ACQUIRED DISABILITY: FROM ACCEPTANCE TO ADDICTION

"Entia non sunt mutiplicanda, praetor necessitatum."
-William of Ockham (attrib.)

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1.0   ABSTRACT

This paper explores the relationship between acquired disability and the potential for the development of a *disability addiction*. It is postulated that this behavioural phenomenon is brought about by the cultural shift that occurs as the individual traumatically leaves the culture of the able-bodied to assume a new identity as an individual with a disability which is unexpected, unwanted, and for which he or she is ill-prepared. Finally, Motivational Interviewing, provided by a counsellor with a disability, is considered as a psychotherapeutic support to help the individual overcome this addiction.

2.0   INTRODUCTION

The purpose of this paper is to make a recommendation about how to support individuals who have acquired disabilities and who have exhibited difficulties in re-establishing a psychosocial balance. To do this, I will first examine the meanings made of an acquired disability. From that vantage point, I will consider a continuum of these meanings – from acceptance to addiction. I will argue that the parallels between this behaviour, exhibited as a response to those meanings of disability, and the behaviours exhibited within such examples as gambling addiction and sexual addiction are sufficiently similar to allow for the framing of this behaviour as an addiction. I will also put forward the notion of a *cultural shift* which occurs as the individual is forced to move from a worldview of the able-bodied to one of disability, as an explanation for *disability addiction;* this will help to locate *disability addiction* within the more generalized concept of addiction and serve as a basis upon which to apply a treatment modality. Finally, I will recommend a psychotherapeutic counselling process intended to support those individuals who fall within the "addicted" side of this scale.

To meet this goal, I will draw upon both qualitative and qualitative data. From a qualitative position that has been informed by a phenomenological perspective, I will discuss the conclusions that have emerged from the stories of support, loss and transition as told by three working age adults who have acquired significant disabilities (Breen, 2008). I will offer an analysis of these elements from a cultural perspective; specifically,

that the process of acquiring a disability forces a transition – a shift in cultural identity - from being a member of the able-bodied community to that of the disability community.

It is during this transition period, in which I believe that the newly-disabled adult can become "stuck", that the individual may develop a *disability addiction*. I use the term "stuck" to represent both a time and a place that is between two cultures; it is a state of limbo into which the newly disabled person has been cast as she is ejected from her membership in the culture of the able-bodied. However, she is not yet prepared or learned how to join her new culture of disability. It is a period of psychological trauma that, like the physical trauma of an accident or injury, may not necessarily heal itself without professional support.

As I will describe in more detail later in this paper, I have done considerable work with clients who have demonstrated a significant reluctance to consider how they may be able to re-enter a more normalized existence following the onset of a chronic illness or disability (CID). As I will describe below, I believe that these individuals have become addicted to their current state of behaviour as a means of meeting a variety of psychological demands in a manner that is similar to those who have acquired other behavioural addictions.

It has been my experience that at least some of these individuals who live with disabilities that have occurred during adulthood have, in a very real sense, become addicted to a self-image of helplessness and resignation as a solution to an unexpected and unwanted future which otherwise is seen as unmanageable. Many clients speak of difficulties in coping with a world that has, for them, been significantly altered by their chronic illness or disability. In addition, they speak of an ongoing sense of meaninglessness and loss of identity, especially those who have acquired a disability through a traumatic event.

Researchers have put considerable effort into trying to establish quantitative correlations between workplace injuries that have resulted in permanent disabilities and the time that it takes for these injured workers to return to work. There are numerous studies within the academic literature that have put forward combinations of variables associated with the successful return-to-work (RTW) of injured workers (Cheadle,

Franklin, Wolfhagen, Savarini, Liu, Salley & Weaver, 1994; Blackwell, Leierer, Haupt, & Kampitsis, 2002). These have been descriptive studies and include such diverse correlates as age, gender, attorney involvement and the relative size of the employing company. However, these studies have not looked at why these correlations might exist. Furthermore, they have not considered the importance of the meanings derived from their experiences which adults with acquired disabilities may connect to their successful rehabilitation. Finally, they have not considered whether these latter factors may influence the successful return to work of an injured worker and whether these may be used prescriptively to help meet this goal.

It should be noted at the onset that I have drawn heavily upon studies directed towards injured workers as being representative of the larger group of those with newly acquired disabilities. There are three reasons for this. First, a scan of the literature associated with acquired disabilities and rehabilitation reveals that much of the research in this area has focused on injured workers. Second, a return to employment is seen by many researchers as being particularly indicative of a successful rehabilitation (Elliott, Uswatte, Lewis & Palmatier, 2000; Livneh, 2001; Tan, 1997). Third, most of those who are of working age and who acquire a disability would prefer to return to work. This is evidenced by the significant body of research that shows a positive correlation between perceived Quality of Life (QOL) and employment status of those living with disabilities such as spinal cord injury (Hammell, 2004; Hammell, 2007). Since there is also considerable evidence that indicates that a significant proportion of these individuals do not do so, (Statistics Canada, 2008a), there may be another mediating and relational issue to consider; that of the individual's psychosocial relationship to his disability. This point assumes special significance when we recognize that the severity of the acquired disability is not necessarily the principal mediating factor associated with return to work (Aronoff & Feldman, 2000).

Finally, I will consider the special relationship that exists between adults with disabilities and the implications that this may have for psychotherapeutic counselling strategies when providing support through the cultural wasteland in which a person travels while acquiring an identity of disability. What are the constraints that hold the newly disabled person in this position of being "stuck"? More importantly, are there tools that may ease them through this period? To explain metaphorically, it is my contention

that the person who is "stuck" is standing atop a ledge of a burning building and has become so disoriented that she cannot recognize that there is a safety net waiting for her or that, in fact, such a thing as a safety net even exists. There is no turning back and, without support and guidance, there is nowhere to go. In the final section of this paper, I will offer a blueprint for that safety net. That blueprint includes the disabled counsellor.

