her gain a little control and independence.

I could have easily hated Gerty for her nightly screaming and moaning sessions, but I realized in the same terrifying situation I would react similarly, thus, I became her partner.

During the day I did not ask her questions. Rather, I commented on various aspects of our lives in hospital. For example, when there was an announcement for me over the intercom, I remarked to Gerty, “I wonder who’s calling. I better go quickly.” When I returned I commented: “That was my mum calling; she lives in Vancouver.” I would then give her some details about my mum’s life. I did this continually. I knew she understood. Gerty always maintained eye contact with me during these episodes, appearing genuinely interested. When we “conversed” I maintained eye contact and was therefore able to see her reactions: The look on her face sometimes gave me information. She began making physical gestures and nodding her head, although she confused “yes” with “no”. When I finally realized this discrepancy, we advanced another step.

Because I had experienced an episode of muteness, I felt that I understood some of her terror, and of her need to be treated as an intelligent human being who could still understand the words spoken to her.

Gerty was of Germanic origin and I am almost sure she had spoken German as her native language. I gently sang Lieder (German songs) and perhaps this forged a bond between us.

I took every opportunity to practice balancing and walking, taking three or four steps, with my right hand on the bedrail. Gerty watched my behavior intently and after about three weeks, I glimpsed her in the mirror standing and trying to reach into the closet. That was the beginning of Gerty's independent movement and exercising.

Gerty had a major breakthrough when she was able to bring her vocal chords together and say the word "no." We wept together; I understood her joy. I was very moved by her achievement, saying: "This is just the beginning, and you will go on to speak more words."

Perchance a temporary friendship was forged while on the unit, but I will never know. I use the word "temporary" because it was but a fleeting moment in time. I treated Gerty with dignity at all times and assumed she was an intelligent human being. Perhaps I was rewarded with her calmer emotional state. I identified with her plight at a time when I felt I had lost everything. Was I successful at this? Did this result in my tremendous sense of having been of value to another human being?

Over the course of my hospitalization and rehabilitation, in the dining room, or my shared bedroom, I overheard the following statements. I was shocked by fact they were made in the patients' presence, by medical personnel.

"She cannot do that by herself."

"You will never be able to stand."

"She does not understand a word that is said to her."

"She does that all the time; just ignore it."

The Phenomenon

This life event led me to be curious concerning how others perceived one particular aspect of such a transforming experience. I wanted to study the personal accounts of women with brain injury as they explained and reflected on their verbal interactions with physicians. The phenomenon of study was the examination of the experience of other women with brain injury. These women had extended opportunities for verbal interactions with their physicians during their hospitalization. I wanted to ascertain the possibility that other women shared my perceptions, as I had come to understand the critical importance of the use of language in medical rehabilitation. I assumed that if I could clarify the phenomenon, I could offer findings as further evidence of the importance of physicians' awareness of the potential impact of communication in presentation of diagnoses and prognoses.

The Research Question

Having lived through the experience of brain injury lead me to ponder and recognize a worthy research question. Examining this experience became the seed - the source of the scope of the research.

I wanted to reflect upon the possible influence and impact on the patient by the physician. A three-element question was formulated: What are the experiences of women with brain injury in their verbal interactions with the physician? What are their personal interpretations of this discourse? Do they believe this personal interpretation of verbal interaction has any effect on quality of healing and rehabilitation?

I pondered the following questions as I began to crystallize the ideas that lead to this study. Does language have no effect, no influence? Conversely, could constant use of the following statements: "She cannot do that by herself." "You will never be able to stand." "She does not understand a word that is said to her." affect the patient's mind? If so, what might the effect be? Was there a possibility of creating self-loathing? Would this result in my distancing from the affected part of my body and virtually disowning it? Would another person experiencing the same phenomenon have reacted similarly?

Cassell (1985) recognized the phenomenon of distancing and de-personalizing of the self, and examined the advantages, disadvantages and possible reasons for this behavior.

Perhaps hearing the same statements over and over from the outset of the injury could have a profound subliminal effect. Cassell (1985) addressed the four dimensions of word meanings and in this way, recognizing the ability of words to impact the whole

person. Thus, he was convinced that when you speak to a person, you speak to that person's emotional as well as cognitive functions. Could mere spoken words be internalized to such extent that the woman consequently altered her reality and authenticity accordingly? Are these internalized words truth or myth?

Prior to my hospitalization, I assumed all physicians, in speaking with their patients, were mindful of their word choice. Alexander (1965) spoke of the fact that the mind rules the body and is a fundamental, essential element of the process of life. I was hospitalized for the first time, and for almost four months experienced direct contact with physicians and other medical personnel. My particular circumstances at that time, the intensity of the experience over those four months, and some statements I overheard, lead me to wonder about the possible influence of word choice.

Perchance we are more than normally susceptible to the impact of the spoken word in situations of vulnerability such as a severe accident or while listening to a potentially life-changing diagnosis. Can the way we speak to another affect major change?

Some theorists stated that lack of diagnosis might cause the patient a sense of foreboding and excessive anxiety (Cassell, 1985; Siegel, 1986). Conversely, the theorist, Anderson stated:

Diagnoses, official and unofficial often concretized identities that limit people; they create black boxes with few, obscure exits; and they form obstacles to more viable and liberating self-definitions. (Gergen, Hoffman and Anderson, 1996, p. 4)

Siegel (1986) and Wolfensberger (1998) suggested that it would be very helpful to the patient if hospitals endeavored, whenever possible, to make the patient's room feel and look like home. Displaying photographs personally significant to the patient, having beloved books, the patient's art, any small belongings of sentimental value and playing the patient's chosen music in the room, are all considered significantly beneficial. Having a window in every patient's room, with a view of nature or the sky has been shown to have favorable effect on the patient's mood and immune system. The patient could be wearing her own appropriate clothing whenever feasible. As much as possible, prostheses, medications, bedpans and any reminders of medical care should be stored in a cupboard.

To me, the hospital zone seemed bereft of all structures, all visual reminders of normal life. Was this actually the case? Did being hospitalized cause me to be more than normally susceptible to the impact of the spoken word? Could another patient also be particularly vulnerable in this hospital setting?

Does diagnosis have any effect on healing outcome and rehabilitation? A sensitive presentation of the diagnosis is called for at all times. Upon hearing the diagnosis, the patient can experience a rapid alteration to her body's chemistry, and therefore also to her immune system (Siegel, 1986).

By caring with the "rational concern" that Cassell (1985), Siegel (1986), Myerscough (1992), and Kleinman (1988) spoke of, the physician reminds the patient that she is much more than a collection of symptoms and her narrative is listened to.

The so-called detached concern we're taught is an absurdity. Instead, we need to be taught a rational concern, which allows the expression of feelings without impairing the ability to make decisions (Siegel, 1986, p.14).

Suppose that words could even make one lose hope and thereby inflict further wounds. I speak on an existential plane (losing hope), as well as a physiological plane, when using the words "inflicting further wounds". Cassell (1982) stated: "The question of suffering and its relation to organic illness has rarely been addressed in the medical literature" (p. 639).

Perhaps, as Siegel (1986) claimed, there are indeed significant physiological changes to the patient's entire chemistry, including the immune system. Might this be a concern for the medical profession? If this appears to be the case, I wanted to understand if the diagnosis has more impact, if the person being spoken to regarded the physician as an unquestionable, unapproachable authority? Some literature stated that most patients have so internalized the perception of the physician as an unapproachable authority, that they (the patients) do not question either the physician, or the western medical model (Cialdini, 1984; Frank, 1991; Sloan, 2000). I wished to explore the possibility that given this situation, words could have a suggestible potential.

Could words spoken thoughtlessly by the physician cause the woman to alter her self-image and lived experience in any way? These statements, "She cannot do that by herself." "You will never be able to stand." "She does not understand a word that is said to her." "She does that all the time; just ignore it.", led to contemplate the effect of hermeneutics and what message was perceived by the patient. Was the patient in a highly

vulnerable state at the time she was hearing these words and interpreting the message? In my case, I was not in a drugged state, and had time to imagine and wonder about this word choice phenomenon. If language had an impact on a patient, might words be tools, with wounding or healing potential?

If words could be chosen in such a way as to minister to the spirit, could this have an effect on physical, emotional and psychological pain?

I decided during the early part of my hospitalization, that this was an interesting question worth further investigation. While hospitalized I realized I could not “prove” the theory behind the question, however I was interested in the interpretations of other patients on this phenomenon. I chose a phenomenological qualitative methodology as the research approach to the studying of this question. This design concerns itself with what it means to “be”, and relies on the interpretation of anecdotal material - the “conversations”. I based the methodology on the research methods of van Manen (1990) and Moustakas (1994). I considered Moustakas’ particular approach to transcendental phenomenological reduction (TPR) to be an appropriate and appealing method for investigating both the nature of the phenomenon under scrutiny, and the research question. Moustakas explains use of the TPR research approach:

The researcher following a transcendental phenomenological approach engages in disciplined and systematic efforts to set aside prejudgments regarding the phenomenon being investigated (known as the epoche process) in order to launch the study as far as possible free of preconceptions, beliefs, and knowledge of the phenomenon from prior experience and professional studies – to be completely open, receptive, and naïve in listening to and hearing research participants describe their experience of the phenomenon being investigated. (p. 22)

In order to view with “the untainted eye of innocence”, I have disclosed my position while hospitalized. Thus chapter one is the beginning of the epoche of TPR.

The Implication

It is my hope that professionals working in the area of rehabilitation and other related fields will read this work. I want to educate and raise the awareness of all health care practitioners, and specialists, regarding politically correct terminology. The current politically correct terminology is severely limited; it is inadequate, it merely avoids the use of “crippled” and a few other “offensive” words.

I desire to increase the sensitivity of health care practitioners working with brain-injured persons, and their extended families. I also wish to engage the interest of health practitioners and the public by holding educational forums. The “public” includes the brain-injured person, all other disabled persons, their extended families, and the general public (not directly involved in the brain-injured situation). These are some aspects of the scope of the work of enlightening the public.

The following thoughts occurred to me while pondering the politically incorrect use of labels, how to increase the sensitivity of persons working within the health care profession, and how to initiate an education and enlightenment of the public.

Perhaps society marginalizes people with disability because viewing disabled human beings reminds us of our own mortality. Perhaps existing social systems for the

disabled mislead “the public” into feeling that they are dealing with the issues of disability and mortality.

Perhaps physicians using discourse that distances them from the patient, do so unconsciously. Intimacy with disabled or terminally ill patients could be an inevitable reminder of their own mortality. Perhaps physicians consciously distance themselves in order to avoid emotional involvement and the consequential pain of loss when a patient dies. Perhaps it is essential that physicians do this, in order to be able to disengage from compelling, troubling situations with patients. Perhaps the physician can be a better doctor by maintaining this distance; perhaps this distancing is taught or inferred in western biomedical training.

Perhaps we are a society that defines death as obscene, using euphemisms: “passed away”, “gone to greener pastures”, “gone to a better place”, “gone to Heaven”, “gone to the happy hunting ground”, “kicked the bucket”, “checked out”, “croaked”, and so on. Ours is a society that avoids using the word “death” and has difficulty saying the words “He’s dead.” “Actively palliative” is the newest term used by clinicians working within the health care system. This term caused me to immediately contemplate “passively palliative”. Would this imply that one can be actively or passively dying? We go to such lengths to avoid the word “dying”! Cassell (1982) explained the need to revisit our perception of the dying patient.

As stated previously, our society is not readily accepting of death; therefore it endeavors to separate itself from mortality. Perhaps we, as North Americans, believe we

can conquer death. Siegel (1986), an oncology surgeon, believed a physician is seen as a failure if the patient dies: the physician has failed as a biomedical engineer.

Perhaps we are too pill oriented. Perhaps, believing the physician to be omniscient, we overlook other beneficial modalities.

Perhaps the physician feels helpless when nothing more can be done. Perhaps something more can always be done (Cassell, 1985; Myerscough, 1992).

Hanson “Patch” Adams, a medical doctor, uses a highly atypical approach to both healing and accepting death. To date, hundreds of physicians have left their practices to join Adams’ Gesundheit Institute. Their mandate states the following:

We are working to replace greed and competition with generosity, compassion and interdependence. Because they're healthy and fun, we want to nurture the growth of grassroots, neighborly mutual support and personal activism. We need your help! About The Hospital ... As a stimulant to broaden the dialogue on health care delivery, we want to build a hospital/healing community where:

- All the healing arts will be welcome.
- All patients will be treated as friends.
- There will be no charge for health services.
- No third party reimbursement will be accepted.
- The health care experience will be infused with fun.
- The Institute will carry no malpractice insurance.
- The health of the staff will be valued equally with the health of the patients. (Adams, 2003, What’s Gesundheit All About, ¶1)

This “Gesundheit” approach enticed me to explore the multi-dimensional possibilities of physician discourse and the experience of patients – a phenomenon worthy of attention.

CHAPTER TWO: LITERATURE REVIEW**Exposition****Introduction**

My investigation differs from prior research in two major areas. To this researcher's knowledge there have been limited narrative accounts, outside the research in health sciences, from women who have sustained a brain injury and are capable of functioning at a high cognitive level.

The professional voice, exclusively that of the physician, psychiatrist, psychologist, nurse and therapist, is heard in the literature. But where is the voice of the brain-injured woman? The volume of the professional voice has overwhelmed the *pianissimo*, the whisper, which is the voice of the lived experience of the woman who has sustained the brain injury. This whisper needs amplification within the literature.

The respondents, (my brain-injured co-researchers who function at a high cognitive level) were given three opportunities to reflect, offer additional data, and clarify any data to their satisfaction. This enhanced the trustworthiness of these data (Osborne, 1990). In addition to analysis of the transcribed narratives, I included an examination of all recorded interviews using the lens of paralanguage (Cassell, 1985). I believe this paralanguage model and tool greatly enlarged the scope of analysis of these data.

Since the attention of medical transcription is largely on physical-pathology and psychopathology, and the coding of various observed behaviors, the patient's lived experience is disregarded in diagnosis and in discussion of that diagnosis (Frank, 1991;

Kleinman, 1988). When we consider that men are most likely to experience a brain injury, it is perhaps understandable that women's experience has not been given voice.

Therefore this study seeks to document the lived experience, within the medical relationship, of women with brain injury. This chapter examines both theoretical and research findings related to those aspects that best reveal the focus of my study.

I began by considering all possible methods of communication. I wondered if we could be influenced through the use of words. I contemplated suggestibility of words being intensified by authority, influence and impact. In pondering my question I therefore searched for anything even obliquely related to words. I considered language development, discourse, hermeneutics, linguistics, meta-linguistics, speech, perceptions, meanings, semantics, dialogue, autism, and communication without the use of spoken words.

I took into account every topic having a remote link or connection with word choice and the possible impact and suggestibility of those words, first, on any disabled or disadvantaged person hospitalized or not, and second, on a survivor of brain injury.

The Thinking that Revealed the Constructs Under Study

Are there human beings who think and convey their knowledge without use of the spoken word? Are there any persons who are not potentially susceptible to words, or to authority and influence, as a consequence of possessing, or using, different cognitive processes? While being cognizant that scientists, composers and choreographers do not

use language in their creations, they nevertheless require language when describing these works to persons outside the domain of that discipline. I sought an answer to this question: are we aware of our thought processes, without language? This question required contemplation and consideration before deliberating over the possible suggestibility of words.

According to Speech-Language Pathologist B. Devolin's (Personal communication, June 13, 2002) definition of language as "an elaborate system of shared symbols and rules for combining into meaningful units...", the signing of the mute is a non-vocal language, and the signs represent letters and words, thus logically, it follows that persons with voice are able to sign and communicate with the deaf.

After working in a non-verbal language, the creator still has to explain his or her creation using words to anyone outside this particular creative field. Albert Einstein, Stephen Hawking, J.S. Bach, Ludwig van Beethoven, Anna Pavlova and Martha Graham all worked in non-linguistic languages. Yet each of these individuals worked within the constraints of systems with shared symbols and exacting rules: mathematics, physics, composition and choreography. In the cases of Einstein, Hawking, Bach and Graham, they creatively exploited and radically augmented the scope of the "language" of their respective fields, all the while playing by, and in concert with, those very rules.

We do think in various non linguistic forms. Perhaps humans are not always susceptible to the impact of words. What of autistic persons?

Definition of Constructs Used in this Study**The First Construct of Communication is Non-Verbal Language**

A definition of language is, as previously stated: “an elaborate system of shared symbols and rules for combining into meaningful units.” Speech-Language Pathologist, B. Devolin (personal communication, June 13, 2002) gave this succinct definition.

I searched for literature on non-verbal mental processes of knowledge acquisition. I learned that not all children or adults think in words. Within the world of autism the spectrum is vast. It is reported by some that autistic children think solely in pictures. Some autistics are predominantly visually inclined, but do have varying levels of language skills, from being unable to explain, with words, anything to do with cognition, to succeeding in articulating their processes of thought. Some autistic persons score fairly highly in IQ tests for language (Grandin. 2002, ¶22).

Grandin (2002) takes issue with van Manen (1990) on language, and entirely disagrees with van Manen’s statement: “Human experience is only possible because we have language” and his alluding to “lived experience ... [having] ... linguistic structure” (p. 38). Spatial intelligence allows Grandin to vividly imagine something, while completely bypassing both van Manen’s statement above, about language, and the process of verbal cognition:

It wasn't until I went to college that I realized some people are completely verbal and think only in words. I first suspected this when I read an article in a science magazine about the development of tool use in prehistoric humans. Some renowned scientist speculated that humans had to develop language before they could develop tools. I thought this was ridiculous, and this article gave me the first inkling that my thought processes were

truly different from those of many other people. When I invent things, I do not use language ... I used to become very frustrated when a verbal thinker could not understand something I was trying to express because he or she couldn't see the picture that was crystal clear to me (Grandin, 2002, *Different Ways of Thinking*, ¶ 2).

Grandin (2002) is an autistic person whose spatial intelligence allows her to create without the use of language. Further investigation within the world of the autistic woman who lacked the ability to articulate thought processes with spoken language, was not appropriate to my research. My investigation sought to reveal the focus of the potential suggestibility of words spoken by the physician to the patient, specifically the female who had sustained a brain injury, and possessed high cognitive post-injury function.

The Second Construct of Communication is Language Acquisition and Cognition

A brief review of this construct was necessary to yield some foundational information. I read Brainerd (1978), Garton and Pratt (1998), and Goodluck (1991) on cognition and language acquisition and development in children. When language acquisition is in place, children begin articulating words at about age two. Piaget considered this language egocentric. According to Piaget's theory (cited in Brainerd), by the age of eleven a child acquires and uses only social language:

They adjust their statements to accommodate listeners' informational limitations, and they explain statements that listeners do not understand. They also listen to what others say, and adjust subsequent statements of their own to reflect the points of view expressed by listeners. Piaget regards statements that attempt to persuade listeners to provide them with some useful item of information as clear signs of socialized language (pp. 110 - 111).

Piaget is still considered one of the founders of theories of intelligence; his findings have significance to other linguists specializing in language acquisition in children.

The Third Construct of Communication is Speaking with Words

I reiterate the following quote from van Manen (1990): “Human experience is only possible because we have language ... [and] Lived experience itself seems to have a linguistic structure.” He further stated: “Experience and (un)consciousness are structured like a language ... [if this idea is] taken literally, all phenomenological description is text interpretation or hermeneutics” (p. 38). I used hermeneutics in van Manen’s literal sense within my phenomenological methodology. In the simplest sense, the word expresses the listener’s interpretation, which is unknown to the speaker. Hermeneutics is derived from the Greek *hermēneutikē*, (*art*) of *interpretation* as defined in the Houghton Mifflin Canadian Dictionary of the English Language (1980). It is the science and methodology of interpretation, originally applied to Scriptural text.

Definitional Issues Regarding the Population of People with Brain Injury

Lack of Agreement on Description of Brain Injury

There are inconsistencies in the description of brain injury, including use of terms such as acquired brain injury (ABI), traumatic brain injury (TBI), head injury, and concussion. The American Psychiatric Association (2000), *Diagnostic and Statistical*

Manual of Mental Disorders (4th ed.) has categories for post-concussion and dementia but has no category for ABI or TBI.

Medical dictionaries (Taber's Cyclopedic Medical Dictionary, 1981; Mosby's Medical and Nursing Dictionary, 1986; The Merck Manual, 1977; DSM-IV-TR 2000, 4th ed.) refer to brain injury generally as damage to the brain caused by an external force. Very often definitions do not include ABI, resulting from damage to the brain caused by strokes, tumors, hypoxia, toxins, degenerative diseases, near drowning and other conditions in absence of an external force.

Brain Injury Statistics

Winslade (1998), reported alarming statistics on brain injury:

... Brain Injury Association [reports annually] more than 2 million people... suffer traumatic brain-injuries, 373,000 ... severe [and] ... require hospitalization.

Brain trauma is the leading cause of death among children and young adults. It kills at least 60,000 Americans annually and leaves 2,000 in a persistent vegetative state (p.11).

I began my search for brain injury statistics with the Southern Alberta Brain Injury Society (SABIS). Few statistics were available for Canada according to the Executive Director of SABIS, Denis Cooney (personal communication, October 9, 2001). Most information is generated by Ontario research agencies and is accessed over the Internet. In Canada approximately 18 thousand patients are admitted annually to hospital with a brain injury. Estimated societal costs are at least one billion dollars:

Although head trauma has been recognized as a serious health issue, there are few Canadian epidemiological studies of this issue that include population-based rates, and no studies have comprehensively examined the full spectrum of blunt head traumas seen at emergency departments ...

Our study was limited ... there was no standardized protocol for assessing patients (Pickett, W., Arden, C. and Brison, R. J., 2001, Interpretation section, ¶2 and ¶5).

Provincial statistics are available for Alberta. Unfortunately as stated above, there are no national statistics available on the gamut of head injuries.

There is only one other website, Acquired Brain Injury Resources, with any available statistical estimates for brain injury in Canada. The third website (The Brain Injury Resource Center), referred solely to American statistics. Therefore, while I used the available Canadian statistics, I drew supplementary information from more extensive American statistics.

In the United States 1.5 million persons sustain head injury annually with 50 thousand deaths and 80 thousand disabling injuries. Further, the cost of emergency care is \$346 million annually; an additional \$54 billion is spent in associated hospital care costs (Pickett, W., Arden, C. and Brison, R. J., 2001, Abstract section, ¶4). The American Heart Association estimates Cerebrovascular accident (CVA) current direct and indirect costs of \$43.3 billion per year. As the American population progressively ages during the next 50 years it is most likely the number of CVA survivors will greatly increase; the projection being that the number of CVA survivors will more than double (Taub, Uswatte, Pidikiti, 1999, Introduction, ¶1). Canadian statistics might well be similar.

Winslade (1998) argued: "Traumatic brain injury ranks among the most serious public health problems facing the developed world. Yet as a society, we are barely beginning to recognize and discuss what is virtually an epidemic of brain injury" (p. 1).

The data collected by the Worker's Compensation Board of Canada (WCB) observes the National Work Injury Statistics Program (NWISP) of coding to promote coding consistency. The purpose of the NWISP is to collect coded work injury and disease cases from each provincial compensation Board or Commission and collate them so that Canadian work injury and disease statistics can be tabulated and made available. The WCB observes International Classification of Disease, 9th revision (ICD9). "The Primary Part of Body Major Group Description" coding used by the WCB that broadly matches the category of injury of interest in this study is 01 *Cranial region/skull*. There are 64 major descriptors, which represent all of the primary nature of injuries associated within 01 *Cranial region/skull* (excluding scalp). They represent all histories contained in WCB on-line claims. Category 0000-traumatic injury/disorder contains an alarming 3,656 unspecified codes, with an additional 360 unspecified codes for multiple traumatic injury totaling 4,016 unspecified brain-injuries out of 11,074 diagnosed cases. This information was provided by Data Analyst, Statistical/Actuarial Services D. McKinlay of the Worker's Compensation Board of Alberta (D. McKinlay, Personal Communication, November 10, 2001). This large number of unspecified cases assumes that there is still much unknown about the groupings of symptoms that connote various brain injuries.

Dr. D. Cooney of SABIS (personal communication, October 9, 2001) defined ABI as resulting from a medical condition causing "specific" or focal damage, while the

effect of TBI is always “universal” or diffuse damage. The impact of both TBI and ABI range from detrimental effects on concentration and short-term memory to coma and death. ABI and TBI are defined as having a long-term disruptive effect on cognitive, emotional, physical, behavioral, psychological, psychosocial and vocational functioning. For the purposes of this study, ABI and TBI are not differentiated in participant selection, both being seen as causing long-term disruptive effects on the lives of those individuals who experience them.

