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The Experience of Affectionate Touch for Survivors of Brain Injury

by

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Abstract

This qualitative study of five brain injury survivors takes a phenomenological approach to understanding the meaning of affectionate touch in their lives. Four themes emerged from the analysis of transcribed interviews. 1) Relationships - included trust, reciprocity, and status issues; and the management of social and gender norms. 2) Giving - clarified what participants intended touch to communicate, the interaction of touch and speech, and the circumstances around assessing others need for touch and meeting that need. 3) Receiving - revealed the nature of obtaining and avoiding touch, and the consequences of being refused touch for survivors. 4) Self-Perceptions of Disability - reflected shifts in family touch since injury, survivors' feelings of independence and dependence, and their self-perceptions that affected giving and receiving touch. Implications for rehabilitation professionals were discussed such as teaching boundaries and safety, and facilitating survivors' creation of close relationships with peers in which touch naturally occurs.

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This work is the result of the five generous people who shared a very personal part of themselves. Their participation has left an indelible imprint on me that I carry into my professional work and relationships. I am grateful for their candidness and thank them for sharing their time, wisdom, and voices with me and my readers.

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My colleagues who support people with disabilities, who reaffirmed that understanding and utilizing touch is important.

***Imagine that you are walking in the woods on a beautiful winter's day with a gentle snow falling all around you. You are caught by the beauty of each snowflake in its crystal clarity as it lingers for a moment on your outstretched hand before melting into nothingness. Suddenly you are startled by a loud crash and you look around to discover that a branch has been shattered and torn from the largest tree in the forest. Which snowflake did it?
Each one of us is as unique, as insignificant, and as powerful as a snowflake.***

Dr. Dorothy Goresky, Physicians for Social Responsibility, 1986

Dedication

**To my parents who led the way,
my sisters who traveled with me, and
my friends who pushed from behind.**

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Chapter 1

INTRODUCTION

It is because of Heather. The finger of causality points to her. I was born into a family whose eldest daughter was born blind and severely disabled. To me this was normal. I grew up spending time in activity centres with young disabled kids, with the Cormacks, with family friends who had disabled kids, and with my parents who were involved in advocacy, program development, and service. At a young age, probably in elementary school, I decided that it was my job to stand proudly beside Heather when we were out in public and glare at anyone who stared at her for more than a moment. They would look at the fluid, serpentine movement of her head and the bird-like movement of her hands, or maybe they would be caught by her repetitive speech, limited to a couple of phrases. I would stand there demanding that they treat her and see her as normal, knowing the whole time that she was different. So literally, understanding difference, being the defender of difference, was unavoidable, it was in my blood. Even as I went off to film school, something totally unrelated to disability, it was in my blood. My sister, Kate, and I directed and edited an award winning film about Heather's life in her group home with her friends. Then I moved away and went off to work in the film business and began to take psychology courses at Simon Fraser University. I worked at the RCMP fingerprinting criminal suspects and investigating hit and runs, but it was still in my blood.

When I returned to Calgary, I found myself volunteering for brain injury organizations and agencies serving kids with learning disabilities, and then it was inescapable, there were no longer any other routes to circle around it. I ended up in

Community Rehabilitation Studies at the university knowing that what I would do, and who I would be, would happen in the disability community, in the rehabilitation environment.

Because I have been in “contact” with people with disabilities all my life, I came to be attuned in some way to family interactions. It is only recently, however, that I have begun to examine the tangible nature of my relationships with others and look at the ways in which people use touch to communicate. As a rehabilitation worker in brain injury, I was in physical contact with my teenage client on a regular basis for physiotherapy and swimming. I began to pay attention to the touch she received and the touch she didn’t. She resided away from her family in a care facility so she wasn’t getting touch from a boyfriend and she wasn’t getting wrestling-around-with-her-sisters-in-the-backyard touch. I noticed that when she had visits with her family their physical contact was limited to her head, hands, and arms because she used a wheelchair. I began to wonder about the nature of affectionate, inter-human touch and what touch experiences really are for survivors of an adult onset disability. What were the consequences of reduced or limited touch? Who provides affectionate, caring touch for survivors of brain injury? With the disruption of family, who can offer touch to survivors?

I began to formulate a plan, partially motivated by the need to write a thesis, to look at people’s touch interactions and how being peripheral or marginal to the world in some way impacted that touch experience. They could be seniors living alone, people with cognitive and physical disabilities, those with serious illness, unemployed single people, gay and lesbian people, or anyone ostracized, marginalized, or perceived as

“other” than the societal norm. Thus emerged my general area of interest and passion. I felt it was important to know what kind of relationships were important for people with disabilities, or anyone, to have in order to be comfortable touching and for that touch to be significant, meaningful, and powerful. To narrow the scope of the study, I chose to look at the experiences of survivors of brain injury.

My assumption was that the consequences of injuries and disabilities, such as changed opportunities for developing relationships and socializing, necessarily influenced touch experiences. Brain injury is particularly effective at producing idiosyncratic difficulties that impact multiple spheres of one’s life. Personality changes, cognitive deficits, emotional lability, and physical functioning resulting from a brain injury can together or separately challenge family and friends. The survivor of a brain injury may lose a sense of self, experience lower self-esteem, and lower confidence and this further exacerbates the ability to develop and hold onto relationships. Most of the consequences of a brain injury have been rigorously researched. Rehabilitation success is measured by the independence of the survivors and their ability to work. What rehabilitation has ignored, deliberately or not, is the human touch experience. Perhaps it is the current hands-off climate of Western culture that creates the fear to touch. Perhaps it is just the unexamined, unconsidered nature of human non-sexual touching. It is time for touch to be explored, examined, and weighed against the existing rehabilitation priorities and practices.

My own use of touch was unexamined. Occasionally I would become aware of the world of deliberate touch because I was being touched by a stranger or a friend with

whom I was not comfortable and my thoughts raced to how to remove myself gracefully. At other times, I felt that reciprocal touch was desired and I had to calculate the delivery and nature of my touch. Sometimes I found myself wanting to use touch to communicate what I could not express and hesitantly doing so. Because of a combination of my family's pattern of restrained touch and my own discomfort with people touching me, I considered myself a guarded toucher. However, I now find myself experiencing a need for affectionate touch. As I get older and more comfortable with myself and my body, I am braver in my solicitations for, and giving of, touch. I find this a preferred state for I can be more at ease, open and intimate with family and friends.

When I tell people that I work with people who have sustained a brain injury they always say, "Oh, that must be so depressing." I always answer, "No. I didn't know them before the injury to know what they were like. I get to see them improving, progressing, changing, and re-creating some kind of life for themselves, so it's not depressing at all." What was different about this experience of researching was that it showed me the other side of the progress, improvement, and increasing independence. I saw what I had carefully denied, the sustaining characteristics of being a brain injury "victim": relationships that fell apart, changes in the essence of ones' self, and altered life paths. The stories within reflect how the effects produced by a brain injury can result in isolation, and low self-esteem. They are also stories of companionship and support of others by people with disabilities.

By the end of my studies at Simon Fraser University, I had read and studied a great deal on human isolation and was keen to pursue it as a graduate research topic. My

activities in brain injury rehabilitation took me down another road. Upon reflection, however, I realize that I have circled around to examine isolation. Not the isolation occurring in a cave, a space station, or an underwater drilling platform, but rather the isolation that can occur in the midst of a circle of family, friends, and professionals.

Just like being Heather's sister, this research was a difficult journey, full of sadness and frustration, delight and discovery. Just like being Heather's sister, I wouldn't trade it for anything.

Chapter 2

**There is really only one sense. It is the sense of touch. All of the other senses are merely other ways of touching.
Spider Robinson, Lifehouse**

REVIEW OF THE LITERATURE

Touch

At its essence, touch communicates to us what is occurring in our world, it connects us to each other, and tells us about ourselves. Traditionally, scientific attention to the importance of touch has focussed around infant development and, more recently, seniors' quality of life. However, touch can play an important part in the lives of many people who may be marginalized from others. This can include people with disabilities, people living alone, people with stigmatized lifestyles, people with chronic illness, and people in institutionalized care. All members of these groups may have limited opportunities to receive touch from friends and family. The impact of lack of touch is unclear. Little research exists to shed light on this situation or any possible solutions.

My exploration of human touch in this study is limited to non-erotic touch that is used to indicate affection, care, and support. I have reviewed the literature on touch in the development of children, comfort of seniors, and its use in health care. As touch occurs within relationships, I have examined the nature of disability and how it interacts with the establishment and maintenance of relationships. Brain injury has been specifically explored, with a critical look at rehabilitation efforts in the area of social skill development.

Touch is communication conveying meaning between people that can be more than

a substitute for words (Pratt & Mason, 1981). As a supplement to speech and in combination with other non-verbal communication, touch contributes to a simple, clear message. The meaning of touch is clearer when it is formally structured (such as a handshake), when the roles of each toucher are clearly defined, and when a statement of intent is given. When the boundaries around touch are understood “ambiguity and anxiety are reduced, security is increased and touching is fully accepted” (Pratt & Mason, p. 53). Touch can be used to express empathic, caring attitudes of concern, acceptance, support, protection, respect, and love. Touch can be spontaneous and natural, laboured and self-conscious, or entirely absent.

Importance of Touch in Development

Touch is the first sense to develop in animals and the last to extinguish (Ackerman, 1990). According to research on mammals, touch plays a fundamentally important role in the growth and development of the brain, nervous system, bones, and in weight gain (Montagu, 1986). The importance of touch to physical health is demonstrated in studies with premature babies. Premature babies receiving massage gained weight up to 50% faster than un-massaged babies (Ackerman, 1990; Harrison, Olivet, Cunningham, Bodin & Hicks, 1996). They were more alert and responsive, more tolerant of noise, and able to more effectively calm and console themselves. Infants deprived of touch, while otherwise fed and cared for, can become psychologically and physically undeveloped (Ackerman). The psychological benefits of touch are demonstrated with children who cease to thrive and grow. When placed with affectionate, touching caregivers the children were able to get back on track psychologically. However, the physical effects of touch deprivation

persisted resulting in smaller builds and increased susceptibility to disease. "In the absence of touching and being touched, people of all ages can sicken and grow touch-starved" (Ackerman, p. 79). As recently as the 1920s, the mortality rate for children under two years old in American institutions was virtually 100% (Montagu, 1986). The climate in these orphanages was one of regimented feedings and minimal handling. It was not until after World War II that the importance of hands-on "mothering" was discovered. Failure to thrive was significantly reduced, if not, eliminated with regular handling, caressing, and cuddling of infants in care.

The importance of touch seems to persist as children get older. Pearce, Martin, and Wood (1995) studied ninth grade students' perceptions of touch. Specifically they looked at how touch experiences interacted with parental bonding and the adolescents' depression, aggression, and criminal behaviour. Teens who perceived themselves as receiving frequent pleasant touch and infrequent negative touch rated their parents as more caring than students who received less positive touch. Students who reported suicide ideation and self-harm perceived themselves as having experienced many fewer pleasant touches and many more negative touches than those who reported no suicide ideation or self-harm. Positive touch experiences in females related to less depression, delinquency, aggression and somatization while frequent negative touches for males predicted increases in those difficulties. Pearce, Martin, and Wood speculated that because individuals develop a sense of identity and appropriate interpersonal behaviour in adolescence, physical contact influences those processes. The number of pleasant and unpleasant touch experiences may be a marker for vulnerability to adolescent problems.

The authors were clear that their study sampled perceptions of received touch, not actual occurrences. I agree with the authors that it is one's perceptions of touch that matter more than documented frequencies.

In 1984, the National Center for Child Abuse in the US reported that over one million children were sexually abused in 1983. This created significant alarm among parents (and teachers) about touch, which is understandable given that Western society has confused and confounded sex, love, affection, and touch (Montagu, 1986). "Unsure of touching as a way of sharing with others we have allowed our fears and discomforts to limit the rich possibilities for non-verbal communication." (Montagu, p. 204).

For both men and women in later years, opportunities to touch diminish at a time, Montagu (1986) believes, when it is most needed, particularly because we are then most dependent on others for support. Tactile stimulation is the most important and neglected need in the elderly, particularly when a loss of acuity in hearing and vision makes people feel vulnerable and in need of assistance. Montagu claimed that it is our evasion about aging and dying that creates our denial about seniors' need for touch. A handshake is not a substitute for a loving caress nor is a peck on the cheek an adequate replacement for a warm embrace. Touch can communicate the emotions of love, trust, affection, and warmth, while it gets through the isolation. In their continual disappointment in receiving affectionate touch, seniors may become uncommunicative about it.

Impact of Touch on Health

The physiological effects of touch extend to immunological T-cells, growth hormones, and other biochemicals important in brain and organ activity (Montagu, 1986).

The levels of these chemicals drop when primates and mammals are deprived of touch and return to normal when handling and stroking ensues. There is evidence that asthma and colic are alleviated when children are held and cuddled. The physiological changes in neural, muscular, and glandular states produced by touch also produce changes in affect. Thus touch is experienced as both a sensation and an emotion.

Those who experience difficulty touching others can have their tactile and related emotional needs met to some extent with pets (Montagu, 1986). Animals provide a physical presence and unconditional love while the owner or toucher provides the pet with support and protection in return. The stroking, caressing, and hugging of pets is a socially acceptable outlet for physical expression and is particularly beneficial for men who may have limited access to non-sexual touch (Montagu, 1986). Some patients in a long-term nursing facility commented that they missed having a pet and the opportunity to pour affection onto it (Routasalo & Isola, 1996). Heart attack survivors with pets live longer than heart attack survivors without pets possibly because touch lowers blood pressure (Ackerman, 1990). Seniors in care facilities also respond favourably to the touch of visiting animals (Czimbai & Zadikov, 1997).

Ethnicity and Touch

Touch is the only form of communication requiring a contract between parties. It is an intrusion into one's personal space that needs permission or acquiescence to be acceptable and accepted (Pratt & Mason, 1981). In Western culture, contact is generally seen as falling into the parent/child or lover/lover categories. Pratt and Mason maintained that even if touch is only intended as affectionate or caring, adult touching implies some

commitment to sex. This societal assumption has deterred both men and women from engaging in affectionate touch.

Cultural, family, and individual patterns of touch exist in broad variation (Montagu, 1986). From birth, we are continually exposed to tactile experiences that reflect our culture and societal values. Our initial influence is parental, but then moves to peers and romantic partners. Ethnicity and geographic location contribute to cultural norms. McDaniel and Andersen (1998) studied cross-gender interpersonal greeting and farewell touches that occurred in public at airports. Unobtrusive observations and brief interviews were made of 154 dyads from 26 nations. McDaniel and Andersen found variation in touch by nationality and dyad relationship. Dyads from northern Europe and the United States were not non-contact as had been presumed, in fact they were among the most tactile. Dyads from China, Korea, and Japan showed an avoidance of touch interactions. For all countries, the number of body areas touched was highest among friends and lovers, moderate between strangers, acquaintances, and spouses, and lowest among family members. Most societies, except Asian nations, engage in a broad variety of touch activities. Cultures high in diversity such as the United States and Germany could not be designated by the researchers as solely contact or non-contact. As Canada is also high in diversity, its citizens may not demonstrate common touch behaviours.

Status and Gender

Touch interactions are mediated by the environment, for example, available privacy, the status of touchers, and their gender (Pratt & Mason, 1981). Hall (1996) observed touches between professionals in psychology and philosophy at conventions and

meetings. The touches were used to greet, introduce, be playful, show affection, and control. The majority of observed touches were hand to hand, hand to shoulder, and hand to arm. Status indicators were the degree completed, the prestige of the institution granting the degree, and current academic affiliation. However, not all status indicators were apparent and Hall assumed that touchers would not necessarily know each others' rank. She found no difference in the number of touches by status but did find that the type of touch used differed depending on the status of the individuals. Spot touches to the shoulder and arm and affectionate touches were more often made by higher status individuals while lower status attendees used more formal, hand-to-hand touches like handshakes. Higher status participants did not use more controlling touch, but rather initiated more familiar and affectionate touches, perhaps, Hall speculated, reflecting their license to interact with more warmth and openness. Higher status individuals may want to display status with their touch while lower status individuals want to gain status or equalize relationships with a polite, yet reciprocal handshake (Hall).

Gender differences were not apparent except when the men and women had equal status. In those circumstances males tended to initiate touch slightly more often. Although Hall (1996) did not assume that being male was equal to having higher status and power as other touch studies have, she concluded that gender may serve as a status marker in the absence of other cues.

Hall's study was limited to the public touch of newly acquainted individuals who may have attended the functions and interacted with other agendas in mind. She concluded that "[a]ny theory about who touches whom may have weak predictive validity

without reference to the moderating effects of the meanings and functions of touch, as well as of situational factors” (p. 41). Qualitative study is needed to illuminate those factors.

Gender is a factor in our touch experiences, however, the reasons and results are not clear. Salt (1991) reported on the touch practices and perceptions of 39 father-son dyads with sons ranging from 7 to 12 years of age. Quantitative and qualitative data was gathered through self-report measures, open ended questions, and video taped interactions. Unlike what might be expected between fathers and sons, rough play was observed only occasionally. Fathers and sons exchanged hugs, kisses, and pats on the back and shoulder. Touch was initiated by fathers 65% of the time. A decrease in sons’ touching and their acceptance of touching was seen as they got older. However, sons touched more frequently at home and in the absence of peers than in public. This suggested that the desire for touch remains, while societal pressures, real or perceived, set parameters around their affectionate touching.

A positive relationship was evident between fathers’ and sons’ attitudes about touch and their perceptions of received touch. Salt (1991) developed a theoretical cycle in which fathers and sons receive feedback about their touching that produced their perceptions and norms, and formed their attitudes about touching. Further engagements in touch provided additional feedback and continued the cycle.

For women, there is less taboo around touch (Montagu, 1986). In the Western world, cultural pressures result in men living as virtually touchless creatures, finding touch mainly in sexual contact. To avoid the embarrassment or shame that is felt when wishing

for touching of a parental nature, the activity of sex is an adult way to get human contact. Many studies have revealed that women also engage in sexual activity to meet their needs to be held and cuddled (Montagu).

Professionals' Use of Touch

We access touch for healing through a variety of practitioners. We go to be fussed over, listened to, stroked, patted, and massaged by doctors, hairdressers, dance instructors, masseuses, manicurists, and prostitutes (Ackerman, 1990). Giving touch and receiving touch are equally therapeutic acts. When touch is not normally part of the professional service, the attitudes of those professionals vary.