2.1   WHO ARE WE TALKING ABOUT?

The most recent and comprehensive data collection tool of Statistics Canada, the 2006 Participation and Activity Limitation Survey (PALS), summarizes the definition of persons with disabilities as those who reported difficulties with daily living activities, or who indicated that a physical or mental condition or health problem reduced the kind or amount of activities they could do" (Statistics Canada, 2006a, p.1). The survey results confirm that the disability rate in Canada increases steadily with age. Among children aged 0 to 14, 3.7% reported a disability, with this rate rising to nearly 11.5% among adults aged 15 to 64 and to 43.4% among persons aged 65 and over. More than half (56.3%) of persons aged 75 and over reported having an activity limitation. It is the group of working age adults with acquired disabilities that I will be considering in this paper.

This definition that is used by the 2006 PALS survey adopts the concept of using functional and activity limitation domains to understand disability. As first introduced by the World Health Organization (2002), it is designed to focus on levels of health and functioning. The qualitative study mentioned above, which included a phenomenological consideration of the stories told by three adults with acquired disabilities, made use of a more concise definition of disability than was used in the 2006 PALS survey. However, it corresponds well to that used by the PALS survey (A. MacKenzie, Head of Research, Statistics Canada, personal communication, September-October, 2005). (See Appendix A for definition).

2.2   DISABILITY ADDICTION

Before I offer a detailed account of the term *disability addiction*, it will be useful to eliminate two potentially confusing considerations of the relationship between disability and addiction. First, I am not referring to the relationship between having a disability and

having a concurrent addiction to drugs or alcohol. Second, I am not referring to the notion of an addiction being a disability, such as is often considered within human rights legislation and various forms of insurance supports, especially as these relate to the addicted employee.

The manner in which I am using the term *disability addiction* is one in which the disability itself has the potential to lead to a state of addictive behaviour. For example, an adult who acquires a significant disability, such as paraplegia, often surrenders much or most of his ability to manipulate her environment, especially in terms of those individuals over whom he may have had some degree of authority or control. This loss is often exemplified by family breakup, loss of employment and income, (Strausser, 1995), and the creation of a new relationship of dependence on others, including outside support agencies such as Workers Compensation Boards and provincial Income Assistance programs. Anderson (1988), in a discussion regarding the relationship between stress and disability, notes that "chronic illness can precipitate changes in beliefs about the self…and about what can and cannot be controlled in life". (p. 5). He goes on to suggest a direct relationship between these changes in belief and the ability to control one's environment with negative changes in the individual's economic and family status. Robert Murphy, in his 1987 autobiographical account of his slow slide into quadriplegia, comments several times on how the adult onset of a significant physical disability typically leads to loss of social status, an economic decline and a struggle to maintain a positive sense of self-worth.

If we accept that the individual typically wishes to maintain or reclaim a position of personal control or self-efficacy following the acquisition of a disability (Strauser, 1995), there seem to be two likely alternatives to follow. The first is to follow a course of what would normally be considered rehabilitation, learning new ways to do the same things, modifying one's goals to accommodate one's current state, employment retraining, additional education, etc. This path is often difficult and fraught with the potential for setbacks and failures (Livneh & Evans, 1984). However, as with most learning strategies, small successes can become reinforcements for future efforts, motivation increases, more significant efforts are made and more successes follow. In many ways, this process can be considered as a parallel to the development of motivation as described by Miller and

Rollnick (1992), where this motivation is necessary to influence behaviour change among those with addictions to smoking, alcohol or drugs.

The second option available to the person with a disability is the one that may lead to addiction. I believe that some people, rather than take the often arduous and only partially compensatory route of rehabilitation, remain caught in another self-reinforcing, and, hence, potentially addictive, process. As described in detail below in Section 3.5, some individuals with recently acquired disabilities become "stuck" in the culture of the able-bodied, unable to move through this liminal period to the culture of disability. Rather than begin to accept that they are now of a different culture and begin to learn how to operate as effectively as possible within it, these individuals reject the dissonance and stress inherent in this transitional period (van Wormer & Davis, 2008), and become increasingly addicted to making use of others' perceptions of their helplessness and neediness to further their own ends. This process does not infer conscious volition. However, in a manner similar to those living within the thrall of other addictions, there is always a justification available for addictive behaviour. They are, as described by Mott & Gysin (2003) when referring to a Narrative manner of framing behaviour, exhibiting "stuck behavior" that would, according to the authors, "otherwise be labeled as addictive behaviour" (p. 10). Murphy (1988) explored the issue of cognitive dissonance with regard to disability by telling the story of a patient of Oliver Sachs, the well-known New York neurologist. That patient, who had lived through a particularly debilitating stroke, had lost the ability to get up from a sitting position. In addition, she could not acknowledge that she had suffered a stroke. When, as part of an examination, she was asked by Dr. Sachs why she would not stand up when he asked her to, she replied that she just did not feel like it.

The intent of the disabled individual is to recapture the degree of authority and control that was previously exercised by demanding that others view him as helpless and unable to exert self-efficacy, thereby causing the acquiescence of others to his or her unstated demands or, in other cases such as cited above, to go so far as to deny the disability. My argument is that this new-found control produces what Parker (as cited in van Wormer and Davis, 2008), when referring to sexual addiction, called "an intense adrenaline rush". It is this "rush" that I think may lead to a behavioural addiction tied to disability. As discussed by van Wormer and Davis (2008), the behavioural addiction of

gambling shows many biochemical similarities to those usually associated with substance abuse. "The anticipation of winning triggers a dopamine rush." (p. 303). This is analogous to the results obtained by those whose behaviour is based upon their *disability addiction;* in this context, winning the pot in gambling is exchanged for winning a degree of control over a situation. I have observed several people with disabilities who appear to derive great satisfaction in being able to control the behaviour of others to attend to them or otherwise perform tasks that were well within the capabilities of the individuals with disabilities.

In his editorial article, Theories of Addiction, West (2001) lists a variety of theories of addiction, several under the heading of Behavioural and Social Theories. It is this group that seems akin to my notion of *disability addiction.* As West (2001) notes, "Individuals who are particularly susceptible to the effects of a given stimulus, whether bio-chemically, psychologically or socially, or in need of those effects, would obviously be expected to be most at risk (of becoming addicted)." (p. 5). The group of individuals with recently acquired disabilities who have begun to rely on their disability as the means to control their environment and enhance their own self-efficacy and who end up being unable to control this behaviour, would appear to fall squarely within this cluster of susceptibilities.