In Alberta about six thousand brain-injuries occur yearly. Dr. D. Cooney of SABIS (personal communication, October 31, 2001) claimed at least fifty percent of brain-injuries are attributed to motor vehicle accidents involving males between eighteen and thirty-five years.

Brain-injuries incurred from sporting accidents also rank high within this group of young males. The highest hospitalizations from brain injury occur during the summer and fall seasons, and incidences of brain injury are lower in the winter and spring. (Dr. D. Cooney, personal communication, October 31, 2001). These facts underscore the statistical connection to sports incurred head injuries.

Two thirds of all brain injuries are sustained by persons under the age of thirty, with young males between fifteen and twenty-four years having the highest rate (Dr. D. Cooney, personal communication, October 31, 2001). In Ontario, it was reported: “The average age of major sport/recreational injuries was 28 years, much lower than the average age of non-sports/recreational cases (44 years). Further, males comprised a higher proportion of the sports/recreational cases (85% versus 69%)” (Ontario Brain

Injury Association, 2003, Hospitalizations due to Major Sports and Recreational Injuries in Ontario 1999/2000, Overall Highlights, ¶3, p.2).

Other major causes of brain injury include cardiac arrest and stroke. In children under the age of five, a fall from a shopping cart is a frequent cause of head injury. Child abuse accounts for sixty-four percent of brain injury in infants.

Incidents of brain injury have increased over the last twenty to thirty years. Along with the physical effects, there are social, emotional and financial costs for the person with a brain injury and the family involved (Dr. D. Cooney, personal communication, October 31, 2001). The U.S. Department of Health and Human Services, National Institutes of Health, having much more statistical information on brain injury, reported in 1998 that as many as 80 percent of head injury survivors do not get the help they need.

Given the enormity of brain injury survivors who do not receive the help they require, the call for further research is evident, particularly in shaping the training and practice of medical doctors and specialists.

Definitions of brain injury are inconsistent and not comprehensive. Much is still unknown as to groupings and symptoms. Insufficient funding for rehabilitation minimizes this essential post injury treatment. Brain injury is a catastrophic health problem.

Research on Patient-Physician Communication

Myerscough (1992) stated: "Terms the doctor may regard as 'innocent' and reassuring may readily create serious anxiety" (p. 93). According to van Manen (1990), "The specific use of words as part of the discourse between patient and medical doctor has received little attention in literature." He explained: "From a semiotic point of view any social behavior or practice signifies and may be read as a text, as a language and one can thus speak of 'the world as a text' " (p. 186). Do these statements imply that discourse and demeanor on the physician's part are of consequence in dealings with the patient? Should the physician maintain an awareness of the patient's possible suggestibility?

Alexander (1965), Cassell (1985), Cousins (1979), Siegel (1986) and Murphy (1987) recognized the power of words spoken by the physician to his patient. The term for this phenomenon is psychosomatic medicine. Cassell explained:

Words have not only cognitive and affective meanings but are also capable of producing somatic sensations and of evoking a spiritual awareness that the subject may find difficult to put into language. Although here the four dimensions of word meaning have been presented separately, in everyday life they are all mixed together. When you speak to someone, you are speaking to the person's body. You are also simultaneously speaking to the person's emotions and thinking function as well the listener's spiritual side (p. 182).

Siegel (1986) described how the emotions and state-of-mind serves as the catalyst that changes the body's chemistry:

Other doctors' scientific research and my own day-to-day clinical experience have convinced me that the state of the mind changes the state of the body by working through the central nervous

system, the endocrine system, and the immune system (p. 3).

Could the physician's use of words incite this chemical reaction? Alexander (1965) claimed that the mind controlling the body is the most fundamental fact of the life process, regardless of this actuality being overlooked by biology and medicine.

Cousins (1979) discussed the significance of the power of the mind in overcoming disease and the relationship between attitude, disease and bleak medical diagnosis.

Murphy (1987) stated:

The unity of mind and body is also an important element [in] phenomenological philosophy ... And the way we experience and understand reality is in good part shaped by the language categories through which we sort out what we take to be real (p. 100).

These five authors seemed unanimous in their opinion that there is a mind-body connection. Could specific word usage by the physician affect thought and belief? Cassell (1985) stated: "Thus it is vitally important to understand all the dimensions of words and how they function, for it is through spoken words that the physician is able to influence the patient's reality" (p.160).

Cassell (1985) claimed patients are susceptible to altering their reality according to the physician's choice of words: "The potential use in clinical medicine is clear: doctors can use the spoken word to change the perception of reality for patients!" (p.56).

Why not try utilizing this power that Cassell claimed the physicians hold? Why not exploit the placebo effect; taking a "sugar pill" that you believe is a potent drug? Most physicians now accept the placebo effect as fact. Approximately 25 to 30 percent of cases show improvement from belief in the placebo (Siegel, 1986). This fact implies the

power of the mind; bodily changes can be provoked by state of mind (Alexander, 1965; Cassell, 1985; Cousins, 1979; Siegel, 1986 and Murphy, 1987).

The nocebo effect (Benson, 1996) has the converse result. This nocebo effect can occur in hospitals when the patient views the physician as an authority, and on that basis changes her self-concept, according to Benson (cited in Sloan, 2000).

The diagnostic label can bring comfort: "When patients do not come up with a name, they may have a sense of dread: a foreboding of 'terrible' and 'horrible,' to which no name is attached" (Cassell, 1985, p.167). The name can serve as reassurance that the physician knows the malady and therefore, presumably, knows what to do in this circumstance. Hence, the label may have value. Now the patient can name her malady. Those close to her are reassured, and remain confident in the quality and expertise of her medical care. Addressing the physician's diagnosis, Cassell explained: "The diagnostic label serves to contain the threat. Sometimes, ... the diagnosis mitigates the threat because of the information it conveys about cause, course, and outcomes ... [While] the absence of a name allows worry to seek its own name" (pp.164, 165).

A diagnosis is stated in words. Can these diagnoses, consisting of mere words, have such impact they become either destructive or productive? Speaking on the subject of diagnoses, I reiterate Anderson's (1996) blunt assertion:

Diagnoses, official and unofficial, often concretize identities that limit people; they create black boxes with few, obscure exits; and they form obstacles to more viable and liberating self definitions (Anderson, 1992) (Gergen, Hoffman and Anderson, 1996, ¶17).

What happens to the patient, if a diagnosis delivered with neither sensitivity nor hope, proves incorrect in the final analysis? The case of Cousins' (1979) misdiagnosis of tuberculosis at the age of ten had the fortunate outcome of bequeathing him with the philosophical attitude regarding the power of the mind in overcoming disease. Nevertheless, Siegel (1986) appeared to concur with Anderson (1996). Siegel asserted: "The truth can always be delivered with hope, since no one can be certain of the future" (p. 42). Myerscough (1992) stated: "Diagnosis is, in effect, a statement of probability which forms the basis on which decisions about management are made. In these practical terms, a satisfactory diagnosis does not have to be absolutely certain" (p. 23). Cousins (1979) described his experience with misdiagnosis at the age of ten, when sent to a tuberculosis sanitarium. Fortunately, this misdiagnosis was corrected. From this experience he became philosophically conditioned, realizing of the power of the mind in overcoming disease.

Could the diagnosis in combination with the nocebo effect, referred to earlier, cause the patient to alter her self-concept? Could this altered reality bring about a sort of "myth making"? I pondered the notion of living an altered reality if we believed an erroneous diagnosis to be truth. Frank (1991) and Cousins (1979) addressed the subject of diagnosis and how a particular patient perceived it. Frank asserted the delivery of a diagnosis, if "pronounced ... like a verdict" (p. 45) can have a different meaning than it would otherwise. Furthermore, Siegel (1986) felt the habit of making a prognosis of how much time a patient has left is a terrible mistake: "[He felt this is] a self-fulfilling prophecy" (p. 39). Cassell (1985) concurred with Siegel on this point.

Cassell (1985) maintained physicians could help patients to distance themselves from their malady by exploiting language's capacity to create images, thus having a significantly beneficial effect for patients. This is the internal content of the notion signified by a word: what "...philosophers call the intension of the word" (p. 157). Furthermore, an imprudent remark is unacceptable; to the patient everything the physician says has significance. There is a covenant between physician and patient that allows the physician's words to be effective: "...make sure that your language usage reflects what you consciously wish to convey" (Cassell, p. 63).

Both Myerscough (1992) and Cassell (1985) categorically claimed words carry a suggestible component. While Cassell reiterated this claim throughout his text, the message of each author is: "Physician, mind your words!" Meaning is multi-dimensional and multi-layered (van Manen, 1990).

Kleinman (1988) explained: "They [medical students] are taught how to record symptoms and medical history and how to reinterpret them as an official diagnostic entity in the authoritative medical taxonomy" (p.131). Since the meaning or interpretation the patients have attributed to the injury is largely interpreted in biomedical terms, did these patients, as Kleinman suggested: "Turn to the cultural authority of the health professions and science [in search of] an answer to [their] predicaments" (p. 28)? As a consequence, was the individual's interpretation or meaning stifled within biomedical ideology, with other non-biomedical lenses disregarded?

Conceivably, the lived experience of individuals with brain injury does not have to be encapsulated within biomedical terminology. Biomedical terminology is

unintelligible to anyone other than a physician. It consists of highly specialized scientific phraseology which can underscore the authority of the physician, while at the same time, provoke fear in the non-comprehending patient (Cassell, 1985). Kaufman, in his prologue to Buber, (1970) stated: "The words do tricks, the performance is brilliant, but much of it is very difficult to follow ... Obscurity is fascinating" (p.19). Imagine a non-physician listening, blinded and bewildered by the dazzling brilliance of these unintelligible expert pronouncements:

‘The chest film shows pulmonary neoplasia with extensive metastases’. ‘We’re definitely thinking this may be a supratentorial problem’. ‘Our concern about hyperkalaemia is that unheralded ventricular asystole may occur’. From language of this sort, the student may acquire more skill in concealing or fudging than in communicating (Myerscough, 1992, p. 183).

Does such phraseology serve to underscore the perception of a physician’s expertise? He could appear to some as almost super human, perhaps even omniscient: the “high priest” of the western world (Sloan, 2000). Sloan described: “In fact, doctors are looked on almost as Gods, having all knowledge, and patients, especially those who have just experienced trauma, tend to believe everything a doctor tells them as being true” (p.224). The perception of the medical doctor as an authority figures prominently in our western medical model and his words bear even greater credence (Frank, 1991, p.19). The doctor could radically change a person’s self image if he is perceived by the patient as an unapproachable authority (Benson, 1996).

While puzzling over the question of authority, I imagined the following scenario: you choose to tolerate a statement by a speaker, tactfully allowing him or her to voice this

belief. To save possibly embarrassing the speaker, you decline to argue the point. But would you even entertain, not to mention be influenced by, or actually internalize the words and messages, if you did not deem the speaker to be an expert or authority? If this is true, are not words and authority inextricably linked? Frank (1991) addressed this theory, and was vocal over the weight given to a doctor's "performance":

When the physician does arrive, he commands center stage... this performance is so stereotypically masculine, although women physicians learn to play it well enough. The patient hangs on what brief words are said, what parts of the body are examined or left unattended... the patient [later] recounts to visitors everything [the physician] did and said, and together they repeatedly consider and interpret his visit. The patient wonders what the physician meant by this joke or that frown. In hospitals, where the patient is constantly reminded of how little he knows, the physician is assumed not only to know all but to know more than he says (p. 56).

The above quote illustrates the absolute attention given by the patient to the physician's words and actions (his demeanor), and the recounting of those words to visitors. This recounting to visitors, of the experience with the physician, exemplifies "the world as a text" (van Manen, 1990, p. 186).

Milgram's research demonstrated the vulnerability of the recipient when that individual perceived the person making the demand as an authority (Cialdini, 1984). Cialdini suggested the extent to which we have internalized the authority of the physician. The majority of patients' perception of the physician as an authority figure possibly explains the patients' tolerance or even preference for biomedical explanations (Cialdini; Frank, 1991; Kleinman, 1988; Myerscough, 1992; Sloan, 2000). Perhaps there

is no space within this scientific and medical discourse which allows the physician to step out of the authoritarian role.

Conversely, possibly through a deliberate, conscious use of language and listening, the physician could bypass this authoritative role and care for the good of the whole person, not simply the disease. Siegel (1986) stated: "The so-called detached concern we're taught is an absurdity. Instead, we need to be taught a rational concern, which allows the expression of feelings without impairing the ability to make decisions" (p.14). By caring with the rational concern that Cassell (1985), Siegel, Myerscough (1992), and Kleinman (1988) spoke of, the physician reminds the patient she is much more than a collection of symptoms, and her narrative is listened to. This narrative is the account of the woman's journey; in this context it is the story of her changes and losses, and may include her history and relationships.

Would it not be possible for the physician to incorporate careful, sensitive choice of words, when speaking of illness to the patient? This is a facet of practicing the art of medicine: an intuitive art, learned by physicians through an immense amount of experience (Cassell, 1985). In practicing the art of medicine the physician endeavors to aid the human being within the diseased body. By attempting this, the physician upholds the Hippocratic oath and makes an earnest attempt to do no harm. Selzer (1976) spoke eloquently on the art of medicine, stating it is the supreme ministry between the ill and the physician, the essence of which is equivalent to pure love. Cassell (1982) stated: "The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick" (p. 639).

Myerscough (1992) and Siegel (1986) asserted that the art of medicine could be lost as a consequence of our scientific medical training. Siegel explained: "... in medical school: the role of mechanic-lifesaver ... defines illness and death as [the physician's] failure"(p.5). Does this place an unrealistic expectation on the physician? Does this tend to produce some physicians who unconsciously exploit the patient's perception of their authority, or who attempt to distance themselves or who view patients as only a set of symptoms? Myerscough believed that the latter could happen to medical students who are "imprinted" with a mindset of disease based exclusively on the physical sciences, and for this reason come to see the patient as merely a chaotic set of symptoms. If the medical student is imprinted with this "symptoms only" mindset, then he can make his judgment before communicating with his patient. Myerscough believed this is true: "... particularly if his main early contacts with the subject of study have been as a cadaver in the dissecting room, or at autopsy" (pp.181 – 182).

Psychological and Social Impacts of Brain Injury

There are aspects to healing that are largely neglected in the context of the medical world. The lived experience of surviving a brain injury may include psychological concerns and losses, and such social phenomena as stigmatization and being aware of one's differences, loneliness and loss of social support, and awareness of one's cognitive losses as a result of the injury (Davis, 1961; Goffman, 1963; Kleinman, 1988; Murphy, 1987; Sloan, 2000; Winslade, 1998; Wolfensberger, 1998; Vanier, 1998). Awareness of the impact of these psychological concerns and social phenomena was

necessary in interpreting the accounts of the women who participated in this study. The intention of this design was to give voice to the women and to embed their understanding in the cultural context of both the biomedical and the personal world. Thus, a summary and critique of literature that spoke to these social phenomena was necessary. Only the main areas that could affect these women were considered. These issues are largely absent from medical literature, and are not commonly entered into medical studies or reports. Therefore, I looked across the disciplines, considering, for example, social sciences, theology and philosophy.

General Psychological Concerns In Rehabilitation from Brain Injury

The medical literature on brain injury rehabilitation has often focused on the physical aspects of recovery with little attention to psychological concerns of individuals in recovery (Davis, 1961; Frank, 1991; Goffman, 1963; Kleinman, 1988; Murphy, 1987; Myerscough, 1992; Sloan, 2000; Winslade, 1998; Wolfensberger, 1998; Vanier, 1998). Murphy explained that however preoccupied he was, he could not predict when “it” would surface, “it” being the feeling of personal disintegration. Murphy illuminated: “It is a Presence. I, too, had acquired an embattled identity, a sense of who and what I was that was no longer dominated by my past social attributes, but rather by physical defects” (p.104).

When psychological aspects of healing and adjusting are reported, they are often described in terms of psychopathology, rather than in terms of change and loss and

subsequent adjustment and coping associated with the injury (Frank, 1991; Murphy, 1987; Myerscough, 1992; Sloan, 2000; Winslade, 1998).

The terminologies of essence, hope, tolerance for diversity, identity and suffering has been adopted into the language of medical sociology, social theory, women's studies, educational research, chronic disease psychology, religious studies, philosophy, phenomenology, ethics, and hermeneutics (Cousins, 1979; Gilligan, 1982; Goffman, 1963; Kleinman, 1988; Vanier 1998; Winslade, 1998; Wolfensberger, 1998), but appears to be lacking in the medical literature. Within the biomedical ideology there is the danger of reducing the patient's narrative account of the experience of brain injury to a series of physical symptoms, lacking categories to describe suffering (Kleinman). H. Allison (personal communication, February 8, 2003) stated: "If suffering is not understood and alleviated, physical pain is intensified." Cassell (1982) stated: "A distinction based on clinical observations is made between suffering and physical distress." He also stated: "Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity" (p. 639). Kleinman explained:

[The focus on biomedical terms] turns the gaze of the clinician, along with the attention of the patients and families, away from decoding the salient meanings of illness for them. [This] interferes with recognition of disturbing but potentially treatable problems of their life world. The biomedical system replaces this allegedly "soft", therefore devalued, psychosocial concern with meanings with the scientifically "hard", therefore overvalued, technical quest for the control of symptoms. This pernicious value transformation is a serious failing of modern medicine: it disables the healer and disempowers the chronically ill (p. 9).

Persons with brain injury may integrate biomedical information in concrete terms. If this occurs, the brain-injured person risks disregarding their psychological losses and the meaning these persons with brain injury may attach to these losses. Could this possibly influence recovery? Murphy (1987) considered the four most far reaching deficits of the disabled to be: "... lowered self esteem; the invasion and occupation of thought by physical deficits; a strong undercurrent of anger; and the acquisition of a new, total and undesirable identity" (p.108).

Buber (1970) and Moustakas (1994) agreed with Murphy (1987) on the devastation of psychological changes. Commenting on Diller and Gordon's study (1981), Moustakas observed that brain injury could change the personality totally; the brain-injured person could become completely unrecognizable to family and friends. Changes could occur on every level of functioning, leaving the victim in a state ranging from emotional impairment to total devastation:

As evidenced in this study, the emotional component of a head injury is strong and dominant, leading to shattered confidence, withdrawal, and feelings of being alienated and disconnected. Relationships with others are seriously impaired and the ability to relate on an intimate level with family members is blocked (Moustakas, commenting on Diller and Gordon, 1981, p. 168).

Buber explained:

...[The psychotherapist] may help a diffuse soul that is poor in structure to achieve at least some connection and order. But he cannot absolve his true task, ...the regeneration of a stunted personal center. That can be brought off only by a man who grasps with the profound eye of a physician the buried, latent unity of the suffering soul, [accomplished] only if he enters as a partner into a

person-to-person relationship, but never through the observation and investigation of an object (p. 178).

When a person experiences losses of the magnitude spoken of by Moustakas, Diller and Gordon, and Buber, the identity crisis that occurs results in an actual loss of “personhood”; identity and personhood are one and the same. Murphy (1987) explained: “My identity has lost its stable moorings and has become contingent on a physical flaw” (p. 104).

Major Psychological and Social Themes

Loss

Adjustments such as changes in, and losses of personal relationships, recreating one’s personal identity, loss of independence and self-efficacy, as well as stressors such as accessibility and other difficulties, do not occur in a linear fashion, but occur layer upon layer, and may lead to a sense of feeling overwhelmed. Kleinman (1988) stated when we deal with devastating situations, we experience loss of perspective and meaning, as in a “house of mirrors”, we lose our sense of place and purpose in the normal world.

Although psychological terminology may be helpful in coding or standardization for professionals, the inference of pathology in “denial”, “false hope”, “over-reacting”, “obsessing” and “depression” may negate the person’s psychological concerns. This may exacerbate and increase the natural effect of loss. Consequently the brain-injured may feel acutely troubled and isolated (Davis, 1961; Frank, 1991; Kleinman, 1988; Murphy, 1987; Sloan, 2000; Winslade, 1998). This isolation or apartness is magnified greatly

when the person doesn't appear or behave "normally". Myerscough (1992) explained: "...disabled people may be treated in subtle ways as somehow less than human, in terms of their personal dignity, and the respect and independence they are afforded" (p. 82).

Murphy (1987) spoke poignantly on the issue of loss. This realization never left him, waking or sleeping:

When I first became disabled, I was still walking, after a fashion, and I remained perfectly normal in my dreams. ... But in the middle of the dream, I remember that I can't walk, at which point I falter and fall. ... In other dreams, I am just walking about aimlessly when suddenly I remember my disability ... Even in sleep, disability keeps its tyrannical hold over the mind (p. 105).

Stigma

Allison, Gripton, Rodway (1983), Goffman (1963), Kleinman (1988), Vanier (1998) and Wolfensberger (1998) saw the question of stigmatization as society's failure to accept difference. Vanier posed the question: "How can we lay claim to making an open and friendly society where human rights are respected and fostered, when the values we teach and foster are systematically excluded from segments of our population?" (p. 45).

Do we, as North Americans, believe that it is obscene to be different in "that sort of way"? Many able-bodied persons believe that they are accepting of the stigmatized, however this belief is nothing but a delusion from which we gain gratification. Davis (1961) affirmed: "... many normals [persons without disability] refuse to grant anything

more than fictional acceptance [to the stigmatized] while at the same time imagining themselves ennobled for having made the small sacrifice" (p. 127).

Allison, Gripton, Rodway (1983), Davis (1961), Goffman (1963), Kleinman (1988), Vanier (1998) and Wolfensberger (1998) asserted that people with any disability, be it mental or physical, are marginalized - set aside from "normal" society. Perhaps these types of differences are distasteful. Allison, Gripton and Rodway addressed the social, emotional and existential cost of marginalized experience:

Unwittingly, society assigns those suffering from cancer [this would include the ABI, with cancer being the precipitating factor] to a marginal, deviant or minority status. Persons with cancer remind each of us of our physical frailty, and the disease is usually presented morbidly by the media. This abhorrence of cancer leads to stigmatizing and exclusion of those who suffer from it. Enforced membership in this minority reinforces patients' negative feelings, increases their sense of helplessness and dependency, and reduces their coping capacity (p.30).

Perhaps people do not want to have to face the truth. Buber (1970) explained: "*Mundus vult decipi*: the world wants to be deceived. The truth is too complex and frightening; the taste for the truth is an acquired taste that few acquire" (p. 9). Perhaps by viewing people who are "different" in "that way", the viewer is reminded of his or her own mortality. Perchance, as Davis (1961), Goffman (1963), Vanier (1998) and Wolfensberger (1998) suggested, ours is a society that prefers things to be neat, simple and orderly. Most "normal" people deliberately overlook anything that reminds us that the world is not tidy, orderly and trouble-free:

Man's world is manifold, and his attitudes are manifold. What is manifold is often frightening because it is not neat and simple. Men prefer to forget how many possibilities are open to them.

They like to be told that there are two worlds and two ways. This is comforting because it is so tidy. Almost always one way turns out to be common and the other one is celebrated as superior. (*I And You: A PROLOGUE*, Kaufman, to Buber, 1970, p. 9)

Reading Goffman (1963), Kleinman (1988), Murphy (1987), Myerscough (1992), Vanier (1998) and Wolfensberger (1998) had vast impact, and changed me. I was left more informed, and with profound angst. I wrote briefly on Goffman, Vanier and Wolfensberger in turn, as they added unique perspectives, and momentous knowledge to the literature.

Goffman's (1963) revelation of the shocking extent to which society marginalizes and shames people, multiplied by his vast knowledge of social systems, situated him at the forefront of authors addressing the issue of stigma. Goffman asserted: "We normals develop conceptions whether objectively grounded or not, as to the sphere of life activity for which an individual's particular stigma primarily disqualifies him" (p. 49). Goffman explained: "...anything which interferes directly with the etiquette and mechanics of communication obtrudes itself constantly into the interaction and is difficult to disattend genuinely" (p. 103). His shrewd social insight enabled him to examine and irrefutably clarify the dynamics of social interactions. Goffman affirmed: "In short, unless there is some alien culture on which to fall back, the more he separates himself structurally from the normals, the more like them he may become culturally" (p. 114). His keen perception enormously impacted the literature.

Vanier (1998) maintained the mentally disadvantaged are the most stigmatized and marginalized of the entire spectrum of disabled persons, and revealed the shocking

way that they are rejected by society, and in many cases, even by their own parents, who frequently disown them. Vanier explained: "Power has a direction: it is always exercised downwards, towards the weak. [and] The exercise of power gives people a sense of identity and worth" (pp. 155-156). In spite of the fact that society loathes the very idea of sects, the harmless ones go unnoticed: "... we can be blind to the innocuous sects that are a part of society" (p. 56). Vanier's distinctive and unique writing led me to an awareness of that which I had overlooked, the obvious.