Psychologists and Touch

Holroyd and Brodsky (1977) studied psychologists' attitudes and practices of erotic and non-erotic touch in treatment with clients. About half of responding therapists believed that hugging, kissing, and affectionate touch might be beneficial occasionally for both male and female clients when used for specific client issues such as grief, trauma, depression, and for general emotional support, and for greetings and terminations. There were no gender differences in attitudes toward touching for same sex therapist-client dyads. Male therapists believed in the benefits of non-erotic touch for female patients slightly more often than female therapists did with male patients. Male therapists were more likely to feel that non-erotic touch would be misinterpreted by opposite sex clients than female therapists.

Holroyd and Brodsky (1977) found that the psychologists' therapy orientation influenced attitudes about affectionate touch. Humanist psychologists believed in the

benefits of non-erotic touch far more often than psychodynamic therapists who feared that the behaviour would be frequently misunderstood. About one fourth of therapists actually engaged in affectionate touch, hugging, and kissing with clients occasionally, with humanistic therapists using touch most frequently and psychodynamic, behaviourists, and rational emotive therapists rarely. Female therapists reported that male clients initiate such contact less than male therapists reported female clients initiating touch. Female therapist-client dyads, however, engaged in slightly more affectionate touching than male dyads. This is an older study, but only limited data was available on non-erotic touch.

Qualitative research undertaken by Geib (1998) in 1981 with women who had been in psychotherapy with male professionals illuminated the conditions around positive and problematic non-erotic touch. Through interviews and subsequent theme analysis, Geib made the following recommendations to professionals wishing to incorporate touch into their practice. 1) The client must direct both the type and duration of the touch if it is to be perceived as positive and healing. When professionals do not ask permission to touch and fail to check the client's comfort level, touch feels unpleasant. 2) Professionals must respond to the needs of clients, not their own needs. Clients should not have to worry about the feelings of the professional nor fear any misinterpretation by the professional. 3) Professionals should encourage open discussion of touch with clients. The pair should lay out the boundaries and limits, and create an environment where disclosure and discussion of the feelings resulting from touch are explicitly discussed. 4) Professionals are responsible for regulating the development of touch and emotional intimacy. The use of touch should be well timed and be congruent with the development

of trust in the therapeutic relationship.

When used with great care, touch can be a powerful tool in psychotherapy. It can help connect clients with the external world, can communicate acceptance which increases self-esteem, and show clients that they can give and receive touch in safe ways that deepen relationships (Geib, 1998). In 1994, Horton (1998) replicated Geib's study with quantitative and qualitative components. Support for three of Geib's recommendations was found. Horton's respondents evaluated touch positively when the touch was congruent with emotional development in the relationship, when clients directed the touch, and when clients were able to discuss touch and any resulting feelings they had. Additionally, responses to open ended questions reflected the majority opinion that touch with a psychotherapist promoted a closeness and sense of genuine caring. Consistent with Geib, Horton also found that for half of the respondents, touch in psychotherapy communicated acceptance and enhanced their self-esteem.

Pratt and Mason (1981) believe, as I do, that there is room for the development of closer and more frequent contact between clients and professionals. Developing practitioners' skill in touching is akin to learning any physical skill (Pratt & Mason, 1981). It is learned and practised with a goal in mind and continual adjustments are made along the way to accommodate responses to it. Additionally, the practitioner must have an understanding of the needs of the client and how the client is responding to the touch by assessing physiological and non-verbal cues. The practitioner must be sensitive to the subtle indications of feeling and attitude expressed by means such as eye contact, facial expression, and voice quality. Pratt and Mason claimed that successful touch interactions

communicate understanding, competence, guidance, and care. Training practitioners to be competent in the use of touch required increase awareness of their own emotional reactions in interpersonal encounters, good judgement, empathy, awareness of own resources, and the needs of others. This training, Pratt and Mason reminded, may be challenging and uncomfortable. Practitioners will still be left with their personal experiences and judgement, making objective and conclusive prescriptions about the use of touch impossible. Pratt and Mason affirmed that:

Touching another human in order to help him is, in the final analysis, a *personal* act. Although constrained and directed by the social and physical skills of the actor, it derives its deeper meaning and force from the human values and attitudes brought to the helping situation; it is part of a belief in 'tender loving care'; it springs from the ability to empathize with another person, to understand how he thinks and feels, to be able to share his world. In this sense the healing touch cannot be applied simply in relation to the client's signs and symptoms: it is not merely another clinical tool. Much more than this, it is part of the whole pattern of the client/practitioner relationship; it is, in this context of care, an act whose implication spread, like the ripples from a stone thrown into a pond, far beyond the place and moment of contact. The touching of another brings both persons immediately into the 'here-and-now'. It may both ask and answer the questions 'Who am I?' and 'Who are you?' It is to do with personal history, personality and the development of the self. All this implies that the caring process in general and the act of touching within this cannot be reduced to a set of rules, but is unique to

each pair or group of individuals committed to it. (p. 105-6)

In conclusion, Pratt and Mason summarized that the use of touch may be beyond explanation, “representing something of the instinctive, the intuitive or the spiritual” (p. 108); the art, rather than the science, of healing.

Health Professionals' Use of Touch

Our belief in the curative power of touch extends back for millennia. For example, some believe that Christ healed with only the laying on of his hands. Since at least the 13th century, royalty was believed to have healing powers; ailing commoners lined up for the King's touch (Montagu, 1986). For those experiencing serious illness, physical contact becomes more important. For example, cancer patients desire for touch increased at diagnosis. Patients with leukaemia who had a reduction in touch experienced isolation, loneliness, frustration, a sense of coldness, and a lack of emotional warmth. The nursing profession has paid the most attention to touch in practice and the bulk of research on the role of touch is found in nursing studies.

Nurses McCorkle and Hollenbach researched the touch experienced by patients with serious illness (Montagu, 1986). They found that patients were seldom touched in non-practical ways, yet touch and physical closeness may be the best way to communicate to them that they are important and that their recovery was related to their desire to improve. They acknowledged that patients learn that much touch in medical care is painful, such as physiotherapy and invasive procedures. In their research and practice McCorkle and Hollenbach introduced caring touch gradually and noted that acutely ill patients receiving caring touch had improved self-concept, less depression, and a shorter

hospital stay.

Non-verbal communication is frequently utilized by medical professionals in their work with patients. Professionals must attend to the non-verbal communication of the patient that provides clues to their emotional states which may be difficult to describe in words (Friedman, 1979). Patients too, rely upon the touch and facial expressions of staff to gauge their own status. Patients may face disability or death, confusing procedures, new terminology, and separation from family and familiar surroundings. Social comparison is used by patients to assess how and what they ought to be feeling, and they will assess the non-verbal cues given by professionals responsible for their care. The non-verbal cues tell patients whether they are liked and respected or repugnant and worthless. As well, patients determine if they are expected to improve or are virtually untreatable.

Effective health treatment involves consistency between verbal and non-verbal content (Friedman, 1979). According to Goffman, stigmatized people in particular are most vigilant in watching for clues as to how they will be treated by the non-stigmatized (Friedman). Those who are serious ill, too, look for information about their illness and prognosis. Inconsistency in verbal and non-verbal information can be distressing. The quality of health care may be improved with the careful use of consistent non-verbal cues such as touch.

Nursing education acknowledges that of all the non-verbal behaviours, touch may be the most important, having a powerful psychological effect on patients (Mooney, 1995; Friedman, 1979). Touch affects the interpersonal and emotional nature of the professional/patient interaction. Its symbolic power in healing may create positive

expectations and consequently impact patients' physiological states. Understanding the multidimensional meaning of touch can help professionals maximize healing.

Although touch is crucial at all stages of life, people who are ill, disabled, have experienced a change in body image, or are older are especially responsive to touch (Weisberg & Haberman, 1989). All retain the ability to respond to touch and its importance may increase when they have limited ability to communicate. Touch can also convey acceptance and support better than words. Working from the position that the opportunity for touch decreases with age as the need for it increases, Weisberg and Haberman implemented a Hugging Week for nursing home residents. They wished to enhance the delivery of their services by adding affectionate touch to the physical contact utilized in meeting patients' physical needs. Throughout the many activities in the week, staff and visitors were encouraged to hug the residents just as the residents were encouraged to hug the staff. Weisberg and Haberman reported that "retiring residents often blossomed when offered a hug" (p. 184). Those staff who were not usually demonstrative rose to the occasion to enjoy closeness. Both huggers and the hugged benefitted. The authors were delighted that Hugging Week had a spill-over effect. Hugging Week buttons were seen on housekeeping staff and administrators. Family visitors hugged not only their relative, but any residents who were receptive to touch. Long after the week was over, Hugging buttons still appeared on lapels; endorsement of the affectionate expression. Weisberg and Haberman did caution that staff must attend to individual preferences for touch and respect privacy and personal space. The ability to defend personal space can be compromised when someone is ill or weakened, so

professionals must be careful not to harm.

Nurses use touch to reassure, explain, instruct, orient, protect, assist (especially with eating and taking medications), and to communicate emotions, care and comfort (Routasalo, 1996). Touch has been shown to increase patients' positive attitudes towards nurses, comfort and calm them, provide reassurance and support, and convey affection. Positive touch experiences are those in which touch is appropriate for the situation, does not impose greater intimacy than is desired, and does not communicate a condescending message like pity. Roustasalo (1996) undertook a statistical and phenomenological analysis of non-necessary touching (touch that was not required in nursing tasks) between nurses and elderly patients in Finland. About half of the total observed touches were categorized as non-necessary. Most frequent were flat-of-hand touches, patting, and stroking. Nurses used touch to get the attention of patients, ask questions, explain behaviour, comfort, calm, and reassure. They also used touch to underline and intensify words, particularly with less verbal patients.

Routasalo and Isola (1996) studied the touch experiences of nurses and patients in a long term care facility using content analysis of interviews. Patients reported that the touch of a nurse was warm, gentle, and comforting while the nurses described their use of touch as important and natural. The exchange of non-necessary touch seemed to be based on reciprocity. Patients felt that non-necessary touch contributed to their sense of safety, comfort, and self-confidence. They would often ask for or look at the nurses to get a hug or pat. Status and familiarity played a role in patients' giving of touch. They tended to find it easier to initiate and respond to touch with nurses than with doctors. Nurses

perceived patient touch as communicating gratitude and they described it as pleasant. However, touch from a male patient was sometimes assumed to have a sexual meaning. Based on the responses of nurses, male patients learn to stop touching. Most patients reported that they were more accepting of a female nurse's touch than a male nurse's. Routasalo and Isola expressed a desire for qualitative studies that tap into the meaning of touching, and guidelines for maximizing the positive use of touch by professionals.

Disability

Social Isolation

Affectionate touch occurs in interactions with others. We search for social nourishment through close relationships (Montagu, 1986). People with disabilities often live with reduced, absent, or altered access to social relationships. Those with severe, multiple disabilities in particular can face a twofold disadvantage when developing social relationships. First, opportunities and societal acceptance are reduced and friendships may only be available with paid caregivers, family, and well meaning volunteers. Second, those with cognitive disabilities may have trouble navigating social waters due to a lack of skills or lack of awareness. Social skills can be broadly defined as learned abilities to initiate and maintain positive interactions with others in a socially acceptable manner (Gardner & Howard, 1991). Social skill training is utilized to improve interactions with others in the hopes of better establishing and maintaining those relationships. The specific nature of social relationships for people with disabilities, aspects of loneliness, and the unique role of professionals in their lives, are important components of their touch interactions. They are reviewed here for a better understanding of how they create and define the social context

for people with disabilities.

Loneliness

Friendships and relationships with community members are critical to combatting the segregation and isolation of many people with disabilities. From special recreation programs to congregations of people with disabilities floating about the community, practices and programs stifle the development of normal relationships (Amado, 1993). Loneliness and isolation are common for people with disabilities who are surrounded by professionals, care givers, volunteers, and job coaches (Hingsburger, 1998). The service system has created the illusion that people with disabilities have support networks and relationships, however, on closer inspection the network is a paid service. Feelings of loneliness maybe present in the person with the disability who is surrounded by others a good part of the day, or with many social contacts (Amado, 1993). People who withdraw to isolated resignation do so with little interference from professionals for they make few demands on resources. The physiological effects of loneliness can include disruptions in interpersonal relationships, and a lack of family and community ties (Amado). Loneliness can also contribute to poor health, illness, and premature death.

While the physical consequences of loneliness and isolation may be addressed, the loneliness itself, a mental health concern, is not treated at all. Perlman and Joshi (1987) investigated the disclosure of loneliness and found that because loneliness is a sign of social failure, regardless of the etiology, lonely people rarely reveal their state. The authors suggested that the revelation of loneliness is mediated by factors such as expecting a negative response, pessimism about useful help being forthcoming, feeling dependent

and unable to solve one's own problems, and poor recognition or insight into loneliness in one's self.

Perlman and Joshi (1987) identified two types of loneliness: social loneliness stemming from an absence of community ties or a social network, and emotional loneliness, characterized by a lack of intimate relationships. Self-disclosure about loneliness occurs in close relationships, therefore those experiencing both social and emotional loneliness have few people in whom to confide. The implications for professionals are that people with disabilities are less likely to reveal their loneliness to psychologists, social workers, and other support workers, and more likely to prefer to share with those in the same situation. It is unclear how the stigmatization of a group such as people with disabilities affects a lonely person's willingness to associate with such a group. If peers and professionals are not available, their loneliness may remain undisclosed.

Loneliness is a common experience, however physical and cognitive disabilities often alter the social environment, limiting available social relationships (Evans & Dingus, 1987). The inactivity and isolation of loneliness in turn creates further emotional problems. Those problems then exacerbate existing relationships, that might otherwise help meet emotional and social needs. The onset of disability evokes a need for relationships vital to maintaining high self-esteem and maximum independence. For those with cognitive or perceptual deficits, expressing their affective needs effectively may be problematic. They often need more social inclusion than they are able to solicit and maintain. Evans and Dingus recommended that when people with disabilities display poor self-esteem,

melancholia, cynicism, and self imposed seclusion, professionals should be alert to the possibility of loneliness.

An alternate and perhaps more useful approach to take in rehabilitation is to reject the notion that all people with disabilities hold common status as a stigmatized and devalued group, and to define their social environment as disabling or enabling (Schwartz, 1993). Schwartz believed that it is these contexts that form the meaning of disability in people's lives.

Friendships

Qualitative research studies undertaken over 15 years by Bogdan and Taylor (1989) has clarified the social meaning of relationships between severely disabled, non-verbal people and non-disabled people, and how they define others in their lives. They identified four common attitudes that underlie the non-disabled's attribution of humanness to their severely disabled friends.

1) Attributing thinking to the other: The non-disabled in Bogdan and Taylor's studies believed and cited incidences indicating that their non-verbal, profoundly disabled friends can think. They read meaning into their limited gestures, movements, and minor sounds. Some non-disabled persons claimed that they could see or read signs of their friend's inner state, for example, in eye expression, in a way that strangers could not. Others were convinced that they intuitively "know", and some took the perspective of their friends to guide them in what is occurring or what is needed. Often the reports of the non-disabled contradict the assessments of professionals. Clinical perspectives are based on a different way of knowing than the perspectives of those in the day-to-day

relationships with people with disabilities.

2) Seeing individuality: The non-disabled persons saw their disabled friends as distinct, unique individuals with specific likes and dislikes, normal feelings and motives, and a life history that produced a clearly identity. The non-disabled typically rejected clinical labels that tend to describe the person in terms of deficits while failing to reflect the person's unique personality. To help construct an identity consistent with their definition of the friend, the non-disabled managed the disabled's physical appearance to reflect individuality identities. The non-disabled rarely discuss physical abnormalities, preferring to accentuate the attractive haircuts and stylish clothes of their friends.

3) Viewing the other as reciprocating: Relationships with the disabled were not one-sided as might be assumed. The non-disabled described the joy of companionship, the increase in their own ability to relate to people with disabilities, and a sense of accomplishment in being able to assist in the well being and growth of a person with disabilities. The non-disabled delight in the small improvements their friends make that may go unnoticed or seem minor to outsiders.

4) Defining a social place for their friend: The creation of a social place for people with disabilities began with the belief of their non-disabled peers that they belong in the social group. Not only did they involve people with disabilities in the routines and rituals of the social group, but they also felt the absence of the person with disabilities in the normal routine. The inclusion of people with disabilities into the smaller social groups provided them with a path to inclusion in the large community. Ultimately, for the non-disabled persons in Bogdan and Taylor's study, mental or physical condition did not

dictate how people with disabilities were treated. Accepting them, including them, and forming meaningful relationships with them demonstrated that they chose to define them as humans with the characteristics and qualities of each of us.

Bogdan and Taylor (1989) asserted that accepting relationships between disabled and non-disabled people contradict the concept that few of these alliances exist and not all people with disabilities experience stigma and rejection as a result of being labelled “unlike us”. The non-disabled in these relationships perceive their disabled friends as “people, like us”.

Traustadottir (1993) offered a glimpse into the gendered context of disabled/non-disabled relationships. The majority of friendships consist of a non-disabled woman and a disabled man or woman. Given that women’s friendships are characterized by acceptance, intimacy, and support, they are more likely to help and nurture friends. Women prefer being together while men prefer doing things together. Balanced friendships between non-disabled and disabled women are based on the exchange of emotional support and closeness provided to the non-disabled women for the physical assistance and accommodation given to the friend with disabilities.

Non-disabled men do form close friendships with people with disabilities, but with less frequency. Some of the barriers may be men’s lack of skills and practice at providing assistance and the taboos around emotional disclosure and physical closeness. The need for close physical assistance required, for example, in the area of personal care, by some women with disabilities places non-disabled men at risk for accusations of abuse and deters the creation of those friendships. To facilitate more normal friendship patterns,

Traustadottir recommended that those involved in the process take into account the influence of gender on friendships. Traditional taboos around men's expression of emotional closeness and any attendant physical closeness must be acknowledged and managed.

Fine and Asch (1993) expressed frustration with research that assumes disability is the cause of all problems and how it fails to determine how people with disabilities engage in and manage meaningful social interactions. In the areas of support, Fine and Asch reminded us that the field of rehabilitation often generalizes the need for assistance in one area of life to all aspects of existence. One-way assistance is assumed to define all relationships of non-disabled with people with disabilities. When examining relationships and affection it is important to uncover the help and support that people with disabilities provide to others, both disabled and non-disabled. In redefining the exchange of support, Fine and Asch suggested that we are all interdependent, with varying levels of control and strength in our lives. They dare to suggest that those who serve and support people with disabilities ask "[h]ow much do the social and psychological problems that many people associate with disability actually pervade all of human life?" (Fine and Asch, p.57).