Although I recognize that a *disability addiction* may not include the same level of "impaired control with harmful consequences" (West, 2001) as do addictions associated with substance abuse or even with those associated with gambling or sexual addictions, there do appear to be sufficient similarities between those addictions and that of *disability addiction* to consider it a true addiction, not merely to be "like an addiction" or even a "disability related addictive behaviour". I acknowledge that it may be easier to demonstrate merely a similarity or a parallel between what I refer to as a *disability addiction* and other, more mainstream concepts of addiction rather than attempting to place the former squarely within the larger concept. However, success in the former case would be a pale victory. It would rob the notion of *disability addiction* of a certain degree of legitimacy and would, to its detriment, relegate the idea to the status of an inconsequential footnote to the larger issue of addiction. My personal and professional experience leads me to argue for a more legitimate position for *disability addiction* and that is the case that I will attempt to make throughout this paper.

At this point, it will be useful to pause for a moment and consider where or whether *disability addiction* fits within the several theories and models of addiction that have been developed over the past century. I will provide a brief gloss of two separate ways of categorizing these sets of theories to illustrate the range and diversity of notions that have been developed to explain addiction.

The first, offered by van Wormer & Davis (2008), ranges from an early 20th century model of individual moral laxity to the disease theory of addiction, the latter of which includes such examples as Alcoholics Anonymous and the Minnesota Model, to more current explanations that eschew theoretical underpinnings in favour of practical, pragmatic behavioural interventions including those found under the general rubrics of Harm Reduction and Motivational Interviewing. A review conducted by West (2001), categorizes addiction theories into five general models. These include a combination of biological, social or psychological processes, the relationship between particular stimuli and the propensity for addiction, individual susceptibility to addiction, the relationship between addiction and environmental and social conditions, and, finally, theories that cut across the others to focus on the concepts of recovery and relapse. This latter group includes the Transtheoretical Model of change, upon which Motivational Interviewing was developed.

In terms of how one could place *disability addiction* within these matrices, my response is that it would appear reasonable to look to those notions that focus specifically on attitudinal and consequent behavioural change without particular concern regarding causation. I suggest this course for two different reasons. First, there is the matter of volition. In the case of *disability addiction*, there is no antecedent behaviour which has brought about the addiction. One could argue no more successfully for a disease model than for one of a lack of moral rectitude. There is no behaviour that inadvertently or otherwise brings about the disease, nor is there any evidence for an *a priori* moral failing; and to consider that a moral failure would arrive as an adjunct to disability is not worth consideration. Rather, this addiction lands upon the individual unannounced, unanticipated and undeserved; more akin to the 16 ton weight of Monty Python renown than as the result, probable or otherwise, of any prior behaviour.

The second reason for my position is raised by the question of whether the

individual's behaviour following an acquired disability could not be seen as the behaviour that leads to the potential for addiction, similar to periods of increasing alcohol consumption or one of the behavioural addictions such as gambling or shoplifting. I would suggest, as I discuss in more detail below, that those who acquire a *disability addiction* do so due to the culture shock of the event itself. I would suggest that we can safely ignore the aetiology of addiction *per se* and find it more productive to concentrate on *disability addiction*, its immediate cause that, as discussed below, is associated with a traumatic shift in culture, and a two-part recommendation for its amelioration – Motivational Interviewing provided by a counsellor with a disability.

As noted in van Wormer & Davis (2008), "researchers are learning that all addictions are more alike than different." (p. 283). In addition, some recent theories of addiction point to the reinforcing properties of brain neuro-chemicals such as dopamine as being instrumental in the development of addictive behaviour (Lyvers, 1997). It is these chemical changes, brought on by repeated and self-rewarding behaviours, which become part of a self-perpetuating spiral of physical change within the brain that leads to an increased need for these behaviours. There does not appear to be any available research that confirms or denies my hypothesized relationship between *disability addiction* and the more mainstream set of addictions. However, the neuro-chemical model of the development of self-reinforcing behaviours could apply equally well to *disability addiction* as it does to other, more well researched addictions.

Regardless of whether this behaviour is maintained to continue receiving an internal "rush" associated with a degree of regained control and authority, to maintain an elevated level of pleasure enhancing chemicals such as dopamine, to foster a sense of control over one's life, or even brought about through some unknown process associated with the "disease model" of addiction, I believe that it falls within a range of behaviour that can fairly be considered addictive.

It should also be noted that that there is at least one significant difference between *disability addiction* and any other form of addiction. Typically, drug, alcohol and behaviour addictions come about through a self-reinforcing process of behaviour that has been initiated by the individual. In the case of *disability addiction*, the addictive behaviours occur as a result of an external event, whether illness or injury, that in all but those

involving self-inflicted harm, befell the individual through no intent or self-agency. The difference, therefore, is that the traumatic event provides the connection, through an acquired disability, to the potential for *disability addiction*. To illustrate, the difference between a *disability addiction* and one such as alcoholism is that the latter may develop within an individual over a period of time associated with increasing levels of alcohol consumption, while *disability addiction* may occur within the individual with an acquired disability without any intermediate stage of volition.

The significance of this difference will become more apparent below when I examine the theoretical concepts associated with understanding and possibly providing relief from this addiction; only by first considering the implications of this trauma can we understand and explore the efficacy of the theoretical models to be discussed within the counselling model to be explored.

The significance of the trauma associated with the acquisition of a disability is acknowledged by Wald & Alvaro (2004), who noted that the psychological trauma associated with the work-related amputation of a limb can include "anxiety reactions including post traumatic stress disorder, depression, grief, body image disturbances, and chronic pain." (p.6). Within this context, the principal difference between *disability addiction* and other addictions is that the former is brought about by an event, while the other forms of addiction are brought about by a process. Although the manner in which the addiction is created is different, the behaviours that occur as a result do not seem to be substantially different. As with other addictions, *disability addiction* results in "continuation despite negative consequences" (van Wormer & Davis, 2008, p. 7).

Although I have demonstrated above a number of similarities and differences between *disability addiction* and other addictions, there is still one other area to consider associated with the cause of addiction that appears to bring *disability addiction* more squarely within the more generalized concept. That is the notion of *stress* that appears generally to underpin all addictions, whether those of substance or behaviour. Although the choice of addiction may not be predictable, these behaviours all appear to be connected to *stress* within the individual. von Warmer & Davis, (2008) cite several studies (Maté, 1999; Slutske, Caspi, Moffitt & Poulton, 2005; Preuschoff, Bossaerts & Quartz, 2006) which discuss the positive relationship between various addictions and underlying

anxiety and stress; the latter of which draws this connection within the context of a tanning addiction which had been earlier observed by the authors in a Norwegian treatment centre for alcoholics.