Wolfensberger (1998) wisely acknowledged the immense power and resistance of societal norms. In spite of his idealism, he was fully cognizant of the rigidity of social norms; he accepted this as given, and endeavored to work within these constraints. He in no way condoned the values and beliefs of these inflexible social constructs.

Wolfensberger (1998) developed strategies and techniques for advancing the status of disabled and therefore, devalued persons. If these strategies were implemented, they could enable the disabled persons to gain more than a modicum of dignity when "entertaining" the "normal" person, thereby increasing the "value" of the devalued persons.

Some of the recommended tactics are simple matters such as attending to appearance and cleanliness, conforming to a normal schedule, and removing all medications, prostheses, and other reminders of the disability, from sight. If the disabled person cannot perform these tasks alone, Wolfensberger's design includes implementation of all the resources necessary to ensure that those who are marginalized appear as normal as possible. His meticulous strategy incorporates considerations such as

the significance of the location and the appearance of homes for disabled. Wolfensberger engaged in an exhaustive examination of all devalued peoples, and what could be done to assist valorization of their social roles.

Loneliness

A visit to the physician is often the only “social” occurrence for a person with brain injury. Therefore the way the patient is received is paramount (Kleinman, 1988). The physician should endeavor at all times to be cognizant of this fact, and in doing so engage himself more fully in what could be a boring, tedious task. Kleinman stated: “... the experience of listening to the patient’s biography maintains the physician’s active interest in the case” (p. 237).

However, Buber (1970) held a different perspective on Kleinman’s claim that by listening, the physician maintained his “active interest in the case” and in his patient:

Every I-You relationship is a situation defined by the attempt of one partner to act on the other side so as to accomplish some goal depends on a mutuality that is condemned never to become complete (p.179)

Buber affirmed that loneliness is inevitable: that every I-You relationship is an unachievable idyllic model. Vanier (1998) tended to agree with Buber. I had to bear in mind that the above-quoted Buber passage was Kaufman’s translation from the original German. As close and accurate as Kaufman’s translation was, “condemned never to be complete” is more forceful than Vanier’s (1998) statement on the value of solitude: “The excluded, I believe, live certain values that we all need to discover and to live ourselves

before we can become truly human” (p. 84). Vanier testified that although the existential condition is an inevitable aspect of human existence, seclusion holds the promise of being of great worth.

Brain-injured females frequently suffer from an epileptic seizure disorder as a consequence of having sustained brain injury (Kleinman, 1988). This can be frightening to all concerned, and can cause others to withdraw from the epileptic. It is therefore both a medical, and social issue. The woman will most likely be stigmatized and shunned, amplifying her experience of loneliness. Goffman (1963) explained: “Since Hippocrates’ time, those who discover they have this disorder [epilepsy] have been assured a firmly stigmatized self by the definitional workings of society ...medical science must withdraw ... [and] ...society can act most determinatively” (p. 124). From his understanding as a medical doctor and psychiatrist, Kleinman described utter chaos visited upon a woman with a seizure disorder: “The epileptic lives under the very point of the sword of Damocles, uncertain when a fit will come” (p. 45).

As Davis (1961) explained, fear of being asked questions, which could possibly embarrass “normal” adults, could lead to avoidance of social situations: “... a small child at a social occasion caused them [the disabled] such uneasiness and cramped their style because they were concerned with how, with other adults present, they would handle some bare-faced question from the child” (p. 129). Thus fear and avoidance become dynamics in the further isolation of the disabled person. Vanier (1998) explained: “It is fear, ironically, that prevents us from being most human, that is, it prevents us from growing and changing. Fear wants nothing to change; fear demands the status quo and

the status quo leads to death” (p. 73). He testified: “Becoming a friend to a marginalized, excluded person is an act of self-imposed exile from most of the world. It is liberating, an act of freedom” (p. 96).

Loneliness is closely aligned to stigmatization. If the stigmatized woman belongs to a marginalized sub culture, the loneliness could, to some degree, be mitigated. If this is not the situation, the woman could feel acute emotional and cultural isolation. Buber (1970) addressed the universal issue of existential anxiety and solitude. However, for the marginalized, stigmatized individual, it must, at times, be almost unbearably acute. Viewed in this light we can better understand suicide (Sloan, 2000).

Loss of Social Support

Kleinman (1988) noted a serious juxtaposition of values between the medical and the social realm. The first is valued; the second is valueless because of indifference or actual denial of emotional suffering. Kleinman asserted: “Cultural issues are allowed to slip by, one after another, in a way that would be regarded as sheer clinical incompetence, if the issues were biological” (p.135).

Addressing the theory of social systems and communication, Goffman (1963), Shreiber and Moring (2001), Vanier (1998) and Wolfensberger (1998), believed that systems exist apart from an individual, and that after a time, patterns of communication are established and are replicated. Once accepted, they become convention and then policy. At this point these patterns or “rules” of communication serve the system rather than the individual, and become ingrained. Is this yet another example of the impact of

words and hermeneutical interpretation? If communication serves the system rather than the individual, is this fairness, equality or justice? Winslade (1998) was concerned by what he saw as society's lack of acknowledgment of basic human rights:

As a bioethicist trained in both philosophy and the law and intensely interested in fairness, I am particularly concerned that people with traumatic brain-injuries receive appropriate treatment. ... Clearly, our Society is neither efficiently nor effectively serving the needs of people who have suffered serious brain trauma (pp. 12-14).

Within these systems, individuality, personal concerns and needs are consistently sacrificed to habitual prototypes (Schreiber & Moring, 2001).

In Canada, a patient who lacks private insurance coverage is discharged from hospital and a health care system takes over. All caseworkers and other personnel dealing with the woman after discharge have the record of the original physician's text. These caseworkers make their decisions based on the physician's written prognosis. Is the fecundity of the individual case then sacrificed to a prototype, a bureaucratic system? If this "system" perpetually refers to the physician's written prognosis, haven't we come full circle, back to the impact of the physician's words? Could the pertinent issue therefore be the prognosis, the expected outcome of the disease, with the consequential loss of the patient's persona? Allison, Gripton, Rodway (1983), Cassell (1982, 1985), Frank (1991) and Siegel (1986) described the havoc wrought on the patient's physical, emotional and spiritual being, provoked by viewing the patient as a mere set of symptoms.

Post Brain injury Cognitive Loss

Brain injury could result in such cognitive loss that the victim could become classified as intellectually disabled (Kleinman, 1988; Winslade, 1998; Wolfensberger, 1998). Vanier (1998) maintained: "... those with intellectual disabilities are among the most oppressed and excluded people in the world" (p. 72). Cognitive losses after brain injury could be an undeniable and undesirable fact. These serious and life altering losses impact the rest of the victim's life. This person has to recreate a life within the parameters of serious constraints (Winslade). This intimate personal disclosure was extracted from Kleinman:

"That's OK, Dr. Kleinman. I'm accustomed to it. I'm just a small person. I'm hardly a grownup anymore. I know the truth." [Now the sheepish grin had left his face and he was crying.] "I'm not all together, up here. I'm a half-wit like they said, aren't I? The world is too fast for me, isn't it? The people are too big. And when they get angry they can hurt you, can't they? It really is too dangerous a place for me. Maybe I should live in a home, you know what I mean, a home for people like me."

I felt a deep sadness break like a wave. I think my eyes teared; I may well have cried with him. Then I felt anger—not at Paul, fortunately, but at the injustice experienced by the weak, the timid, the vulnerable in a world of man eaters (p. 196).

Rehabilitation is essential for the brain-injured victim to achieve her maximum level of function. This necessary rehabilitation is not occurring for the simple reason that every victim does not have the necessary catastrophic health coverage (Winslade, 1998).

It is not unusual for the victim to be entirely dependent on others (Wolfensberger, 1998). However, Vanier (1998) informed: "... weakness carries with it a secret power – the one who is weaker can call forth powers of love in the one who is stronger" (p. 16).

Xavier LePincheon, (cited in Vanier) explained that over the span of evolution: “people have become more human as they opened up to the weak and to the reality of suffering and death” (p. 96).

Kleinman (1988) painted a compassionate and striking picture in describing a brain-injured client:

“I don’t even know how to be competent at being a brain-injured patient, do I?” Paul Sensabaugh’s personality had become immature and his cognitions seriously limited, but his sensitivity to others’ reactions was intact. His constant effort was to show others and himself that he was no less human than they. I often wondered: a hospital is organized to protect physically those patients who are in wheelchairs, or who are blind, or who need oxygen or special diets or assistance in caring for themselves; but is there anything in a hospital, to say nothing of the world outside, that protects a patient’s sense of shame (p. 168)?

Summary

Some of the literature suggested there is evidence that word and language choice do impact the patient. Words affect body and mind, and thus hold a “suggestibility” component. These words have either a beneficial or deleterious effect. Two of the factors that impact the patient, are the sensitivity and the awareness of the physician speaking to her. Innocent terms spoken by the physician could create acute apprehension for the patient. This is a consequence of patients listening very closely to the physician’s words. In fact, according to the phenomenological semiotic perspective of van Manen (1990), all experience systematically communicates something of meaning, therefore both humanity and the world can be read as text. He believed any social situation is open to interpretation. This would include physician-patient interaction. The ultimate,

undesirable risk within the physician's discourse would be to provoke a change in the patient's perception of reality.

Both placebo and nocebo reactions are realities, provoked by the power of belief. This suggests credibility in Alexander's (1965) claim that the mind rules the body. If this claim has any basis in reality, it follows that the state of mind and the emotional "temperature" are capable of provoking bodily changes. This phenomenon was described in the literature by Allison, Gripton, Rodway (1983), Cassell (1982, 1985) and Siegel (1986).

Almost all patients need a diagnosis: lack of a diagnosis is frightening to most patients. A diagnosis may imply that the physician knows what to do to cure or contain the disease, thus the diagnosis serves as a mitigating factor. However, some patients view diagnosis from the opposite perspective, in which case the diagnosis can be an impediment to a freeing self-definition. A diagnosis can become a self-fulfilling prophecy.

Biomedical terminology can be frightening to the patient, and the use of biomedical terminology serves to underscore the perception of authority in the physician. This perception of authority combined with biomedical terminology multiplies the impact of the diagnosis. In spite of this fear-provoking terminology, most patients prefer the biomedical model.

The art of medicine could be intuitive, however, not all physicians are equally adept at this art. If the physician practices this art, he can help the patient distance from

the diseased body part, thus distancing language can be utilized to the patient's benefit. The physician can always say something of benefit for either the patient's physical body or emotional state, which is an aspect of practicing the art of medicine.

Narrative accounts are extremely valuable as a therapeutic tool; in all cases the narrative account should be heard.

Medical training defines illness and death as the physician's failure. However, no physician, even when viewing the patient as a collection of symptoms, can pronounce a definitive prognosis.

The separating of psychological and sociological issues is, in some ways, artificial: these themes overlap, intertwine, intersect.

Psychopathological terminology, with its inference of pathology, is not beneficial to the victim of brain injury, although, as stated earlier, psychological labels may be helpful with coding or standardization. These labels may exacerbate and increase the natural effect of the losses the woman has sustained.

Psychological terminology might prevent recognition of beneficial strategies for coping with treatable life problems. This "terminology distraction" could immobilize the practitioner and cause the brain-injured victim to view herself as powerless.

Women with brain injury can, to their detriment, disregard psychological losses. Changes and stressors such as difficulty with physical accessibility do not occur sequentially. Due to the fact that they occur simultaneously in layers, the impact on the

woman's emotional well-being is compounded; this can lead to a sense of feeling overwhelmed.

Lowered self-esteem, preoccupation with physical deficits, anger, and undesirable self-image may result from the brain injury. If the identity undergoes change, and that change is based solely on the physical impairments, the disabilities, especially if physical, may never leave the mind, even when the person is dreaming.

Isolation, or solitude, is greatly magnified when the person does not look normal or behave "normally". A seizure disorder is not unusual after brain injury. These abnormal episodes serve to magnify fear for the victim and would-be companions. The effect of change in appearance or behavior is exacerbated, if the injured person's personality alters in a way that causes the "new" woman to be completely unrecognizable to family and friends. The phenomenon of personality change is not atypical for victims of brain injury.

Human rights are not respected and fostered when disabled persons are systematically excluded; a society's failure to accept difference is stigmatization. People with any disability, be it mental or physical, can be marginalized and set apart from "normal" society. A brain-injured woman may be classified as intellectually disabled, and therefore at risk of this systematic exclusion. The tendency to stigmatize and marginalize may be a fundamental aspect of human nature. At the very least, societal norms are, and always have been, entrenched.

If the brain-injured female perceives herself as stigmatized by “normal” society, she could withdraw into a sub-cultural haven of fellow brain-injured persons. When a sub-culture upholds the opposite of what a society values, it is deported into devalued status. Ironically, the attitudes of the sub-culture mirror the attitudes of the society that forced the formation of the sub-culture. Loneliness is inherent in stigma; these experiences greatly impact the person’s emotional well-being. Although loneliness is a universal experience, if the disabled woman chooses to sequester herself, she may be marginalized or stigmatized nonetheless, sometimes with devastating consequences.

Our North American society desires order and predictability. Most “normal” people prefer not to “see” (recognize), anything that reminds us that life, and our world, is not as we would wish: safe, predictable and free of physical and mental anguish.

Strategies and techniques exist within societal values and norms, which when exploited, advance and valorize the status of devalued persons and groups. Although these persons will still remain less valued than “normal” society, this endeavor is well worth undertaking.

Throughout history, power has been applied downwards toward the weak, the poor, the physically disabled and the mentally disadvantaged. Used in this way, power can lead those who hold it to an immoral sense of identity and worth. The mentally disabled are the most stigmatized and marginalized of all disabled persons. But weakness can contain a very significant gift; it can draw compassion, empathy, assistance, and ultimately love from the “stronger”. In order to become fully human, we all need to understand and embrace particular values which some marginalized people live.

The construct of social roles constitutes a tremendously beneficial instrument for analyzing and understanding the dynamics of devaluation, and for creating instruments which improve the lot of devalued peoples. This construct deserves to be fully exploited. Unfortunately, the needs of the disadvantaged individual are still being sacrificed to social systems, and habitual prototypes consequently develop.

Those victims of brain injury without disability insurance may not have access to the optimum amount of rehabilitation necessary to regain as much function as possible. As our society does not recognize the magnitude and catastrophic outcome of brain injury, it neither efficiently nor effectively serves the needs of the brain-injured.

Sadly nothing in our society serves to mitigate the first and most powerful emotion for the brain-injured. This emotion is shame.

Given the large degree of change that occurs when one experiences a brain injury, it is surprising that so little literature focuses on the ability of women to understand and cope with the consequences. This study collected the accounts of women and offered recommendations based on their interpretations. Practical considerations arose from the data having implications for the training of medical professionals and all those who work with women with a brain injury, including the women themselves. The phenomenological nature of this study served to explore this area further.

The literature on the effect and interpretation of the spoken word was limited and I read across the disciplines in the hope of supplementation. In contemplating my research question, I had to consider the potential influence and authority of the physician.

I anticipated having to interpret my co-researchers' data hermeneutically. Therefore, in addition to reading authors on medicine, I reviewed literature in the areas of authority and influence (Cialdini, 1984), theology (Buber, 1970; Vanier, 1998), psychiatry (Anderson, 1996; Kleinman, 1988), sociology (Frank, 1991; Goffman, 1963; Schreiber and Moring, 2001; Wolfensberger, 1998), social welfare (Allison, Gripton, Rodway, 1983), linguistics (Goodluck, 1991), philosophy (Buber; Garton and Pratt, 1998; Vanier; Winslade, 1998), journalism and medical philosophy (Cousins, 1979), ethics & law (Winslade), anthropology (Murphy, 1987), education (van Manen, 1990) and psychology (Brainerd, 1978; Cialdini, 1984; Garton, 1998; Gergen, 1996; Gilligan, 1982; Moustakas, 1994; Osborne, 1990; Sloan, 2000), special education and rehabilitation (Brainerd, 1978). This summary provided the theories and findings of experts in these areas, and laid a foundation for pursuing the lived experience of women who had experienced a brain injury.

The voice of the brain-injured woman is absent from the literature. What do these women have to say? I conversed with the participants in this study in order to visit their lived experience of brain injury. Did these women feel the influence of the physician? What were their responses to conversations with their own physicians? Did they feel and think the medical discourse with their physicians was of any consequence? It was essential that the women themselves describe their own responses to conversations with their physicians. To undertake this form of research meant finding a method of study that illuminated my research question. Hence, a phenomenological tradition offered a way of gaining access to the interpretations of these women.

Research Approach

If the spoken word or the text is open to an individual's interpretation, could we ever know how our message is perceived? Cassell (1985) asserted: "Remember you are already dealing with two translators in any conversation: the patient's understanding of your meaning, and your understanding of his or hers" (p. 55). Moustakas (1994) quoting Gadamer in *Hermeneutics of Suspicion* (1984) illuminated: "We can never be sure, and we have no proofs, of rightly understanding the individual utterance of another" (p. 9). Speaking on Ricoeur (1976), van Manen (1990) proposed that we can choose how to interpret any social situation, that we can interpret it as text, and can therefore search for the metaphor that appears to govern the "text" of the social situation. Hermeneutics is one of the five phenomenological research methodologies used in human science research. I did not use it as a methodology; I borrowed and utilized it solely as a lens, as an interpretative tool, a perspective for analysis of the "shared worlds" spoken by the co-researchers and myself. This lens became an additional angle from which to view the second element of my question: what were the women's personal interpretations of this discourse?

Given the findings of the literature, and my perceptions as an "insider", I have chosen the transcendental phenomenological reduction (TPR) methodology; a more appropriate tool for addressing the research question. This methodology allows an "intuitive grasp" on the elusive, but everyday, lived experience of women who have had

to communicate with experts (physicians) while living with a life transforming experience.

CHAPTER THREE: METHODOLOGY**Development**

Corona: A Pause Sign Above a Musical Note Indicating Time Should be Taken or Allowed, Before Moving Forward with the Thematic Material.

I used this analogy to indicate that I took “the time”, “paused” to consider my methodology from all possible angles.

Introduction

The rationale for undertaking the study was to attempt to ascertain whether or not the ramification of the words spoken by medical personnel had any effect on healing and recovery of brain-injured females classified as having cognitive high function. Did this question of discourse occur to any of these women? If the words did impact these women in an unhelpful way, how did they cope? Did they live with any of the other social and psychological issues referred to in the literature? What was the lived experience of women after brain injury?

I was interested in the interpretation of experience through the interview process. I chose phenomenology; this is an approach that allowed for collection of experiences of the brain-injured women. A qualitative approach was adapted to undertake this line of phenomenological inquiry.

There is no such thing as *the* phenomenological method. Phenomenological methodology is more of an orientation than a specific method. The particular procedure used in any study depends upon the question being posed (Osborne, 1990, pp 83 – 84).

Research Design

Given there is only minimal and superficial research literature reflecting the voices of women in describing the experience of living with the rehabilitation process as a consequence of sustaining a brain injury, a quantitative study (for example, a survey approach) seems premature. Before clinicians can expect to design larger sample studies to pursue this line of inquiry, an exploratory study is a necessary approach to finding the relevant questions. Assuming this to be necessary, a qualitative design allows the space and depth for conversing intimately with women who can reflect over time on their interpretations of the nature of discourse with “experts” (the physicians). Therefore, a qualitative design contributes to finding the “right” question for further research.

As stated in the Preface, Moustakas’ (1994) particular perspective of the transcendental phenomenological reduction (TPR) using imaginative variation is one of the phenomenological models in human science inquiry. I based the research design on Moustakas’ version of this methodological approach. Following the phenomenological model, I approached the collection, organization, analysis and synthesis of data using open-ended, topical, minimally guided personal interviews.

The investigation begins with the epoche process requiring an open and naive approach of looking, seeing and not judging. Although epoche may ultimately be an unachievable principle, the process is nevertheless a worthwhile endeavor as it inspires one to consider prejudgments and improves one’s openness.

This methodology reflects the “phenomenological” tradition. It examines the lived experience, changing it into a simple occurrence or phenomenon. It then “reduces” the phenomenon and brings us back to our experience of the way things are.

The imaginative variation of Moustakas’ particular design allows creative freedom and the exploitation of fantasy, which attempts to uncover the essence and make the hidden become evident. This “finding” is core to the imaginative variation process. The search of imaginative variation can include the use of metaphor, divergent perspectives, juxtapositions, and role reversal, ultimately arriving at the synthesis of meanings and essences. According to Husserl, epoche and reduction occur naturally in human interaction and understanding (Moustakas, 1994). The person sees what she considers apodictic (self-evident), and then verifies or modifies the interpretation with co-researchers (Moustakas, 1994). In doing this we are ultimately lead to a more precise and comprehensive understanding of the meaning of the phenomenon.

Moustakas’ (1994) version of TPR with imaginative variation allowed the sifting of other women’s experiences with brain injury through my own experience. This sifting process was crucial to the procedure used in analysis of my data from the interviews conducted. Being aware of my particular bias around this issue, Moustakas’ version of this design was perhaps the most appropriate methodological approach: It offered the opportunity to use the epoche process. The epoche process was a consciousness raising process: I was aware that I chose to react to a co-researcher’s thought, or that I chose to draw out this response from that woman. In endeavoring to strictly adhere to the challenge of epoche, I attempted to see with the eye of innocence, stripping myself of all

biases and freedom from supposition. This epoche process sharpened self-awareness and enhanced my abilities as an interviewer in this research project. I welcomed the challenge of listening carefully and presenting the actual narrative account of the woman. Listening in this way, I was more confident that I heard the woman's story with awareness of my bias; and understood the meaning reflected by the brain-injured co-researcher.

Method of Collection

Participants of this study were volunteers selected from the SABIS Brainstormers women's group (Brainstormers Approval letter, Appendix B). Please refer to the letter from SABIS giving their consent to proceed with the study (SABIS Approval letter, Appendix C). In order to draw forth the richest data from the interviewees, I endeavored to have the women view their involvement as being co-researchers or participants. "The two parties co-constitute a relationship" (Osborne 1990).

Each member of the group who consented, participated in an initial personal interview, followed by one or two subsequent shorter interviews clarifying and expanding the content obtained from the first session. The initial interview lasted approximately one hour (Sample Interview Questions, Appendix D). If conducted, the two subsequent interviews lasted approximately one-half hour.

I spoke to representatives of the Brainstormers Group to ensure they understood the purpose of the study. Upon receipt of my letter of introduction to the study (Letter of Introduction, Appendix E), I ensured that all potential volunteers were willing to

participate, were aware of the purpose of the study, had the ability to participate, and had the time. This was done by means of a verbal summary (Verbal Summary, Appendix F). Only then was a written individual consent form gathered from each participant prior to the first interview (Consent Form, Appendix G).

After engaging in the interview process, reviewing her narratives, verifying my understanding of her story, and confirming satisfactory completion of the interview process, the co-researcher was sent a thank you letter for participating in the study (Thank You Letter to the Co-Researcher, Appendix H).

In order to provide orientation to the phenomenon, I bracketed my own value perspective through rigorous self-reflection, before and throughout the interview process (Moustakas, 1994; Osborne, 1990).

Once interviews were transcribed, each participant received a copy of the transcripts for her reflection prior to the subsequent interviews. "Successive data-gathering interviews create a re-spiraling effect and enable a more complete illumination of the phenomenon" (Osborne, 1990, p. 84). This served as a reminder of the previous interview, which lead to elaboration, confirmation or change of content (van Manen, 1990). Subsequent interviews also allowed a checking-back, which increased the internal validity of the study and the themes revealed (Osborne, 1990).

The analytical procedure included horizontalizing data, viewing each relevant statement as having equal value. The meaning-units were gathered or clustered into common categories yielding a skeleton without repetitive statements. From this skeleton I built or developed "textural descriptions of the experience" (Moustakas, 1994, p. 118).

Analysis of the transcriptions drew additional interpretations based on description, thematic interpreting, and metaphoric insight looking for any commonality of experiences (van Manen, 1990). This coding technique also allowed me to consider the fecundity of the individual story; the “textural” analysis.

Methodological Analysis:

- Bracketing the Question

I endeavored to set aside my subjective feelings, preferences, inclinations and expectations, which could have impeded comprehension and appreciation of the lived experience of the brain-injured female. Constructs, theories, scientific concepts, internalized themes were consciously set aside. In doing this vivid but unreal reduction, I needed to see past or through the individuality of the lived experience, in an endeavor to see the absolute essence of the experience or phenomenon. Therefore, I used the epoche process (“stripping”, “eye of innocence”) to facilitate clearing space in order to view with an untainted eye. I continued to visit the experience or phenomenon under investigation until I felt I had, at that time, exhausted all analytical possibilities. I realize that if I were to revisit the data at any future time, it would likely be with an altered perspective.