Relationships with Professionals

Research that is undertaken with significant contact and involvement with people with disabilities can begin to explore the notion that disability does not define the lives of people with disabilities and that contexts in which it is not handicapping can exist (Fine & Asch, 1993). Rehabilitation professionals should examine their own biases, assumptions, and expectations of clients. Consistent with the philosophy of Fine and Asch, Garske and

Soriano (1997) identified counsellor empathy, “the ability to understand and feel from the clients’ own insides” (p.13) as the most important facilitating condition in rehabilitation counselling. Through empathy, combined with unconditional positive regard, counsellors build relationships with people with disabilities that maximize their self-improvement. Remembering that people with disabilities share a common humanity with the non-disabled can help them towards an understanding that despite their disability and a discriminating environment, their journey through life incorporates the same, feelings, desires, disappointments, fears, and concerns as any one else (Garske & Soriano).

When staff and clients become friends, the staff may move into the role of advocate, protecting and supporting the person with disabilities (Traustadottir, 1993). At its worst, the client becomes a pet or a child-like figure. At its best, the staff provides vital support to the client that has a broader impact, affecting other clients and the attitudes and knowledge of the general public. Friendships develop between professionals and clients when each identifies with the other and recognizes the other as a potential friend (Lutfiyya, 1993). Professionals must acknowledge that “[c]oncern for friendship means hard work to minimize the status and power differences between people with disabilities and the people who assist them.” (O’Brien & O’Brien, 1993, p. 17). A mutual sense of similarity builds a sense of attachment through which a common history is established (Lutfiyya). These relationships are challenged by critical events such as the relocation or transfer of staff and a conflict of interest. Plans to stay in touch after staff have moved on can fall apart or further strengthen their ties. When staff maintain both the roles of support worker and friend, tensions may arise when these come into conflict. (Lutfiyya,

1993). "Close personal relationships between paid caregivers and clients are not substitutes for other relationships. Humans need a variety of relationships with a variety of people" (Lutfiyya, p. 98). People with cognitive disabilities in particular may have trouble understanding the dual roles assumed by staff and feel betrayed when the friend acts in the capacity of agency employee (Hingsburger, 1998). Friendships with paid staff should be valued, but not romanticized; respected but not seen as a replacement for necessary supports (Lutfiyya) or unpaid friends in the community (Hingsburger).

Touch and Disability

Dependence in others for a high level of assistance shifts the assumptions about the need for affection and sexual contact (Jurkowski & Amado, 1993). Prohibitions around the expression of common precursors to sex, like affection and warm touch, extend from the generalized concern that such actions lead to procreation. Viewing people with disabilities as asexual is common and results in denial or neglect of basic needs for touching, caressing, and tenderness. For example, a participant in a qualitative study by Jurkowski and Amado (1993) commented, "I never knew what it was like to get a good hug or kiss, until I was seven and stayed at my aunt's house for a sleep over" (p.136). People with disabilities' considerable need for affection can leave them vulnerable to abuse under the guise of love (Jurkowski & Amado). Abusive violations may be the only affection they experience and they may not be aware that it is inappropriate. When their personal care requires that staff have access to their bodies, people with disabilities are not armed to resist abuse (Hingsburger, 1998). They are not aware that their privacy has been violated and have no skills with which to resist intrusions. Conversely, when people with

disabilities want to express affection towards others they model the touch they have experienced. This inappropriateness can land them in trouble in the community.

Professionals are challenged to facilitate the meeting of affection and touch needs, while keeping people with disabilities safe (Hingsburger).

Jurkowski and Amado (1993) insisted that social skills training around friendships and relationships cannot occur without a discussion about sensuality and sexuality issues. Enlarging the person with disabilities' social network in the community cannot be done safely without providing the social skills that allow them to avoid and prevent abuse. The skill training must go beyond anatomy, contraception, and emotions to encompass self-esteem and identity, relationship building, and decision making. (Jurkowski & Amado)

Pratt and Mason (1981) provided an anecdote illustrating the use of touch to bridge two very different men. A 19 year old man with a long criminal record of theft was imprisoned in England with a few days each week out in the community. At his community site worked a 29 year old severely handicapped man who liked to hug and be hugged. The disabled man began hugging the younger fellow and those hugs cut through the barriers of difference between the two men's backgrounds and abilities. The two men developed a strong friendship and, in a natural and spontaneous manner, were able to express and fulfill a need for closeness and camaraderie.

In a similar manner, Sinclair, an American massage therapist visiting rural Mexico, was able to connect with children with severe disabilities, many the result of medical negligence (Mower, 1997). Without speaking the language, Sinclair was able to soothe them, promote healing, and demonstrate to the children that they were valued. Sinclair

was convinced that even the children who were very ill or close to death were reachable with the massage. To continue the benefits of touch, Sinclair trained the staff and parents how to massage the children before she left.

Brain Injury

Acquiring a significant physical or cognitive disability after “normal” development can result in a shift from existing in a relatively accommodating environment or at least a relatively manageable one, to an inflexible, disabling environment. Those who sustain a traumatic brain injury face not only physical, sensory, and cognitive changes, but secondary effects such as changed mobility, changed relationships, and changed status in society.

General Consequences

Depending upon factors such as location and nature of injury, duration of coma or unconsciousness, further damage from complications, and the effectiveness of acute treatment, the consequences of a brain injury vary greatly (Stratton & Gregory, 1994). The intensity of the changes in cognitive, sensory, and physical functioning, and individual and family response to injury are unique to each survivor. Cognitive deficits typically seen after a brain injury occur in the areas of attention, concentration, memory, perception, judgement, orientation, communication skills, and self awareness (Stratton & Gregory, 1994; Miller, 1993). Physical deficits, such as paralysis, loss of sensation and poor balance, are not nearly as detrimental to the survivor as cognitive deficits that affect their processing of and responding to stimuli. Rehabilitation programs incorporate cognitive re-training to minimize the consequences of the injury on survivors’ independence,

management of social environments, family life, vocational possibilities, and educational pursuits. Personality and emotional changes occurring as a result of brain injury vary depending on the location of the injury, time since the injury, and survivors' subjective experience of the change in their sense of self.

The impact of brain injury on a family is highly variable but typically includes high stress due to increased care giving, relationship difficulties, and loneliness (Miller, 1993; McClelland, 1988). Changes in family interactions can occur as a result of the brain injured member's lack of impulse control, reduction in initiative, denial of injury, and shift in personality or behaviour. If rehabilitation outcomes are in some part determined by family support and functionality (Cripe, 1989), then there is strong justification for increasing family "health" and connectedness through the use of affectionate touch.

A survivor's family and support network's response to the injury and the changed survivor is as varied as the other aspects of brain injury. The composition of the family group, their social placement, the role of the survivor, and the family's resilience and coping skills affect the experience of the brain injury by the family and the survivor (Stratton & Gregory, 1994). Personality, emotional, and cognitive changes create the most stress on families relative to physical changes. Family support, particularly for those experiencing high dependence, is crucial to the survivor's recovery. Rehabilitation that addresses the needs of both the survivor and the family, for example, education and counselling, produces the best outcomes (Stratton & Gregory).

Family outcomes for survivors are often viewed by researchers as a matter of burden and stress. Perlesz, Kinsella, and Crowe (1999) suggested that research, primarily

qualitative, that explores family outcomes to determine the factors contributing to family resilience and coping is more beneficial to rehabilitation than studies measuring the negative impact of injury. Increased family cohesion, the presence of external supports, and the positive, hopeful attitudes of family members are examples of some adaptations that can occur. The nature of family relationships determines outcomes. For instance, Perlesz, Kinsella, and Crowe found that spouses of survivors experienced more distress than parents, likely because parents have cared for children when they are more dependent, whereas spouses had a more reciprocal relationship. Siblings, too, experience a unique response to a survivor's injury. They tend to be left out of the process and often are neglected for years while their siblings are in rehabilitation. Professionals need to attend to the home, family, work, and friends of survivors in rehabilitation planning (Dawson & Chipman, 1995).

Social Skills

Difficulties coping in the social sphere occur when cognitive and emotional changes affect behaviour while communication skills are compromised (Stratton & Gregory, 1994; Miller, 1993). Factors such as impulsivity, inflexible thinking, impaired insight, and the reduced ability to read the social fabric contribute to survivors' difficulty functioning in the world as they did before the injury. Often these result in behaviours that are perceived negatively in social interactions. Depression, reduced motivation, impulsivity, and aggression are assumed to contribute to poor social functioning (Stratton & Gregory, 1994). It is unclear, however, how much these problems contribute to social adaptation and how much they may be a result of altered social experience and reduced

social opportunities.

Morton and Wehman (1995) identified four areas of concern that contribute to survivors' post-injury experiences in the community. 1) Severe traumatic brain injury places survivors at high risk for reduced social supports. Survivors report that social isolation and a loss of social contact are their greatest concerns. Pre-injury friendships tend to fade away 6 months to 2 years after the injury. For many survivors, the injury comes at a time when they are developing independence in many life areas and developing intimate relationships. Decreased social support is detrimental to the establishment of self-identity and independence. Survivors often live in group homes or with parents, forming only casual acquaintances. Even survivors who have reached a level of independence that allows them to live alone tend to lead solitary lives. 2) Opportunities to develop new friends and social networks are decreased. Chronic unemployment also contributes to fewer social contacts and leisure activities. Conversely, with job success comes improved social interactions. 3) Survivors are less likely to access and engage in leisure activities. Mobility barriers, inaccessible facilities, reduced interest and motivation, and loss of skills affect survivors ability to actively engage in leisure pursuits, which are also a source of social interaction and community participation. Survivors are more likely to engage in solitary activities such as watching television and listening to music. 4) Emotional and psychological disturbances persist for long periods at high intensity after the injury. Depression and anxiety are common in the majority of survivors and tend to worsen over time. Depression is less likely if survivors have a close friend in whom they can confide. This is consistent with the view that anxiety and depression are the results of decreased

close friendships. The availability of friends and social integration is reduced for survivors, however, it appears that the quality of relationships they do have are comparable to those of non-disabled individuals. Professionals can best serve survivors by facilitating the creation of close friendships and utilizing natural supports to teach social skills.

The incidence of traumatic brain injury is highest among adolescents and young adults who are beginning to form serious relationships and choose career paths (Stratton & Gregory, 1994). The injury significantly impacts the survivors' ability to complete secondary and post-secondary education. Both scholastic achievement and social interaction can be compromised in academic settings. These difficulties are similar in vocational environments where cognitive and personality problems, as well as poor job choice, affect the working and socializing aspects of the job. Only about 50% of survivors of moderate and severe injury are able to sustain paid employment (Stratton & Gregory). Consequently, self-esteem and financial status are effected which can further erode survivors' social abilities. Communication deficits and left hemisphere damage can result in speech impairment while damage to the right hemisphere impacts the skills of expressing and comprehending the emotional content and abstract ideas in speech, and the ability to derive meaning from language. Right hemisphere damage produces difficulties in identifying different emotions in speech and understanding emotional scenes (Stratton & Gregory). The inability to understand the emotional content of verbal messages is well documented in right hemisphere injury, however the ramifications of this deficit on non-verbal gestures like affectionate touch is unclear.

Social Skills Training

Only one study on social skill development after brain injury seems to have made specific reference to the use of touch in interactions. Johnson and Newton (1987) utilized social skills training along with self-understanding techniques in an attempt to improve both the behaviours of severely brain injured survivors in social settings, and the self-perceptions and beliefs that influenced their behaviour. For over one year the group met once a week for an hour and a half for general discussion of a social skill or issue, small group practice, feedback, and generalization. The inappropriate and appropriate use of physical contact and touch was the topic of one week's session. Other topics included listening and questioning skills, non-verbal communication, and managing difficult social situations. Unfortunately, the only change apparent at the end of the training was a slight increase in the number of social activities survivors engaged in as reported by relatives. As a group, no improvement was seen in social performance or self-esteem; however, some individuals progressed better than others. Johnson and Newton concluded that the general slow recovery of survivors necessitates a longer, more intense intervention program to affect change. Fundamental to personal existence is self-esteem, a variable mediating all behaviour. Without increasing self-esteem, little recovery of social skills is likely. Repeated cycles of failure and frustration further erode survivors' willingness to engage in social interactions, resulting in a lonely, isolated existence.

Social skill training is best achieved in a natural setting with others, such as residential staff, who frequently interact with the client with multiple disabilities (Gardner & Howard, 1991). An apparently new and more effective approach to teaching

communication skills emphasizes the interaction between communicators, the environment and interpretations, beliefs, and perceptions of communicators. McGann, Werven and Douglas (1997) recommended that skills not be taught in isolation or for a particular environment, but rather that professionals acknowledge the communicative requirements of the roles played by survivors in various social interactions, and the types of relationships survivors wish to foster.

Need for Affection

In a study of college students with and without disabilities, Huebner, Thomas and Berven (1999) found that women who did not receive physical assistance had a stronger need for inclusion and affection, perhaps because they responded positively to the social aspects of assistance. Men who received physical assistance expressed a reduced need for social inclusion and affection, perhaps because their perceived independence is undermined. Huebner, Thomas and Berven suggested that professionals can be a source of unconditional, positive regard for clients with disabilities who enter relationships with hostility and expectations of failure. The therapeutic relationships can be a practice ground for social skill development and successful interactions.

Addressing the Gap in the Literature

Evidence of the importance of touch has been established in studies with infants, teenagers, and seniors. Affectionate touch seems to play a vital role in our relationships and interactions with close friends and family. The subjective experience of touch and the feelings and perceptions about giving and receiving touch are not well known. It seems clear that seniors in long term care respond favourably to the physical contact provided by

staff. People who are temporarily disabled generally relish the touching provided by nurses. In a time of uncertainty, fear, and some isolation, nurses provide warmth and support in the care facility. Are there parallels here for people in rehabilitation, specifically brain injury survivors?

Despite approximately thirty years of effort in North America to include people with disabilities in the community, most live isolated, lonely lives with mainly paid workers for “friends” (Traustadottir, 1993). Being physically in the community is no guarantee of being a part of it. Without connections to “natural” community supports, and solid relationships with them, people with disabilities do not participate in the larger social fabric. Access to close relationships can be limited for people with disabilities for a variety of reasons. The impact of reduced socialization upon affectionate touch experiences is unknown. The role of rehabilitation professionals in facilitating touch must be illuminated.

Brain injury survivors, too, face difficulties with social relationships. Physical and cognitive disabilities that result from the injury change the person in significant ways. Social skills may be compromised by cognitive deficits, further exacerbating the problem. Old relationships and patterns of socialization change. Survivors certainly initially face insecurity and fear. It may be that for them touch is as important as it is to the generic health care patient.

This study explored the experiences of survivors of brain injuries who are assumed to have more in common with non-disabled people than not. Many of the study’s findings would parallel the findings of a study of non-disabled people. The non-disabled reader will find no alien concepts within this text. It is the essence of humans to be social, to

want to connect with others with varying intensity, and to feel supported and cared about.

This study attempted to answer how touch experiences contribute to these phenomena.

At the same time, the participants can be viewed as exemplars of people with a range of disabilities who, to varying degrees, have limited opportunities to develop social relationships and to participate in the community at large.

Chapter 3

Actually real science is more like a fishing expedition than most of my colleagues would care to admit. . . . God forbid that you should just try to do something entirely new that's just based on a hunch!

V.S. Ramachandran, Phantoms in the Brain

THE RESEARCH PROCESS

Qualitative research reflects the perspective of the researcher, the type of data collected, the process of analysis, and the presentation of findings (Altheide & Johnson, 1994). All elements of research are interrelated and interdependent. The researcher cannot be extracted from the research. Therefore, it is the responsibility of those speaking with the voice and authority of social science to make their perspective on the data and interpretation clear to readers (Altheide & Johnson). Qualitative research rigor requires documentation of all aspects of the research process so that others may follow the trail of study, and if needed, reconstruct the processes that lead to the conclusions (Morse, 1994).

As this research progressed, it occurred to me that qualitative researchers find common "truths" and essences of the human experience not because each methodology is replicable, but in spite of differing methodology. The specifics of this study could not be replicated by me, let alone someone else. I have changed in the last two years and it would literally be a different me undertaking the research. The researcher *is* the process. It cannot be unbuckled from me like a flight suit and handed to someone else. Epiphanies, sleepless nights of rumination, and the synchronicity of my work and research activities all happened under unique circumstances.

Upon the advice of a colleague, I attempted to create a flowchart documenting the processes that took place in this study. I abandoned the task when it became apparent that a flowchart demands organization, distinction, and delineation. This study was far more organic. In addition to not being privy to all the forces involved and the non-conscious cognitive connections that occurred, I literally could not accurately note down all the events, feedback loops, hallway discussions, dreams, and struggles that I had. Throughout this section, however, I have endeavored to make my presence and general decision-making explicit.

Scope of Inquiry

My position is that inter-human touch is important in rehabilitation and has not been formally examined. There may be a role for family members, care givers, and professionals to re-instate the human right to touch. It is important to understand what relationships made touch comfortable and clearly non-sexual.

After reflecting upon the nature of touch, my own experiences, and observations of others engaged in touch, I conceptualized human touch as four dimensional with continuums of intention, quality, intimacy, and sexuality. My four dimensions of touch were not intended as an exhaustive definition of touch, but were utilized to identify important elements of its meaning.

- Touch actions can range from unintentional and incidental to deliberate and meaningful.
- The quality of the touch can range from tender to abusive.
- The level of intimacy in touch can range from impersonal to personal.
- The level of sexuality in touch can range from non-sexual to sexual.

This study looked at deliberate, tender, personal, non-sexual touch, i.e. affectionate touch.

My review of the literature on touch and my observations as a rehabilitation practitioner led me to the following convictions:

- 1) affectionate, non-sexual touch is vital in human existence;**
- 2) affectionate touch is over-regulated or absent in the lives of many clients in rehabilitation;**
- 3) within the parameters of the “qualia” problem: that mental states are essentially private and difficult to communicate (Ramachandran, 1998), information about affectionate touch was likely to be easily available to me via interviews, unlike, perhaps, sexual touch; and**
- 4) affectionate touch can play an important role in a holistic rehabilitation approach involving the participant, family, friends, and professionals.**

Method of Inquiry

I wanted to describe and understand the meaning of affectionate touch in the lives of brain injury survivors. Describing the ‘what and how’ of the lived human experience is the realm of phenomenology (Karlsson, 1993). “A ‘phenomenon’ does not represent an inaccessible inner world, but rather the external world perceived in a particular way. A phenomenon reflects the way in which a human subject attributes meaning to certain aspects of the world” (Giorgi, 1995, p. 38). In studying the internal experiences that are relayed in the language of those studied, the phenomenologist “affirms the life-world experience and proceeds by critically examining it, in order to describe its essence, structure, character” (Karlsson, 1993, p. 43).