Through a review of another study conducted by the National Center on Addiction and Substance Abuse (2003), von Warmer & Davis, (2008) note that "the impact of stress and trauma" (p. 286) are significant risk factors for substance abuse and eating disorders. When considering women with bulimia, these same authors found that "because compulsive eating stimulates a rise in the levels of mood enhancers in the brain, food can serve as a drug to curb the feelings of shame, self-disgust, and depression that often accompany compulsive eating problems" (p. 291).

3.0   CONCEPTUAL CONTEXT

The conceptual context within which I have positioned this study is split into two sections. The first section is a review and analysis of the literature associated with several aspects of acquired chronic illness or disability. The specific topics include:

- return-to-work and associated variables;
- the relationship between chronic illness or disability and psychological trauma:
- the meaning of meaning;
- adjustment to disability;
- disability and culture.

In the second section, I will offer a brief overview of the data developed and the conclusions reached within a qualitative study which I conducted earlier this year, entitled "What stories of support, loss and transition are told by employed adults with acquired disabilities?".

The first of these topics within the academic literature is the work which considers the connections between the successful return to work of injured workers and the specific variables which may influence this relationship. It should be noted that the literature focuses on the subgroup of injured workers within the larger context of adults with acquired disabilities. This is understandable since much of the research in this area is associated with how quickly or whether injured workers can return to employment and the consequent financial impacts on insurance and workers compensation organizations.

However, since injured workers tend to have more financial support than most others with acquired disabilities, successful employment by the latter group would appear to be more of a challenge, rather than less.

In the second area, I examine the impact that the trauma of an acquired chronic illness or disability can have on how the individual sees herself in relation to her environment. This issue comes to be of critical importance when considering that the trauma has been brought about by external forces and occurs at an adult stage of life when these relationships have already become well established.

In the third area of research review, I examine the relationship between the individual, his environment, and the meanings that develop from that relationship. Specifically, I will consider how a change in this relationship may cause the individual to become "stuck" in a place between the meanings that had previously been used to interpret this relationship and the yet unformulated, new meanings that would otherwise be incorporated into one's self-image as a person with a disability.

In the fourth area, adjustment to disability, I will consider the several theories of adjustment that have been developed to monitor and describe the process through which individuals with acquired chronic illnesses or disabilities typically progress from the point of illness or injury to a state of coping or acceptance.

The fifth area focuses on the connection between disability and culture, with a particular focus on the effect that being "stuck" between the able-bodied and disabled cultures may have on the individual. I offer a review of each of these below.

It should also be noted at this point that much of the research discussed below, especially that section that is immediately following, is presented to illustrate how I have attempted to synthesize a variety of unrelated material to arrive at the topic that this study will consider. As will be noticed by its absence, there does not appear to be any scholarly information available that directly supports the proposition that acquiring a disability is analogous to undergoing a shift in cultural membership or, indeed, that it may lead to *disability addiction*. Since I am unable to offer others' clear, concise images of

sections of the path to be taken, I thought that a detailed map of the countryside through which this path will meander will be of some value.

3.1   RETURN-TO-WORK AND ASSOCIATED VARIABLES

As will be noted below, there is a significant body of scholarly material that speaks to the relationships between successful, often equated to earlier, return-to-work (RTW) of injured workers, and a host of variables that appear to have various degrees of positive correlation(Cheadle, 1994). There is also a body of material that focuses on the relationship between counselling and people living with chronic illness or disability (CID). However, there is little that considers counselling directly associated with acceptance of disability, and none was found that addresses the specific issue of the disability-related characteristics of the counsellor.

The characterization of the variables that affect time loss of injured workers has been presented through a variety of broad analyses of psychosocial, demographic and other individual characteristics as compared to time-loss. For example, in a large scale study of 28,473 workers' compensation claims filed in Washington State from 1987 to 1989, Cheadle (1994) notes that "older age, female gender, and a diagnosis of carpal tunnel syndrome or back/neck sprain significantly predict longer duration of disability" (p. 194). He also found a number of other factors that showed a lesser but noticeable relationship than those noted above. This latter group included "divorced marital status, firm size of fewer than 50 employees, higher county unemployment rates, and construction and agricultural work." (p. 194). Blackwell, Leierer, Haupt & Kampitsis (2002) found a different set of variables associated with "age, education, attorney involvement, mandated vocational rehabilitation, and timely provision of services" (p. 108) that served to offer a positive relationship between workplace injury and the extent of time-loss observed before return to work.

In a review of studies that had measured the duration of time-loss following a workplace-related illness or injury, Krause, Frank, Dasinger, Sullivan & Sinclair, (2001) recorded 26 variables that had been found to affect return-to-work times. Interestingly, several of these variables were found, in different studies, to either impede or accelerate the return to work period. Variables included age, marital and family status, union

membership, history of mental illness, smoking, occupation and general health. Participation in psychotherapeutic counselling was not mentioned. Most interestingly, the studies that were reviewed presented a host of variables associated with return-to-work that were clearly posited prior to the initiation of the actual information gathering processes; there was no mention within the review of participants offering their own thoughts about the factors that either accelerated or hindered their return to employment. These variables are, at times, contradictory, and generally ignore the psychosocial issues associated with return-to-work.

In a study that examined what clients find most helpful in psychotherapy, an analysis by Levitt (2006) revealed what she referred to as six clusters of positively associated characteristics. These included commitment to therapy, a caring therapeutic environment, out-of-session processing by the client, a trusting therapeutic relationship, characteristics of the therapist, and the therapeutic intervention style. Of particular note was the fact that there was no mention, even within the cluster that described characteristics of the therapist, of personal characteristics such as disability. Rather, these characteristics focused on the degree of purpose exhibited by the counsellor and by his or her apparent demeanor of caring. Although this is a purely speculative comment, it could have been that none of the counsellors exhibited physical disabilities or that the author saw no reason to pursue this line of inquiry.