- Restricting Horizons or Meanings

The horizons equated only the invariant qualities of the experience or phenomenon under study.

- Horizontalization

Each statement from the individual transcript was initially considered as having relevance. The statement was then scrutinized. To arrive at the individual textural description, each transcribed interview was systematically stripped of all statements that were irrelevant, redundant or overlapping with regard to the topic. These statements were discarded. Relevant statements that contained the themes, or sub-themes of the phenomenon under study, were then coded as meaning-units.

- Individual Textural Descriptions

The individual textural description provided a picture of each co-researcher. This allowed for the fecundity of the individual case, which was of importance to this study of the lived experience of brain-injured women. The meaning-units of the individual co-researcher were incorporated with minimal quoted examples. Pseudonyms were assigned to each co-researcher. This was done to ensure that the individual within the Brainstormers group remained anonymous.

- Invariant Qualities and Themes

All of the individual scaffolding or frames, constructed out of these meaning units, were then clustered together. Common themes, sub-themes or phenomena ultimately produced the composite textural-structural descriptions.

- Composite Textural-Structural Descriptions

To be considered composite and these invariant meaning-units, the sub-themes and themes, had to be common across the group of nine co-researchers. This resulted in a

group of universal textural-structural descriptions. The search for commonality of experience among the group of co-researchers was then complete.

Imaginative Variation

The essential task of imaginative variation is to consider all possibilities; thus, anything becomes possible and must be scrutinized in an attempt to grasp the structural essence. To aid this process, I endeavored to approach the three-element research question from many perspectives, turning the question over and around in my imagination, viewing it from differing angles, utilizing different lenses. Juxtaposition, intent and reversal of roles were considered.

As stated in the preface, in addition to intuitively reflecting, imagining, and thinking creatively, I deliberately exploited the comparison with the extended progressive symphony form, used musical metaphors, incorporated the “voiceprint” based on Cassell’s (1985) concept of paralanguage (the music of language), as components of imaginative variation.

Using fantasy and intuitive reflection, a possible list of structural qualities was built. The list was developed intuitively using imaginative fantasy themes (the “perhaps” list of chapter one) to reveal hidden meanings. For the individual co-researcher, sub-themes, themes and structures were combined to build a picture of that co-researcher.

In order to arrive at a composite structural description, the following procedure was used: all pertinent, common pictures (across the group) were combined, yielding an all-embracing or universal structural description.

A synthesis of composite textural-structural descriptions was arrived at through the intuitive-reflective amalgamation of the composite textural and composite structural descriptions. I reflected upon my personal and particular interpretations in conversation with co-researchers. Metaphoric insight was utilized. Was there any commonality of experience? Thematic interpreting was done within the context of the brain-injured female.

The final imaginative variation component I chose to use was the taped, aural description of the individual's experience, the "voiceprint". This proved to be an invaluable tool. Without the use of the voiceprint, much of the transcribed data could have been misinterpreted. One can hear anxiety and joy in a person's voice, for example, which are undetectable in the written transcript. In many cases, the "voiceprint" prevented misinterpretation. This analytical tool takes into account all of the elements of the "music" of spoken language.

All imaginative variations, including the voiceprint analysis, were combined with textural-structural descriptions to achieve the textural-structural synthesis of meanings and essences. The essence was the kernel or seed, distilled from the individual and group experience. Individual and group were then set aside in order to manifest this common or universal essence.

Aural Description of Themes

I used the aural description from the audiotapes as a parallel analytical tool, which captured meaning from both text and voice. This “voiceprint” can be considered an aspect of imaginative variation in Moustakas’ (1994) approach to the TPR methodology.

I considered the audio taped interviews as if they were musical compositions. I based my analysis of these voiceprints on Cassell’s (1985) innovative paralanguage method.

- Speech rate

Slow (*Largo*)

Leisurely (*Andante*)

Quick (*Allegretto* to *Presto*)

Changing (*Sprechgesang*)

Lively (*Allegro*)

Hurrying (*Drängend, Eilen*)

- Pause-speech rate ratio

Agitated (*Concitato*)

Flowing (*Legato*)

Choppy (*Staccato*)

Stuttering (*Gorgheggio*)

Long Pauses (*Lunga Pausa*)

Short Pauses (*Corona*)

Slowing down (*Allentando*)

Pause (*Pausa*)

Laboring (*Stentando*)

Halting (*Agitato*)

Getting slower and slower (*Allargando*)

Urgent (*Dringend*)

Extremely quickly (*Di Molto*)

Quick (*Geschwindigkeit*)

- Tone or Voice Quality

Clear (*Chiara*)

Brassy, harsh and blaring (*Cuivré*)

Dull and unchanging (*Drone*)

Shrill (*Schmetternd*)

Breathy (<i>Fiato, Sfogato</i>)	Mocking (<i>Moqueur</i>)
Deep (<i>Sonorous</i>)	Young and high (<i>Coloratura</i>)
Throaty (<i>Gorgia</i>)	Piercing (<i>Strident</i>)
Resonant (<i>Resonance</i>)	Soft (<i>Crooning</i>)
Dark, somber (<i>Cupo</i>)	Lamenting (<i>Déploration</i>)
Sharp (<i>Dièse</i>)	Sweet, Gentle (<i>Dolce</i>)
Hard, stern (<i>Duramente</i>)	Mournful (<i>Flebile</i>)
Sonorous (<i>Klang</i>)	
▪ <u>Pitch</u>	
High (<i>Soprano, Tenor</i>)	Medium (<i>Mezzo Soprano, Baritone</i>)
Low (<i>Alto, Basso</i>)	
▪ <u>Volume</u>	
Almost inaudible (<i>Estinto</i>)	Whispering (<i>Bisbiliando</i>)
Weak (<i>Debile, Schwach</i>)	Increasing (<i>Crescendo</i>)
Decreasing (<i>Decrescendo, Diminuendo</i>)	Medium (<i>Mezzo forte</i>)
Loud (<i>Forte</i>)	Extremely Loud (<i>Fortissimo</i>)
Wide Ranging (<i>Piano-Forte</i>)	Even (<i>Resonant</i>)
▪ <u>Articulation</u>	
Extremely short and precise (<i>Délié</i>)	Slurred (<i>Gebunden, Legatura</i>)
Smooth (<i>Legato</i>)	Stretched out, sustained (<i>Gedehnt</i>)
Lively (<i>Lebhaft</i>)	Dragging (<i>Strascinando</i>)

 ■ Choice of words

Distinct (<i>Distinto</i>)	With fire (<i>Con Fuoco</i>)
Appropriate and accurate (<i>Schrittmässig</i>)	Chaotic (<i>Extremely dissonant</i>)
Dramatic (<i>Empfindung, Sturm und Drang</i>)	Theatrical, imposing (<i>Pomposo</i>)
Poetic (<i>Ode</i>)	Metaphoric (<i>Improvisation</i>)
Beautifully expressive (<i>Espressivo</i>)	Sad (<i>Mesto</i>)
Formal, dignified (<i>Maestoso</i>)	Informal (<i>Piacere</i>)
Inappropriate (<i>This researcher knows of no musical equivalent</i>)	
Distant (<i>Lontano</i>)	Solemn (<i>Feierlich</i>)
Bizarre (<i>This researcher knows of no musical equivalent</i>)	
Repetitive (<i>Istesso Tempo</i>)	Merry (<i>Giocosso</i>)
Sorrowful (<i>Dolente, Doloroso, Lacrimosa</i>)	Heartfelt (<i>Innig</i>)
Compassionate, sympathetic (<i>Pietoso</i>)	Emphatic (<i>Forza, Marcato</i>)

 ■ Sentence construction

Simple (<i>Einfach</i>)	Elaborate, flowery (<i>Fioritura</i>)
Uneducated with errors (<i>This researcher knows of no musical equivalent</i>)	
Intellectual, serious (<i>Serio, Seria</i>)	Mocking (<i>Semiseria</i>)
Rhetorical (<i>Oratorio</i>)	Metaphoric (<i>Simile</i>)
Awkward (<i>Scordatura</i>)	Decisive (<i>Décidé</i>)
One long drawn-out breath (<i>Filar La Voce</i>)	Fluently (<i>Facilmente</i>)
Menacing (<i>Minaccevole, Minacciando</i>)	Vigorous (<i>Kräftig</i>)
Resolute (<i>Risoluto</i>)	Articulate (<i>Deutlich</i>)

Comfortable, easy going (*Gemächlich, Gemütlich*)

▪ Logic

Logical (*Consonance*)

Illogical (*Dissonant, Al Rovescio*)

Extremely Illogical (*Dissonant-Cacophony*) Straightforward (*Ossia*)

Irrational (*Musique Concrète*)

Consistent (*Paradiddle*)

Complicated (*Umkehrung*)

Reasonable (*Giusto*)

Contradictory and ambivalent (*Spezzato*)

Repeating (*Da Capo*)

Obtuse (*Poi: in way not made clear by notation*)

▪ For all categories

Wide range of variations (*Largo to Prestissimo*)

Rapid variation (*Con Moto*)

At the same speed (*Movimento*)

Less movement, less quickly (*Meno, Meno Mosso*)

CHAPTER FOUR: RESULTS***Transition or Retransition*****Explanation of Approach**

I spoke to nine women, with a maximum of three interview sessions per ‘co-researcher’, over the period of one summer. The age range of the women was approximately twenty to sixty years.

Six co-researchers were anxious to have their identities revealed, however three wanted to remain anonymous. Therefore, I have respected the anonymity and confidentiality of all co-researchers. I used the pseudonyms: Athena, Iris, Iphigenia, Niobe, Aphrodite, Euphrosyne, Electra, Demeter and Artemis when quoting individuals. These names are part of the rich mythology of ancient Greece. Each woman possessed some attribute reminiscent of the particular Greek mythological character assigned to her.

These women were exceptionally co-operative and generous with their time, energy and resources. I am indebted to them all.

Co-Researcher Histories

Co-researcher number one sustained her brain injury 26 years ago. She called herself a “fighter”. After sustaining her brain injury, this woman became a single mother to several children. At the time of the interviewing this co-researcher was not gainfully employed.

The second co-researcher sustained her brain injury approximately three to three and a half years ago. At the time of the interviewing this married woman had one child, and was not gainfully employed.

The third co-researcher experienced a stroke over 30 years ago and was misdiagnosed as having no residual damage. In 1995, she was again, at her own insistence, assessed. The new assessment showed brain injury as a consequence of stroke. With this definitive diagnosis, the recognition of her brain injury, the woman experienced hope. She was a single mother of several children and was not gainfully employed at the time of the interviewing.

The fourth co-researcher sustained her brain injury less than two years ago. This woman was a single parent and was not gainfully employed.

The fifth co-researcher sustained her brain injury more than one year ago. She was a single female and was gainfully employed.

The sixth co-researcher's injury was sustained ten years ago. This woman was not gainfully employed.

The seventh co-researcher sustained a brain injury more than three years ago. She was a single mother. I was unable to ask whether or not she was gainfully employed, however, I learned she was working on a part time basis.

The eighth co-researcher sustained a brain injury more than three years ago. She was a single mother, and was not gainfully employed.

The ninth co-researcher suffered a brain injury three years ago. She was not gainfully employed.

Individual Textural Descriptions

Mathematicians tend to use the adjectives “positive” and “negative”. In that context they are pure and absolute. In the most basic psychological sense however, positive and negative have come to equate “good” and “bad”. Negative carries the inference of pathology. This small piece of qualitative research considered the lived experience of women who have sustained a brain injury. Situated within the research, the adjectives “positive” and “negative” would have been considered judgmental. I endeavored to avoid judging the content of the following textural depictions, by choosing adjectives that are more neutral in their psychological associations. Therefore, I used “beneficial” and “unsupportive” throughout the following textural descriptions.

Voiceprint-Aural Description of the Tape-Recorded Interviews

When I used the word “inappropriate” within any voiceprint description, it had very particular meaning in the context of this study. This expression was not used as a term of judgment, but rather, reflected a woman’s misplacement or out of context word usage. Perhaps this was caused by cognitive impairment associated with the brain-injured. However, this did not impair my understanding of the intended meaning.

“Athena” – Textural Description

I found Athena to be an interesting, intelligent, insightful, thoughtful woman. For example, she had a noteworthy perspective on rehabilitation:

I suggest the word 'habilitate' because ... you have to habilitate yourself to whatever the new reality is. So rehabilitation to me is saying you're not good enough, we've got to get you back. Rehabilitation implies that someone has to take you there ... I didn't have formal rehabilitation, but it is in my understanding, a place where someone who has 'the abilities' is...[attempting to lead you back to]. The concept of rehabilitation is: we've got to get you back to normal. But this new habilitation, if you think on it, is an almost sacred type of place, where something that we consider menial work becomes a beautiful thing and treasured for what it is.

This woman had accepted her brain injury and, as with all other co-researchers in this study, she had hope.

Athena believed some part of her physical condition had changed in the month after the brain injury surgical intervention, and her physicians did not recognize this. This awareness of altered physical condition was ultimately detected, confirmed and diagnosed.

When admitted to hospital, she was "in her early twenties, thin and spoke in a whisper". She claimed that in 1975 a thin young woman was considered "a girl". Due to these factors Athena believed she was perceived as a "hysterical female" when misdiagnosed.

She still felt overwhelming anger whenever she heard an Eastern European accent, which she associated with a physician who, she felt, was particularly arrogant. Hearing this accent 27 years later still served as an emotional trigger. Athena elaborated: "How it impacted even my relationships with people with such an accent. How strongly emotions are affected and how strongly they stay... Oh boy!"

She felt discounted by the physicians and the surgeon after her operation: “They truly felt it was a miracle and gee, you know, the double vision is a small price to pay for such a miracle.”

Athena felt betrayed by her surgeon. She later obtained the actual medical records. A comment at the end of the surgical report led to complete mistrust: “No cranial nerve was damaged or torn during the surgery. [Athena claimed] ... the nuclei of the cranial nerve were damaged –the ocular motor nerve.”

Upon being photographed by the hospital staff without prior notice, she felt embarrassed, humiliated, angry and that she was being “... photographed as a specimen”.

Athena explained that the physicians, who spoke to and about her after the surgical intervention, used patronizing, condescending language. She was trained as a health professional; she would have understood medical terminology, consequently she felt further anger and frustration. However, years later, Athena felt validated when an oncologist decided against several treatments due to her medical history: “...that’s a doctor who sees you in a whole picture.”

This woman believed we hear even when anesthetized: “...we are more conscious, even when we’re unconscious, than science would leads us to believe.”

“Quality of life” is not necessarily taken into consideration by the medical profession. She felt that by not being looked at as “the whole person”, the patients were in danger of being treated as “robots in the medical system.”

She spoke of the importance of the physician calling the patient by her name and taking a narrative account, neither of which occurred during her hospitalization. She

suggested placing an attractive photograph and the patient's name on either the chart or next to the door; alternatively a genogram (gathering data) could be displayed, giving the physician a picture of the woman in her familial environment. (The genogram is a diagram identifying positive and negative influences surrounding an individual.) Any of the foregoing was preferable to "the hip fracture down the hall".

According to Athena, physicians did not recognize the importance of rehabilitation – "the recovery aspect of movement therapy". I noted that physicians, over 26 years ago, might not have realized what they now know – the extreme importance of rehabilitation as soon after surgery as possible. Perhaps as a result of a surgeon's comments that he did not believe in physical therapy and occupational therapy, Athena had no formal rehabilitation: "My aging surgeon said, 'Oh I don't believe in all that physiotherapy and occupational therapy. You know what comes back, comes back.'"

As with six other co-researchers, Athena felt that the medical system is geared towards the "convenience of the physician". She believed it was extremely important the woman felt sustained by her physician.

"Cementing new learning takes time and is part of the healing process." Athena stressed the importance of time in healing a brain injury: time in relearning, time as a healing agent and allowing ourselves time. She then moved to a deeper level: "Time, wonder and simplicity" when combined, result in "the Zen-like quality of living in the moment".

She also felt music can be effective as a healing agent:

I think about the spiritual aspects of movement and how I believe it needs to be cultivated in exercise or therapy or movement of any sort. It makes me think of the work of Gabrielle Ross and she has developed over time the – oh gosh – actually it's called the five rhythms. And basically there are five rhythms that are in all types of music – every sort of music... Gabrielle Ross first began this when she was working with some severely mentally ill clients in a hospital. And she found that... they would respond to music where nothing else worked.

Athena spoke openly of her short-term memory loss, problems with balance, her extremely impaired vision, the issue of shame, and of her loneliness.

Athena's Voiceprint-Aural Description of the Tape-Recorded Interviews

Her rate was leisurely (*Andante*). However, it definitely accelerated and could be identified as hurrying (*Drängend*) when we discussed the mistrusted surgeons' comments. Speech rate was slow (*Largo*) when she was close to tears.

The pause-speech rate ratio was halting (*Agitato*) when she spoke about highly emotionally charged issues. The pause-speech rate slowed down (*Allentando*) when she was close to tears. Otherwise, the pause-speech rate ratio consisted of short pauses (*Corona*) appropriately placed.

The tone or voice quality was clear (*Chiara*), sweet and gentle (*Dolce*). I heard a mournful (*Flebile*) quality when she addressed emotionally charged issues. A mocking (*Moqueur*) tone was heard when she quoted the surgeons whom she mistrusted.

The pitch was generally medium (*Mezzo Soprano*), however it rose whenever Athena spoke of the surgeons. When the vocal pitch dropped, the co-researcher was speaking of less highly charged emotional issues. I then classified the pitch as low (*Alto*).

The volume was generally medium (*Mezzo Forte*), however it became weak (*Debile, Schwach*) when Athena was speaking about issues potentially evoking emotional pain.

The articulation was smooth (*Legato*) when Athena was speaking without much emotional involvement. It was dragging (*Strascinando*) whenever she described emotionally difficult situations.

The choice of words, with few exceptions, was appropriate and accurate (*Schrittmässig*). Whenever Athena was mimicking the surgeons whom she distrusted, her words became contemptuous and theatrical (*Pomposo*). While almost always appropriate and accurate, Athena frequently chose words that were sorrowful (*Doloroso*), heartfelt (*Innig*) and compassionate (*Pietoso*).

The sentence construction incorporated frequent use of metaphors (*Simile*) particularly during the final interview. Her sentences were fluent (*Facilmente*) at all times during all three interviews. Whenever speaking of the surgeons she mistrusted, she adopted a sardonic or mocking (*Semiseria*) sentence construction.

I observed a logical (*Consonance*), straightforward (*Ossia*) and consistent (*Paradiddle*) judgment in Athena.

Her conversation was always clear (*Deutlich*).

Within all the foregoing categories, the first interview was classified as having less movement, less frequently (*Meno, Meno Mosso*). In the second interview I heard a wider range of variation (*Largo to Allegretto*). In the third interview there was less range, and a general leveling off to the same speed (*Movimento*).

If I were to choose a single word that captivated the spirit of that initial interview it would be sorrowful (*Doloroso*). In the second interview I heard a move into a livelier mood (*Lebhaft*). By the end of the third and final interview, I clearly noted a shift to an awe inspired, reverent whispering (*Bisbliando*).

Athena definitely exhibited hope.

“Iris” – Textural Description

Iris is an optimistic and sociable woman, and is very involved in the activities of her church. She commented on her involvement with Brainstormers, which she thoroughly enjoys: “Yes. It was just like getting together with the ladies and being able to talk about difficulties that each of us are having and being able to brainstorm together to solve things.”

Iris experienced only beneficial verbal interactions with both of her physicians, and her interpretation of the discourse with her physicians was entirely constructive. Iris believed everything her doctors told her.

A singular incident occurred with a nurse, which Iris chose to interpret in a hopeful way. She overheard the nurse remark:

‘Oooh [sic], she’s lucky to be alive; she’s lucky to be here. She was only three on the Glasgow Coma scale and Stars Ambulance had to fly her in.’ [Iris explained] ... it was kind of shocking to hear about how severe the accident was ... [and her reaction to this information was]... Grateful, yeah [sic]. Happy that I was there.

The Glasgow Coma Scale (Teasdale and Jennett, 1974. Trauma Scoring: Glasgow Coma Score. ¶1) is rated between three and fifteen with three being considered the worst possible rating.

Referring to rehabilitation Iris said “It’s going good [sic]. Slow, but it’s good.” I noted that this unquestioning belief in her physicians’ words might have played some part in Iris’ quality of healing, and in the very significant gains in rehabilitation and physiotherapy.

I noted a deep faith. Furthermore, Iris consistently turned every comment, and every question, back to her faith. She possessed determination, for which she credited God. Issues of psychological and social concern, which can impact brain-injured women, might not have had any impact this woman due to her deeply held beliefs: “God allows some things to happen in our lives to teach us things – you know? Not as punishment.”

Iris – Voiceprint-Aural Description of the Tape-Recorded Interview

The speech rate was leisurely (*Andante*).

The pause-speech rate ratio was consistently choppy (*Staccato*) and halting (*Agitato*).

The tone or voice quality was dull and unchanging (*Drone*). Voice quality was also child-like and high (*Coloratura*).

The pitch was reliably high (*Soprano*).

The volume was medium (*Mezzo Forte*). Surprisingly, she sustained this vocal volume throughout the entire interview.

The articulation was consistently short and precise (*Délié*).

The choice of words was frequently inappropriate (I knew of no musical equivalent) and highly repetitive (*Istesso Tempo*).

The sentence construction was extremely simple with grammatical errors, often leaving a thought dangling, to pursue a different thought. The musical equivalent of the simple sentence structure is *Einfach*. Sentence construction was also somewhat awkward (*Scordatura*).

The logic of her words and sentence structure was at times irrational (*Musique Concrète*), and repetitive (*Da Capo*).

Within all the categories, without exception, she spoke at the same speed (*Movimento*) with no range of variation.

The phrase that embraced the vocal quality of this interview was childlike and high (*Coloratura*).

After reviewing her transcript, Iris was satisfied with the results of the initial interview. When asked if she would like to undergo a second interview she declined, telling me that she had nothing further to add. She offered to assist me in any other way.

Iris exhibited fierce determination and faith: "I'm going to be able to do this some day, is what I think. I'm going to keep trying cause I'm not going to let this get me down." Iris continually uttered hopeful words.

“Iphigenia” – Textural Description

Iphigenia was an intelligent and articulate woman, with no hint of mental impairment. This most unfortunate woman had to bear the brunt of misdiagnosis for 25 years: self-loathing and depression accompanied this misdiagnosis. Nevertheless, for the past eight years she sustained hope, which she saw manifested in frequent, small improvements.

Iphigenia believed that she knew something which the physicians were not recognizing about her physical condition soon after surgery. She stated that the physicians should have listened to her description of what she felt was occurring within her body. Furthermore, no physician took a narrative account of Iphigenia’s situation.

Her experience in verbal interaction with her physicians was that of not being believed and being ignored. She waited 25 years for the correct diagnosis: brain injury as a result of stroke. Consequently this woman mistrusted physicians. Iphigenia elaborated:

Because I’d had an MRI, he [the physician] thought nothing would show it [the residual damage]... he said, ‘If there is any indication that you have some residual damage from your stroke then I will call you and explain it to you.’

The physicians initially thought that no damage to her brain was sustained, and that she was just being overly emotional. Iphigenia suspected that she was mentally impaired. She “struggled, tried and super-compensated”. The belief that she had lost cognitive function was her interpretation of the medical discourse. This interpretation also extended to her personal lived experience; she suffered extreme anguish that was clearly heard in the voiceprint, when she described what she endured for those 25 years.

She never had rehabilitation, floundering in the incorrect diagnosis of emotional instability.

Iphigenia still felt acute shame that echoes from within.

In 1995, this woman finally found a haven in a community which understood her medical issues and what she had endured.

Iphigenia – Voiceprint-Aural Description of the Tape-Recorded Interview

Iphigenia exhibited vast changes within all categories. The speech rate varied from slow (*Largo*), to quick (*Allegretto to Presto*), to lively (*Allegro*), changing abruptly (*Sprechgesang*). What follows is an example of the vast quantity of emotion contained in a *Sprechgesang* utterance: “And I know the cultural thing shouldn’t matter ... but oh God – she [a family physician] saved my life.” Within this brief phrase I heard extreme variety in the rate of speech, vocal quality, pitch and volume.