Phenomenological inquiry is the search for meaning, a subjective and idiosyncratic construct (Karlsson, 1993). I very deliberately chose to take a phenomenological perspective to provide me with the necessary parameters I needed in what is only my second foray into qualitative research. My strong academic background in positivism, documentary film making, and work with the RCMP might lead me to search for facts. My urge to confirm the 'facts' of the reported experiences with those touching the participants, for example, their family and friends, was curtailed by my choice of methodology. Phenomenology forced me to attend to the subjective experiences of the participants and their meaning, rather than explain their behaviour or find support for and against patterns of behaviour.

Participants

To solicit participants, I posted notices and presented my study at brain injury rehabilitation centres where I had established contacts. Management and staff of the agencies aided me by circulating an information letter (Appendix A) and a consent form (Appendix B) to those clients expressing an interest in the study. I was contacted by the agencies with the names of potential participants, and by the individuals themselves. Other interested participants replied to the announcement I placed in the local brain injury society's newsletter. Through personal contacts I connected with survivors of brain injury who were no longer in rehabilitation.

I met with all interested participants and reviewed the purpose of the research, the nature and duration of their involvement, their right to cease participation, and the other conditions of consent. Five participants were selected on the basis of gender and on a 'first

come-first served' basis. I ensured that participants who were currently enrolled in a rehabilitation program understood that involvement in the study was not related in any way to their rehabilitation program. Staff at the rehabilitation centres supported my efforts to make this clear.

Three men and two women who had sustained a mild, moderate, or severe brain injury as adults were interviewed. All had received rehabilitation assistance at some point after their injury. All were able to communicate verbally. Three used wheelchairs or walkers. All participants were over 18 years old and resided in southern Alberta. Participants received no remuneration for their time and participation.

Instrument

In order to treat people humanely one must "accept their commentaries upon their actions as authentic, though revisable, reports of phenomena, subject to empirical criticism" (Harré & Secord, 1972, p. 101). Qualitative researchers have a plethora of data gathering instruments and techniques at their disposal. The nature of my study excluded the use of observation. Observation, although time consuming, provides a look at behaviour that can be catalogued and counted, but does not illuminate the intentions nor the results of such behaviours. In addition, the observer's presence would be too intrusive given the nature of touch. Archival study requires that documentation exists on the topic of interest. I was unable to find a rich source information on touch, and certainly little on touch and disability. Since gathering comprehensive information about touch interactions through observation and archival study would not provide information about subjective experiences and meaning, I needed to interview my participants.

Interviewing allows individual experiences to be expressed and the meaning of touch in the participants' lives to be explored. Also, this is a relatively undocumented domain and my priority was to begin my search for understanding with the participants. Typically, exploratory phenomenological research dictates an unstructured interview approach (Fontana & Frey, 1994). Given the cognitive and language limitations of the participants, I wanted to provide more structure within the interviews to accommodate their needs. I chose to obtain participants' commentaries on their subjective experiences through loosely semi-structured interviews.

Semi-structured interviewing at its best is a normal conversation marked by purpose and structure (Kvale, 1996). Rather than composing standardized questions, Kvale suggested that only topics of interest be outlined. This leaves the researcher free to be more responsive to each participant's experiences and gather more comprehensive information. Within the loosely structured interview, the researcher can verify interpretations, follow up on topics, clarify points, and confirm the relevance of the material.

The reciprocal nature of interviewing places participants on a more equal footing with the interviewer. Flynn (1986) asserted that when interviewing participants with disabilities, less-structured and unstructured interviewing encourages individuals to speak at their own pace and about areas of interest to them. Mishler (1986) described unstructured interviewing as affording the participant status as the important and valued source of information and knowledge. Both researcher and participants shape the research and gain something valuable in the process. Semi-structured interviewing can also reflect

the researcher's awareness that people understand their world in various ways. Through the use of unscheduled probes, the researcher can better understand the participants' perspectives and become more fully involved in the interview process (Berg, 1995).

Qualitative researchers' reliance on language demands that interviews with less articulate informants incorporate flexible strategies (Biklen & Moseley, 1993).

Participants with cognitive difficulties may struggle to make a comparison or analysis.

Biklen and Moseley recommended that interviewers ask about people, things, and activities separately. As well, taping the interview allows the researcher to replay the tape as needed and clarify the contributions of participants who may have poor pronunciation.

Choosing a comfortable home-like environment may reduce the anxiety of participants with disabilities and increase rapport with the interviewer (Biklen & Moseley). I incorporated these strategies throughout the research process.

I used a loosely semi-structured interviewing strategy to facilitate discussion on touch during the two interviews with each participant. I opened each first interview with the request: **"Tell me about your affectionate touch experiences."** The following prompts were used as needed depending on participants' language and cognitive abilities.

- meaning of touching
- magnitude of touching (both its significance and the desired amount)
- context of touching
- types of touching
- comfort level and safety issues during touching
- emotions experienced during touching and in its absence

- relationships between touchers
- role of gender
- conditions for initiating or avoiding touch
- communicating need for touch
- responding to others' need for touch
- nature of touch from professionals
- differences between functional, casual, and deliberate touching
- perceived changes in touch experiences since injury

Neuman (1994) cautioned that with set topics and similar structure within the interviews, researchers may inadvertently omit important areas and issues. As well, not all participants may understand the meaning and wording of the questions. I worked hard to provide an opportunity for the participants to bring up areas of their own interest or concern. Having two interviews with each participant allowed me to become more familiar with them, build trust and rapport, and verify our understanding of the material.

When building a conversation spontaneously, the sequence of questions and topics is altered, making each interview substantially different from the next (Patton, 1990). To counteract this to some degree, I reviewed all the participants' transcripts before engaging in the second interview to ensure all topics were covered and given comparable discussion time. However, the individual stories remain as they were told and no further attempt was made to homogenize the raw data.

Data Gathering Process

All interviews were conducted by me and took place in a private office or a private

area in the participants' homes as determined by each participant. The second interview was conducted in a similar manner one to three months after the first interview. The interviews were recorded on audio tape with the consent of all participants.

First Interview

The first interviews averaged about a one and a quarter hours each. I restated the opportunities for each participant's withdrawal of consent before beginning each interview. The parameters of "affectionate touch" were reviewed to ensure that participants understood the definition of affectionate touch and that the research was neither an exploration of sexuality nor a discussion of abusive and violent touching. I encouraged participants to ask any questions they had about their involvement prior to beginning the interview. Throughout the interview participants asked questions about my research, my personal and professional background, and other topics not directly related to the study. Participants took a break from talking about touch to share with me upcoming events in their lives, to show me items of personal importance, or to ask my assistance with tasks. Discussion flowed naturally from touch experiences to personal topics and back to touch; evidence that they felt comfortable talking to me and perceived our time together as a conversation between equals.

I had to adjust my interviewing style to meet the needs of the participants with cognitive limitations such as concrete thinking. I restated the same question using different wording, returned to topic probes at different times, and asked closed (yes/no) questions. Closed questions are less precise in obtaining idiosyncratic information, however, breaking questions into parts helps researchers to understand participants'

perspectives through successive approximations (Biklen & Moseley, 1993). I felt a self-imposed pressure to elicit richness and profundity from participants and may have passed this pressure on to them. Upon realizing that this may be occurring, I relaxed my approach, became less reliant on my list of probes, and let the stories emerge naturally. I continued to self-monitor during subsequent interviews.

Second Interview

Each interview was transcribed by me, word for word, then reviewed twice for errors. During the second interview, the participant and I reviewed the transcript of the first interview to:

- clarify incomprehensible material on the audio tape
- verify the accuracy of the transcript
- provide a context on paper for follow up questions (As the interviews were one to three months apart, this was a vital process for the participants.)
- obtain consent to quote material from the transcripts

I gave participants a copy of their first interview transcript to keep. All participants gave me consent to quote any and all material from their two interviews.

In my original research design I stated that the second interview would be restricted to the purposes noted above. However, the second interviews became full discussions of topics extending from the first interviews. These conversations lasted up to one hour and a half, past the agreed upon duration of half an hour. One participant had to end the interview after 30 minutes to get to another appointment. The others were able to talk as long as necessary and seemed happy to do so. I was careful to ensure I understood

the new material presented in the second interview knowing that I would not return a third time for clarification. However, participants were able to contact me by telephone at any time with further thoughts or questions.

Data Analysis

Data analysis occurs throughout the research as data is reduced (selected for inquiry, themes extracted), displayed (summarized, graphed) and interpreted (verified, conclusions drawn; Huberman & Miles, 1994). The following section is devoted to my analysis of the transcribed text.

Theme Development

On successive passes through the data, the researcher moves from describing to understanding, from the concrete to the more abstract (Huberman & Miles, 1994). I selected and employed some of the tactics recommended by Huberman and Miles to “generate” meaning. These included:

- noting patterns and themes
- seeing plausibility that makes intuitive sense
- clustering the data by concepts
- making contrasts and comparisons
- noting relations between variables
- finding intervening variables

These strategies of primarily analytic induction conform to the grounded theory approach (Huberman and Miles). Rather than proceeding through to developing a theoretical coherence at this early stage of exploration, I chose to establish a conceptual framework

for the emergent themes.

My qualitative analysis consisted of brief frenetic moments of documentation and writing interspersed with long periods of steeping in the data. I found that a cycle of inductive and deductive reasoning allowed me to intentionally identify and explore the themes present. For example, on my first pass through the transcripts, the themes gradually emerged. In my next pass through the data, I searched for deductive evidence of the themes. Variations within the themes were noted as well as the variations among participants and any cases of contradiction.

My first theme development reflected my quantitative background. I dissected the participants' world of touch into many pieces, creating a maze of 22 themes. In his 1820 criticism of science, John Keats (1899) asked in the poem, *Lamia*, "Do not all charms fly at the mere touch of philosophy?" In my act of 'reductio ad absurdum' I had left behind the unity and coherence of my data, proving Keats correct in his belief that science can "unweave a rainbow". My struggles to create a linear presentation out of a complex, multi-dimensional topic led me to consult a faculty member skilled in qualitative research. After a long discussion about my research experience and what I had learned from the participants, we modified my theme structure to better honour the participants' experiences and, to some extent, re-weave the rainbow. While the content of the themes remained constant, the relationships between the themes and the breadths of each of them changed. For example, minutia I had extracted was subsumed under related concepts. I then took the new theme structure to my supervisor who helped me further clarify, distill, and finalize my themes into a holistic structure. She also re-emphasized to me that I was

looking for meaning, not simply descriptions. This was a necessary reminder that, along with my continued reading in qualitative research, marked a major shift in my thinking. I was finally able to leave behind the remnants of my quantitative background. I then returned to the transcripts with my four themes and their subthemes to confirm the “fit”. When I reached the point of writing my analysis, which involved further interpretation as part of the process, it was informed by my metamorphosis.

In the second interviews, I asked the participants for their impressions of my preliminary analysis and adjusted my understanding of each story in accordance with their feedback. One participant contacted me several times by phone to discuss portions of her transcript. Her input was valuable in helping me better understand her experiences.

The final step in data analysis was to provide a visual map that reflected my understanding of affectionate touch for survivors of brain injury. To illustrate the key themes and the relationships between them I formed a conceptual framework.

Auditing

The use of multiple raters as a method of assuring rigor (others are asked to read and code transcripts to affirm that the content is as the researcher sees it) is disputed (Morse, 1994). Other raters, responding to only limited data (portions of transcripts), lack the necessary insight for coding. Synthesis of the data is best done by the researcher who has access to all the research process experiences and the complete raw data. The best use of auditors may be for them to review the study to check for bias, error and analytical rigor (Huberman & Miles, 1994).

To increase the trustworthiness of the themes I had identified, portions of the

transcripts (with names and identifiers removed) were circulated to a few colleagues who were asked to note the themes they found. These raters were not informed of the themes I had identified. The themes they noted were then correlated with my themes and subthemes. While the language used by my colleagues varied to some degree from what I had used, the essence of the emergent themes was consistent. I continued to solicit feedback from my colleagues and supervisor throughout my report writing.

Trustworthiness

How does one judge the reliability of interpretation in qualitative research?

Suggestions range all the way from adopting quantitative research criteria to resisting any assessment of the reliability of qualitative research due to its very nature (Denzin & Lincoln, 1994). I consulted several sources to guide me in my production of legitimate research.

Qualitative research rigor is in part determined by adherence to the concepts of adequate saturation (Morse, 1994). The researcher reaches saturation when repetition of the information is evident and previously collected data is confirmed. Saturation is also marked by the presence of negative cases that enrich the emergent model. My themes emerged from the repetition of reported experiences. I confirmed data in the second interview. My analysis of the data included a search for conflicting data and negative cases.

Triangulation, a form of verification, is an ongoing process. It is present when participants make the same claims independently, when the phenomena is seen in many sources, and when other researchers find convergent data (Huberman and Miles, 1994).

The development of my research topic occurred as a result of seeing the phenomena of touch, and its absence, in many situations, in literature, and in professional discussions. The literature review highlighted the work of other researchers, primarily quantitative, who illustrated both the importance of and need for physical contact.

Other strategies I utilized to confirm my conclusions and to draw out bias included some of those recommended by Huberman and Miles (1994). I checked for the representativeness of the sample, with a range of family makeup, ages, and residential situations. I explicitly revealed the “lens” I brought to the study in my written portions. The second interviews were useful in obtaining feedback from the participants as I collected and interpreted data. Auditors were used as outlined above.

Ethical Considerations

Research with potentially vulnerable groups such as people with disabilities requires specific attention to the ethical concepts of confidentiality, and informed consent. I felt that it was my responsibility as the researcher to be particularly vigilant about participants’ competency to give consent, their willingness to be involved in the study, their disclosure of personal information, and any discomfort they might experience during the interview and research process.

Informed Consent

Determining participants’ ability to give consent is particularly important when researching with people with cognitive disabilities. The guidelines developed by psychiatric and elderly care practitioners for assessing competency to give informed consent for treatment have valuable application in research participation (Tymchuk, 1997;

Hoffman & Srinivasan, 1992; Draper & Dawson, 1990, and Finucane, Myser & Ticehurst, 1993). In applying these guidelines to informed consent for research participants, the following standards were used:

Participants had to articulate an understanding of all of the following.

- ▶ The nature of the research project such as what will be done with the findings and who will have access to the study.
- ▶ The specific activities of their participation including the time commitment and who they will be working with.
- ▶ Any risks and benefits of participation.
- ▶ The limits of consent; that it can be withdrawn at any time or limited by the participant.
- ▶ The consequences, if any, of refusing consent.

Participants may demonstrate their understanding of these issues in different ways.

Hoffman & Srinivasan (1992) employed a semi-structured interview in which psychiatric patients were asked about the above with their answers recorded for review. Ontario practitioners utilized an examination form with a list of questions to ask to determine competency (Draper & Dawson, 1990). These assessments not only help practitioners to determine the patients' ability to make decisions about treatment, but they also provide a forum in which patients can receive further information and explanation about the proposed treatment.

Competency is assessed by practitioners whose qualifications and experience is assumed to be up to the task. However, researchers should be aware their biases and assumptions about their participants, in addition to cultural and communication barriers,

influence this process (Hoffman & Srinivasan, 1992) . Seeking guidance from those experienced with the population as a whole, and with potential participants in particular such as support workers and family (Finucane, Myser & Ticehurst, 1993), will help gauge competency to consent. Processes similar to those outlined above can be adopted by researchers working with people with cognitive disabilities.

This study required participants who had receptive and productive language skills, who could understand the subject of the research, and who could engage in lengthy discussions. Recruitment notices were aimed at this group. Rehabilitation agencies understood the nature of participation and brought the study to the attention of those who could give informed consent and meet the requirements of participation.

Participants in this study were informed by me during the pre-interview information session and on their consent sheet of their right to refuse to answer any questions and right to cease their involvement without penalty. Prior to commencement of the first and second interviews, participants were reminded of their right to withdraw their consent at any time without penalty. Participants were assured that quotations used did not contain proper names or identifying information. Special care was taken to ensure that participants in group home situations maintained their right to consent without coercion. This involved discussing the study with them in private, outside of the group home setting and away from the influence of family, staff, and roommates. This also meant that their participation was kept confidential. The five participants were clearly competent and eager to participate.

When I met with participants, I asked for their understanding of the process and

their rights as a participants following the guidelines provided above. My experience with the brain injured helped me assess their decision making and ability to comprehend the study. Consent was obtained from one participant's guardian after confirmation with the participant. This was to ensure that involvement in the research was desired by the participant and that the guardian did not dictate participation against the individual's wishes. Primarily, the participant's guardian is consulted for financial matters.

Confidentiality

After the pre-interview information session, during which consent was obtained, I separated the name and demographic information from each interview guide and assigned the participant an alpha-numeric code. The coding sheet was then filed separately from the raw data. Interview tapes and transcribed interviews were labelled only with the participant's alpha-numeric code. Confidentiality was maintained during the transcription process. Material extracted for quotation was pertinent to the subject matter and did not contain material that could identify participants or others.

The research does not require the release or publication of participants' names. The alpha-numeric code assigned to each participant was traceable back to the participant's name and demographic information only by me. The coding sheets with the participants' names were kept separately from the interview data in a locked cabinet in my home office. The interview data (both taped and transcribed) was kept in a different locked file cabinet in my home office. The guardian of one participant did not have access to data collected in the interview.

At the completion of data analysis, I replaced the alpha-numeric codes I had

assigned to each participant with pseudonyms for ease of presentation. The pseudonyms were chosen randomly and are intended to reflect only the gender of each participant. Any published articles or presentations of the research results will be done without the identification of participants or agencies.

Risks to Participants

This study involved the self-disclosure of personal information and experiences by participants. Precautions were set up to maximize the confidentiality of everyone's involvement and the content of their interviews. Participation involved no risks beyond those normally encountered in everyday life. I had a selection of counselling resources available if the disclosure and discussion of personal experiences caused discomfort or distress in any participant (as identified by me or the participant). Participants did not express or display any undue distress during the interviews. I did refer one participant to a counselling resource for a personal matter she disclosed during an interview.

Disposal of Records

Raw data, both tapes and transcriptions, and the coding sheets will be destroyed two years after the thesis is defended.

Chapter 4

FINDINGS

My research findings are solidly rooted in the voices of the participants. I was most comfortable having the participants speak for themselves and having the reader draw her own interpretations from the quotes. I conceptualized my commentary between the participants' quotes as the "connective tissue" holding together the "meat" of their experiences. My commentary reflects both the participants' material and my synthesis of the interviews, data analysis, literature review, and the research process itself. The reader is left to explore the quotes and determine the appropriateness of my descriptions and interpretations. A brief discussion of my touch interactions with participants is presented at the end of the chapter.

To maximize readability and clarity, pauses and off-topic material was removed from the quotes. My voice as the interviewer is absent. Entries in brackets are used to orient the reader to the question to which the participant was responding, and to make content clear. Given names and place names were substituted with general descriptions to maintain confidentiality.