The above examples of quantitative inquiry into the relational variables associated with acquired disability serves two purposes. First, it clearly identifies the hypothesis-driven nature of this form of inquiry. As discussed in detail by Hammell (2007), one of the principal difficulties with this sort of inquiry within this field is that it is driven by preconceived sets of variables to be studied. If the researchers fail to consider those variables that are of specific concern to particular individuals, those variables are not measured and, hence, do not become part of the conclusions of the study. For example, if "pain" is not a variable to be measured in a study that seeks to correlate several personal attributes with early RTW, it is not factored in to the final analysis of those variables that affect this result.

However, the relationship between psychosocial attributes and the return-to-work process has been acknowledged by Wald & Alvaro (2004). They wrote that "the

rehabilitation field has recognized the importance of psychosocial variables in adjustment from physical injuries and that these factors play a much more important role than objective physical injury variables." (p. 6). In addition, Wald & Alvaro (2004) acknowledge that the psychological trauma associated with the work-related amputation of a limb can include "anxiety reactions including post traumatic stress disorder, depression, grief, body image disturbances, and chronic pain." (p.6).

The acknowledgment of psychological trauma as being associated with work-related injury is useful in that it at least supports the proposition that some method of psychological intervention may be required. Of particular note is that the focus of these studies is on what variables are linked to early returns to work rather than on what may be psychologically beneficial to the worker. Even the above mentioned acknowledgments of the connection between RTW and the existence of psychological trauma do not address the cause of these symptoms and effects nor the manner in which they may be most successfully ameliorated. I have included these several studies above, which appeared to me to be typical of the work being done in this area, to demonstrate the descriptive nature of current research and to point out that there appears to be a space available for research and theory development that would result in a more prescriptive approach to resolving the outstanding issues associated with acquired chronic illness and disability (CID).

3.2   RELATIONSHIP BETWEEN CID AND PSYCHOLOGICAL TRAUMA

If we accept the notion that there may be a relationship between psychological trauma and an acquired chronic illness or disability, the next step is to examine what that relationship may be and what causal links may be associated between these two variables. The change in relationship between the individual's sense of self and her environment, brought on by the onset of the chronic illness or disability, appears to be a fruitful starting place for this examination. This relationship shift, coming at a time that is well beyond the psychologically formative years postulated by stage theorists such as Freud, Jung and Adler, leads us to consider a theory of human development that allows for ongoing growth, development and change for this phenomenon.

Since the circumstances that have led to this change in perception have befallen individuals who are already functioning as adults within a social and vocational environment, it seems prudent to consider an explanation that incorporates the inter-relationship between the environment and the self as well as one that understands human development as being a life-long exercise into any explanation of this sudden change in self-perception. Such a model is found within Life-Span Development Theory. As noted by Gergen (1980), "shifting socio-historical circumstances" (p. 36) play a significant role in life-span development. Although Gergen's interest is in the change in relationship between the self and the environment when there are changes in the environment, the relationship is equally changed when there are changes in the self.

This notion is reinforced by Guidano (1987), who sees psychological dysfunction as the result of an overly rigid maintenance of one's current *self* (italics added) in the face of environmental stimuli to the contrary. He describes the person as, inherently, a problem-solver, and states that knowledge is a "theory of the environment to which the organism has adapted". (p. 7). These descriptions of human development appear to take into account the two most salient aspects of the client group under consideration. These are their pre-injury, functional adult relationships to the world and the sudden change in those relationships brought on, not by a change in their environment, but by a profound change in their *self* or at least in their interpretation of their *self* and how it relates to their environment.

This discordance between the client's view of her *self* pre-CID and post-CID also fits well into a Rogerian understanding and explanation of what he refers to as psychological problems. Rogers' notion of *incongruity* as the gap between what he calls the *real self* and the *ideal self* (Rogers, 1956) is not dissimilar to the relationship described above by Guidano.

Each of the explanations above, although they focus on the changing relationship between the individual and the environment, assumes that the change in relationship is due to a relatively constant *self* struggling with a changing environment. However, Parker, Schaller, Hansmann (2003), argue for a model of understanding the psychosocial adjustment to disability that is based on Chaos Theory, which postulates that significant changes in the individual's behaviour, thoughts or feelings may be precipitated by

relatively small differences or changes in the psychosocial position from which the persons enters his or her reality of CID. The authors maintain that changes in the relationship between various impacting variables such as stress and psychosocial instability may create wildly different results, depending on the relative position of a third axis such as the initial psychological stability of the individual.

Each of the above models that has been developed to explain the discord between the *self* and her relationship to the environment following the acquisition of a CID either explicitly or implicitly raises the issue of the discord in meanings created by that CID. A more detailed analysis of that concept is offered below.

3.3   THE MEANING OF MEANING

The concept of meaning, as it is imposed by the individual on her interaction with the external world, is considered by theorists within the human development model of Symbolic Interactionism. Beginning with George Herbert Mead, the notion of the *self* is seen as a developing construct that is inextricably linked to the accumulated meanings that develop through the relationship that the individual has with her environment. According to Mead (1925), the "environment does not exist in the consciousness of the form as a separate milieu, but the consciousness of the organism consists in the fact that its future conduct outlines and defines its objects." (p. 256). Mead's idea of the *self* as being comprised of "future conduct" fits well with the concept of a cultural shift, in that it explains the effect that a consideration of the future has on the *self* in the present. In this case, that consideration was frequently voiced as one of trepidation and fear.

Mead also equated actions, speech and one's own thoughts, insofar as these can all be forms of communication, with those objects that, through that communication, make up our environment. As Mead (1925) explained, "it is not necessary that we should talk to another to have these ideas. We can talk to ourselves, and this we do in the inner forum we call thought." (p. 272).

According to Manis & Meltzer (1972), a significant tenet of Mead's theory was that it moved beyond a behaviourist approach to include what Meltzer called "*covert*

activity" (p. 4) which allowed for the thoughts of the individual to be included in the compilation of social acts which make up human behaviour. This behaviour, the authors go on to discuss, is differentiated from the behaviour of other, lower animals by the human response to the intention of others. A human individual's action and corresponding relationship to another is predicated upon the intention of another.