The pause-speech ratio heard was between agitated (*Concitato*), choppy (*Staccato*), flowing (*Legato*), laboring (*Stentando*), and at times with long pauses (*Lunga Pausa*). These noticeable differences reflected what was being discussed at any given moment. Whenever she uttered the word “stuck”, she literally sounded stuck, and as if the word was “stuck” in her throat. She took a lot of time over the articulation of this word.

The tone or vocal quality was clear (*Chiara*), vulnerable, child-like, young and high (*Coloratura*), soft (*Crooning*), lamenting (*Déploration*), sweet and gentle (*Dolce*),

and mournful (*Flebile*). The particular vocal quality at any given moment perfectly matched and reflected the words being spoken.

The pitch oscillated between high (*Soprano*) and medium (*Mezzo Soprano*). The subject of discussion at the time brought on these changes.

The volume was very wide ranging from soft (*Piano*) to loud (*Forte*). This range included the almost inaudible (*Estinto*), weak (*Debile*), and whispering (*Bisbiliando*). The whispering volume (*Bisbiliando*) was heard when Iphigenia was speaking about her misdiagnosis and her belief that she was mentally handicapped. She also spoke with medium (*Mezzo Forte*), and loud (*Forte*) volume. The loud (*Forte*) volume was only heard when she shouted: “And he [the physician] kept saying, ‘It’s emotional. It’s emotional. You’re just emotional, and there’s nothing physically wrong with you and there’s nothing, you know [sic] ... go [sic] live your life and just get counseling.’ ” This was her interpretation of the physician’s words.

The range of articulation consisted of smooth (*Legato*), lively (*Lebhaft*), stretched out, sustained (*Gedehnt*), and dragging (*Strascinando*).

The word choice observed was sorrowful (*Doloroso to Lacrimosa*), emphatic (*Forza*), heartfelt (*Innig*), and sad (*Mesto*). Her conversation was always clear. (*Deutlich*).

The sentence construction was simple (*Einfach*), and Iphigenia sometimes left a thought dangling to pursue a different thought. I frequently heard one long, drawn-out breath (*Filar La Voce*), as well as decisive (*Décidé*), fluent (*Facilmente*) and finally vigorous (*Kräftig*) sentences. When speaking about her pleasure in visiting the

hairdresser earlier that day, her speech rate noticeably accelerated and her vocal quality became “chatty”.

Apart from the incomplete sentences from time to time, Iphigenia’s speaking was logical (*Consonance*).

For all categories, I observed a wide range of variations (*Largo to Prestissimo*) and rapid variation (*Con Moto*).

Two vocal qualities were outstanding and would categorize the interview. These qualities were poignancy and vulnerability, which were clearly heard in the voice. I was unaware of musical equivalents for these qualities. In the interest of the most accurate reporting of results, I decided not to substitute less accurate words having musical counterparts.

I conducted only one interview with Iphigenia. After receipt and review of the transcribed interview, she informed me that she felt her story had been heard and understood.

This woman loved her volunteer work in the brain injury community. She found a haven in this community and the gift of hope. “[They] ... like the volunteer work I am doing!”

“Niobe” – Textural Description

Niobe seemed lost within her brain injury, anticipating further healing, and determined she was going to experience this further healing. Lost, yet determined, she was an enigma.

Niobe underestimated her own significance within the patient-physician relationship, and was consistently understated in her remarks. Niobe believed in the authority of the physicians. She discussed an experience with an occupational therapy assistant, who had made comments about how far Niobe had come, and how impressed she was with Niobe's improvements. Niobe wished she had heard these words from a physician, feeling that they would then have substantially more meaning.

She felt both her male and female physicians showed much compassion, patience, encouragement and sensitivity. She spoke of her male physician: "He was very sensitive to my special needs [during a gynecological examination]. He was patient."

Her experiences in verbal interactions with her physicians were constructive. However she wished that she had heard the following:

You've made great strides so far, and we're really impressed with what you've accomplished to date. You have really come a long way, so there's every reason to believe that you can continue along that path, and that your efforts can continue to pay off in the future. We will do everything that we possibly can to help you along that road.

Niobe described the above statement, which she has never heard: "It's kind of like a fantasy or a dream."

Cognitive loss was exhibited by difficulty with short-term memory and easy distractibility.

The issue of shame affected Niobe. She felt both embarrassment and shame that she was left with a seizure disorder. She linked this to what she referred to as "that time of month". Niobe was far more comfortable with female physicians, believing that male

physicians would not understand: “And it’s something I would certainly tell a female doctor, but I’m not sure I would tell a male doctor because I’m not sure he would understand.” I noted the contradiction with the earlier statement attesting to the patience and sensitivity of her male gynecologist. I also noted the woman’s extreme embarrassment over having menstrual periods. She could not bring herself to utter “menstrual period” to me, another woman.

Niobe – Voiceprint-Aural Description of the Tape-Recorded Interview

This woman’s speech rate was slow (*Largo*), but became livelier (*Allegro*) at two points. When answering my question regarding what she would tell a patient with a brain injury, the speech rate noticeably accelerated with the comment:

You’ve made great strides so far, and we’re really impressed with what you’ve accomplished to date. You’ve really come a long way so there’s every reason to believe that you can continue along that path and that your efforts can continue to pay off in the future. And we will do everything that we possibly can do to help you along that road.

I noted that these words were also stated in a whispering (*Bisbiliando*) volume, suggesting an emotion of excitement. The speech rate became livelier and more enthusiastic when she discussed her rehabilitation. At this point her speech became easier and her sentence construction became fluent (*Facilmente*).

Her shame over menstruation was clearly detected in the voiceprint-aural description when she dropped her head and whispered “that time of the month”, with the emphasis on the word “that”.

The pause-speech rate ratio was laboring (*Stentando*), sometimes trailing off, therefore getting slower and slower (*Allargando*) with long pauses (*Lunga Pausa*). Short pauses (*Corona*) were detected intermittently, and finally, the speech was sometimes halting (*Agitato*).

The tone or vocal quality was dull (*Drone*), throaty (*Gorgia*) and dry (*Sec*).

The pitch was medium (*Mezzo Soprano*).

The volume was weak (*Debile, Schwach*) except for the one instance quoted above regarding her validating experience with an occupational therapist, at which point it was whispering (*Bisbiliando*).

The articulation was short (*Délié*) and dragging (*Strascinando*).

The word choice was appropriate and accurate (*Schrittmässig*), distant (*Lontano*) and solemn (*Feierlich*).

The sentence construction leaned towards intellectual, serious (*Seria*) and decisive (*Décidé*).

Her conversation was clear (*Deutlich*).

Her speech, word choice and sentence construction were logical (*Consonance*), and straightforward (*Ossia*).

For all categories there was little change apart from the noted deceleration when she was laboring (*Stentando*), and halting (*Agitato*). At times, Niobe's speech trailed off, getting slower and slower (*Allargando*).

I summed up the quality of this interview in two words, distant and dry (*Sec*).

I conducted only one interview with Niobe, during which she made many requests. For this reason the tape recording had to be stopped after almost every question. After receipt and review of the transcribed interview, Niobe informed me that she felt her story had been heard and understood.

“Aphrodite” - Textural Description

Aphrodite was an intelligent, and extremely determined co-researcher.

She believed in the authority of the physician. I noted that Aphrodite referred to the physician as a professional.

This woman believed that when in coma one still hears. She was deeply touched by the honesty of her male physician, who told her he did not know what brought her out of her comatose state.

Aphrodite believed that physicians should think carefully and clarify any information given directly to the patient, and unsupportive or discouraging discourse from the physician, should not be used in conversation with the patient. This woman claimed that only the worst-case scenario was presented to her parents; she would need everything done for her, twenty-four hours a day.

I was aware of the propensity for fatigue in brain-injured persons. This would most likely explain the following illogical statement: “Before the accident ... [sic] successes? Well, I learned how to walk.”

Aphrodite spoke of loss combined with depression, and stigmatization. She stated that she felt like “damaged goods.”

Aphrodite - Voiceprint-Aural Description of the Tape-Recorded Interview

The rate of speech was, for the most part unchanging and leisurely (*Andante*), but I noted that it was not leisurely in the sense of being at ease with the subject matter. Her speech rate accelerated to quick (*Allegretto*) and lively (*Allegro*) when she was voicing her feelings of excitement about life just prior to her brain injury.

In the pause-speech rate ratio, I noted Aphrodite stabbed at every other word. Her speech was extremely choppy (*Staccato*) and agitated (*Concitato*). Her speech contained short pauses (*Corona*). However, it accelerated to extremely quick (*Di Molto*) and urgent (*Dringend*) when she described her feeling of excitement about all of her life's possibilities prior to sustaining the brain injury.

The tone or vocal quality could only be described as unchanging (*Drone*), sharp (*Dièse*), harsh and stern (*Duramente*). The voice quality completely changed, becoming noticeably softer, the pitch rose significantly, and the voice warmed, when we were discussing her physician's discourse. This change was noted when she remarked: "I didn't feel rushed when my doctor would finally come in. If I had twenty questions, I could ask twenty questions and get answers, so that was good."

The pitch of the voice ranged between low (*Alto*) and medium (*Mezzo Soprano*). I believed this was not her natural pitch; it rose significantly and lightened when she was speaking about her physician as noted in the previous paragraph. I believed the higher pitch was her natural voice. The other clue that this was not her natural pitch occurred

when the co-researcher was briefly telling me of her past career. At this time, I heard both a rise and lightening of the pitch with articulation becoming smooth (*Legato*).

Aphrodite almost consistently stabbed (heavily accented) every other word, and in this sense the volume was not consistently medium (*Mezzo Forte*).

The articulation was extremely short (*Délié*) to the extent of sounding forced. The short, forced articulation abated only when she was addressing the subject of constructive, beneficial discourse with her physician; and when describing her past career. In these cases, her articulation became smooth (*Legato*).

The choice of words, apart from the use of clichés, was distinct (*Distinto*), but also theatrical (*Pomposo*), as if she was saying things but not believing them. I also heard distance (*Lontano*), as if the co-researcher was distancing from herself. I noted that incomplete sentences sometimes were spoken. When this occurred, it was due to not using “I” when referring to herself.

The sentence construction leaned towards intellectual (*Seria*). The construction was also awkward (*Scordatura*). As noted earlier, her frequent non-use of “I” when speaking of herself, produced incomplete sentences. This avoidance of “I” was heard when she was speaking of her deficits and losses.

I noted the contradiction of logical (*Consonance*) and illogical (*Dissonant*): “...my name was being paged through the intercom for whatever reason...but then you know I was sleeping [sic] so I probably just rolled over and went to bed.”

For all the foregoing categories, Aphrodite exhibited a small range of variation, with the following noteworthy exceptions. I heard Aphrodite's laughter at two points during the interview. This laughter was *Moqueur*, with a hardening of the vocal quality:

So for somebody [the physicians] to say 'Gee, we thought you'd died' isn't necessarily something that I needed to hear because there's [sic] been [sic] really some down times where I almost wish I had died...<laughter> and ... So just to sort of end things off on a more positive note <laughter> ... I guess I've said before it's been a life-changing event and very traumatic.

I heard deliberate, but perhaps not conscious, hardening and lowering of Aphrodite's vocal quality and pitch. I heard anger in the voice, which was demonstrated clearly with the effect of stabbing at every other word.

Two words summarized the quality of this one interview: forcing and stabbing. There was no musical equivalent, but I used this phrase in the interest of most accurate analysis.

Aphrodite was offered the opportunity for a second interview. She returned the first transcript with editing. I made the changes and sent them back to her. This being done, Aphrodite was satisfied, and had nothing more to say.

When the data was analyzed using the voiceprint tape recording it told a different story from the transcript description. Aphrodite was voicing all the desirable, healthy thoughts and belief structures; however, as already mentioned, I clearly and consistently detected that she was speaking as though through clenched teeth.

I inferred from the following two statements that this woman had hope:

So I guess my determination and being disciplined continued on but at a whole different level than what it had been before ... [and]

... so I hope someday down the road, even if it's two, three, four, five years I can be the one to say, 'yeah, it's a miracle'.

“Euphrosyne” - Textural Description

Euphrosyne was a magnanimous, insightful, intelligent, articulate woman with an appealing sense of humor; I can still hear her peals of laughter.

She chose not to be gainfully employed:

I had to make major simplifications to my lifestyle though, such that I am no longer gainfully employed or spread as thinly as before. With fewer demands on me, it's no longer the immense struggle it was, more immediately, post-injury. Still, the pressures I feel with brain injury surpass all former ones, even with all the efforts to simplify. I have a stronger than ever sense of urgency. When I commit to a task, I can be desperate to get it done. Usually there are no legitimate reasons for the urgency in the first place, except perhaps the fallibility of my memory.

She had profound love in her life, and plenty of hope.

Euphrosyne was emphatic that: “... the patient knows best the dynamics of the experience that they're going through.”

When asked about patient-physician discourse she remarked that she felt the language used by the physician was frequently patronizing and condescending. She elaborated: “More than being stigmatized, I feel misunderstood and invalidated by the [medical] profession.”

Euphrosyne felt extremely angry over many of her interpretations of the physician's discourse. The physician's prognosis may have led this woman to hold inappropriate expectations:

I spent at least two deeply depressing years believing ...I could measure up to their [her physicians] expectations for my recovery. I became convinced that I was a dismal, worthless failure. The doctors led me to believe that I was on a road to full recovery.

This resulted in loss of trust in her physicians.

She believed discourse with the physician is significant: "Maybe they [physicians] could ask, 'So what works best for you and how can I help?' " Euphrosyne addressed the bedside manner and demeanor of the physician: "I truly believe that a lot of outcome is dependent on what goes on in the mind not what goes on, you know, attached to the machines and on the I.V." Euphrosyne believed the physician should always speak mindfully, and with sensitivity: "There's a period of return that requires a high degree of sensitivity and gentle assessment. It is a wiser professional who facilitates a realistic assessment and works at developing coping strategies, rather than suggesting that setbacks are temporary." Finally, on discourse, she stated the physician might employ manipulative language for a beneficial outcome. She described this as a "deliberate arousal of fighting spirit."

Euphrosyne explained that she now refers to herself as brain-injured; she believed this term was not used ten years ago, being considered too harsh: "When someone finally got through to me that my behaviors and confusion were the result of damage to the brain; I deliberately switched my terminology."

We spoke of the aftermath of the injury: "Doctors need to emphasize to patients and their supporters that the sooner they accept and adapt to challenges like diminished

memory, fatigue, confusion, overwhelm and agitation ... the better their chances of enjoying life.”

Physicians are unapproachable authority figures, according to Euphrosyne.

Euphrosyne believed that she heard, on some level, while in coma. She expressed the following concern: “I’d like to believe that in the future we’ll develop more therapeutic approaches to people in comas. Bedside manner still counts.”

She articulated the healing process: “Recovery, just like the cliché, is a long journey, lifelong in the case of brain injury.”

We spoke of a narrative account being taken of each patient:

It’s vital that doctors take my word for it when I’m trying to convey my challenges or frustrations. There needs to be an exchange of information. Isn’t what I have to say of value in treating me? One very empowering counselor dealt effectively with my memory deficit by saying, ‘Okay so we’ll meet again Friday – is that something you need to write down?’ Yet by leaving me a choice ... she left my dignity intact.

Euphrosyne admitted to having suffered from depression and suicidal feelings that abated when she realized that there was a simple solution. She expanded her awareness to incorporate the realization of the inevitable; tomorrow frequently brings with it a different perspective. She also believed that shame has to be recognized and then overcome. Euphrosyne had to come to terms with stigma, loneliness and short and long-term memory losses, “There are some big gaps in my long-term memory.”

Euphrosyne – Voiceprint-Aural Description of the Tape-Recorded Interviews

This woman spoke coherently, almost eloquently, at all times. The speech rate varied between leisurely (*Andante*) and lively (*Allegro*).

The pause-speech rate ratio was flowing (*Legato*) without exception, and with the appropriate pauses.

The tone or voice quality was beautiful (*Bella*) and clear (*Chiara*).

The pitch was high (*Soprano*), but never shrill (*Schmetternd*).

The volume was consistently medium (*Mezzo forte*).

The articulation of this co-researcher was both smooth (*Legato*) and lively (*Lebhaf*).

The choice of words was distinct (*Distino*), appropriate, accurate (*Schrittmässig*), poetic (*Ode*), and finally beautifully expressive (*Espressivo*).

Her conversation was always clear (*Deutlich*).

The construction of the sentences was, without exception, fluent (*Facilmente*), and intelligently elaborate (*Fioritura*) when appropriate.

She was a logical (*Consonance*) speaker.

For all categories, without exception, the range of variation was appropriate to the subject. The speech rate was constant (*Movimento*), and congruent. In other words, all ranges were logical and accurate.

I heard frequent laughter, which was always appropriate. I did not detect in the Euphrosyne's voice any contradictions with the statements being uttered. The data

reported from the “voiceprint” was beautiful to listen to. *Bella*, or beautiful, would be the one word to express the quality of speech heard in all three audiotapes.

Euphrosyne willingly undertook all aspects of the three-interview process.

She was a very determined woman. She spoke of her profound love for her child: “I’m very conscious of being a role model. We have a deep understanding of each other and are so phenomenally close.”

This woman also exhibited hope and was very insightful.

“Electra” - Textural Description

Electra was a dynamic and fearless woman. She possessed admirable social skills, determination, drive, and essential coping skills: “Finding ways of combating depression is very individualistic. I use walking upon a treadmill until the endorphins are released ... until the mood shift is stabilized. Afterwards, I turn on some music that helps maintain the upward mood level.” She provided plenty of data and unusual but worthwhile ideas.

Electra knew something about her physical condition post-injury, which the physicians were not recognizing, and felt that this information should be shared with the physicians, having the potential to be mutually beneficial. She claimed that she was not given the opportunity to share this information.

Electra was angry about the way she was treated when hospitalized: “Three years have gone by and I’m still very, very angry.”

Electra spoke of the potential for life altering discourse with the physician. In her case such discourse permanently changed her belief vis-à-vis the possibilities of the human brain. This woman's grandfather, a physician, told her that medicine is sixty percent science and the brain can bring about miracles. Perhaps the very inspirational words of her physician grandfather served as catalysts fueling her determination, drive and hope.

Electra stated she believed that most of her physicians were set on the fact that there was brain damage: "... and you can't go any further and don't worry if you can't go any further." She felt distanced, discounted and discouraged by this attitude, so she intervened on her own behalf: "I stopped them [the physicians] and I said excuse me, I have something to say, I have an agenda. The whole room just stopped dead." The woman succeeded in turning what was experienced as unsupportive discourse and discounting (being talked about as if she was not present), into inclusion, and a more beneficial behavior. Electra then changed course in her conclusion: "Firstly, the squeaky wheel gets the grease. Secondly, communication, empathy, and trust are the three most important skills [for the physician]."

Electra was disappointed when she claimed the physicians and hospital staff

... stopped generating all the excitement and trying really hard to come up with ways for me to do things. What they [the physicians and medical staff] did, under the auspices of love and kindness, [sic] they dropped me in the black hole.

She chose to remember and focus upon her physician-grandfather's words, instead of her interpretation of the statements of some of her physicians, which for Electra, were entirely devoid of hope.

Electra had an excellent rapport with one physician, whose words and demeanor were of assistance, due to the fact that he engaged her as a partner.

Electra was cognizant that physicians may be perceived as seemingly unapproachable authority figures: "I mean, a surgeon is supposedly God, but the GP actually *is* God. The GP sees the person all the time. We need our GPs to coordinate, and need our GPs to advocate."

She believed that we do hear while anesthetized: "I remember when I was unconscious... 'Don't go near her, don't touch her.' "

Electra often felt frustrated by the conversational demands of social situations, however she continued to grapple with these challenges, determined not to give up on the demands of "normal" life.

This woman was still having formal rehabilitation with a physiotherapist, with the exciting experience of great return of function.

Electra held the belief that it is necessary for most physicians to distance themselves from their patients, and she gives evidence of understanding this dynamic.

She believed it very unhealthy to have patients with brain or spinal cord injury, housed together on the same ward. She elaborated that it has potential to teach you unhelpful behaviors. Furthermore, this phenomenon of "like with like" was acutely depressing for all, but perhaps more so for patients' classified as less critically ill.

Electra spoke of the necessity of physicians being team oriented in the practice of hospital medicine: “But these are skills, they [the physicians] are trying to do their job but there are too many physicians who aren’t team players. The team is what is essential.”

Electra had a theory about time:

I feel there’s a timeframe and, unfortunately, in our society we have lost the ability to realize we have to take time. The physician should do no harm. However time unfortunately eliminates a lot of that. They do their best with the timeframe they have, but as money is the main object they cannot devote the time.

This woman made a noteworthy, but sometimes overlooked, point: “... empathy is key because it changes the conversation.”

Electra believed hope has mutual, intrinsic value: “The ideal quality is giving the patient time to show we [sic] can succeed. And when you start doing that, you give the patient hope. When the doctor sees the success of hope, it’s a reward to him.”

This woman felt shame: “I don’t want people to watch me when I make a mistake, which they do now.”

On short-term memory loss she stated: “We have to put everything to long term memory and it’s surprising how we learn to do that.”

Ironically, in spite of her enviable social skills, Electra still suffered from loneliness. The “normal” world did not accept her as readily as she wished, in spite of her continued attempts at connecting.

Electra – Voiceprint-Aural Description of the Tape-Recorded Interviews

The speech rate of this co-researcher vacillated between a quick (*Allegretto to Presto*), and leisurely (*Andante*) pace, which was determined solely by her level of energy or fatigue. During the second interview I noted a move towards the leisurely (*Andante*) and even slow (*Largo*) pace, when exerting considerable effort to voice her thoughts.

The pause-speech rate ratio was quick (*Geschwind*) and choppy (*Staccato*). I heard long intermittent pauses (*Lunga Pausa*) during the second interview.

The tone or vocal quality of the co-researcher was sometimes clear (*Chiara*), and sometimes breathy (*Fiato, Sfogato*). When the breathy tone quality was heard, it was due to fatigue showing itself in the voice.

The pitch was medium (*Mezzo soprano*).

The volume ranged from medium (*Mezzo forte*) to weak (*Debila, Schwach*) during the second interview.

The articulation was extremely short and precise (*Délié*)

The choice of words fluctuated from appropriate and accurate (*Schrittmässig*) to repetitive (*Istesso Tempo*) and inappropriate. I knew of no musical equivalent.

The sentence construction was simple (*Einfach*), highly rhetorical (*Oratoreo*), decisive (*Décidé*) and at times repetitive (*Da Capo*).

The logic heard was sometimes contradictory and ambivalent (*Spezzato*). In most instances Electra made intelligent points and was logical (*Consonance*).

Within all the above categories, over the two interviews, a wide range of variations (*Largo to Prestissimo*) was heard.

I chose one word to sum up the quality of both interviews: irregular. I knew of no musical equivalent. I did not categorize this woman's speech as chaotic, which has the musical equivalent *Extremely Dissonant*; this would have been an exaggeration. Electra's speech was unpredictable due to the wide range in speech rate, pause-speech rate ratio, volume, choice of words, and logic.

She completed two interviews. After the editing was incorporated, the transcripts were satisfactory to her.

Electra was very ambitious, determined and possessed great drive. The woman also had a very social personality.

Electra definitely exhibited hope: "When I've accomplished a goal, it gives me such a high that I grab hold of that and hold on tight. I desperately want to be alive – that's a decision I have made."

"Demeter" - Textural Description

Demeter was a woman who possessed ambition, drive, tenacity, determination, intelligence, insight and excellent coping skills. This woman appeared to have accepted her brain injury: there was no evidence to the contrary on the voiceprint.

Demeter felt discounted by the surgeons immediately after surgery: "They [the surgeons] told my father that they were convinced that they had removed all the cancer. They [the surgeons] felt my deficits were a small price to pay for being alive."

This woman believed in a healing process that requires time, repetition, diligence and patience. She stated further: "... there is an organic healing process that takes place at a level that does not require physical or mental practice."

Demeter spoke bitterly of the medical profession's brilliant technology: "life at all costs", whenever they use heroic measures to keep a person alive. She did not agree with this.

She spoke of a validating experience with her surgeon after she was discharged from hospital:

He was truly amazed when I stood up quickly and started to walk for him. He then remarked that I might expect, and experience much improvement over the next six months. [The woman elaborated.] When I told my physiotherapist that I had seen my surgeon, and that he'd told me that I might experience much return of function over the next six months, the physiotherapist's comment was to the effect that the surgeon did not see me on a daily basis, and had no basis on which to make this claim. I was absolutely devastated. I could not block that physiotherapist's words from my mind. They still haunt me from time to time. Whenever I attempt a move and initially fail, his [the physiotherapist's] words ring loud and clear in my mind.