Participants

Upon meeting the participants and getting to know them better, I was pleased to discover that they were a heterogeneous group. Rather than compromising my research, I believe this diversity contributed to a broader, richer "snapshot" of brain injury survivors' touch experiences. The five participants, who range in age from late-twenties to mid-fifties, have a broad variety of life circumstances. They are married, divorced, living

alone, with family or in a group home. Their injuries occurred as recently as a year ago and as long as 22 years ago, and were due to sport and motor vehicle accidents and violence. Some attended a rehabilitation program, some worked, and some were neither working nor volunteering. A few had accessed further education at some time after their injury.

Themes

Four common themes emerged from each participant's interview. While I have presented these themes in a linear fashion, and to some extent partitioned them from each other for discussion, it should be reiterated that touch is a complex and multifaceted phenomena. Each piece of the touch puzzle influences and informs the others. The themes Giving and Receiving could not be clearly separated, so there is some overlap from one theme to the other. The first three themes are presumed to be universal to the human condition. The final theme, Self-perceptions of Disability, extends the discussion of touch into the areas of disability, independence, and self-worth through comparisons of life before and after a brain injury.

The four themes and their subthemes are:

- **Relationships.** Subthemes: Qualities of a touch relationship, Touch with professionals, Societal constraints, and Gender issues.
- **Giving.** Subthemes: Whom I touch, What my touch means, Sensing others' need for touch, Responses of others to touch, Benefits of giving, Touching animals, and Touch and words.
- **Receiving.** Subthemes: Working versus affectionate touch, What touch means

to me, My need for touch, and Indicating need for touch.

- **Self-Perceptions of disability.** Subthemes: Touch before and after injury, Independence and dependence, and Difference.

Relationships

There's not a word yet/For old friends who've just met
Paul Williams & Kenny Ascher, I'm going to go back there
someday

Touch does not exist as a separate entity like food to be consumed and participated in. Valuable human touch that communicates caring and affection (unlike casual, fleeting touch) occurs within relationships with others. These relationships have specific qualities and characteristics to them. Through touch, participants developed relationships with family, friends, and professionals.

Qualities of a Touch Relationship

Participants gave and received touch with people with whom they felt comfortable such as family members, spouses, friends, co-workers, professionals, and acquaintances. They attempted to describe the qualities of trust, reciprocity, and power or status balance that they needed in a relationship in order to feel comfortable touching. Trust was characterized by a solid mutual knowledge and understanding, and an ease between the touchers. Reciprocity was based on the assumption that touch would be accepted and returned, and would be similar in intention and level of intimacy to the type of touch offered. Participants expressed a concern about power and control in the relationship, wanting to neither be dictating inappropriate actions nor receiving unwanted touch.

I have to know who it is. I have to feel comfortable enough with them as a

person, as a friend. I don't want to be in a position to be controlling the other person. There has to be a relationship there. There has to be something there. You know, I just can't come up to a stranger and put my hand on their shoulder and say, "Hey, I'm there for you". There has to be a bond of some type, be it teacher-student, be it friend, lover, whatever. There has to become acknowledged relationship perceived by both sides. So there is not one [person] overpowering the other. *Miguel*

[I touch] long-term or even short-term friends, but they must be friends. My friends for sure and my family are about the only ones I'm sure won't shy away from me. They're familiar people. They know me. They know that I'm that way [a toucher] and, I mean, the more you know somebody, the more comfortable you are with anything. It won't offend you or scare you. There is a trust between us. *Fay*

You respect [them] and they hug you back. Trust. *Steve*

I don't mind giving either one of them a hug. [Even though] my brother and sister are closer [to each other] than I am because they are three years apart, so we are 6 and 9 years apart. So they've grown up together and closer. *Miguel*

For Diane, what needed to be present for her was elusive; an intuition-driven "knowing" that was difficult to articulate.

I don't know [how I know it's okay to touch a friend for the first time]. I just know. [My male friend at rehabilitation centre] was my friend from early on. Close friend. We were just close, from the beginning. *Diane*

While they may not anticipate or initiate touch unless it is within a relationship, some were accepting of touch from anyone, providing it was not sexual or dangerous. Glen is accustomed to using touch within business. Fay is proud of her ability to accept touch while protecting herself, and Steve seems indifferent or at least reluctant to offend by refusing touch from strangers.

I used to work in [a specific] business and everybody shakes hands. Everybody. You meet somebody new to do business with, you shake their hand. You're thoughtful. It goes a long way. *Glen*

I tolerate everyone's touch. I know how important touch is to me. I am just wise in that way. I am not afraid of anything in life except failure, but I am not afraid of people and if they are too touchy around me, and I really don't like it, I just won't go back there. *Fay*

[When strangers touch me] I just ignore it, just let it happen. *Steve*

Although sometimes challenging to put into words, the touch 'radar' that is used by participants in relationships seemed to evaluate trust, reciprocity, and power balance. Participants placed their touch needs within these parameters and expected solid relationships to accommodate their needs. Individual contemplation about touching varied with some participants being very cautious and analytical in their touch exchanges, and others acting more intuitively.

Touch with Professionals

Touch added to the development of relationships with professionals whether touch is part of service or not. The term "professionals" refers to any paid care giver and provider of service to the participant. This may include medical, psychological, personal care, and rehabilitation professionals. Participants expressed an understanding of unspoken boundaries that are typical between professionals and clients. Trusting relationships with important or pivotal professionals may include affectionate touch in addition to any working touch. According to participants, when personal, affectionate touch occurred or evolved in interactions with professionals, it had a humanizing and personalizing affect in their relationships. The qualities of trust, reciprocity, and power balance are present as with other touch relationships, however, participants initiate touch far less with professionals than they do with peers. Reciprocity and power equality are

less likely and not always encouraged in relationships with professionals.

After my accident, the best thing that happened was my physio[therapist]. One month after the accident [he] gave me treatment every day. Like he gave me stretches and stuff, but he did it in a caring way. Everything he did for me, he did for the good of it. He was the physio, like, he treated—he was more like part of our family. And he was very affectionate and stuff, and he was good to everyone in my family. *Steve*

I will generally, softly, quietly touch my doctor. I trust my doctor. I know her, therefore, I trust her. But actually my doctor is a little more touchy than most professionals are. It kind of personalizes our relationship. *Fay*

I asked my [other] doctor to give me a hug as I was going through incredible emotional turmoil. A hug from a professional is so asexual. It just feels like a good hug. It didn't make me feel so much like a number, a profit [fee for visit]. It made me feel like he saw more. It made me feel human. *Fay*

I've always been close to them [case manager and others] emotionally, but I think I've gotten to the point where I'm closer, physically closer. Hugging. I just sort of realized that you only have one life to live and I was, two years ago, not living it. And a year and a half ago I was not living it. I was hemiplegic and I was brain dead. And I've recovered so far and I'm recovering more and more daily. And I would like to think that — I am emotionally close to them, yes, but I would also like to be physically close to them. As a reflection of the emotional aspect. *Diane*

For some, the opportunity to touch professionals was not adequate to reflect the magnitude of the relationship. Diane expressed a need and willingness to stretch boundaries as her need for connection increased.

My case manager, she and I were close from the beginning but not physically close. I think she was reticent to be physically close because of the professional/patient relationship and I understand that. But I don't agree with it and I do agree with it somewhat. That kind of policy would be beneficial in that you could make no mistake over sexual harassment or some such thing. But I don't agree with it because friendly hugging, friends hugging is: [sings] Four hugs a day, that's the minimum. Four hugs a day, not the maximum! Speaking from a personal level, I would prefer more touching from my case manager. *Diane*

Rejections of touch and bad touch experiences impacted the professional/client relationship and participants' subsequent behaviour. Participants vulnerable or dependent on the care of others were careful when touching professionals, especially those they learned were not keen on touching clients.

Some home caregivers, excuse my French, but they were just assholes. Like one day my home care worker put on my splints on my lower ankles cause I had an operation on my feet and they put them on the wrong feet and sent me off like that. *Steve*

I have one doctor whom I gave a hug. I actually kissed his hand and he freaked out. He said, "What are you doing?" So that kind of ended my touch with professionals. I am always open to any touch from them, [but] I am reluctant to initiate any touch. *Fay*

Relationships with professionals had a quality of tentativeness, as if the unspoken constraints of our hands-off society permeated them. Some participants' relationships with professionals developed to mirror friendships in which they felt comfortable touching within the acknowledged boundaries of client/professionals interactions. Other participants had relationships that were more formal and therefore they waited for professionals to make the initial touch contact. With varying degrees of success, they resolved the complex issues of boundaries, power balance, odds of reciprocity, rejection, and touch need. It is evident that the exchange of affectionate touch with professionals allowed the touchers to both strengthen and evaluate the relationship.

Societal Constraints

As a corollary to the limits on touch with professionals, participants articulated the unspoken rules around touching others. They had to balance those constraints with their personal need and the need for touch that they saw in others. They modulated their own

behaviour with these constraints in mind. They had to maintain dual roles of participating in touch and withholding touch. Short-circuiting a powerful, natural need created considerable stress and reduced self-esteem. Hindering spontaneous expression of affection could limit their relationships with others.

We live in a, well, cold society really where people don't touch one another, primarily, I think, because people don't trust one another. I need to work on, perhaps, controlling my urge for needing friendship and take more time to build more trust rather than trust right away. *Fay*

I don't think society has gone the right way in its hands off policy. *Miguel*

Touching is wrong here [rehabilitation centre]. They won't do it. *Glen*

Family have been getting massages forever. Friends have been getting massages, rubs, shoulder rubs, things like that. Coming from that background and stepping into the 90's with no instruction manual that says, "Keep your hands off!" (Especially with the damaged kids that I'm working with now.) That's a "no!". Because now times are that that's sexual harassment and I get myself in trouble because of that. Okay, now if I'm consciously thinking about it, "Hey! Hands off. No. No, I can't, you know. I'm not going to touch. Forget it." But that bothers me because I am compelled to show them that I feel for them and the only way I know how to feel for them is letting them know through touch. *Miguel*

The rejection of touch or the limits on receiving touch had emotional consequences for participants.

You can't touch anybody [in group home]. [I think it's a written down rule] 'cause I've tried and I get told off. I shake their hand. That's bad. There's no more of that. I don't understand it. Here it's a bad rule. Bad here. You feel not trustworthy. Sad. *Glen*

Anyone in power has the potential to cause some trouble for these kids and in a lot of cases they have. So I can understand. Unwanted touch, regardless of the intent, is something that can trigger bad memories. *Miguel*

At the same time, social constraints were useful in providing a way out of giving touch

and a way to dodge unwanted touch without serious emotional consequences.

We live in a society and some people are unfamiliar with touch so they [mainly men] expect not being touched. *Fay*

Societal constraints and norms around touch worked for and against participants.

Constraints against touching further limited participants opportunities to touch important people in their lives. Rejected offers and attempts to touch created self-doubt and reduced feelings of self-worth in participants. However, for Fay, constraints allowed her to withhold or minimize touch in uncomfortable situations without raising suspicion or bad feelings.

Gender Issues

All participants were very clear on their perspectives of gender in touching. They assessed the obvious and subtle problems hidden in cross gender touching and acted accordingly, reflecting further their sensitivity to societal norms. Both men and women were equally concerned about misinterpretation when touching the opposite gender.

My conditions are: just friends, hugging friends. No problem! But then the sex enters into it and ... um ...and I'm not likely to raise any gender issues but he is likely, able to raise gender issues and I don't like that in a man.

Diane

Men take advantage of women. Point blank. And I don't know — if she's a woman who is brain injured — whether she should be with a man who is a care giver. *Diane*

They think [if I ask for touch] it is too sexual. *Glen*

I don't trust him because I think it would be taken sexual in nature. *Diane*

When you appreciate someone, touch them a bit. That's all. Not physically, passionately - not of love. But friendship, that's all. Kissing is something else. *Glen*

Participants monitored their own giving and receiving of touch with members of the opposite gender. Their understanding and management of cross gender touch meant that they could protect themselves from dangerous situations and false accusations.

Can't touch a woman anywhere. *Glen*

I don't touch the girls [students I work with], you know, unless it's something that they have. They never ask for it outright, but there have been a couple who are really, really hurting and maybe a hug doesn't do too much harm. *Miguel*

I feel very separate from men and I feel they do not understand or even begin to try to understand how I feel. Also, I am wary to feel a touch from a man. Sometimes I misinterpret a touch from a man that is forward as sexual, whereas touch from a woman feels there for me. *Fay*

[I don't avoid someone's touch] unless it's sexual. *Glen*

I have a harder time showing my affection to a male peer whereas an older person, the sexual aspect is diminished, so I feel more comfortable and affectionate with them. *Fay*

He [participant at rehabilitation centre] wouldn't try to touch me unless I give him the okay and I wouldn't give him the okay. I just withhold some part of myself. I mean I'm open with them to a certain point. And I don't go open beyond that. *Diane*

With guys I'm a little more wary. I actually, consciously, leave them completely alone. *Fay*

I'm likely to say, "Friendly hugging okay. But sexual hugging, not okay." I would just push him away! *Diane*

Steve expressed a need for intimate sexual touch that he knew was necessary for building romantic partnerships.

[If I never touched a girlfriend] then I might as well commit suicide. [Because I'd] miss out on a lot of fun and stuff. It's a relationship and it's good. I'm just saying, like, if you want to have a girlfriend, you've got to touch and stuff. *Steve*

I'd like more [touch] from friends, like girls and that. *Steve*

Along with trust, reciprocity and power balance, participants assessed the gender dynamics present in touch relationships. The women seemed more comfortable touching women, while the men were more restrained and cautious in their use of touch with women. All the participants deliberately avoided touch that could be interpreted as sexual when their intention was to express affection.

Giving

There's one thing you don't get much in Starfleet — a hug. They ought to have a couple of people in charge of hugs, just to dispense them randomly.

J. Vornholt, Behind enemy lines: The Dominion war - Book one.

All of the participants demonstrated a well honed ability to be empathetic and compassionate. They understood the power of touch and its ability to ameliorate pain. They recognized when other people needed touch and knew how to deliver that touch with dignity. They retained this ability and this practice even when their own yearning for touch went unrecognized by both family and caregivers. The ability to help someone else put them in the unique position of giving support rather than being the recipient of support. As well, as givers of touch, they were able to exert personal power that they could not exercise as strongly when receiving touch, being at the mercy of others' offers of touch.

The delivery of affectionate touch meant more than just caring. Touching was used to convey connection, support, and empathy. The rejection of touch was not just a

rejection of a physiological event, but also a rejection of the giver. Participants expressed that the rejection of their touch overtures were often devastating and they interpreted it as a rejection of themselves.

Whom I Touch

The participants touched a variety of people in their lives, from family members to friends. Some were willing to touch those less known to them if they recognized an obvious need in them for touch. Others were assertive with their touching; meeting their own needs for touch by offering to touch others. For Steve, giving was sometimes done reluctantly, out of obligation.

I hug members of the [rehabilitation] centre. My male friend, specifically and — Oh, I held his mother a couple of weeks ago, just because she was frustrated and crying. I held her. *Diane*

I am more affectionate towards my grandparents now that they are older. Oh, they need touch. I have to give touch. This isn't a chore, as it sounds — I have to touch them. I like to touch them! No one can touch forever. So I don't think we should be greedy about our touch. I don't think we should hold back how we feel. *Fay*

Because of the stuff I have gone through, I have much more empathy for anyone else who is going through stuff themselves. Because of things that have happened in my past, I am more sensitive to their hurts. If anyone is in pain or in dire straits, then that's a trigger for me to want to, you know, help. *Miguel*

Every once and a while I hug her, but that's not like I ever did anything like, "Oh, god. I can't wait to hug Mom!" [Laughs.] *Steve*

She [Mom] gets, she always, you know, stuff going on and she's doing dishes or whatever, I'll come up behind, give her a massage. That's always there. It's a standing invitation anytime I'm around. Massage: gotta give it. *Miguel*

I give hugs to people when they are warranted. I rarely ask for a hug

because I need it. I am always more than happy to have their needs come before my own. *Fay*

When I hugged my male friend, it was that I needed a hug. My female friend — I gave her a hug yesterday, and my male friend — I gave him a hug the day before yesterday. I needed it. *Diane*

I do not [hug with brothers and sisters], but sometimes you just do it so you don't look like you're being rude or nothing. So you just go along with it. *Steve*

I try some [hugs, handholding] and I get told off. I touch them [people at rehabilitation centre], they tell me off. Hold their hand, that's all. They tell me off. *Glen*

What My Touch Means

Touch was primarily used to communicate concern, empathy, and connection with friends and loved ones. Participants intended to express more than words with their touch.

It tells people we are in love or whatever. It's a good feeling. *Steve*

A man, have a conversation with him, shake his hand. Show him I'm friendly. Nothing to it. That's all. Friendship, close friendship. I do it to show them here is a friend. You say you are trustworthy. *Glen*

[With family it's] a sign of love, that's all. *Glen*

[I mean] just closeness. *Diane*

A lot of the kids that I work with, through their violence, through their attacking, through their trying to hurt people, they have, many of them have tried to hurt me. So when these kids try their tactics I'm able to render them not helpless, but I hold them down in such a manner that I can tickle them and this breaks through a lot of their stuff. Now they are like Cato in the Pete Sellers' [movies]. So it's their way of reaching out to be tickled to show that there is something there. They pick on me more than the others [staff]. *Miguel*

It's obviously non-verbal. There's support: "And I know that you are

hurting and I know that you're in aches and pains and I know that you are hurting. I'm here in case there is anything else you want. If you need help in any areas." So what I am trying to do is lend support in that through non-verbal means, through letting them know I'm there to help. Maybe I try massage, maybe I try whatever, um, just to touch them, to let them feel that it's okay. *Miguel*

I means, like, you love them and it's good. You need to trust them. *Steve*

When I hugged my male friend's mom I felt sorry for her. It was a caring feeling that I was approaching her with. *Diane*

Fay in particular utilized touch to ground herself and strengthen her sense of self.

In life we are really alone, so without touch I would feel really alone. I have to touch to bring me back to the realm of people, the realm of human beings. I use touch to remember who I am. *Fay*

I am very quick to trust people. My way of letting them know I trust them is by touching them. I want them to know. I like to touch their arm or their shoulder to tell them I understand and that I feel compassion for them. Empathy, compassion, sorrow, if need be the case. Joy, elation, understanding, and caring. And I touch to show people I'm a feeling person too. And I can feel what they are saying to me. *Fay*

Touch seemed to provide a way of connecting and communicating with others that was powerful because it was non-verbal. It is used to break through verbal and emotional walls.