To engage in shared behaviour, groups of people must have similar understandings of these interpreted stimuli or imaginative activities. Without these shared meanings, there could be no common expectations and understandings. In addition, Manis & Meltzer (1972) note that Mead's concept of shared meanings applies within the individual as well as between the individual and others. Therefore, meanings are equally available within thoughts as they are within language. Either can take on the characteristic of a *significant symbol* and, therefore, enter the realm of perceived objects. If we accept this explanation of the *self* as including thoughts, one's present thoughts being of the future could explain an immediate difference in the meanings assigned to them.

Finally, Manis & Meltzer (1972) turn to a discussion of *objects*. Mead, they explain, views the environment as a compilation of the function of each individual's determination of *objects*. For each individual, an *object* is perceived only as its qualities impact on the individual's plan of action towards or about that *object*. These *object*s are largely shared by a group of individuals and make up what Manis & Meltzer (1972) call the *effective environment*, or "common patterns of activity of individuals." (p. 15). This collection of *objects* as a *common pattern of activity* begins to look very similar to the underpinnings required to sustain a culture, such as that of disability.

According to Blumer (1986), Symbolic Interactionism is derived from three basic premises. These are that:
- people react to things based on the meaning that those things have for them;
- the meaning of those things is derived from the social interaction that people have with each other;
- these meanings are derived from interpretations made by the person who deals with these things.

Blumer notes that the "things" that he refers to can include everyday objects and people as well as more conceptual "things" such as institutions, individual characteristics and communications. What leads to a separation of Symbolic Interactionism from other psychological and sociological explanations of the relationship between people and the external environment, or *objects* is that "the meanings that things have for human beings are central in their own right" (p. 3). This separation is completed with the understanding that Symbolic Interactionism does not assign these meanings to either something inherent in the *objects* or to what Blumer calls the "psychical accretion" brought forward by the individual who relates to the *object*. Instead, meaning arises "out of the ways in which other persons act toward the person with regard to the thing." (p. 4).

Blumer reiterates Mead's position that the *self* must be considered as a process of self-interaction. In other words, "a human being may become the object of his own action." (p. 62) by relating to *objects* whether internal or external, in a way that is beyond merely responding to stimuli. By creating meaning within this relationship, the individual initiates an action based on an interpretation of these stimuli. None of this, however, implies that the person will necessarily choose the best action. According to Blumer, the individual may fail to note key information, exercise poor judgment or misinterpret information.

It is this poor judgment or misinterpretation of information that may be at work within the person with a newly acquired disability. Prior meanings, which have been developed over a considerable period of time, are now demanding reconsideration. In his discussion of the *self*, Cooley (1902) notes that when an individual believes that his image is somehow depreciated in the eyes of others, that person succumbs to "shame, confusion, abasement, humiliation, mortification, meekness, bashfulness, diffidence, shyness, being out of countenance, abashed or crestfallen, contrition, compunction remorse and so on." (p. 213). This change in perception may be legitimately based on the interpretations of others or only on the change in meaning ascribed to by the individual; however, the result is the same. Even if our reason tells us that nothing has changed, "dread and doubt" (p. 217) will not allow us to believe it; the meaning that we have previously ascribed to our perceptions of ourselves by ourselves and others have been overshadowed by these new circumstances.

Cooley's discussion about the layers of meanings is illustrated by his notion of how we can often see ourselves as a reflection of how we are perceived by others, what he called "the reflected or looking-glass self." (p. 152). As others perceive us, we interpret their perceptions and assign ourselves an emotional response to this interpretation – from pride to shame. An acceptance of these latter emotions can also lead to a withdrawal from others. As Cooley (1902) notes, this withdrawal can be physical or can lead to a more subtle level of withdrawal "by curtailing ambition, by trimming down one's idea of himself to a measure that need not fear further diminution." (p. 220).

Goffman (1959) makes use of a dramaturgical metaphor to describe the *self*. We each, either individually or in teams, inhabit a life stage on which we perform. In addition, we each have "secrets". These fall into three categories – dark, strategic and inside secrets – each of which may or may not be known by or disclosed to others not on the individual's team. These images of "secrets" and their corresponding availability to others appear to be analogous to the Symbolic Interactionist concept of "meaning" and how it is created and transformed on an ongoing basis.

Goffman (1959) also speaks of individuals taking on "discrepant roles" (p. 151) that can lead to their becoming "non-persons" (p. 151). If the metaphor is sufficiently deconstructed, Goffman's image is one of the individual who is now incapable of fitting into his original role as "actor" or a new role of "audience". This loss of grounding or position is reminiscent of Cooley's notion of the individual's "depreciation" that is brought on by a negative change in a perception of the *self* by others, or by the individual himself.

Goffman's imagery appears to demonstrate the transitory nature of the meanings created from the interaction of the *self* with her environment. What happens when these meanings transform into conflicting positions will be discussed below.

3.4   ADJUSTMENT TO DISABILITY

According to Livneh & Antonak (1997), acquiring a physical disability begins a "chain of psychological reactions in the affected individual, viewed as a special case of coping with a traumatic life event" (p. 17). These psychological reactions have been characterized within several models including pendulum models, stage models, and chaos theory, (Parker, Schaller & Hansmann, 2003). Each of these has been developed to offer

either a theoretical understanding of the process that an individual with an acquired chronic illness or disability undergoes or as a framework for psychosocial intervention.

The stage model or theory is perhaps the most well-known of these; several variations of this model have been extensively reviewed and incorporated within a wide array of research findings into the specific model put forward by Livneh & Antonak (1997). These authors put forward a stage model with eight phases. These include - shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement and adjustment. In a later publication, Livneh (2001) increased the complexity of the explanation by including the idea of antecedent variables associated with the individual as having additional and complicating effects on the movement through the stages.

The stage model has come under a variety of criticisms (Parker et al, 2003). These include those from the pendulum theorists who argue that a stage theory does not sufficiently allow for a repeated or ongoing cycling through stages as observed in some studies. Others criticize the stage model on the basis of the reliability of the research data underpinning the theory. Much of the data, according to these critics, suggests that there is a paucity of evidence that certain phases, especially denial and depression, are necessary or even frequent responses to disability (Wortman & Silver, 1989). These authors maintain that a lack of several or most of the phase responses to disability does not necessarily imply a degree of pathological response.