She believed there should be patient-physician dialogue; a patient can, and must inform her physician of her symptoms and any experience with pain.

Demeter commented that physicians could use humor. She went on to draw a parallel between destruction of "creative spark" and destruction of hope.

When I inquired about her greatest achievement, Demeter simply said, "Staying alive."

Demeter had to face depression and suicidal feelings in the first weeks after surgery. She claimed these suicidal feelings have passed; she was hopeful about the future at the time of the interview.

Demeter spoke with candor about her feelings of shame around her cognitive losses, and of ongoing loneliness.

Demeter - Voiceprint-Aural Description of the Tape-Recorded Interview

The speech rate was normal, and leisurely (*Andante*).

The pause-speech rate ratio consisted of short pauses (*Corona*), appropriately placed.

The tone or voice quality was clear (*Chiara*).

The pitch was medium (*Mezzo Soprano*), however, in this case it would be better classified as *Lyric*, due to the soprano-like lilt, and inflection.

The volume was medium (*Mezzo Forte*).

The articulation was smooth (*Legato*).

The choice of words was distinct (*Distinto*), appropriate and accurate (*Schrittmässig*), formal and dignified (*Maestoso*).

The sentence construction was intellectual and serious (*Seria*), resolute (*Risoluto*), with metaphors (*Simile*).

The speech was logical (*Consonance*), and consistent (*Paradiddle*).

When listening to the voiceprint, I heard nothing remarkable, or inconsistent with the textural description. Within all categories the variations were consistent with the

logic of the thoughts being expressed. The text description and “voiceprint” were congruent. For this reason, I did not use any of Demeter’s statements in the voiceprint description.

I summarized the quality of the interview as intelligent (*Seria*) and consistent (*Paradiddle*).

Demeter completed one interview. She read the transcribed interview and did a minor amount of editing. After I amended the transcript, Demeter was satisfied and had nothing more to add.

Similar to Electra, Demeter was very ambitious, determined, and possessed great drive. She appeared to possess excellent coping skills. This woman also had insight, similar to Euphrosyne. Perhaps this insight strengthened her coping skills.

Demeter exhibited hope; she held the belief that physicians cannot always pronounce definitive prognoses: “I throw myself into the fire daily, challenging my body with physiotherapy exercises... I experience a surge of joy and renewed hope.”

“Artemis” - Textural Description

Artemis had a most appealing personality and sense of humor. She was at times rather understated in her comments about her physicians; she nevertheless, possessed insight. This woman gave every appearance of having accepted her brain injury: “I was very positive before and I just think that is partially what has carried me as far as I have gone.” Furthermore, Artemis was extremely hopeful about her future.

Artemis expressed the wish that the physicians speak in everyday language. She spoke of her difficulty in the first year with comprehending the physicians when they were speaking to her; too much time was taken up by trying to grasp each word, therefore the rest of the sentence was lost. She stated clearly that as a person with a brain injury, she was highly reticent to ask for more time and clarification:

They [the physicians] spoke very fast, it would have been nice if they maybe went a little bit slower and gave a bit more time. But the medical world seems to be going way [sic] faster [than] me [sic] with the head injury can handle.

Artemis spoke of her surgeon's comment that the healing process could take between 2 and 15 years; the surgeon did not elaborate. She would have appreciated more information but was afraid to ask. She stated that her surgeon "...was very good". When her surgeon explained the prognosis, she took it as a challenge, and was motivated to heal much more quickly than the surgeon had predicted. She spoke with intensity of her disappointment; her surgeon never asked to see her again. This woman had questions that she would have liked to pose to her surgeon.

I inquired about the quality of her interactions with her physicians: "They [the physicians] gave me the impression that they were very rushed. I felt like I was interfering with them if I asked too many questions." When I inquired if she had more questions to ask, the reply was a simple, "Yes."

From the phrases: "very rushed", "I was interfering" and "too many questions", I inferred that Artemis believed the physician was an authority figure. She stated: "[It was] a combination of sort of emotional stress of ...not wanting to ask for too much ... it's

almost the doctor's responsibility to take the initiative and say [what treatment modality is required], not focus on themselves so much."

Artemis wanted to elaborate on her interactions with her surgeon. She explained that for legal purposes a written report had to be submitted to the lawyer. This record contained an error in the description of the accident. Artemis stated:

...one thing that was a little frustrating...[in the] records it will always say that I was in a single car accident, but I wasn't, I was hit by someone else. That was a little bit frustrating because to me it's really important to keep everything clear and on line. My lawyer talked to her as well, and her response is, well it was a report that she got from the hospital so she can't argue with it. But that was a bit frustrating because, you know I didn't want that false information out, that I had been in an accident caused by someone else, for legal purposes.

I noticed her tendency to qualify each statement about her frustrations with "little", "little bit", and "a bit".

Artemis spoke of the aftermath of the surgery, and listed her particular disabilities: "Fatigue, struggle in reading, speaking for long periods of time, intense concentration, [loss of] fitness."

She spoke of her very helpful experience with her plastic surgeon: "He did a very good job ... and his comedy, his humor I found quite funny, saying it will turn into a wrinkle is a good sense of humor."

Artemis described an incident with her eye specialist as "... the most horrible experience." She gave a vivid, passionate and highly detailed portrayal of her interpretation of this occurrence. Artemis felt it inappropriate for an eye specialist to be asking why she was seeing a counselor, and if she was experiencing psychological

problems. She found this question insulting, and told the specialist that it was none of his business. "I almost had a bad feeling towards doctors after that." I wished to draw attention to Artemis' insights vis-à-vis her emotions:

I have to admit that at the time I was having more problems with my emotions and he [the eye specialist referred to above] pushed my buttons, and I got quite upset with him, and said that if my eyes are fine... and I walked out, and don't have any intent of going back, although he is the one specialist that does what I need for diabetics.

The woman ended the discussion about her eye specialist: "But that's okay, although I have to admit I don't really want to go see him again." I noted Artemis was understating her emotional reaction by using the words "that's okay".

Artemis believed dialogue would be enhanced between physician and patient, if the physician could transmit, before hand, the issues to be discussed. The woman felt that if this were done, she could formulate her questions accordingly.

Maybe, before I go, he [the physician] could somehow fax me what we're going to talk about so that I could then think if I had any questions. Sometimes in the appointment, they would start talking about something and it wasn't until I was back at home just about to fall asleep that I thought, well if that's the case, what about this?

When I asked Artemis to reflect on her achievements since the brain injury, she stated: "...just accepting that I'm just a little bit slower than I used to [sic], maybe that was one of my biggest accomplishments."

Lack of reading ability concerned her, but caused her no sense of shame. She instigated this subject, and spoke with candor and ease about her reading difficulties.

Interestingly, she was the only woman who was not ashamed of having difficulty with reading, or of lacking this skill.

I noted the incongruence of the qualifiers “really” and “little” which were used when she spoke about her concern over lack of reading ability. The woman used the word “really” only once. Thereafter she used qualifiers “little bit disheartening”, “a bit” and “a little”; this juxtaposition of qualifiers gave me the feeling that she could possibly be attempting to mask, by making light of the subject, feelings of greater frustration over her reading problem.

The other cognitive issues that this woman spoke openly and comfortably about were short and long-term memory loss.

Artemis never spoke of depression, but spoke of frustration several times. When I asked how long her frustrations typically lasted, she replied: “It varies. It depends, it could be an hour, up to three days depending on the situation I was in, my activities during those times, my energy level, yes.”

It came to my attention at the extreme end of the final interview that this woman was on medication for emotional stability. Perhaps this figured into the co-researcher’s voiceprint, which sounded consistently encouraged, cheerful and optimistic. The reading and analysis of the transcript alone would not have yielded this emotional information.

Artemis - Voiceprint-Aural Description of the Tape-Recorded Interviews

The rate of speech was consistently lively (*Allegro*). Artemis uttered the following: “And yes, I know there’s a lot of information on the Internet that you can get,

but I don't read well enough to do that." An analysis of the text only could have led me to interpret this as a very hopeless, or at the very least, discouraged statement. However, listening to the "voiceprint" gave an entirely different sense to this statement. I heard acceptance and optimism in this phrase, which otherwise would have been lost.

The pause-speech rate ratio was flowing (*Legato*), with appropriately placed short pauses (*Corona*). However, the one exception to this was the word "humungous" which was said with a dramatic, long pause (*Pausa*), so that I heard a "humungous" pause.

The tone or voice quality was light and clear (*Chiara*), sweet, gentle (*Dolce*), and chatty, of which I knew no musical equivalent. The voice quality was also young and high (*Coloratura*).

The pitch was consistently high (*Soprano*).

The volume was medium (*Mezzo Forte*).

The articulation was lively (*Lebhaft*).

The choice of words was appropriate and accurate (*Schrittmässig*) for the most part, although there was great discrepancy between the transcript and the voiceprint. The transcript showed inappropriate use of words, unfinished sentences and mixed tenses. However when I listened to Artemis' speech, the content was much more understandable as a result of the inflection and timing of the pauses. The earlier reference to inappropriate use of words, unfinished sentences and mixed tenses notwithstanding, her word choice was for the most part, appropriate.

I heard consistently informal (*Piacere*) speech. Artemis sounded merry (*Giocoso*).

Her conversation was clear (*Deutlich*), in spite of inappropriate use of words, unfinished sentences and mixed tenses. I experienced this enigma in a few other voiceprint reports.

Particularly obvious when listening to the voiceprint tape was the tendency to understate. All of these following examples of understatement occurred within her brief description of dealings with her lawyer and her physician: “That was a little frustrating for me ... that was a little bit frustrating because to me it’s really important ... but that was a little bit frustrating because ...”

The sentence construction was simple (*Einfach*), decisive (*Décidé*), resolute (*Risoluto*), comfortable, and easy going (*Gemütlich*).

Despite inappropriate use of words, unfinished sentences and mixed tenses, Artemis’ thoughts were logical (*Consonance*), although I did not truly grasp the logic until I commenced the voiceprint description.

Within all categories, variations in movement occurred naturally and at the same speed (*Movimento*).

Artemis stated: “So when I clunk my head again, I will know how to deal with it. But I don’t want to clunk my head again <laugh>.” This statement was said with humor, lightness and acceptance. The comment was followed by peals of joyous laughter. The “voiceprint” musical equivalent would be *Coloratura*, as if her voice was running up and down scales.

Only by using the voiceprint description could I hear that Artemis had truly accepted her brain injury.

The voiceprint description reflected a much more optimistic co-researcher than the textural analysis. I heard, in the voiceprint, an acceptance of self, a woman full of insight and wisdom. Every nuance and inflection within all categories showed this.

Artemis had many experiences with past challenges. These included severe diabetes, mononucleosis, kidney and gall bladder problems: “I had a very good life, I still do, it’s just different.” Artemis, post brain injury, in addition to the foregoing, had thyroid problems: “[The physician] just did a whole bunch of blood tests consistently [sic] and ultrasounds all the time ... I just got [sic] thyroids done last Friday ... it’s just ongoing.”

Artemis stated: “I had always been a very determined person.” Other aspects of her personality, which may have assisted in bringing her thus far, included optimism and cheerfulness.

I noted Artemis disclosed at the end of her final interview that she was on medication to stabilize her emotions.

After editing the transcripts, Artemis was confident her story had been told.

As exemplified in the above data, these women felt compelled to speak of things other than the actual research question. I appreciated and acknowledged the willingness of the women to share their stories, which enriched the data, providing many sub-themes. My perceived position as an “insider” (Sloan, 2000) privileged me with confidential narratives. The women felt safe to unmask, to speak to me of intimate details of their lived experience with brain injury. I am quite sure, based on the findings of Sloan, that this would not have been the case had I been a “normal” person. Still, only when the

women had completed their narratives, were some able and willing to address the actual research questions.

What follows are the sub-themes, which were gathered from the data of the nine co-researchers (the actual interviews, the “voiceprints” and the transcriptions). Five of the sub-themes were composite and universal. Seven sub-themes were not directly related to the research question, but were of significance in the fecundity of the individual case. For this reason I have incorporated these sub-themes only within the individual textural depictions. Following is the summary of these sub-themes (appropriate only to the individual case).

Two women spoke of the value and meaning of time. In all other conversations, an individual woman shared the following experiences or thoughts, which were unique to this data: an insightful perspective on rehabilitation, the belief that empathy effects physician-patient communication, music is effective as a healing agent, faxing could be beneficial to communication between family physician and patient, the issue of employment, and finally, physicians who practice in hospitals could benefit by using a team approach.

Summary of Individual Textural Descriptions and Composite Textural-Structural

Descriptions with Quoted Examples

Euphrosyne, Electra and Athena were particularly perceptive; I have quoted these three women more frequently than the others.

The group was unanimous in their belief that there was no escaping the aftermath of surgery as a consequence of sustaining a brain injury. Electra: "A brain injury requires retraining at the most simple [sic] level. In other words, one returns to the basics and must take baby steps." Euphrosyne:

No longer does anything come naturally, reflexively or immediately. It needs to be well thought out, and is frequently a struggle. I can slur my words, experience difficulty finding words, blank out momentarily to my current situation, and stumble or stagger. Who knows what people's conclusions are when witnessing this, I would bet brain injury isn't the first thing that comes to mind.

These women were also unanimous in believing there was a healing process involved, which required time, repetition and "cementing new learning." Demeter: "I realize that it, the healing process, requires time, diligence, and patience with oneself."

When speaking of the physicians' use of language being at times condescending and patronizing, Aphrodite said: "If I was a doctor, I would really watch what I was saying", and Iphigenia said: "And he [the physician] kept saying, 'It's emotional. It's emotional. You're just emotional, and there's nothing physically wrong with you and there's nothing, you know ... go [sic] live your life and just get counseling.' "

Almost all believed some physicians had no idea what the woman was experiencing during and after brain injury. Euphrosyne:

It's easy to discredit someone's hard work with a few words like, 'well, I do that too, and I don't even have a brain injury', or 'what a great recovery you've made, dear.' ... I feel damaged and I would like that damage and the consequent extra work acknowledged, validated.

Electra spoke on the phenomenon of the distancing: “They, the physicians, have to distance themselves.”

Speaking for those who observed that most physicians lack humor Demeter said: “Depending upon the situation, use humor or words that prompt the patient to transcend the situation.”

Euphrosyne spoke of manipulative language used by the physician with the intent of being helpful:

The odd doctor who says, ‘ you may never be able to read again’ when I was having difficulty ...provoked the reaction, ‘oh yeah, I’ll show you’. Like a kind of defiance and maybe that was a deliberate arousal of my defiance, maybe that did sort of conjure up my fighting spirit.

Athena and Iphigenia described awareness of an “imperceptible” physical change in the weeks following surgery. Most of the group related to this experience, supposing this change was undetectable or not taken seriously by the physician. Athena: “The patient knows best what they’re going through.” Iphigenia: “I realized that there was something not quite right with me, you know – that I was different from the way I was prior.”

Some felt sustained by their physicians. Iris: “My family doctor has been very helpful and optimistic.”

Many spoke of need for validation of their accomplishments (the need to be heard and acknowledged by an understanding person), after having sustained the brain injury. Artemis: “He’s [the general practitioner] impressed at how well I’ve done so far. I feel like patting myself on the back, like all this hard work is paying off.” Athena:

A doctor recognized my medical history of stroke and brain surgery, he is an oncologist and he said, 'I'm sorry, we really shouldn't use chemotherapy on you because of your arteries, and because of this history we shouldn't use tomoxithen on you.' ... I was feeling this in my gut, but he was validating that fact ... that's a doctor who sees you in a whole picture.

The majority experienced anger toward their physicians. Euphrosyne: "... but glaring invalidations of my injury, and the efforts it demands, don't give me much faith in the individual I'm dealing with. That's pretty unsettling when it's someone [the physician] who does this for a living."

Most women related to feelings of ongoing depression. Euphrosyne:

... its no wonder depression is so common to survivors of brain injury, as many of us have been led to believe that the shortcomings we experience are the result of poor attitude or lack of effort. This may have been a belief that we, too, held prior to injury, and it gets endorsed everywhere we turn for support, friends, family, co-workers.

Many women spoke of shame. Euphrosyne:

Prior to my injury in my professional life I absolutely lived out of my Daytimer™...it was a useful tool at that time, but post-injury my attitude changed. There was a lot of shame for me in not being able to remember ... and I think it was just the connection to failure.

A few spoke of having suicidal thoughts since the brain injury. Euphrosyne: "There were times post-injury where I was suicidal and ready to give it all up and I'm quite sure that I'm permanently divorced from that right now. I'm really sure."

Speaking for the few who addressed the impact of loss Niobe explained: "I've already lost use of my left side, and I would be finished if I lost use of my right."

Some women related to, or spoke of, cognitive loss. Artemis: “Although one challenge that really frustrated me was my inability to read. And to me it was a little frustrating. My reading ability is still very challenged ... that was a little bit of a disappointment.”

Euphrosyne spoke for those who shared this experience: “Short-term memory, particularly when I’m fatigued or overwhelmed, isn’t functional. Certainly I know I cannot trust my memory.”

Several women spoke of long-term memory loss. Artemis exemplified this: “Oh dear! I guess the other person ... I’m sort of starting to have memories ... what was her name? The one I saw...”

Athena and Euphrosyne spoke for the group, explaining quality of life had been radically altered. Athena: “I think it takes you into a place not many people live and I think that’s a lonely place.” Euphrosyne: “It’s terrifying to imagine establishing a new relationship without all the cards on the table, only to have to reveal brain injury later. It affects me every minute of every day, why pretend otherwise?”

Speaking for those who were experiencing ongoing loneliness, Electra explained: “[People were] leaving me out of the conversation. Brain injury elicits fear in all persons. ‘There but for the grace of God’ ... All persons should recognize that the brain ...can experience fatigue.”

Addressing stigma, Euphrosyne explained: “I feel stigmatized in the general public, because brain injury is still relatively unknown. Doctors often offer stories about

other survivors that are simply not applicable to my situation. Now I feel both stigmatized and invalidated by the profession.”

Loss of identity was considered extremely significant. It was precipitated by not using the patient’s name. The importance of the narrative account in the process of reclaiming identity is inferred in Athena’s statement: “... the first thing that happens when you are born is your naming ... they [the physicians] would name me: ‘The Stroke Victim, Breast Cancer Mastectomy Survivor, Tubal Ligation Down The Hall.’ ”

The group related, or acquiesced to the perception of the physician as a seemingly unapproachable authority, whose “authority” extended beyond medicine. Euphrosyne: “I think collectively, doctors underestimate their influence. When they use words like ‘recovered’ and say, ‘she’s ready to carry on, life as usual’ to survivors, their family members and the media, they perpetuate public misunderstanding of brain injury.” Niobe: “To hear it from a doctor would be even more encouraging ... they’ve been through extensive training and they have experience to just sort of [sic] see what will work and what won’t work.”

These remarks illustrated some women’s mistrust in their physicians. Iphigenia: “Because I did not have the diagnosis [of brain injury] at the time of brain injury, I went through two and a half decades of thinking I was mentally ill ... not trying hard enough, just self-loathing really for that period of time.” Euphrosyne: “My impression was that eventually, if I continued to work hard and maintain a positive attitude, I would someday be all better. There was no indication of the permanence of brain injury.”

The majority believed the medical system is designed for the physician's convenience. Artemis: "They [the physicians] would only give me a small, ten minutes maximum [sic] and then it was obvious that they would have to go."

Electra spoke on the disadvantages of housing patients with similar afflictions, "like with like", together: "I don't believe like should remain with like, cause [sic] it teaches you the worst."

Demeter spoke of the creative spark: "Physicians should never inadvertently, destroy the creative spark, which gives meaning to life, and thereby, hope."

The group was hopeful for the future, anticipating further healing and rehabilitation gains. (This meaning-unit was included in two of the five major themes.) Demeter: "But with every little change or achievement I experience a surge of joy and renewed hope." Aphrodite: "I hope someday down the road, even if it's two, three, four, five years, I can be the one to say yeah, it's a miracle."

As previously explained, I attempted to broach the research question and found the women had to tell their stories first. Some women did not answer the research question directly. In some cases I did not have the opportunity to ask the three-element research question, therefore, I was forced to infer from the information given, the understandings that these women communicated through their narratives. This in no way means that the data collected was unimportant, but rather that interpretation was necessary. I respected the women's natural way of telling their stories of the changes and losses, resulting from brain injury. Moustakas' (1994) version of the transcendental

phenomenological reduction (TPR) methodology, with its imaginative variation and multiple lenses, proved an extremely useful approach.

Addressing the Research Question

After I listened to these narratives, some women were able to provide data addressing the actual three-element research question. Not every one answered the questions directly. However for clarification I have summarized their aggregated thoughts as follows.

The entire group felt that the physician's words do impact the patient, and the physician's choice of words can be life altering. Athena: "She [the physician] has no idea ... what an ignorant, totally unfeeling person ... and that experience changed my life." Euphrosyne: "The doctors led me to believe that I was on a road to full recovery. There was no indication of the permanence of brain injury."

The majority were experiencing beneficial verbal interactions with their physicians. Electra: "And this was wonderful, everyone was excited for me and they all helped. And the physicians were helping and the physiotherapist started to smarten up and be a little more co-operative and not so negative [sic]." Artemis: "Well, my family doctor very much supports me behind [sic] where I am [sic], and understands when I have a hard time, and just gives me the confidence to have more patience. He has been really good."

Verbal interactions with their physicians were also felt to be unsupportive by most of the group. This overlap was due to each woman having more than one physician; overlapping can be inevitable, particularly with small qualitative studies. Euphrosyne:

Respect and tact and regard for my ability on an intellectual level [are necessary] because the flip side, of course, is those doctors that practically pat your head while they're saying in a few octaves higher, 'are we going to remember that dear?' I think that the word 'dear' was meant in a very kindly, yet patronizing way. That doesn't make it acceptable.

Interpretation of the physicians' discourse was perceived as beneficial by a minority. Iris: "I've come a long way and she [the physician] hopes to see a lot of improvement...."

The interpretation of the physicians' discourse was felt to be unsupportive and discouraging by the majority of women. Electra: "No, it was not a helpful message and it's a textbook message that has actually been proven wrong many times over the years."

Iphigenia:

You know, I was different from the way I was prior ... anyway in 1995, I went back to the neurologist – the original one – at least three times trying to find out why I was the way I was, and he kept saying, 'It's just emotional ... there's nothing physically wrong ... go live your life and just get counseling.'

The interpretation of this discourse, and its effect on the quality of healing and rehabilitation, was thought to be beneficial by more than half the group. Artemis:

It made me feel like I had to get better ... but as soon as she [the surgeon] said it was going to take me that long, it pushed me to be better and much faster [sic] and prove to her that I don't [sic] have that much of a challenge ... I have my own beliefs [sic] what my disabilities are and my challenges [are], and that's how it is.

Euphrosyne and Iphigenia were quoted on behalf of those who felt the interpretation of this discourse, and its effect on the quality of healing and rehabilitation, was unsupportive. I noted in one case the co-researcher found the interpretation of the discourse and its effect on the quality of healing and rehabilitation of assistance on one occasion and unsupportive on two occasions, and noted another woman did not directly answer the question, but inferred that it was not beneficial. Euphrosyne: “ ‘This is what’s best for you. We professionals know better than you survivors; it’s right here on page 42 of the textbook.’ ” Iphigenia:

And he said, ‘Well just continue on.’ And I said, ‘Well no, I can’t continue on - I have been, and I’ve done that for two and a half decades, and I really have to be able to function in society, and I haven’t done a very good job so far.’ He said, ‘Oh alright, well I’ll just refer you on to someone at the Foothills and then they’ll do a neuro-psych [sic].’

Some women were convinced words are heard on some level in coma or under anesthetic for surgery. Athena: “I truly believe we are more conscious, even when we’re unconscious, than science would lead us to believe.” Euphrosyne:

I believe that in a coma, yes I did hear them on some level... A close friend of mine is also a reverend, and she acted as a spiritual police officer, making sure nothing negative was said in my presence. There was an intern who would visit... that same intern would visit periodically and he gave me what seemed like an irrational uneasiness. I did not like him at all, and one day I blurted out my reasons at him aggressively... ‘You filthy bastard, you thought I was going to die.’ He muttered something dismissive like, ‘Well, you have made a miraculous recovery’ and quickly left, with a bright red face... He may still wonder how I knew that, but the fact remains that I did and do, beyond a shadow of a doubt. I don’t know that he ever spoke the words, ‘She’s not going to make it’, but he did try to forewarn my parents to be prepared for ‘all outcomes’. He offered no hope...It was offensive

that he didn't believe in me...that was pretty powerful, especially with a total stranger. I now believe that when people are comatose they pick up words, attitudes, vibes if you will.