Sensing Others' Need for Touch

In determining others' need for touch, participants assessed obvious physical signs of emotional distress as well as more subtle behaviours. Responding to the distress of others, however, was driven most strongly by intuitive empathy.

Extreme ends, extreme ends, maybe they are crying. Maybe they have got that certain look on their face that is difficult to describe. But they appear lost or they appear really upset with something or they are in some kind of pain. I put my hand on their knee or on their shoulder or on their back or,

you know, kind of, “I’m here to help”. *Miguel*

Simply by the context of their voice. I just think that every human — you are born with logic and compassion and if you feel a friend who confides in you, [that] he or she is hurting, that a hug should be given. *Fay*

I rely on my wisdom and how I feel and if I would need a hug. *Fay*

You can just tell. They are quiet and they just don’t seem to be like themselves. *Steve*

I touch my mother more often now because I just, I feel it’s important. I just know that she would like me to be physically close right now and I am physically close, hugging. And I know that intuitively. *Diane*

[I hugged my mom because it] sort of seemed like the right thing to do. So I did it. *Steve*

She [male friend’s mom] was crying! And she was talking about her son and how she thought he’d fallen flat on his face if she’s let him move out too quickly. And I suppose that’s an innately motherly concern. And I just thought she could use a hug. I knew she could use the hug and held her for about five minutes. *Diane*

Participants were motivated by the need of others, which they assessed by taking the perspective of others. They touched others as they wished others to touch them.

Responses of Others to Touch

Participants used feedback to determine if touching was the right thing to do.

Responses to their touch were both positive and negative.

They’ve said, “It always feels so good when you touch, when you’re doing that or when you give a massage”. A lot of times it [touch] is not solicited, but it’s always appreciated. The staff enjoy it. *Miguel*

Well, they usually welcome the hug or formally they give me or show me their appreciation. Sometimes I don’t know. I just have to go with my gut. *Fay*

They either laugh or they will hug you back or whatever. *Steve*

[People] think I'm forward. I've asked them [other group home residents]. They won't touch. So, they don't want to. I don't think they like it. *Glen*

Well, I can say [they are sometimes] a little shocked, a little taken aback by that, but it's something I need to work on. I forget why people are uncomfortable with that touching, with forward touching. *Fay*

She [male friend's mom] stopped crying! And she put her head on my shoulder. *Diane*

Responses ranged from explicit endorsement of the touch, to reciprocity, to avoidance.

Benefits of Giving

Receiving positive feedback from their touch gestures had a favourable impression on the participants. They felt good about what they had done and about themselves.

There's a little, um, little pride in being able to do something that they acknowledge, that they enjoy, that they want to have continued. It's a sense of accomplishment, if you will, that I am capable of doing that or affecting someone or assisting someone in a manner that they want more. And that's kind of nice too, because I haven't had a terrific amount of successes since I got racked up. *Miguel*

Contact. Contact is good. *Glen*

Satisfaction that maybe I'm helping someone. *Miguel*

I felt good. And well, I said she shouldn't worry about her son and I knew she would worry about him, but I said she shouldn't and I meant she shouldn't. *Diane*

Endorsement of themselves and their behaviour affirmed that they had done the right thing at the right time. They felt good about their successful social interactions.

Touching Animals

Glen, the participant who received the least touch relative to his touch needs, was able to get caring touch from a neighborhood cat. The touch they exchanged played an

important role in bringing Glen happiness and some semblance of his pre-injury life.

[Touch from a cat makes me] very happy. Especially when he purrs. [It means] happiness to see me. Very happy. That's old times, old times come back again. *Glen*

Cats purr and dogs don't bark, they [wag the tail], when you stroke them. It's worth it. It's good. Makes me happy. Happy to make them happy. When they get happy and purr, I'm happy. *Glen*

In their giving of touch, participants negotiated the meeting of their needs and the needs of others. Touch was sometimes given, or rather exchanged, to meet their own emotional needs. They recognized others' need for touch by taking the perspective of the receiver and by considering visual cues in body language and facial expression. Some could only describe the process of assessing someone else's need for touch as intuitive. Alternatively, they would respond to specific, verbalized requests for touch. Participants gave touch as a way to express powerful emotions. For some, touching was part of their identity and they took pride in continuing to give touch. At its best, their touch was warmly received, created good feelings about themselves, and reaffirmed that they had taken the right action at the right time.

Touch and Words

Touch was used alone and as an accompaniment to spoken words to emphasize disclosed feelings. Two participants conceptualized their touch as syntax in their speaking. They used the metaphor of punctuation to express what they intend their touch to do.

It expresses just how deep those words are and how much they really mean to you. *Fay*

For the most part we [family] don't hug a lot. We are getting that way now because I'm pushing for it. 'Cause you can tell them that you love them. You can tell them lots of things, but it's like this is the sealing point, the final seal that the act has happily been; that they've got what I've said, for communications. Rather than say, "I love you" and walk away. That doesn't show love. What I'm doing is showing the love through the hug and, "I appreciate you going through stuff and I'm always there for you and I love you", and then a little hug, you know, a big hug, whatever. So that puts the period on the end of the sentence. That finishes it off. That takes it one step beyond just a verbal thing and then walking off. *Miguel*

Words are like a saucer. Touch is a cup full of feeling. Words are shallow like a saucer. And I mean one of the reasons I also like to touch people. I want to advertise that I really mean what I say. And to me, touch is kind of like an exclamation mark. *Fay*

In addition to augmenting spoken words, Miguel used touch to access those resistant to words and to calm them.

Words for a lot of these [emotionally disturbed] kids, they don't listen. You're just another noise to tune out, so I touch. A lot of the kids are not capable of verbal or otherwise, you know. They settle down. It's like the music relaxing the wild beast or soothing the wild beast. A hand on their shoulder relaxes them. *Miguel*

Participants used touch alone as a superior alternative to words for communicating emotions such as love, support, and caring. It was also useful in situations where speaking about strong emotions was difficult or uncomfortable.

A whole bunch more powerful than words. *Steve*

Talking is okay but friendship is touching. That's, "Hello, how are you?" Pat on the back, handshake. That's natural. [It means] closeness. Closeness. Friendship and trustworthy [person]. *Glen*

You can talk at them until you are blue in the face but you can't come close to reaching out and touching them. You can't even come close. And I just presume that they care enough about you to hold you and you care enough about them to hold them. Simple as that! It would [mean] more if they came up and gave me a hug. And, "I care about you," is just words in

my ear and I don't care about words in my ear. *Diane*

It's difficult to convey the thoughts through the words. Some of the kids get really tied up in wordage and maybe I'm using something that they're not familiar with, or if they are familiar with it, it's coming from someone who is yelling at them all the time. So, then, you know, I want to change things. It is supposed to be a non-invasive intent behind just a gentle touch. Doesn't work always. *Miguel*

It's easier. For both me and the other person. Because I think to myself, "If I say this or if I touch him would it put more stress on me or him?"
Steve

Well, emotions [spoken] are so fine, so good, but they only go so far. A touch can make or break the relationship. I'm realizing that more and more as of late. *Diane*

It's more quiet and more affectionate and stuff. [I hug with my mom] because she would never say the words to me. *Steve*

The emotional intensity of some situations required moving from verbal to non-verbal expression, from words to touch. Touch provided a way to express emotions for which they did not have adequate words. The participants seemed to suggest that giving touch rather than words strengthened relationships and was a sign post of a healthy relationship.

Receiving

I ain't asking for too much/Just a simple touch
Doug Bennett, (I Don't Want to) Walk Away

As powerful as the giving of touch, receiving touch is equally, if not more, meaningful. To have another person initiate touch is to be accepted, embraced, and trusted. While not always receiving the amount or type of touch they desired, participants attributed received affectionate touch as an indication of support. It was

distinct from working touch.

Working versus Affectionate Touch

The quality and intention of touch is determined by the nature of the relationship in which it occurs. Participants could perceive the differences between working /functional touch and affectionate touch. Touch used in personal care and physiotherapy, for example, was business-like and done to achieve certain goals. It played little or no role in communicating personal affection.

Working touch is functional and there is little or no feeling in it. It's kind of cold. *Fay*

It doesn't — feeling doesn't come from the heart. It comes because they have to. They're doing their job. That's all. Not friendship touch. Just on the job, trying to do your job properly. Friendships is, "Hi, how are you? I trust you, pal." But physical touch is stretching [physiotherapy] and that's all. It's not saying, "How are you doing, friend?". *Glen*

Participants articulated the boundaries they either put up or understood as delineating the difference between affectionate and working touch.

Hugging is — my soul needs to be hugged. It's my soul entirely. And massage therapy is — my body needs to be hugged. And I don't feel that my soul needs to be touched by him [massage therapist]. *Diane*

The touch that I had there [in the hospital] was maybe one of the physiotherapists who came up to my shoulder and was holding my hand because I'm tottering down the hall 'cause I had to relearn how to walk again. . . . So I was tottering and that, so it was supportive. The touch was there to help me get through stuff and there wasn't anything to it nor was there any intent behind any of the touch that I've done [with hospital staff]. It's there to support only. *Miguel*

Working touch given within the context of a close, trusting relationship was seen as having the intangible element of genuine concern. Attributing affection to the touch was

a result of the quality of the relationship, not the physicality of the touch. For example, family and friends who assisted participants were perceived to touch with love and support.

Working touch from my family members or friends is not cold because it's done in the name of love. *Fay*

Work stuff is just work and friends' stuff is more like a loving, caring touch so it's better. *Steve*

Affectionate touch and working touch are distinct phenomena. When working touch was received within a relationship of trust, reciprocity, and power balance it felt more like affectionate touch. However, most working touch occurs in relationships where trust may be present but reciprocity is not expected. Participants do not touch caregivers in the same way they are touched during the delivery of service. As well, the power is unequal. Participants, particularly those who are less independent, are vulnerable to the quality of care received, placing them in a less powerful position. It is less likely, but possible, that participants are perceived of as employers with higher status.

What Touch Means to Me

Participants received touch from friends and family. Affectionate touch was perceived as communicating warmth, support, and love..

She [Mom] loves me. *Steve*

My wife [touches me] now. Dad, when he's talking to me in a serious note or when he's, you know, "Miguel", and then this big warm mitt (like, his hand is about three times the size of mine), when he comes out and his hands are always warm. That's such a comfortable feeling when this warm hand rests on you shoulder or on the back of your neck. *Miguel*

I always get a handshake and a hug from my brother and I always get a hug

from my sister and her kids, and, you know, it's always been there. *Miguel*

[When family touches me it means] they love me. They understand me. They care about me. They want to take away my pain if I am feeling any at that time. *Fay*

[When my friend shakes my hand he is telling me that] he likes me. He's very good like that too. When he's shaking my hand, he'll come running up and say what he is feeling like. He'll say, "I really like you, Steve." He'll say what he is feeling, like, he's not very, too shy at all. He'll just squeeze my hand and it will make my arm feel like it is going to fall off because he is a pretty powerful guy. He's very cool. I like him. *Steve*

Called friendship. They trust you. Close. Very close. *Glen*

When they do touch you, you know that they appreciate you. *Steve*

Steve's relationship with his mother's touch was mediated by his comfort level in public versus private spheres. As a young adult, he was particularly sensitive to the opinions of peers, and struggled with his mother's desire to give him affection publicly.

[When my mom hugs me] it bugs me a bit, but I just let it happen. [It bugs me] when there's a shit load of people around and you're in a mall and she's trying to hug you and hug you and hang off you like a vulture would. [It only happens] every now and then, but she knows better. So that's good. *Steve*

There's a time and place for, a right time and a right place for, and a wrong time and wrong place for it. Just say I'm in school and I won a wrestling match and so my mom wants to hug me because I won. That would be okay because that would make me feel better. But a wrong place, it would be wrong if I won and all my friends were around and she wanted to hug me then. I wouldn't like that. *Steve*

[If she stopped], well, that wouldn't be good. I like hugging my mother. I feel better. I feel okay. Ummm, better. [Long pause.] Relieved and stuff. You know, because it's a mom, a mother type of thing. Just, like, no one else can do it except the moms can do. *Steve*

Affectionate touch evoked feelings in the participants about those giving them the

touch, about themselves, and about their relationships. Despite his attempts, Glen had a difficult time getting touch from his roommates.

Touch has always been, for me, a fairly important part. Someone's coming up and touches you on the knee or just touches you on your shoulder, is trying to console you. And it is comfortable. You get a warm hand that's there resting and you know that there is someone behind it, behind you in whatever you are choosing to do. Then, uh, I try to convey that to the kids or to whomever. *Miguel*

When I met him [Rick Hansen] downtown, I shook his hand and it was like he was going to tear my arm off. But he's in really good shape. [It was] cool. It felt good. Because it gives me, gives me some— it felt like he gives me, like, some kind of hope. I shake his hand and then I could feel the power in his hands. And mine, he shakes it, [I thought] "Oh, God, This guy's tough." That's good. *Steve*

But they [group home residents] never smile, they never look happy. That's why I say, "Hi, how are you?" They say [silence]. They look like this [makes frowning face]. Don't smile or shake my hand. *Glen*

[After I got a hug] I just felt, ummm, more at peace with myself. *Diane*

Oh, emotionally helped beyond help. It's helped me beyond help! And physically, I just would like to know by a pat on the shoulder if I'm doing okay physically. *Diane*

My Need for Touch

The amount of touch needed by the participants was as varied as what they received. Miguel implied that he was still resistant to lots of touch, but tolerated more now than he used to. Steve and Fay expressed a need for touch within a romantic relationship. The sting of inadequate touch was felt most sharply by Glen. Diane seemed resigned to minimal touch, the result of few close friendships and a dissolved marriage. How Fay felt she was doing and how strong she felt affected her need for touch.

I probably don't need as much [touch] as I, umm. Yeah, for myself, for

myself I get enough. It may not be enough as everyone else would want, like my wife is always looking for more and — No, I get as much as I need. And I try to meet others' needs too, but I'm not as ready to accept, I'm still not ready to accept a lot. It is getting better. It is taking a long time.

Miguel

Well, up to this part [break up with boyfriend] I would say yes. Maybe if you could come back in three or so months and ask the very question you may get a different answer. I don't know at this point if I will get the touch I need. I would like to be touched with a loving hand of someone's who is special, who really means the touch. But as for touch, what I receive is adequate. *Fay*

[If I wasn't getting enough I would feel] not very good. I know I'm getting enough because I'm surviving. I'd like more from friends, like girls and that. *Steve*

I don't [get touching]. None. Nothing. Nobody shakes hands with me. Nobody, even men. Very traumatic. [Not getting enough touch,] true. Even friendship touch. *Glen*

[If I got enough touch I would have] a feeling of worthwhile. A feeling of being worthy. *Glen*

I would like to get more but it's not going to come my way and so I'll live with that. I just don't have enough friends. I mean, my female friend, my male friend, and another male friend at the centre are all the friends I have. My female friend was my friend pre-injury and my two male friends are my friends here at the centre, and I'm just alone much of the time. *Diane*

I just don't see him [male friend] that often. He's here once a week. *Diane*

It makes me feel, at times, alone, lonely for a hug. And I know that my husband and I used to hug consistently. And I left him [last year] and since then I haven't been getting enough hugs. *Diane*

Being a whole person is important to me and I feel that when I am propping up myself, sure of what I'm doing, touch is less important. *Fay*

Individual need for touch was influenced by participants' relationship needs and current friendships. Only Miguel and Fay claimed to receive adequate affectionate touch.

Four participants, including Fay, expressed a need for more touch from friends and romantic partners. The lack of affectionate touch impacted Glen most profoundly, to the detriment of his self-worth.

Indicating Need for Touch

When communicating their own need for touch, some participants asked outright for what they needed. Others were more reserved or had given up trying.

Actually I don't [get the touching I need]. I don't. Actually the further answer is not entirely true. See, I don't [ask] because actually I am the initiator. Very few people really touch me the way I touch others. Quite honestly, it is very rare that my friends come to me needing support. It is more often that I go to them for hugs and more support. *Fay*

I do [ask] sometimes. I have done. I get turned down. [Group home staff] just say, "No." I say, when I get my hair combed, I say, "Please can I have a kiss?", usually on the cheek. They say, "No." So I don't bother. I've been turned down a number of times. It gets boring after that. Boring. *Glen*

I wanted to say, "Can I shake your hand, please?" They usually say yes or no. If they say no, I drop it. *Glen*

I ask for it. "It's about time. Stop. Hang on. Give me a kiss, need a kiss. Okay, need a hug too. Okay that's good. Alright." We can get on, get about our stuff. We go back to work. *Miguel*

Participants rarely avoided well-intentioned affectionate touch. Uncomfortable, unsafe, and sexual touches were likely to be rejected. As Diane's relationship with her mother waxed and waned, so did her desire to touch her mother.

When I'm not physically and emotionally close to her [mother], she kind of presses me. And I'm not feeling up to my mother right now and I want to be away from her. *Diane*

[I avoid touch] if it feels bad. *Glen*

When we're going in the pool or something I don't always feel safe. Like when they lower me in the water or something because they don't know how to do it properly. I say something. You have to or else it will never get fixed. *Steve*

I've been open to that always [unless it's sexual]. *Diane*

Fay's emotional well-being and sense of self was significantly affected by the touch she received. When touch was unavailable to her, her self-confidence began to slip. Her need to have physical contact overrode her dislike of her romantic partner.

Often we would just cuddle all night and I really never felt more happy. It was so peaceful. I mean peaceful as in no one could touch me, no one could harm me. I was very content. The building could have collapsed and all I cared about was being in his arms. [I was] at the point of euphoria. Not the traditional euphoria that comes with others being there, but rather a euphoria that came from within. And nothing at that time, nothing could take it away. It was wonderful. I felt like a whole person and when we would cuddle, I didn't feel alone. There was nothing between him and I. Well, actually, I felt a connectedness to myself because the feeling alone made me proud of who I was and who I am. *Fay*

I craved the touch and I tolerated his touch [before the break up] even though I, at the time, actually knew I hated him. There is something about touch that is irreplaceable. Every touch is unique and every time you are touched it involves different feelings. [With break up of relationship] I realize that I won't have that touch, that cuddling anymore. Immediately I feel very alone. And although he only left a few hours ago and I should really be glad he is gone, I feel afraid without that touch. Suddenly I feel a little unsure about myself than I want to. I guess this is what makes you need someone else to make you feel confident, and really, I was used to his touch. Now that I'm pretty sure, realize it is gone, I feel less confident without that touch. *Fay*

Participants received touch from professionals, family and friends. Working touch rarely had the same qualities as affectionate touch, primarily due to the relationships and expectations involved. Affectionate touching, mostly handshakes, hand holding and hugs, was well received by participants. Received touch and the absence of touch told them

about themselves, and what others thought of them, impacting their sense of self-worth. As feelings about loved ones shifted, the desire to touch fluctuated. For Fay, the need to touch, at times, was more powerful than the need to protect herself from exploitation.