A second area of criticism to the stage theory comes from the very recent work of Livneh & Parker (2005) themselves as these authors expand upon the work of chaos theorists Parker et al, (2003). More recently named Chaos and Complexity Theory (CCT), this model rejects the linearity of stage theories and the periodic nature of pendulum theories, including their comcomitant lists of specific necessary and sufficient stages, as an explanation and guide for the journey between the onset of an acquired disability and a resulting level of acceptance. Instead, CCT posits that human response to an acquired disability takes place within a non-linear, self-organizing, open system of behaviour that characterizes all human responses within the ongoing and changing relationship between the self and the environment (Livneh & Parker, 2005; Parker et al, 2003). The proponents maintain that, within systems such as these, response to increased chaos (e.g. trauma)

typically generates increased levels of anxiety which, in turn, cause the individual to pursue adaptive forms of behaviour that result in an ultimately more stable and adaptive level of functioning.

Two points about CCT are especially worthy of note as they apply to the thesis of this paper. First, the psychosocial adaptation that follows the onset of an acquired disability includes an interaction of three components. These include "cognitive appraisals, such as appraisals of loss; emotional experiences, such as experiences of anxiety and sadness; and behavioural responses, such as retreat from social encounters" (p. 22). Second, following the CCT notion that very minor adjustments to a non-linear, open system can result in significant variations in result, rehabilitation interventions provided early during the period of chaos that follows the onset of an acquired disability "could quickly transform into long-term and more fundamental behavioural changes and life pursuits (Livneh, 2005, p.23).

3.5 CULTURE AND DISABILITY

Each of the above descriptions has, as a basic premiss, the notion that there has been an immediate change, at least at the cognitive and emotional levels, between the individual and his relationship to the environment. Furthermore, this change has introduced some form or degree of trauma, dissonance or chaos into a previously held, relatively stable relationship. The next issue to be considered is whether that change in relationship can be associated with a specific variable that will serve both a theoretical and practical function.

My observations have led me to believe that this change in relationship is brought about by a change in cultural membership; the individual has given up his or her membership in the culture of the able-bodied and has been thrust unawares into the culture of disability. Furthermore, this cultural shift is no less traumatic than would be waking up tomorrow as a member of a different ethnicity or in a location where no one speaks your language.

The literature presents a variety of models that embed the notion of disability within the concept of culture. Peters (1996) discusses five different approaches that have

been used to define the modern categorizations of disability. These include a social model, a minority group approach, a category of social policy, an outcome of definition and, finally, as a cultural categorization. This latter model is perhaps the most interesting in that it does not require membership being imposed by the larger community through oppressive or bureaucratic process but rather through choice or recognized commonality.

Conyers (2003), in a discussion about the relationship between disability and culture, puts forward the notion that disability culture exists, not only for the Deaf community, which shares a common language, but for all of those within the disability community at large, which shares common worldviews and ideologies.

Unfortunately, the literature seems focused on what makes up a culture of disability rather than how one becomes a member. The relationship between the acquisition of a CID and the psychological shift, its concomitant stresses, and the psychotherapeutic support which may smooth the transition period required to successfully join this cultural group are not addressed. It is this transition period, in which the person with an acquired disability may become "stuck", that requires further investigation. What are the constraints that hold this individual in this position? To explain by analogy, it is my contention that the person is standing atop a ledge of a burning building and has become so disoriented that he cannot recognize that there is a safety net waiting for him or that, in fact, such a thing as a safety net even exists. There is no turning back and, without support and guidance, there is nowhere to go.

4.0   STORIES OF SUPPORT, LOSS AND TRANSITION

The data and conclusions presented in this section were derived from a qualitative study that I carried out earlier this year. Entitled "Stories of support, loss and transition told by employed adults with acquired disabilities", this study was intended to explore the meanings made of acquired disabilities. The inclusion of the details of this qualitative study within this paper is intended to serve as a practical filter for the various theoretical positions put forward above. In addition, it will help to meet the difficulties associated with relying too heavily on quantitative studies to explore the possibility of new theoretical possibilities. As noted by Hammell (2007), "quantitative methods are…best suited to studying relationships between variables that are already well known…This would seem to

support an exploratory, rather than a hypothesis-driven approach to researching an issue that is as complex as QOL (of individuals with spinal cord injuries)" (p. 125).

Although I recognize that this study has not been peer-reviewed or published, there appear to be several conclusions available from it that will at least serve to bolster, if not confirm, the recommendations that I put forward in the last section of this paper. In addition, it serves to foreground the discussion regarding the potential value of making use of a counsellor with a disability to assist those "stuck" between two cultures. As noted above, there does not appear to have been much consideration of this option within the research literature.

The study included a purposive sample of three adults with acquired disabilities. All participants were males. Each advised me prior to their interview that they believed that they fit within the definition of disability provided to them, (See Appendix A). Interviews ranged in duration from 40 minutes to 75 minutes. Although I sought equitable gender representation for the study, given the small number of subjects and the greater number of males of working age with acquired disabilities (Statistics Canada, 2006), gender parity was not attained.

Each of the participants had been employed for at least three years following the acquisition of a disability, with one being employed for approximately 20 years. Each had required at least six months of rehabilitation following their accident/injury. I assigned the pseudonyms of Bob, Dan and Larry to the three participants. Bob is 47 years old and was disabled in a motorcycle accident. He is a quadriplegic. Larry is 57 years old and was disabled in a diving accident. He is a ventilator-dependent quadriplegic. Dan is 31 years old and was disabled through a brain haemorrhage. He reports a loss of concentration, ongoing fatigue, and difficulties with balance and vision.

I selected an approach that was informed by phenomenological research processes and intentions. This decision was based on the consideration that the several subjects to be interviewed have all experienced the same phenomenon - that of acquiring a disability, undergoing a prolonged period of rehabilitation, and re-attaching to the labour force. As pointed out by Creswell, 2007, the phenomenological approach "provides a deep understanding of a phenomenon as experienced by several individuals. Knowing some

common experiences can be valuable for groups such as therapists…" (p. 62). These key attributes of a phenomenological study fit well with the goals of this study.