From the previous summary, these data were distilled yielding 44 meaning-units or sub-themes. The analysis of these sub-themes revealed that seven were reflective of the particular thoughts and beliefs of the individual, while six sub-themes appeared to be directly applicable to the research question. These sub-themes were then reduced to five major themes.

Five Major Themes Reported by the Women

The themes are reported here in a particular order, as they best reflect the sequence in which becoming brain-injured was experienced by the co-researchers. The phenomenon that I chose to study was only one of many phenomena experienced. As explained earlier in this chapter, only when the women had given their narrative account (which is reflected in the order of these themes), were some of them able to address the final theme, which was the research question.

- Brain injury is “Crisis”. (This major theme, and the following four major themes embrace the sub-themes, which were reduced to the particular major theme. Without exception these sub-themes were reported in, and extracted from data.) These data “spoke” of the aftermath of surgery, and of the realization that healing the brain injury demands time.
- The manner in which the diagnosis and prognosis are presented can result in disastrous, catastrophic and tragic or encouraging, promising and hopeful

-
- interpretation. Sub-themes: Interpretation is dependent upon the physician's sensitivity, empathy and reticence to use patronizing and condescending language, his demeanor, his listening and interpretive skills, his cognizance of the benefit of "everyday language" when speaking with a patient, his awareness of the tendency of some physicians to distance themselves from the patient, the willingness to use humor when appropriate, and the use of manipulative language with beneficial intent.
- Losing "self" is a dangerous psychological and social concern. Sub-themes: The narrative account in this particular context, is the catalyst in grieving physical and cognitive losses, which amount to loss of "self". Awareness of change, denial and the tendency to disassociate from the body through language, short and long term memory loss, ongoing loneliness, anger towards physicians, depression, shame, stigma, radically altered quality of life and relationships, destruction of hope and suicidal thoughts, and the need for validation by a physician are all at play in this psychological and social dynamic.
 - The opportunity of finding the lost "self" exists through awareness, and changing some deeply held beliefs. Sub-themes: The narrative account figures greatly in regaining lost "self". It is the utterance in which "self" can be found, the creative spark. Awareness of the following: inner self-talk, the seemingly unapproachable authority of the physician, medical gender issues, mistrust for physicians, the belief that the medical system is designed for the physician's convenience and housing patients "like with like" together, is necessary. Acquiring coping behaviors and

strategies and learning to accept the new “self” is empowering, resulting in hopeful expectations regarding healing, rehabilitation and life.

- Consideration of the physician’s words. The following sub-themes were reported in response to the three-element research question. The women believed words do have an impact. Patients listen very closely to the physician’s words and analyze his demeanor after he has left the consultation. In particular, the women spoke of the tone of the medical conversation and explained when it was more or less hopeful and inspiring. Some women heard words, on some level, under coma and anesthetic. Suggestibility and influence resulted from the perception of the physician as an unapproachable, omniscient authority figure.

Although the three-element research question was posed, most women initially responded indirectly by reflecting on their personal accounts over one or more interviews. As previously stated, only after giving their particular account were some women able to directly answer one or all aspects of the three-element research question. Therefore this last major theme is evident from the data as each woman told her story.

CHAPTER FIVE: DISCUSSION AND INTERPRETATION OF RESULTS

Recapitulation**Analysis of Findings, Interpretation of Results**

The “voiceprint” tool provided, in most cases, significantly more data than the traditional text analysis. The tape-recorded voiceprint aural analysis, as explained later in this chapter, never deceives or lies. The emotional state of any person is heard through attentive and careful listening to this analytical tool. The “voiceprint” makes the findings (the conversations) transparent and indisputable, thus it is of the utmost importance in data analysis.

Although I relied on the trustworthiness of interpretations, rather than the actual medical/scientific terminologies and diagnoses, I had to be cognizant of the primacy effect when analyzing the data. The primacy effect refers to a patient having better recall of, first, information related at the outset and, second, the information that they consider most important (Ley, 1988).

Obtaining subjective data proved to be of great worth. All of the co-researchers have lived the experience of brain injury. The two most recent brain injuries occurred close to two years ago. All of the women have had numerous consultations with their physicians. At the time of the interviews, each co-researcher was still seeing at least one physician. I felt fortunate and privileged to be interviewing women who were involved on an ongoing basis with their physicians. I believe that the circumstance of continuing involvement between physician and co-researcher may have served to mitigate the

primacy effect. Due to this belief (that the primacy effect was being moderated), I felt the data, which suggested the woman believed she had internalized her interpretation of her physician's words or statements, was possibly more reliable and trustworthy. If the co-researchers had not been consulting their physicians at the time of these interviews, I would have had to put more emphasis on the primacy effect. In the analysis of the data, I took the primacy effect seriously, and constantly questioned the possibility of it being a factor in the results.

Co-Researcher One

I heard in the "voiceprint" what could be described as a transformation into a euphoric, passionate state of being, over the course of the three interviews. In the initial two interviews the vocal pitch dropped only when she was speaking of highly charged emotional issues. The woman's voice became much weaker (*Debile*), whenever she addressed issues that I suspect evoked emotional pain.

I heard this woman sing her statements, her voice modulated to match her word choice: this woman sounds like a gifted storyteller. In the third and final interview, the effect of her reverent whispering was compounded every time she discussed her philosophy regarding simplicity, awe of physical movement and reverence for "the lonely place" (the place of solitude experienced by few persons). This is addressed in the literature by Kleinman (1988) and Vanier (1998).

I believe that this co-researcher's transformation has been born, perhaps, out of pain and loss.

Her change is complete; she has successfully addressed her core problems, coming to a place of wisdom, acceptance as well as loneliness. I feel that through the co-researcher's self-reflection, she has achieved "a sense of wonder".

Co-Researcher Two

This woman trusts unquestioningly. She enjoys supportive discourse with both her physicians; perhaps this explains her significant recovery. I noted that the other issues of psychological and social concerns, which can impact brain-injured women, may not impact this particular woman due to her deeply held religious beliefs: she directed every question back to her faith. She feels God gives her determination: her great involvement with her church sustains her. She is optimistic, sociable and has hope. Cousins (1979) and Siegel (1986) stated that maintaining hope could overcome unimaginable obstacles. This woman showed no evidence of feeling marginalized or stigmatized.

Co-Researcher Three

I observed that this woman is dealing courageously and determinedly with her core problems. This co-researcher experienced twenty-five years of anguish, believing she was mentally ill. Perhaps the current little happinesses she now experiences, serve to mitigate the misdiagnosis of mental illness. Cassell (1982) stated: "The physicians' failure to understand the nature of suffering can result in medical intervention that

(though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself” (p. 639).

This woman told me that small steps towards a goal are not insignificant. She is in the process of reclaiming her “self”, and therefore has hope. This would explain her survival. Vanier (1998) addressed the issue of cognitive loss and its cost for the mentally disadvantaged. Cousins (1979) described misdiagnosis. Allison, Gripton, Rodway (1983) and Cassell (1982) spoke on the issue of suffering.

Co-Researcher Four

Although this woman was very needy (I had to pause the interview process after almost every question to allow for her needs), she exhibited strength and was definitely addressing her core problems with courage and hope. Thus she was in the process of reclaiming the lost “self”. Cousins (1979) and Siegel (1986) addressed the power of hope.

Co-Researcher Five

I noted fairly early into the voiceprint interview analysis that this co-researcher was speaking of herself as if she was talking about someone else. Cassell (1985) addressed the use of distancing language (p. 60). In this woman’s “voiceprint” she seldom says “I”. Possibly she is attempting to control her pain by the use of consistent distancing language, clichés, understatements, inappropriate forced laughter and deliberate, but perhaps not conscious, hardening and lowering of her vocal quality and

pitch. I believe that this lowered voice is not her natural voice or pitch: it rose significantly, lightened and became smoothly articulated when she was speaking about her helpful physician, her life prior to the brain injury and when telling me of her past career. For this reason, I believe that this lighter, higher pitch is her natural voice.

I also heard anger, which is demonstrated clearly in the “voiceprint”, by her stabbing at every other word, almost like discussing something detested. She sounded as if she was speaking through clenched teeth. When she stated: “Not that life each day is full of misery or anything like that but like I said, if something does happen – again I attribute it to the accident and it just brings me down” her vocal quality was again incongruent with her spoken text. By attributing everything to the life changing accident which caused her brain injury, she is speaking about loss of the “known self” before her brain injury. She also told me more than once that she had lost her “self”: she wasn’t as she used to be. Cassell (1982) clarified suffering and grieving the lost “self”. Frank (1991), Murphy (1987), and Sloan (2000) addressed the issues of anger and loss.

In spite of what I have reported, this woman has fierce determination and is clearly addressing the core problems she faces. She ended her interview with these two hopeful statements: “So I guess my determination and being disciplined continued on, but at a whole different level than what it had been before ... [and] ... so I hope someday down the road, even if it’s two, three, four, five years, I can be the one to say yeah, it’s a miracle.”

Co-Researcher Six

This woman has addressed all of the core problems sustained with her brain injury ten years ago. She was frequently outspoken about her disillusionment with her physicians and the medical profession. She deplored the misuse of authority by the medical profession, and was vocal about the presentation of diagnoses. The issues of authority and of diagnosis were addressed by Cialdini (1984); Cousins (1979); Frank (1991); Gergen, Hoffman and Anderson (1996) and Kleinman (1988).

With courage, tenacity, determination and independent spirit, this woman is successfully reclaiming her “self”. She has undergone transformation; she has love and hope.

Co-Researcher Seven

This extremely determined, social, uninhibited woman made herself known to the hospital staff, demanding the best healing regimen possible. She refused to be viewed simply as a set of symptoms and held on to as much independence as was possible in her circumstances. Cialdini (1984), Frank (1991), and Siegel (1986) addressed the issue of authority and the patient’s struggle to maintain independence when interacting with the physician.

This woman considered brain injury to be a challenge and faced it with courage. She is well into the process of reclaiming her “self” and is enormously hopeful in the present and for the future.

Co-Researcher Eight

This woman admitted to feeling, and realizing the powerful impact of her interpretation of words, even those spoken by a therapist. She described her devastation over her physiotherapist's discouraging statements, following upon her inspiring consultation with her surgeon and found this ironic: the surgeon had so much more training and experience than the physiotherapist. Alexander (1965); Cassell (1982, 1985); Gergen, Hoffman and Anderson (1996); and Siegel (1986) all stated that words spoken by a physician do affect the patient, and can have devastating consequences on the patient's physiology and emotional well-being.

This woman is addressing all of her deficits. She is in the process of finding her lost "self", having felt truly heard when telling her narrative account. This woman is tenaciously, deliberately and fearlessly working through her grieving process. She is reconstructing her "self": she is creating new meaning for her life and consequently, is finding hope once again.

Co-Researcher Nine

This woman had significant emotional insight: "Sometimes I'll get frustrated, ... I don't know if its so much the doctors ... or ... my emotions, keeping them [sic] steady."

She tended to qualify and soften her statements about her frustrations with medical professionals, and with her reading deficit, of which she spoke openly. The tendency to underestimate one's own importance, and assume the physician is an unapproachable authority in the physician-patient relationship was addressed by Cialdini

(1984), Frank (1991), and Sloan (2000). This woman underestimated and discounted herself, and her significance in physician-patient dialogue and discourse, by using understatements. She all but forgave an eye specialist with the words: “But that’s okay, although I have to admit I don’t really want to go see him again.”

Kleinman’s (1988) patient, “Paul Sensabaugh”, described almost exactly the same emotion as this woman. He said: “The world is too fast for me, isn’t it?” (p. 196). The co-researcher stated: “But the medical world seems to be going way faster [than] me with the head injury can handle.”

I found this woman delightful to interview. She has the gift of humor and frequently laughs at herself. She is fearlessly addressing all of her core issues and problems, facing them with courage and determination. This is definitely heard in the “voiceprint”, which is light, cheerful, determined, courageous and, for the most part, happy. One can detect acceptance and hope in the “voiceprint” when speaking of her lack of reading ability. However, from seeing this statement in print, one could easily assume that the woman was feeling discouraged or even depressed about her reading problem. This is but one example of the usefulness of the voiceprint data analytical tool.

Addressing the Research Question

Siegel (1986) described the work of Bennett, a psychologist at the University of California Medical School at Davis, confirming the phenomenon of unconscious awareness.

Bennett tested his hypothesis about unconscious awareness. During surgery he played a tape recording to anesthetized patients. The patients were asked to touch their ears in a post-operative interview, signaling that they had heard the message while undergoing surgery. During the post-operative interview, it was observed that a majority repeatedly enacted this behavior without being aware of it, and none of the patients could remember the message that was given to them during the surgery. In another experiment, Dr. Bennett asked unconscious patients to make one hand warmer than the other, and the temperature was observed to be, indeed, warmer in one hand after having received this suggestion. The third experiment involved the non-hypnotic pre-operative suggestion that the patient's blood would leave the hip area during surgery. It was noted that blood loss to the hip area was reduced by half (p. 46).

I noted that some co-researchers were convinced that they had heard something while anesthetized or while in coma. This might suggest that there is validity to the claim of unconscious awareness. If so, the implication is that the physician's words to the patient are heard, regardless of the patient's waking or anesthetized state. I could not prove this unconscious awareness.

A few of the brain-injured co-researchers were motivated by their interpretations of the diagnosis and prognosis presented to them by their physicians. These women interpreted this discourse as helpful and inspiring.

Most of the co-researchers were engaged in what they interpreted to be unhelpful discourse with their physicians. These women's personal interpretations of the diagnoses and prognoses were perceived to be discouraging. Each of these particular co-researchers

was determined to resist the diagnosis and prognosis. But even in their resistance, they reported they continually examined their physician's words. Cassell (1985) claimed: "Patients pay very close attention to what their physicians say to them, including their paralinguistic cues" (p. 29).

"Studies which followed a cohort of patients longitudinally overwhelmingly report that compliance decreases with increasing duration of treatment" (Ley, 1988, p. 68). Similarly, the co-researchers in this study (who interpreted discourse as unhelpful) attempted to resist and discount the prognoses presented to them by their physicians, and, over time, took the physicians' words less seriously. The longer the treatment, the lower the impact of the physicians' words. The co-researchers reflected this by frequently commenting on their mistrust of their physicians' competence.

The analysis of these data revealed that all co-researchers were affected by the physician's words. The results of this study are consistent with the literature reported by: Alexander (1965); Cassell (1982, 1985); Cialdini (1984); Cousins (1979); Gergen, Hoffman and Anderson (1996); Siegel (1986) and Sloan (2000).

Synthesis of Meanings and Essences

The chosen methodology, being a phenomenological and not a quantitative design, privileged me to visit and share the lived experience of brain-injured women. The data obtained from these co-researchers was intimate, and of significant impact to the analysis. In attempting to address the three-element research question first posed, I came to understand that the women found various ways to respond to the question. It was

humbling to realize that these women interpreted my interest in differing ways. Oakley (1990, p. 32) stated: "Interviewing, which is one means of conducting a survey, is essentially a conversation." I experienced this "conversation" phenomenon with my co-researchers. They told me their story, their narrative account, and I found the richness of these data was an indirect or interpretive attempt to answer my preoccupation with the research question.

With brain injury, loss amounts to loss of personhood (Cassell, 1982, p. 639). Personhood is the equivalent of, and implies, persona. Using determination, the brain-injured woman can address her core post-injury deficits and reclaim her lost "self" or persona, which brings hope with it.

Two ancient Chinese calligraphic characters are used together in the definition of a crisis: One of these characters represents danger the other character represents opportunity. Borrowing this ancient Chinese definition, brain injury is, therefore, a crisis, loss of persona is danger and reclaimed persona is opportunity and hope.

We have now arrived at the synthesis of meanings and essences: Crisis is both danger and opportunity.

Differentiating My Analysis from the Literature Review Findings

I learned of the concept of paralanguage by reading Cassell (1985), who created and developed this concept. Few physicians and few theorists (excepting Cassell; Ley, 1988; and Myerscough, 1992) spoke of the use of language analysis in the context of the art of medicine.

I utilized the paralanguage voiceprint analysis outside the field of medicine. I also expanded upon Cassell's paralanguage analytical tool.

As a professional musician, I am intensely aurally aware; I deliberately exploited this. I took the idea of paralanguage literally as meaning "the music of language" (Cassell, 1985), and approached the aural tape recordings as if they were music, or compositions. I obtained much enlightenment from these data, by using the paralanguage analytical tool in this way.

The importance of the narrative account (Kleinman, 1988) deserves more attention in a therapeutic sense. The narrative account used in this particular context, as stated earlier, connotes catharsis, and is the story of the journey, with its losses and changes. In this circumstance, the essence of the narrative account is the story of suffering (Cassell, 1982). I found in my analysis of the data, that the hearing of this story by an understanding and responsive person was a catharsis, absolutely essential for the brain-injured female. This narrative account allowed the brain-injured female to initiate the process of grieving, healing and reclaiming the lost identity or self. Upon reflection, I realized that the individual textural description was, in every case, the narrative account.

Implications of this Research for Further Study

To my knowledge, Cassell's (1985) paralanguage tool has not been used outside the discipline of medicine. Perhaps his concept of paralanguage could be deepened and broadened. The voiceprint analysis which I have initiated is in its embryonic stage. It could be developed further, which would allow the interpretive potential of this tool to be

utilized in other disciplines. It could perhaps be considered an enhancement to the practice of social work, social welfare, psychology and psychiatry.

Musicians possess acute aural awareness: the best musicians have the innate ability to perceive subtle changes in pitch, tempo, and vibrato, which might not be detected by a non-musician. A musician could possibly initiate the growth of this voiceprint tool, by educating professionals, working in a clinical capacity, to detect subtle nuances in the above areas. Cassell's (1985), paralanguage is a technique and tool deserving further attention and exploitation.

Limitation in Methodology

This methodology is limited in that it is only exploratory. It is designed to yield richness and depth of understanding, rather than breadth drawn from large sample sizes. This methodological design is interpretive and presupposes my particular frame of reference. I am limited in my endeavor to be explicit and humbled by efforts to be transparent.

The imaginative ability, the intuition, the quality of the interviews, plus the intellectual prowess, expertise, competency, experience and awareness of myself as a researcher would obviously impact the data analysis, the synthesis of meanings and essences, and the conclusion drawn from these processes.

Limitation in Findings

Could I have found a better way to ask the three-element question? I was humbled in some cases, not to have the research question answered directly.

My findings were limited due to the number of co-researchers. This phenomenological research design could possibly have been enhanced with a larger number of participants. The number of co-researchers reflected the targeted group - Brainstormers. This group is small and the membership prerequisites are limiting and very specific. Although the group met the requirements of my investigation in all ways, a larger membership would possibly have advantaged my position as a researcher. However, no similar group existed at the time of this research.

A greater number of interviews would have yielded more data. I would have welcomed more than three interviews with each co-researcher, however this was unrealistic: all these women felt satisfied that they had been heard, and that their stories had been understood within the recommended (Osborne, 1990) three interview process. That being said, my co-researchers provided much rich data, and I am satisfied that this data was adequate.

A possible further limitation in the findings could have been the timeframe - one summer - during which the interviews took place. Perhaps the interview process could have yielded more data if it had spanned one or more years, providing the co-researchers with additional time for reflection. This was not realistic however, as membership

quickly changes. A reduction in the number of participants would not have aided my study.

Conclusion

Words spoken to a patient by a physician do have significant impact on the patient's emotional, cognitive and spiritual sides according to Alexander, 1965; Cassell, 1985; Cialdini, 1984; Frank, 1991; Gergen, Hoffman and Anderson, 1996; Siegel, 1986 and Sloan, 2000.

All the women interviewed were highly cognizant of the words spoken to them by their physicians. According to these women, when they perceived the words as beneficial, these words validated, inspired and supported them in their struggles with their brain injuries. When the women's interpretations of their physician's words were felt to be helpful, there was no need for energy to be expended in an effort to resist the physician's words: These women felt sustained within the healing and rehabilitation process. Thus, the desired outcome, reconstructing the lost persona, was enhanced.

According to the women, when the words were not perceived as being beneficial or helpful, they fought against these words in a conscious attempt to disregard them. When the interpretations of the physician's words were perceived by the women to be unhelpful, unwelcome or "wrong", this drained energy from the co-researchers, and therefore these women had less energy to use in their healing and rehabilitation. In this way, then, words interpreted as being unhelpful ultimately impeded the desired outcome,

reconstructing the lost persona. Therefore, the words spoken by the physician and interpreted by these women had significant impact.

Epoche

It is now my belief that how we speak to another can affect major change. This is where I situate myself in the scope of knowledge and the question posed. I make reference to this phenomenon in the auto-ethnography of Chapter One.

Prior to being hospitalized, I was unaware of physician-patient discourse, and the possibility of negative ramifications. Most physicians do their best to ensure optimum care of their patients. It was only when I was hospitalized that it occurred to me that there might be a power of suggestibility in the physicians' words. Furthermore these words could be delivered without sensitivity or conversely, with both understanding and compassion.

When a woman sustains a brain injury, a whole cycle of events may occur, especially if the woman is without considerable financial assets, or a very large disability insurance policy. The cycle also involves the "machine" (a system or social net) which can take over when the woman is discharged from hospital. It begins with the medical doctor's prognosis. These written words inform the caseworker, and can be subjected to her hermeneutical interpretation. Furthermore, after a time, the "discourse" of the system may move into an accepted set of rules, which bear more weight, and become more important than language and listening to the individual.

I suspected this non-supportive “support” system could lead, in fairly short order, to loneliness, alienation and even loss of the “self”, through the processes of stigmatization and separation from mainstream society. In addition, some authors wrote of being treated with suspicion (Davis, 1961; Frank, 1991; Goffman, 1963; Kleinman, 1988; Murphy, 1987; Vanier, 1998; Wolfensberger, 1998). Could this potentially make the brain-injured female feel dishonest?

Ensuring continued assistance from this system can rob one of time, cause undue frustration and weakened self-esteem. That was my experience with the system.

Most of my self-advocacy involved only the telephone. The fundamental effects of these telephone conversations were emotional reactions ranging from frustration and anger to discouragement, humiliation, embarrassment and ultimately acute shame. I had to mentally block the inherent message: “You are stupid, and not able to deal with your circumstances and life.” I was actually told: “We decide what’s best for you, when you are fit to work again and to what rehabilitation and line of work you will be assigned. Although we will assist you with this decision.” This statement is contradictory, however these words were spoken to me.

My medicals records were being referred to continuously. Other health care professionals or even persons outside the medical field, holding positions of power and authority, were interpreting the physician’s words. These people were making decisions based upon their particular interpretation; thus the significance and power of hermeneutics.

Under these circumstances it is clear that a downward spiral may exist, leading to loss of belief in the “self”. When I was discussing my theory of loss of “self” with a registered nurse, she commented that many other brain-injured females do end up in this downward spiral. “They just weep and give up.”

Even the brain-injured females with financial means might be vulnerable to this phenomenon (loss of belief in “self”). If a brain-injured female were desperate enough, would she consider possibly withdrawing from mainstream society, in an attempt to achieve a more contented life? I must disclose that in my most desperate moments I wished that I could sever the despised umbilical cord that attached me to the system. This is a potent political issue. We have now come full circle, back to the hermeneutical impact of the physician’s diagnosis and prognosis.

I still wonder if internalizing the words of a physician - “You will just have to settle for less, accept the fact that you are a brain-injured female now” - could potentially lead to myth making. Without exception the nine women I interviewed felt apart from mainstream society; they all felt a comfort zone within the haven of SABIS. With only one exception, these women were not gainfully employed. Perhaps this “retreat” brought about less demand to socially interact with the “normals”, and a consequent lack of confidence in their social selves. Is this an example of myth making becoming lived reality? If the myth becomes the lived reality, we are in very dangerous territory.

Implications and Recommendations for Physicians

The physician could consider these questions: what is the intent, versus the effect, of diagnostic labeling on brain-injured females? Should the wording of the diagnosis be tailored to fit the individual? Are there other words that could be used? Does the patient show any evidence of myth becoming a reality as a result of incorrect recall or the patient's misinterpretation of the words chosen by the physician?

The training of the physician could include comprehensive education in the use of paralinguistic analysis. If this paralinguistic tool were to be implemented, it could possibly be of great benefit to both physician and patient. Cassell (1985) stated a medical student can do practically anything. This tool could become another aspect of medical training; implementing it could make the hospital's protocol more effective.