Self-Perceptions of Disability

Come, hold my hand. I have need of it.
Maureen Hunter, Transit of Venus

Giving and receiving touch within relationships is a universal experience. The three prior themes have explored common human events. Brain injury changes lives tremendously and the participants' touch lives are no exception. The last theme covers the changes in touch that occurred in families and within participants when cognitive and physical disability resulted from serious injury.

Touch Before and After Injury

A number of the participants talked about how touch was a barometer of their recovery and their sense of self in relation to others. Diane perceived others willingness to touch her as a measure of her increased "hold-ability" and normality. Steve believed that the touch he got was a measure of his independence. Less touch equaled more independence. It was a signal that others believed him to be a grown-up again and he felt like an adult. Withdrawal of parental care and reassurance touch was correlated with recovery, as a natural transition, or was explicitly avoided by participants.

Steve's hospital experience immediately following his injury highlights the fine line between affectionate and pitying touch.

[In the hospital, hugs from family told me] that they love me. And that they were there to care for me. That's true. People liked to show me they

loved me. That they cared, and that worked. Sometimes it bugged me, sometimes okay. I didn't like it when people, like, "Oh, poor little kid" or whatever. Feel sorry for you. I didn't mind that [supportive touching]. Yeah, that was good. [They were saying with their touch], "It's good to see you alive. It's good to see you didn't die." *Steve*

Changes in touch patterns differed after the injury. Glen experienced a significant decrease in touch with tremendous impact on his self-esteem and sense of worth. Steve reported that touch in his family was not affected by his injury.

Used to be [a touchy family], but not anymore. She [wife] left me. I've lost so much. [When I don't get touch I feel] a little bit strange. I miss being touched lots. I miss friendship touch. I miss it so much. I miss it. Nobody talks. Nobody touches. It's very sad. *Glen*

[I feel] a bit low. I feel very odd. Very outside, a stranger to everybody. That's why nobody wants to know me. *Glen*

[Family touch] stayed about the same. *Steve*

For Miguel, the picture is more complex. He was hesitant to let others in and connect emotionally with friends and family after his traumatic accident and this resulted in a reluctance to receive affectionate touch. Additionally, the physical sensations on his skin immediately after the injury made touch very uncomfortable.

I worked with many of the people from European backgrounds. "Oh, Miguel!" [Arms wide to give a hug.] And they'd come up, and this is the way. Okay, so fine. Tradition. So you hug. That took a real time to get through that barrier. Before the accident it was, "This is great, this is just neat. All these friends and all the things that are going on. Wonderful." After [the accident] it was scary because I would always think that there was something, something— ulterior motive behind. I don't think I want them to do whatever they want to do because it will hurt. So that coupled from, not just the accident, but the divorce and stuff just all at one time, could have led up to another hurt. And so I wasn't, I wasn't open to the experience. I would, I shut myself off. It was okay if I was controlling it, but I wouldn't allow anyone to get in to help me. Part of it, too, was the super sensitivity of the skin. Anything like a fly walking across my hand

was like people poking needles into it. The nerve endings were pretty raw.

Miguel

Other participants experienced an increased need to touch and their families were eager to engage with them. The touch seemed to express an acknowledgment that the injury could have resulted in the loss of life. I had the sense that they were embracing a second chance.

More affectionate touching. They touch me, showing that they are happy I'm alive. I touch them out of gratitude for something they've done. It's — touch, some touch is just nice. *Fay*

Oh! It's gotten to a newer level. I need touch more, but I'm not afraid to tell you about this because— I do need touch more and it's not as though I can put it off until tomorrow. It's now or never, you know. And I thank God that I'm still here and breathing now. *Diane*

[Touching with my mom is] a lot looser than it was. It's more open now than it was. Because I was, with my black and white [thinking], was a little less diplomatic when pointing out that some things had to be done and some things had to be met. So, it's tempered now so that I can see the gray areas and work within them. I was a real miserable, rotten sod. We are a lot more capable of showing emotions whereas before it was pretty slim. *Miguel*

"Well, you were so close [to dying]. We lost you and you came back to us." So through Mom and Nana there is a connection there. That there was a realization that I had been, "Poof!", so they are all glad that I'm here again. *Miguel*

Independence and Dependence

As feelings of dependence on others changed from the time of injury, the need for touch changed. Dependence on others was necessarily high at injury and reduced over time throughout recovery.

The independence that I had had been taken from me and left me in a position where I was more dependent on other people for love and support.

I couldn't deal with the love, I couldn't deal with -- People that I met would say, "I love ya". Just: Wow! But I couldn't accept it 'cause I had trouble loving me, forget about loving anyone else. *Miguel*

When you first have your injury, you are dependent on people, you need more touch. As you progress it's like "Okay, get away from me. I am on my own now. I don't need it." *Fay*

The more touch that I have received through caring, through loving, through support has coincided with the recovery process. I can't say that it was a main part of it, but it certainly was there. *Miguel*

[I don't need as much touch now] because I'm pretty much cured. The only thing I can't do is walk. But I'm pretty sure I will walk again. I don't notice— feel pity and stuff. I'm all grown up now and I don't need that. *Steve*

Touch acted as a strong indicator of acceptance, a measure of self, and a connection to the non-disabled world. For Fay in particular, touch was wrapped in some ambivalence. It reflected her struggles with dependence and independence and her place in the world.

Before my accident, I was a toucher, but it was nothing like now. It means a lot more for me to be touched. Because actually through or because of my accident and through the recovery process I have been quite unsure of who I am. The touch is like the acceptance of other people. Like, "Hey, you are okay". And that makes me believe in myself all over. But to add another twist: the more touch I need, the more dependent I feel on others. That is why touch isn't always a good thing. *Fay*

She [mother] hugs me most, probably, because I'm a disabled kid. I'm the only disabled kid. And she doesn't want to see that. *Steve*

Well, I think that as I've touched more, I've gotten more better. [Laughs.] I assume it's gotten better because I'm more "holdable". *Diane*

Well, touch has played a very important role whereas I was always on my own, on the move, and then— I can't really remember how much touch before I — With my accident there are many mountains to climb. Often those are emotional mountains and often I am on the emotional roller

coaster. Now more than ever I think anyone who is trying to make their life as close to what it used to be there will be real big emotional highs and lows that come with the accident.

People know that somehow I need to know people are there because, all in all, me in the wheelchair, having a speech impediment, you really are in a world of your own. So it is important for me to connect with the other world through touch. The other world would be the world of busy people, normal people who are getting on with the business of what they would say that we don't. We are in slow motion and the other world is the tape in fast forward.

If I am in a bad mood or really down, I have feelings of helplessness and hopelessness and that would make me very much in the world of the severely disabled. *Fay*

While her environment may remain relatively constant, Fay's definition of herself as able or disabled fluctuated with her internal states.

Difference

Being different or disabled meant that others may have interacted with them in a withholding manner. Some participants noticed a clear difference in how people responded to them before and after their injury. Their explanations for the behaviour of others varied. Some were able to take the perspective of those who find them different and empathize with the hesitation. For others, continual battles to be accepted led to frustration and despair.

I'm sorry to paint such a bad picture. I appreciate it here [group home], but it's been nice, but it could be so much better. More friendly. *Glen*

I am a touchy person. That perhaps isn't the ideal way to present myself. I know that given my condition, it makes many people feel very uncomfortable and actually, on the flip side of that, when people I don't know are very touchy with me I don't really like that. Well, people are afraid of what they don't know. I am guilty of that. I too am a little afraid and apprehensive of what I don't know. So I might be something that people don't know what to make of me, how to treat me, how to act around me. *Fay*

If I'm ever in a crowd, they see my wheelchair in a crowd, that's all. *Glen*

So if I say to somebody, a man or someone, "Can I shake your hand please." Say hello and they say "okay", they will. They still come for it. It's very slow [getting the handshake]. They say, "Hmm, okay, well, just once". Very particular. Everybody's uncomfortable, everybody. Even men. Apprehension. They are very suspicious. They're very I think there's more to it: They think I'm peculiar. Or else they don't want to take no chances. They don't know. They are afraid of hurting me. Everybody thinks I'm a cripple. They're afraid of catching my disease. *Glen*

Get turned down so many times though. I get turned down a hundred times. How many times can you get turned down? Rest of my life get turned down? Whole life? How much longer, all my life get turned down? All my life? *Glen*

The lack of touch affected perceptions of self and may have reinforced beliefs that one is a devalued 'other'. Glen's feelings of being different persisted to the point of internalization of the 'otherness'. Glen was so disconnected and so untouched that he described himself as an object. He had only the absence of touch to tell him about himself, to tell him that he is not progressing and not making new friends.

I feel like an invalid. I feel like an invalid in a chair. I'm an obstacle, that's all. Not human. Big cost [from lack of touch]. I'm a nobody now. I'm a nobody. What's the point of doing life? No point. [pause] Can't walk, no kids, no wife, no house, no car, nothing. *Glen*

It's bad now, very bad. People think it's odd. Cause they say, "Don't touch me". So it's a bad reaction. Firstly [I] was sad, but it's just natural. I deserve it. *Glen*

However, participants could still see that societal constraints against touching may be the reason for the lack of touch, rather than any obvious disability.

Perhaps they are afraid of me or maybe just being touchy is uncomfortable and rather inappropriate. Actually, whether I am or whether I am not in a wheelchair, the way I feel society is that most people are uncomfortable with anyone touching them. *Fay*

[They are afraid] that you are smarter than them or you could beat them up or something. Who knows? Many different reasons. *Steve*

It's very typical for Canada, not to touch in Canada. But in [my country] you touch, shake hands. There should be classes here teaching how to be friendly. *Glen*

For the participants, brain injury brought with it a change in relationships, self-esteem, and societal status. These factors affected the giving and receiving of affectionate touch. For some, seizing the opportunity to touch and connect became vital after their near-fatal experiences. For others, the opportunities to touch virtually disappeared as friendships fell off and living situations changed. Attempts to obtain affectionate touch in new relationships were met with enthusiasm or rejection, directly influencing feelings of self-worth and further touch behaviour. Touch was an important conduit to the world of the non-disabled and was accessed with varying vigor and success by these extraordinary survivors.

Summary

The experiences of touch are phenomena whose quality, meaning and importance is contextually based. Caring, affectionate touch is located within a close relationship with another person. Affectionate touch occurs within a complex web of relationships, self-worth, prior experience, personal need, opportunity, social norms, and gender influences. The meaning of touch flows from the relationship within which the touch occurs. The participants' self-perceptions and self-knowledge determined the nature of their relationships and the touch they engaged in which in turn informed them about themselves.

My Interview Experience

As a naive interviewer, I underestimated the amount of discussion participants devoted to personal issues, achievements of which they were proud, and their day-to-day struggles. In hindsight, I should have expected this. I was invited into the private domain of each participant and should have anticipated the tangents that occurred. The participants who were most socially isolated or depressed engaged with me the most. The interviews with them stretched to many hours. I was not just a researcher, and perhaps had never been just a researcher. I was interested in listening, had set aside time to do so, and had “clicked” with them. I became a participant with them in a dance of touch. . Four of the five participants initiated a touch after we had exchanged a handshake. Fay invited me into long, vigorous, full body hugs at the end of each interview. Steve requested that I set his watch while still on his wrist which required that I touch his hand, arm, and shoulder. Other touches from participants occurred in response to my questions or illustrated the touching they engaged in. Diane reached over to touch my forearm during her discussion of the power of touch with friends. Glen repeatedly shook my hand as he demonstrated his perseverance in requesting the same from his caregivers. I received no touch beyond the handshake from Miguel, the married man, who had his touch needs met at home. He didn’t need it from me. Steve, who would like his touch to come from an eligible mate, initiated the least touch. Perhaps our exchange of touch transpired because I had tapped into a very real, very visceral need they had, and could provide them, however briefly, with a relationship in which they felt comfortable touching. The touch I received indicated that the elements of trust, reciprocity, and power balance

were present in my relationships with participants. The genuineness of my findings is strengthened by the evidence that the participants and I shared more than time.

Reflecting upon the dynamics within the interviews, I felt sad. I knew that their indicators of need and my reciprocation of touch only met the “tip of the iceberg” of their touch needs. I gave them what I could while I was with them, but for most it was not enough. At the same time, I was motivated by the inadequacy and transiency of my touch with the participants to promote relationships within the rehabilitation profession that provide safe, affectionate touch for those who need and want it.

Chapter 5

To be taught, one must be willing to learn. One must be willing to change, sometimes in fundamental ways, because to learn *is* to change.

Bill Roorbach, Writing Life Stories

DISCUSSION

Highlights of Findings

Qualitative research reflects its socio-political and cultural context. The fear of sexual harassment and exploitation of clients by professionals appears to have resulted in a withdrawal of caring touch. The bulk of the research on touch took place in the 1980s and has only recently experienced a resurgence. The current 'hands off' climate may be a costly one, particularly for those who are already peripheral or marginalized in society. What was lost will never be known, but we can get a sense of what can be gained when we begin to use touch again.

The five brain injury survivors who were interviewed about their affectionate touch experiences all expressed that touch played an important role in their relationships and in their understanding of themselves. Touch is a very tangible, simple act that can be described in concrete, straightforward terms. Yet its effects, its connotations, are abstract and elusive. A few of the participants tried to describe the nature of touch's intangible qualities. They tried through metaphor and simile to describe it and to communicate the meaning of its presence and absence in their lives.

The four themes that emerged were Relationships, Giving, Receiving, and Self-Perceptions of Disability. Touch experiences in relationships, both positive and negative

influenced participants' giving and receiving of touch, which in turn further affected their relationships (see Figure 1). The intensity of self-perceptions of disability, including feelings of independence, dependence, and difference, fluidly wax and wane. For some participants, self-perceptions of disability exerted a strong force upon their touch interactions while other participants expressed little disabled identity. For all, however, self-perceptions of disability were fluid, affected by relationships, touch experiences, and daily life.

Affectionate touch was exchanged in relationships in which the participants felt trust, touch reciprocity, and equal power status. Forces such as professional boundaries, societal constraints, and gender tempered their touch interactions. In giving touch, participants were empowered. They could communicate support and empathy. They utilized perceptive social skills to recognize and meet others' need for touch and comfort. Received touch, when genuinely intended as affectionate, as opposed to the more neutral working touch, was perceived as warm, supportive, and validating. Participants used the touch they received to evaluate their relationships and to assess their self-worth. Most expressed a desire for more affectionate touch and shared some ways in which they attempted to solicit it. Self-perceptions of disability were founded upon post-injury experiences. Patterns of touch after injury had changed for all but one participant. Participants felt that family were grateful they had survived and communicated that through touch. The interaction between touch and independence/dependence was less clear. Some participants felt more recovered with increased touching, while others felt that less touching indicated their increasing independence and improvement.

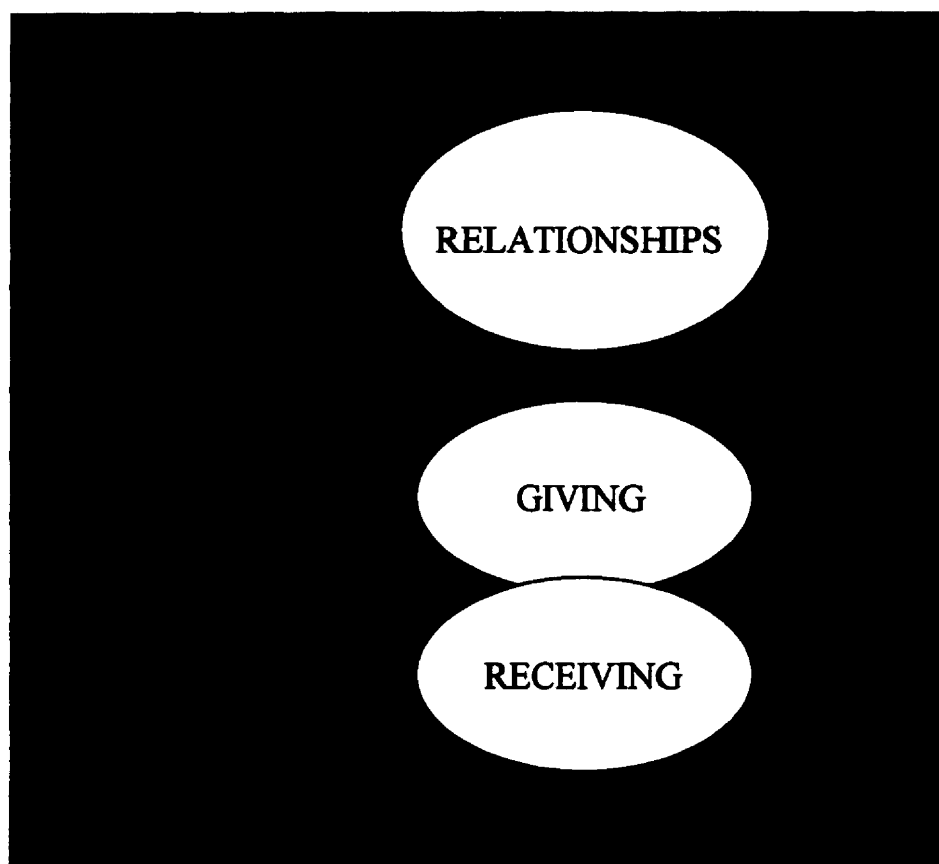


Figure 1. The experience of affectionate touch. The three themes of Relationships, Giving, and Receiving influence each other in a cycle. The theme Self-Perceptions of Disability underlies the others; its impact varying in strength over time.

Touch in Rehabilitation

It must be acknowledged that there still exists a pervasive concern about touching in society. It is appropriate to be cautious about exchanging touch and to be alert to its association with sexual behaviour. However, it is excessive to throw the baby out with the bath water. For people with disabilities, society is even more restrictive. Preferring to frame them as asexual, touching with or by people with disabilities often looks more like parent/child touching than peer touching. Attention must be paid to the abuse rates of people with disabilities. They can be vulnerable to abusers who hide behind the facade of care and affection that is not available from others. Rather than remove opportunities to receive touch safely with genuine intentions, people with disabilities can be armed with knowledge about body privacy, personal empowerment, and the right to say 'no'. They can learn to protect themselves from abuse.

Health Implications for Brain Injury

Taking a cue from nursing, rehabilitation can incorporate affectionate touch with clients, resulting in many potential benefits. Brain injury rehabilitation aims to re-develop cognitive abilities in survivors. Receiving and giving touch may be as physiologically beneficial to brain injury survivors as it is to developing babies. For those recovering in adulthood from a significant physical and psychological trauma, the road through development and healing may be similar and require similar stimulus such as touch and the connections to others that touch provides. Additionally, if psychological well-being tracks with physical health improvements, affectionate touch that alleviates isolation and depression and communicates positive recovery expectations can enable the patient to

better heal physically. Hospitals and medical equipment can often isolate survivors from the physical contact of family and friends. Healthcare and rehabilitation professionals can encourage family and friends to express affection through touch. This may involve explicitly coaching touch, assuring loved ones that touch is not harmful or painful to the survivor, clearing a path through equipment, and modeling appropriate touch.

Managing Barriers to Touch

Ideally, affectionate touch throughout early rehabilitation will come from family and friends, however survivors who may have few supports will need their touch to come initially from professionals. Positive relationships with professionals can deepen if family and friends withdraw or fade away. The amount of time spent with physiotherapists, occupational therapists, and case managers, for example, can be greater than that spent with loved ones. The perceived higher status of professionals may deter survivors from initiating or reciprocating touch. Regardless, touch from professionals is apt to comfort and reassure while communicating that survivors are valued (Routasalo, 1996).

Professionals who typically do not use working touch as part of their duties (e.g., psychologists, speech therapists) may be less comfortable using it. Pratt and Mason (1981) believed that affectionate touch is a teachable skill which professionals will acquire with varying proficiency. Just as survivors assess the appropriateness of their touch, professionals will receive feedback from clients that will guide their future use of touch. Bearing in mind that clients may not be comfortable rejecting professionals' touch nor speaking up about it (Horton, 1998), taking a conservative approach is best. Touch must be modulated to be appropriate for the situation while not implying greater intimacy than

is wanted (Routasalo, 1996).

Touch is likely to be perceived as positive and healing when professionals create opportunities to discuss openly their use of affectionate touch with clients, have clients govern the touch, and parallel the exchange of touch with their developing trust and emotional intensity with clients (Horton, 1998). Touch will tend to be perceived as genuine when it is consistent with verbal content and other non-verbal cues (Cormier & Cormier, 1998; Friedman, 1979). Touch powerfully communicates what often cannot be said. Schanberg (cited in Ackerman, 1990) claimed that touch is ten times stronger than verbal or emotional contact. It conveys acceptance and support more convincingly than words (Weisberg & Haberman, 1989). Patronizing or pitying touch is not appreciated. Professionals, who generally hold higher perceived status than clients, must be careful not to give condescending touch (Routasalo, 1996).

For those with sensory and perceptual deficits, the importance of touch is magnified. Just as seniors with reduced sight and hearing rely more heavily upon touch (Weisberg & Haberman, 1989; Montagu, 1986), survivors of brain injury with similar deficits come to depend upon touch for communication. Similarly, survivors with compromised verbal skills are likely to rely upon touch as non-verbal seniors do to augment their language reception and production (Routasalo, 1996).

Social Skills

All the participants in this study appeared to have good to very good social skills. They were able accurately to assess and meet the touch needs of others, interpret feedback from their touch, and learn from their touch experiences. They touched within social

norms and managed gender protocols. A few participants had moderately limited vocabularies with which to discuss touch and to solicit desired touch. The reduced ability to obtain the touch they needed due to difficulties asking, in conjunction with limited opportunities for touch, significantly impacted their sense of self and self-worth.

This study has demonstrated that perceptions and expectations about touch influenced attitudes and behaviour. The participants in this study seemed to perceive and act on touch consistent with Salt's (1991) theoretical cycle. Their perceptions and expectations determined their attitudes. They then touched or withheld touch in accordance with their attitudes. Responses to their touch created new perceptions and attitudes, further influencing their touch behaviour. When they evaluated their touch interactions, participants learned about themselves, with whom they could exchange touch and under what circumstances.

Survivors with cognitive deficits can begin to relearn social skills in their touch interactions with professionals (Huebner, Thomas & Berven, 1999), family, and friends. They can be assisted to experience success that is vital to their self-esteem (Johnson & Newton, 1987). Professionals can discuss with them how their touch with clients differs from that exchanged with family and friends. Clarifying the roles and relationships between parties is needed so that survivors can begin to make such distinctions themselves and act accordingly (McGann, Werven & Douglas, 1997). With safety and abuse prevention adequately addressed, both the survivor and professional are better protected from harm and exploitative touch.

Gender must be factored into affectionate touch interactions. It seems unavoidable

that females are more free to use affectionate touch and that their touch is perceived as less sexual than touch from males (Routasalo & Isola; Montagu, 1986). The opportunity for male professionals to model affectionate touch with male clients can provide them with the skills and ease to engage in caring touch, rather than substitute sexual behaviour for affection.

Ethics

Professionals are bound by ethical codes and standards that limit relationships which may threaten objectivity or lead to the exploitation of clients. Certainly, having unclear roles is confusing for clients (Hingsburger, 1998; Lutfiyya, 1993) and inappropriate for professionals. However, developing a good relationship with trust and ease of disclosure is necessary to achieve therapeutic goals. The Canadian Code of Ethics for Psychologists (CPA, 1992) does not specifically address affectionate touch, but it states very clearly that dual relationships and sexual relationships, with or without the consent of clients, are not permitted. The Code protects both the client and the professional. The responsibility for balancing the thin line between being a caring professional exchanging affectionate touch with clients and not having dual relationships with those clients is left to the professional. Meeting their own emotional needs through touch with clients is never acceptable. However, mutual touch can benefit professionals (Routasalo & Isola, 1996) by humanizing their relationships with clients and positively impacting their mental health.

The Underground Movement

After many discussions with colleagues, psychologists, and other professionals, it

was apparent to me that affectionate touch was part of many working relationships, regardless of agency policies, written or unwritten, to the contrary. Professionals disclosed to me that they hugged clients “when the boss wasn’t around” or gave affectionate, supportive touch behind closed doors. They could not not touch, particularly when clients were in obvious distress or specifically asked for physical contact with their trusted supporter. Some professionals placed the true needs of clients ahead of professional and agency rules. Rehabilitation professionals should not have to feel like junior high students smoking in the bathroom. Both they and their clients deserve to have the benefits of affectionate touch acknowledged.

Management and administrators need to create flexible policies that meet the needs of clients and set up sound practice guidelines for the safety of both clients and professionals. In the meantime, the challenge for professionals is to use affectionate touch with consent, use it transparently and with clear boundaries, and monitor each other’s touch behaviours. Hingsburger (1998) cautioned that clients need to have other ways to give and receive affection other than touch, in light of the abuse rates for people with disabilities. Affectionate touch with clients with cognitive deficits requires further vigilance and specific training to avoid misinterpretation or misuse by clients in the community.

Fostering Friendships in the Community

The above being said, however, professionals are not the ideal candidates for providing affectionate touch. Friends, parents, and siblings are more desirable sources of affectionate touch for survivors, people with disabilities, and everyone. Safe, affectionate

touch is exchanged between trusting friends. Touch relationships are best developed with those we choose, rather than those who are assigned or paid to be there. People experiencing reduced or changed opportunities for socialization (be they brain injury survivors, people with disabilities, seniors in care, or anyone with limited avenues into a social network) also experience reduced affectionate touch. They have literally 'lost touch' with the rest of the world. Genuine friendships between people with and without disabilities can blossom only when they have access to each other. Participation in the larger community affords opportunities to meet and grow close to others (Traustadottir, 1993). Professionals cannot pre-arrange friendships nor can they be the sole conduit to the community. They can, however, ensure that clients have the skills to develop and maintain relationships (Jurkowski & Amado, 1993), that they have physical access to the community, and ample occasions to link with community members. Individual needs and abilities will dictate the level of support needed for each client.

A lack of friendships produces chronic loneliness that can further jeopardize physical and mental health. People with disabilities who are involved in a rehabilitation or day program may not feel social loneliness because they interact with a variety of people. They may experience the more subtle emotional loneliness, the lack of close relationships in which emotional sharing and the disclosure of loneliness occurs (Perlman & Joshi, 1987). Unnoticed and unaddressed, this more insidious type of loneliness leads to other emotional and psychological problems (Evans & Dingus, 1987). People with depression, low self-esteem, and social withdrawal tend not to attract many friends, further exacerbating their loneliness.

Professionals must be alert to the signs of loneliness and depression, and strive to address emotional loneliness. Often day programs, seniors facilities, and similar centres do not grant unsupervised down time for clients to visit with each other. Privacy is often not available to those requiring care (Hingsburger, 1998). Without these moments to simply 'be' or 'do' together in the absence of staff, relationships cannot deepen. It is in those relationships that affectionate touch occurs, that emotional needs are met. Trust, equal power and status (i.e., peers), and reciprocity must be present, and can be present, if allowed.

Group homes can also play a role in facilitating community membership for their residents. The assumption that living in a community results in successful participation is challenged by the experiences reported by Glen. Surrounded by paid staff and fellow residents, Glen feels devalued; his only source of affectionate touch the neighbourhood cat. This example of inclusion 'failure' is probably not unique. Many people living with family or living alone in the community lead solitary lives (Morton & Wehman, 1995). Another participant, Fay was a 'success'. She lived in an apartment with minimal support, was medically stable, and had completed her rehabilitation program. At the same time, she had remained in a unpleasant relationship to have her touch needs met. The resilience that sustained her through her recovery must now serve to sustain her through a lack of affectionate touch.

The close friendships participants did have exhibited some of the elements identified by Bogdan and Taylor (1989). Their friends, disabled and non-disabled alike, treated them as peers and reciprocated emotional and physical closeness. In these social

contexts, participants were not defined as disabled and different, but rather were accepted for characteristics that have nothing to do with disability. Conversely, in contexts where their efforts to connect with others were rejected or when they felt low, participants reported feeling more in the realm of the disabled and feeling worthless.

Family

The level of family support and cohesion after brain injury significantly influences outcomes (Stratton & Gregory, 1994; Miller, 1993; Cripe, 1989). Families can cope well with a member with disabilities. They can maintain cohesion and be resilient amid the struggles (Perlesz, Kinsella & Crowe, 1999). For four of the five participants, family was an important support network offering closeness and affectionate touch. Glen's isolation was the most pronounced perhaps because his family was not present in his life. The other families were able to adapt to changes after the injury and maintain a positive attitude. Discussions about family members' affectionate touch needs, as well as their feelings and perceptions around giving and receiving touch, may increase families' adaptation to brain injury. Family support is often a constant, yet it has a different flavour from the support provided through other affiliations. Those whose families are present still need the support provided by a variety of relationships.

Contributions of the Study

To understand the subjective experiences of people, researchers must be able to tap into their perceptions and feelings. To place the person with a disability into the role of informant benefits not only the participant but also the researcher and the field of rehabilitation and disability studies. People with disabilities are used to having things done

to them, for them, and around them. Often they are not in a position of authority and power over their own lives. This study honoured their self-knowledge and encouraged them to share rich examples of how they help and support others. It also emphasized that the majority of their experiences, perceptions, and actions are common to the human experience. All of us have endured loneliness, isolation, and low self-esteem. Their disabilities do not solely define who they are or what they can do. The consequences of their disabilities in an unaccommodating environment, however, may limit their opportunities to feel loved and supported and, occasionally, erode their sense of belonging and worthiness.

This study is a wake up call for rehabilitation, an urgent reminder that clients are more than destroyed brain cells and behaviour problems. It is not adequate to address only deficits. Professionals can facilitate the re-connection of clients both into the larger community and within the intimacy of strong friendships with disabled and non-disabled peers. Professionals are not responsible for befriending their clients, nor would it be appropriate to do so, but they do have a role to play in ensuring that clients' social and relationship needs are satisfied. If clients cannot establish solid relationships and feel loved and supported, there seems little point to other rehabilitation efforts.

The act of research is a political one. My intent is to now use my findings to nudge rehabilitation towards a more holistic approach that supports people who need to make connections with others. It is an approach that looks beyond training, employment, and independent living success. It is not an objective, mechanistic role for professionals. It is a matter of being an active participant in nurturing clients' relationships with peers. I

have been able to bridge my research with my work for the Persons with Developmental Disabilities Resource Team. Through in-services and client consultations, I have been able to discuss safe, affectionate touching and encourage people to think about its implications in their work.

Limitations of the Study

The five survivors whose stories are presented here have the common experience of brain injury, but that is where their commonality ends. The diversity of their lives allowed me to draw out differences in their touch experiences. Comparisons to the lives of isolated, marginalized people were then suggested.

Giorgi (1995) stated:

...generality means that the results of a study should have application beyond the situation in which they were obtained. Universality of application is of course a desideratum, but science often has to remain content with degrees of generality because many contextual or random factors limit the application of the results.

(p. 26)

While the generality of the findings is for the contemplation of the reader, I contend that the findings here are representative of the needs of most humans and illuminate the specific social barriers of those marginalized in society. The voices of the participants, in conjunction with my interpretations, can inform our thinking and actions around touch in rehabilitation and suggest what may be going on for those who cannot speak for themselves.

This study was limited to survivors of brain injury who can describe their realities

and can form, with varying degrees, concepts and abstractions. These participants may not be exemplars of the brain injured population because they do not reflect the experiences of those who cannot communicate verbally. Touch may be a more powerful form of communication for those who are non-verbal.

Some participants, as I perceived their responses, struggled with articulating the abstract aspects of touch. Some of their difficulties may be due to the consequences of their brain injuries. Perhaps they did not have the vocabulary or perhaps the English language does not provide the words we need to talk about the aspects of touch that transcend the physical.

This study provided a snapshot of participants' lives. It can only reflect their experiences and perceptions to date. Very different results may be seen with significant changes in their relationships and socializing. As well, work opportunities and family involvement contribute to their touch lives and these change over time.

I did not gather the perceptions, beliefs, and intentions of others in the lives of the participants who are giving, receiving or withholding touch. Other parties in the dance of touch should be interviewed so that their voices can be added to our understanding of the meaning of this human interaction.

Areas for Further Research

Rather than produce firm conclusions, this study has generated more questions than it has answered; not unexpected given its exploratory nature. The complexity of affectionate touch provides numerous areas for future inquiry. Understanding the attitudes of professionals and community members, evaluating the structure of rehabilitation

programs and policies, and illuminating the motivations and hesitations of family and care givers will all help shape the suitable delivery of affectionate touch and further clarify its importance. For example, why do some care givers fail to recognize the need for touch even when it is explicitly requested? If they are uncomfortable touching, what affectionate gestures can be substituted?

Touch needs that pervade the life cycle need further clarification. Longitudinal studies should follow the effects of adequate and inadequate affectionate touch, and therefore relationships, for people with disabilities. Ethical considerations must be explored including current standards and both client and professional impressions around dual relationships and boundaries. The importance of touch for those with few or no verbal abilities and how it can enhance communication needs to be determined.

Curiously, therapeutic touch, which does not entail actually touching the patient, has been used widely in illness care. It may be the attention provided to patients or the placebo effect rather than the alleged manipulation of energy fields that results in improved healing. Regardless, the use of affectionate touch deserves considerable attention, study, and use. It is unacceptable that those surrounded by rehabilitation professionals and caregivers may hunger for human touch. Continuing to develop a greater understanding of the subjective experience of touch through qualitative research is essential.

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Appendix A

THE EXPERIENCE OF AFFECTIONATE TOUCH FOR SURVIVORS OF BRAIN INJURY

My name is Dana McKie. I am a graduate student in the Department of Educational Psychology at the University of Calgary. I am specializing in Community Rehabilitation. I am conducting a research project under the supervision of Dr. Jean Pettifor as part of the requirements towards a Master of Science degree. I am writing to provide information regarding my research project, The Experience of Affectionate Touch for Survivors of Brain Injury, so that you can make an informed decision about your participation.

The purpose of the study is to explore survivors' experience of affectionate, non-sexual physical contact with family and friends. I hope to understand the meaning and importance of affectionate touching for you. Affectionate touching includes hugs, hand holding, pats, and caresses. As part of the study, you will be asked to meet with me for two interviews, a few months apart, to discuss the non-sexual affectionate touching that you exchange with family and friends, and with care providers.

The two interviews will last approximately one hour each. The interviews will be recorded on audiotape and then transcribed onto paper. With your permission, I may be using direct quotes from your interview in the write up of my results. However, any quoted material will not contain any proper names or information that could identify you or others. The second interview will be conducted to discuss material from your interview that I wish to quote directly and to obtain your consent to do so. You should be aware that even if you give your permission to be interviewed, you are free to withdraw from the study at any time for any reason without penalty. You are free to refuse to answer any interview question at any time without penalty. You are also free to demand that your responses or portions of responses not be directly quoted in any publication of the study.

Participation in this study will involve no greater risks than those ordinarily experienced in daily life.

Data will be gathered in such a way as to ensure your anonymity. You will be assigned a code letter and number that only I can trace back to your name. The coding information sheet with your name will be kept locked separately from the interview data. Once collected, the interview data tapes and transcripts will be kept in strictest confidence and locked in a file cabinet in my office. Reported results will present or quote your specific response in a way that will not identify you individually. The raw data (tapes and transcriptions) and the coding sheets will be destroyed two years after the completion of the study.

If you have any questions about the study or the nature of participation, please feel free to contact me at 284-9788, my supervisor, Dr. Jean Pettifor at 289-5161, the Office of the Chair, Faculty of Education Joint Ethics Review Committee at 220-5626, or the Office of the Vice-President (Research) at 220-3381. Two copies of the consent form are attached. Please return one signed copy to me and retain the other copy for your records.

Thank you for your interest and cooperation.

Sincerely,
Dana McKie

Appendix B

CONSENT FOR RESEARCH PARTICIPATION

I, the undersigned, hereby give my consent to participate in a research project entitled **The Experience of Affectionate Touch for Survivors of Brain Injury**. My consent is given only for the duration of the research project.

I understand that such consent means that I will take part in a one-on-one interview with the researcher lasting about one hour. A few months later I will participate in a follow-up interview that will last about one hour.

I understand that participation in this study may be stopped at any time by my request or at the request of the researcher. Participation in this project or withdrawal from this project will not adversely affect me in any way.

I understand that this study will involve no greater risks than those ordinarily occurring in daily life.

I understand that my responses will be obtained anonymously and kept in strictest confidence.

I understand that my responses may be directly quoted in any published reports, but that those quotes will not contain any identifying information or names. I can withdraw my consent to have any material directly quoted and will not be penalized for this demand.

I have been given a copy of this consent form for my records. I understand that if I have any questions I can contact the researcher, Dana McKie at 284-9788, her supervisor, Dr. Jean Pettifor at 289-5161, the Office of the Chair, Faculty of Education Joint Ethics Review Committee at 220-5626 or the Office of the Vice-President (Research) at 220-3381.

Date

Signature

Guardian

Participant's printed name