The narrative account, through which the brain-injured female tells the story of her losses and grief, is an absolutely essential therapeutic tool for the healing and successful rehabilitation of the brain-injured woman. If this story of loss is not taken seriously, and is not a part of the rehabilitation process, the brain-injured woman can remain stuck and without identity. The physician should be aware that the narrative account is of the utmost importance and significance.

Being aware of the significance of lost identity, and the significance of the narrative account, the physician could take the time necessary to actively listen, which would be time saved in the long run as far as effective rehabilitation is concerned. Or, as the physician works within severe time constraints, he could refer the brain-injured female to another physician, possibly a psychiatrist who would actively listen. Either

way, the physician would be doing even more for beneficial and productive rehabilitation of the brain-injured female.

Active listening includes being present on all levels for the brain-injured female. Maintaining eye contact throughout the interview, listening sympathetically, reading body language, making the appropriate soft sounds that tell the woman she is being understood, not thinking about a rebuttal, or letting the mind stray in other ways are all components of active listening, and of good interviewing technique.

The fact that I received overwhelming gratitude from all nine co-researchers underscores the extreme value of active listening, of being 100 percent present for the brain-injured female. The gratitude of my co-researchers points to the need for, and importance of, the narrative account. By allowing the brain-injured co-researchers to give their narrative account, I effectively "validated" the brain-injured female's experience. The fact that physicians do not currently use it could be addressed.

A voiceprint analysis of the tape-recorded interview should always be utilized during the process of hearing the woman's narrative account. This should be carefully reviewed, as it will yield further emotional information. With the addition of this voiceprint analysis tool, we have active listening: the "voiceprint" never lies or withholds information while, as Kaufmann explains, spoken words alone, can be blinding.

There might as well be a screen between them on which one watches the antics of his words instead of listening to him. The words do tricks, the performance is brilliant, but much of it is very difficult to follow. Obscurity is fascinating (Kaufmann, *I and You: A PROLOGUE to Buber*, 1970, p. 19).

For the reason that the “voiceprint” makes the data transparent, I recommend its use in medicine, psychology and the social sciences, including social work and social welfare.

Physicians should be cognizant of the fact that a brain-injured woman, within the confines of the hospital, loses her sense of self. This is not pain, but the foundation of suffering. Cassell (1982) distinguished between pain and suffering. Although Cassell stated that the physicians in a hospital do understand about pain, he considered it a myth that physicians and nurses understand the meaning of suffering. He stated: “Suffering can include physical pain but is by no means limited to it” (p. 639).

Siegel (1986) explained: “The word ‘hospital’ comes from the Latin for ‘guest,’ but seldom is the institution truly hospitable” (p. 17). A hospital is vastly different from a hospice. What has been stated in these implications for physicians excludes the physicians practicing medicine for palliative care and the hospice.

“To contemplate hospice and palliative care is to acknowledge an open health care system that reaches into the community and utilizes community resources” (H. Allison, personal communication, February 8, 2003).

The term palliative care implies alleviation of distressing or painful symptoms associated with physical deterioration and infirmity. Terminally ill patients are living persons in the process of dying who may require palliative care to sustain both their physical and emotional integrity (Allison, Gripton, Rodway, 1983, p. 29).

“When palliative care is administered the doctor-patient relationship becomes a working partnership” (H. Allison, personal communication, February 8, 2003). The partnership

incorporates medicine, nursing, pharmacy, social services, rehabilitation, home care, pastoral care, and volunteers. Palliative care is comprehensive and holistic.

Family members come under the umbrella of hospice services. The immediate family's concerns and grief are attended to before, and after, the patient dies. The husband, wife or partner is treated with respect and without discrimination; the hospice staff does not stigmatize gay and lesbian couples. The immediate family, and "significant others" are welcomed into this compassionate setting.

Family participation within the hospice team, serves to enhance the quality of care for the terminally ill, for the burden that is shared has reduced its weight by half. In an ideal world, the standard of health care is raised to its highest level and palliative care services serve as vanguards of support for the terminally ill (H. Allison, Personal Communication, February 8, 2003).

Hospitals and prisons are uniquely similar. Although this may seem an extreme analogy, hospitals, like prisons, are closed systems. These systems have a "we-they" mindset. The patient, or the inmate in a prison, cannot cross the "line". The "line" is an invisible, but clearly understood and respected delineation between those who hold the power (the physicians and nurses or prison wardens) and those who are powerless (the patients or prison inmates).

The hospital-prison analogy extends further. When a woman enters the hospital, similarly to entering a prison, she is stripped of her identity. She is given a number on a wristband, which also contains pertinent information including, usually, her room number. Her clothes are removed. She is dressed in a gown, identical to the gowns of all other patients. A physician writes orders with which she is expected to comply. The

woman, who enters the hospital as a patient, becomes categorized in a particular way, classified by the symptoms that she exhibits. All of the brain-injured co-researchers in this study spoke of these phenomena: loss of privacy, loss of respect, loss of dignity, loss of name, and of being viewed simply as a set of symptoms. In these ways the woman loses her independence, and consequently is deprived of her sense of safety. Cassell (1985); Frank (1991); Gergen, Hoffman and Anderson (1996); Siegel (1986); and Sloan (2000) attested to the adverse affect of these phenomena.

The physician could endeavor to view these issues through another lens. Moreover, the wise physician could help the patient, by alleviating as many of these problems as possible. At first this might seem an impossible task, however any reduction of the patient's fear and loss of identity, could have a beneficial effect (Cassell, 1982, 1985; Cousins, 1979; Frank, 1991; Gergen, Hoffman, Anderson, 1996; Siegel, 1986 and Sloan, 2000). Wouldn't a potential enhancement of the healing outcome make these actions well worth consideration for the non-emergency phase of treatment? Wouldn't these actions, if found to be of benefit to the patient, aid in reducing costs and shortening hospital stay, both of which would be politically and fiscally advantageous? Possibly, for the patient, reduction of fear and perception of loss of identity could also enhance the art of medicine, the physicians' art (Cassell, 1982).

A woman with brain injury is impacted even more than the experience described in the forgoing paragraphs. She will suffer gross losses whether they be cognitive, movement impairment, impeded speech or personality changes. Diller and Gordon (1981) spoke of changes to the brain-injured of such magnitude as to make the person

virtually unrecognizable, even to their intimate friends and family. Paskiewicz (1988) spoke of neurological disorders, such as multiple sclerosis and strokes, having comparable symptomatology to brain injury.

The brain injury has such impact that the victim struggles to maintain her identity while experiencing threats to her emotional equilibrium, decreased cognitive function and awareness, fear, feelings of alienation and disconnection: this is a struggle of the greatest magnitude.

Obviously, the physician can do little to alleviate gross loss of abilities and functions. These have to be grieved for and, if possible, worked through, to reconstruct and reclaim identity. Cognitive loss, suicidal thoughts, depression, shame, stigma, short-term memory loss, long-term memory loss, loneliness brought about by stigmatization and self alienation, are some of the gross losses of abilities, functions and social concerns that can accompany the aftermath of a brain injury. It is inevitable that the woman will have to deal with a number of these losses and changes (Ben-Yishay & Diller, 1983; Cooney, D., Personal communication. October 9, 2001; Davis, 1961; Kleinman, 1988; Murphy, 1987; Paskiewicz, 1988; Pickett, Arden & Brison, 2001; Sloan, 2000 and Winslade, 1998). These losses and changes result in suffering. When a physician does not understand the nature of suffering, and is successful in alleviating only physical pain, he fails not only to relieve suffering, but the woman's suffering is increased (Cassell, 1982).

Should the physician and patient move into a collaborative, problem solving partnership? Is this possible? Siegel (1986) stated: "I know patients who are literally

being killed by their relationship with their doctors” (p. 4). How could this collaborative, problem solving partnership be created and structured?

Implications and Recommendations for the Brain-Injured Female

It is of great significance that the woman be allowed to tell, to give voice to her story. This is the point where the healing of lost identity starts. This was a universal theme (finding the lost “self”) among my co-researchers.

The most challenging struggle for the brain-injured female is to heal, reclaim and reconstruct lost identity. She is stripped naked in all senses, viewed as a set of symptoms without name, talked of as if she is not present after admittance to hospital. Yet entering the closed system of the hospital is only the starting point; the experience of being hospitalized deprives the woman of her independence and serves as a catalyst to loss of sense of “self”. Cognitive losses, emotional and psychological changes in personality, loss of physical function, or loss of the ability to speak, serve to grossly magnify loss of the “self”, which leads to loss of persona. Shame over her physical and cognitive losses are inherent in loss of “self” or persona. This was a phenomenon experienced by all of my co-researchers. This loss of “self”, this suffering is the most problematical and challenging outcome of brain injury.

Persona or personhood includes the woman’s spirituality, her emotional makeup and her social self. It embraces all the qualities of the person including the ability to be compassionate and understanding. The woman’s persona is her core and essence. Her self identity and persona have to be reclaimed, restructured and healed.

The women who I interviewed were, without exception, dealing simultaneously with more than one extreme challenge. With a single exception, these women have children and seven of the eight brain-injured mothers were single parents. Struggling with lack of finances, single parenting, dealing with the bureaucratic system in Alberta, while wrestling with the challenge of reclaiming lost identity were all occurring simultaneously rather than linearly. Kleinman (1988) addressed this issue.

I credit my father, Walter Allison (Personal communication. November 30, 2002), with his perception: while a single extreme challenge can be devastating, simultaneously dealing with more than one extreme challenge can be the factor that keeps one from being destroyed.

While overwhelming losses and “world collapse” can seem devastating (Sloan, 2000), there is also wisdom in Allison’s (Personal communication. November 30, 2002) insight: two or three extreme challenges, occurring in tandem, can save one from downfall. All of my co-researchers were successfully dealing with numerous concomitant challenges. “World collapse” or finding strength in the distraction of manifold concurrent life problems may hinge on the personality traits of a “survivor”: tenacity, fortitude, courage and determination.

The brain-injured woman could possibly, and understandably, seek shelter in the cloister or haven with similarly brain-injured women. Could the eventual consequence of “like with like” be loss of confidence in the social skills necessary for successful interaction with the non brain-injured?

A brain-injured female should be aware of the gender bias that exists in medicine. Frank (1991) described a female member of his family who experienced this discrimination when she asked more questions of her physician than he thought appropriate. The physician affirmed that he was "in control" and accused the woman of "trying to control" her treatment. Frank felt that these medical situations occur more frequently between physicians and female patients (p. 58).

The brain-injured female should also be aware that there might be a moral issue attached to the label of brain injury. Brain injury is not always a consequence of an illness; nevertheless it might be classified as such, particularly if one of the after effects is a seizure disorder. Frank (1991) stated that society perceives a disease as a body "out of control" and society equates this with the person having "lost control" of herself. Illness carries with it a stigma: it is classified as "moral failure" and "irresponsibility" (p.58).

The brain-injured woman should not underestimate the disastrous outcome of brain injury; she is confronting a challenge of the greatest magnitude, requiring much courage. The woman has to reconstruct her life by reclaiming her personhood, which implies her persona. If this trial is successfully faced, it leaves the woman with great strength of purpose.

This strength can be exploited to excellent advantage. The brain-injured woman can inspire other disabled persons and become a role model for them. Thus, the brain-injured woman will undergo a transforming experience. The prize for wrestling successfully, in possibly the greatest contest the brain-injured woman will endure, is her metamorphosis.

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APPENDIX A:
Community and Health Resources You May Find Helpful

- ❖ **Medical Referrals**
- ❖ **Social Support**

- Southern Alberta Brain Injury Society,** Phone: 521-5212
 137-2723 37th Ave. N.E.
 Calgary AB. T1Y 5R8 hours: 9am to 4pm Monday to Friday
 *you may leave a message at 521-5212
 ext.3 after office hours
- Universal Rehabilitation Services** Phone: 272-7722
 808 Manning Road NE Fax: 273-7852
 Calgary, AB T2E 7N8
 Contact: Laurel Pilling
- Association for the Rehabilitation of the Brain Injured (ARBI)** Phone: 242-7116
 3412 Spruce Drive SW arbi@cadvision.com
 Calgary, AB T3C 3A4
 Contact: Mary Anne Ostapovitch, Program Director
- Brain Injury Rehabilitation Centre (BIRC)** Phone: 297-0100
 #300, 815 – 8th Avenue SW groenewe@acs.ucalgary.ca
 Calgary, AB T2P 3P2
 Contact: Curtis Steelting
- Community Neurorehab Services (private)** Phone: 215-1500
- Distress Centre Crisis Line,** Phone: 266-1605
- Calgary Family Services,** 200, 707 10th Avenue SW Phone: 269-9888
 3810 17th Avenue SE Phone: 974-1928
 #206, 8989 Macleod Trail S Phone: 253-0223
 5000 Bowness Road NW Phone: 974-1525
 6501 Bowness Road NW Phone: 288-7732
 6617 Centre Street N Phone: 974-1510
 255, 495 36 Street NE Phone: 299-9693
- Catholic Family Service,** 250, 707 10th Avenue SW Phone: 233-2360

Calgary Counseling Centre, (phone for appointment)

Phone: 265-4980

Private Counseling

Private counseling can also be considered. Look for psychologists, social workers or registered nurses dealing with brain injury. (You may require a referral from your physician).

APPENDIX B:

Brainstormers Approval Letter

May 26, 2001

To:

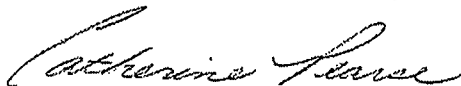
The Conjoint Faculties Research Ethics Board
University of Calgary
Calgary, Alberta

In support of:

Leslie Allison's application for ethics review

We, members of the SABIS Brainstormers women's group,
would like to participate as interview subjects for
Leslie Allison's research project for her Master's thesis.

Sincerely,

A handwritten signature in cursive script, appearing to read "Catherine Pearce".

SABIS Brainstormers representative
On behalf of the Brainstormers members
Calgary, Alberta

APPENDIX C:
SABIS Approval Letter



Southern Alberta Brain Injury Society
L500 - 1400 Kensington Road N.W.
Calgary, AB, T3P 2N9
Phone 521-5212 Fax 283-5867

The Conjoint Faculties Research Ethics Board
University of Calgary
2500 University Drive NW
Calgary, Alberta
T2N 1N4

June 11, 2001

Re: Leslie Allison

The Southern Alberta Brain Injury Society (SABIS) has given authorization to Leslie Allison to interview SABIS clients for her research project. Specifically, the members of our Brainstormers group have agreed to be interview subjects for the Master's thesis that Leslie is completing.

Sincerely,

A handwritten signature in cursive script that reads "Heather L. O'Bray". The signature is written in black ink and is positioned above the printed name and title.

Heather L. O'Bray, RSW, BCR, BA
Client Co-ordinator

APPENDIX D:**Sample Interview Questions**

Existential-phenomenological methodology necessitates “open-ended, minimally structured questions” (Osborne, 1990, p. 84), sensitivity to the moment, and reverence for ontological silence (van Manen, 1990), to give voice to the lived experience.

I shall endeavor to create an atmosphere of warmth, caring, openness, ethical integrity and respect for my co-researchers, and a relationship that leads to willingness to share rich data. I will close with a question that attempts to draw the co-researcher into a positive frame of mind. Therefore I might ask questions such as these, in this order:

1. How is it for you?
2. In what ways do you consider yourself a success?
3. What do you feel has been your greatest challenge in dealing with life after brain injury? Or: Could you describe some of the challenges since you injury?
4. How do you describe your brain injury?
5. How was your brain injury described to you, when you were diagnosed?
6. If you were to give advice to medical personnel about speaking to persons with brain injuries, what might it be?
7. What has been your greatest achievement since you sustained the brain injury?

If the conversations resulting from the above questions (particularly number five and number six) do not include a discussion of experiences in talking with the medical profession regarding the rehabilitative process, then I will pose questions about this issue. Thus I shall respect the existential-phenomenological methodology, therefore asking only as many minimally structured questions as necessary to converse about rehabilitative processes.

Examples might be:

8. Do you feel that you are participating in rehabilitation?
9. How is it for you with your rehabilitation?

**APPENDIX E:
Brain Injury Study**

**“JUST WORDS: The Conversational Experience of Women with Brain Injury
with the Health Profession during the Rehabilitative Process.”**

Dear Participant:

My name is Leslie Allison. I am a graduate student in the Division of Educational Research, Faculty of Education, Community Rehabilitation and Disability Studies Program at the University of Calgary. I am conducting a research project under the supervision of E. Anne Hughson, Ph.D. as part of the requirement for the M.A. degree. I want to provide you with information regarding my research project examining the Cognitively High-Functioning Adult Female Brain Injury Survivor, so that you can make a decision regarding your participation.

The general purpose of this study is to research the lived experience of the brain-injured female. You will be asked to participate in one interview that will last about one to one and a half hours. This interview will be audiotaped. Your interview will be transcribed and this transcript will be returned to you to read, reflect on and edit to ensure the clarity and trustworthiness of the interview. Further interviews are expected to last no longer than half an hour. These will be conducted to ensure that I have understood your input, and to ensure that you have given voice to all relevant experiences. It is expected that this procedure will entail no more than three interviews. Even if you give your permission now, you are free to stop the interview at any time and for any reason without penalty. Without penalty includes no loss of support and services from the Southern Alberta Brain Injury Society of which you are all members.

Participation in this study will involve no greater risks than you experience in your daily life.

Data will be gathered in such a way as to ensure anonymity. Participants will be assigned a code number, and all data collected will be identified only by that code. All documents will be locked in a filing cabinet at the University of Calgary; separate from the coded form that identifies participants. In written presentation of results, any information cited from participants will not contain any identifying criteria. Each participant will be given a pseudonym for the purpose of bringing important themes into the written product. The raw data will be kept in a locked file cabinet and destroyed three years after the completion of the study.

If you have any questions, please feel free to contact me at 244-4507. Please note: It is necessary to allow the telephone to ring nine times before leaving a message. Please do not let this deter you. You may also contact my supervisor, E. Anne Hughson, Ph.D. at 220-6273. Research Services Office at 220-3782 is available to address questions or concerns about the research in general. Two copies of this consent form are provided. Please return one signed copy to me and retain the other copy for your records.

Thank you for your cooperation.

Sincerely,
Leslie Allison

APPENDIX F:**Verbal Summary Prior To Consent**

I shall introduce myself to the members of Brainstormers and shall explain all that follows:

1. As a student researcher I expect to increase my understanding of research methods and cognition by conducting this study.
2. Although the volunteer participant will obtain no direct benefit including no remuneration from participation in this study, intrinsic benefit may be derived from viewing the self as a co-researcher giving voice to the experience of being a female brain injury survivor.
3. Giving voice to this experience may increase the public's awareness and understanding of the many issues and challenges, some being invisible, involved in the life of the brain-injured female.
4. The potential participants will have the right to withdraw at any time, without consequence. This includes no loss of benefits from association with SABIS. I intend to review with the group the steps that will be taken to assure complete anonymity and confidentiality regardless of whether they withdraw or complete the study.
5. I will explain the three-step interview process. The first-step consists of an in-person interview involving tape recording. This preliminary interview will not last more than one and one-half hours. We will agree upon a safe, quiet and private setting for this interview. All these in-person interviews will be at a time that is convenient for both the researcher and the co-researcher. While the interviews will not involve more risk than would occur in normal, daily living, a list of community counselling referrals will be supplied to all interview participants along with advice that immediate intervention shall be provided, if required. This information will be available at the time of signing the consent form.
6. Someone will be at the initial interview to set up the tape recorder and to assist me. This person will not be present in the room during the interview and is there solely for my benefit before and after the actual interview.
7. It will be necessary to hold a second and possibly a third interview, not lasting more than approximately one-half hour. These will be held in-person and will

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- also be transcribed. Again someone will be waiting in another room to assist me before and after the interview.
8. I would like the volunteers to consider themselves, as I shall, to be co-researchers in this study examining the lived experience of the brain-injured female.
 9. Transcripts of the interviews will be provided to each participant for reflection, editing and feedback. In the first follow-up interview, it is my intent that the transcript provided from the initial interview will produce a catalyst effect prompting the co-researcher to reflect on the lived experience, thus providing us with rich data.
 10. I am aware that one of the symptoms of brain injury may involve becoming easily fatigued. Therefore, I will from time to time, ask the co-researchers how they are feeling. I shall also be looking for signs of fatigue and will adjust the length of the interview accordingly.
 11. I will review the consent form with the group offering further clarification.
 12. After the verbal summary, I will leave a copy of the consent form with all interested members for thorough perusal. (An arrangement will be made for witnessing of signatures and retrieval of consent forms from those members who are willing to volunteer their time as co-researchers.)
 13. The group will be informed that their signature on the consent form indicates that they have understood to their satisfaction the information regarding participation in the research project and that they agree to participate as subjects. They will be assured that their signature in no way waives their legal rights nor releases the investigators, sponsors, or involved institutions from their personal and legal responsibilities. Participants are free to withdraw from the study at any time.
 14. Time will be made available for any questions about this process or any related issues.
 15. I will state in closing that it is important that the volunteers' continued participation should be as informed as their initial consent, therefore they should feel free to ask for clarification or new information throughout their involvement in the study.

APPENDIX G:
Consent Form for Interview for the Brain Injury Study

Research Project Title: "JUST WORDS: The Conversational Experience of Women with Brain Injury with the Health Profession during the Rehabilitative Process."

Investigator: Leslie Allison, graduate student in the Division of Educational Research, Faculty of Education, Community Rehabilitation and Disability Studies Program.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The purpose of this research is to discover if and how the physician-patient discourse and specifically language impacts the healing outcome and rehabilitation of the brain injured female.

Participation in the initial in person interview will require about 1 to 1 1/2 hours of your time, and will be tape-recorded. The resulting transcript will be provided for you to read, reflect upon and edit as necessary. With your permission, I will be phoning you after the initial interview to confirm that you have read your transcript and to schedule the second interview date. Following the second interview, I will be sending you a second transcript for further necessary reflection. I will be phoning you once more and we will repeat the in-person interview, if necessary, to ensure that I have understood your experience and given you voice. Thus, in total we may meet three times. It is of the utmost importance, to ensure the trustworthiness of the text, that it is your story that is being told.

Participation in these interviews will not pose any risk greater than you would experience in your everyday life. Please answer the questions only in ways that make you comfortable. If any question causes you any discomfort, please notify the interviewer. You are free to decline to answer any question. You will not benefit directly from participation in this research. However, your participation in this interview will give you the opportunity to reflect upon your experiences with your physician and allow you to give a narrative account of your ongoing relationship with your physician.

The research will increase understanding of research methods and cognition on the part of the researcher. Society may have a better understanding of the lived experience brain injury when the research is completed.

Your participation in this interview is completely voluntary. If you do not want to participate in this interview, you are free to withdraw without penalty. If you decide during the interview that you would like to stop, you are also free to do so. Your decision to withdraw from the interview will not in any way affect the services you receive, or may receive in the future from The Southern Alberta Brain Injury Society. Should you decide to withdraw, all your information obtained from the interview will be destroyed.

Confidentiality will be respected. You will be assigned a code number, and all the data collected from you will be identified only with that code and not your name. Only the investigator will have access to the data. In written or oral presentation of the results of this study, you will not be identified in any way. Any information that may identify you such as name will be changed to ensure that you remain completely anonymous.

Disposal of all records will occur three years after completion of the study, except in the case of those who may withdraw before the completion of the study, in which case the data will be destroyed immediately. At the time of disposal, written transcripts, recorded notes, and coded forms will be shredded and audiocassettes will be overdubbed.

You will not receive any remuneration from your participation.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does it waive your legal rights nor release the investigators, sponsors, or involved institutions from their personal and legal responsibilities. You are free to withdraw from the study at any time. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact Leslie Allison at 244-4507. Please note: It is necessary to allow the telephone to ring nine times before leaving a message. Please do not let this deter you. You may contact my supervisor, E. Anne Hughson, Ph.D. at 220-6273. If you have any questions or issues concerning this project that are not related to the specifics of the research, you may also contact Research Services Office at 220-3782 and ask for Mrs. Patricia Evans.

Participant's Signature	Date
Investigator's Signature	Date
Witness' Signature	Date

A copy of this consent form has been given to you to keep for your records and reference.

APPENDIX H:**Letter of Thanks**

October 12th, 2002

Dear Co-Researcher:

Thank you for meeting with me and sharing your brain injury experience. I appreciated your willingness to share your unique thoughts, feelings, events and situations.

Thank you for reviewing the transcript that was provided to you and for reflecting upon your experience, especially discourse and language used by the physician and yourself during conversations. Your comments in the subsequent interview, after reading the transcript and reflecting upon it, provided me with rich data. The way you told your story was critical to the study.

I have greatly valued your participation in this research study and your willingness to share your experience.

Sincerely,

Leslie Allison