The principal method of data collection was individual, semi-structured interviews with the participants. In an effort to most realistically understand the lives revealed through this research (Creswell, 2007; Hanley-Maxwell, Al Hano & Skivington, 2007), I approached this process from a perspective of developing a "thick description" (Geertz, 1973) of the experiences shared by the informants. To "thicken" the descriptions offered by the participants, I asked, on several occasions, for each to provide additional information on particular topics, especially about how they felt about the specific topic under consideration.

Prior to each interview, I advised each participant that I was interested in hearing their stories as a way to make use of their experiences to benefit others who had not yet been able to move back into employment.

I began each interview by asking the participants to tell me the details of how they acquired their disability. Although I intended to use a variety of other prepared questions to encourage discussion, I found that the participants, to a large degree, moved to additional topics of their own accord. I also made an effort to bracket out my own experiences in order to hear the stories of the participants from a new and non-judgmental perspective.
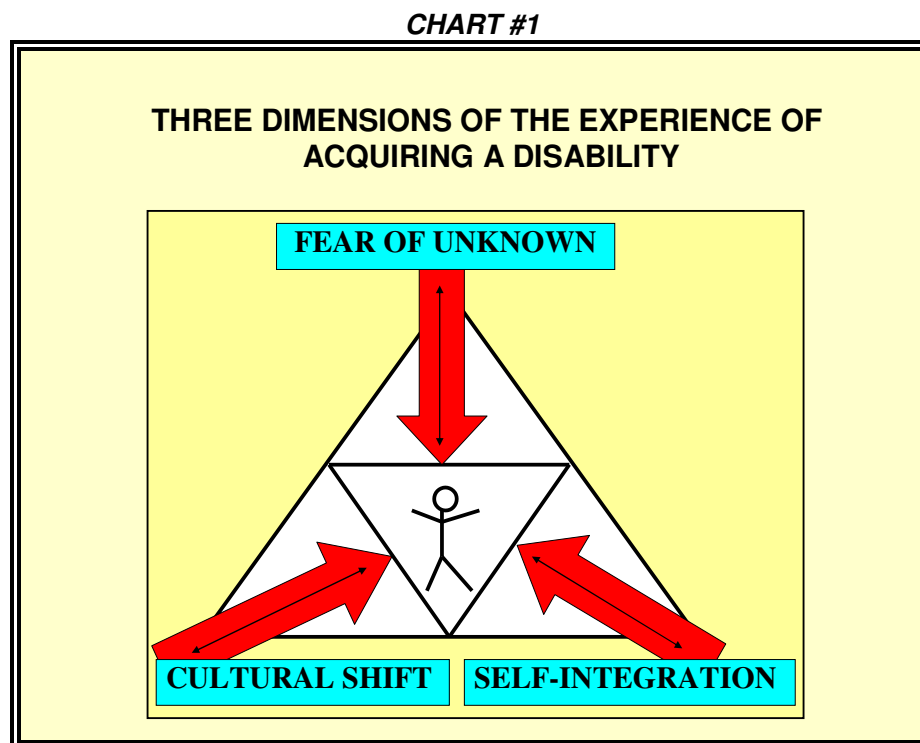
Although I recognized that it could be difficult or impossible to completely remove myself from the data and its interpretations offered by the participants (Creswell, 2007), I made efforts to not inject my own understanding of the several topics discussed by the participants at least until after they had exhausted their own perceptions. This latter point was of particular salience within one of the interviews in which the participant was clearly looking for my perspective on the topic of revealing the particulars of one's disability to others.

I purposely did not ask the participants if they believed that having access to a counsellor with a disability would be of value for those who had acquired a disability. I was more interested in hearing their stories with as little prompting as possible. I also

believed that this question would be begging a particular response since I was, in essence, describing myself.

4.1   RESULTS OF QUALITATIVE RESEARCH

From the three interviews, I extracted 137 phrases and statements which clustered into eight themes. The first three themes were those that most immediately appeared from the data. These are represented below as three forces that come to bear on the individual as he acquires a disability.

CHART #1

THREE DIMENSIONS OF THE EXPERIENCE OF ACQUIRING A DISABILITY

FEAR OF UNKNOWN

CULTURAL SHIFT   SELF-INTEGRATION

The remaining five themes were developed as a result of further data coding and classification. A representation of all eight of these themes and the number of their related phrases and statements is shown below.

CHART #2

THEMES AND RELATED PHRASES & STATEMENTS					
#	THEME	LARRY	BOB	DAN	TOTAL
1.	Cultural Shift	4	6	5	15
2.	Fear of Unknown	3	2	2	7
3.	Self-reintegration	5	5	2	12
4.	Comfort with Others with Disabilities	4	11	5	20
5.	Support by Others	8	7	5	20
6.	Shattered Reality	5	9	19	33
7.	Institutional/Bureaucratic Barriers	1	2	10	13
8.	Opportunity for Growth	9	3	5	17
	TOTAL	39	45	53	137

FIRST Most commonly referenced.   SECOND Second most commonly referenced.

4.2 THEMES

I will briefly discuss each of the eight themes below, offering examples of key phrases and statements as well as my comments about the relationships between the themes and the observations made by the participants. When referring to comments made by individual participants, I will use their pseudonyms – Bob, Dan and Larry.

4.2.1 CULTURAL SHIFT

Each of the participants spoke about how their normal ways of behaviour and relating to their environments changed following their disability. Larry, who was injured in 1968, spoke of a total change in his reality. "(I was) in Institute 51 from the polio days. I was there for several years…38 people in an open ward." Bob, who was injured in 1978, had vivid reminiscences about his feelings of being "transported into a different country with, not knowing what to do, where to go, what the language was, being lost." Dan, who acquired his disability in 2004, spent considerable time talking about the changes in his life and his outlook. "My neurologist says that…this is your life now. (I have) a different view of the world." He also noted that the differences in his life are so profound that he sees himself as a different person as compared to who he was before his disability. "I don't know the other guy. I know me now."

4.2.2 FEAR OF UNKNOWN

All three of the participants discussed the fears that had been created by their disabilities. Two of them, Larry and Bob, spoke of the fears that they lived through shortly after their accidents and during their extensive periods of rehabilitation. Bob commented that "I was laying there for five weeks with, you know, 50 pounds of weights hanging off my neck…(I was) thinking what the hell's going to happen to me. I was really, without admitting it, scared to death."

Dan spoke of his ongoing, present day fears. "I keep waiting for the other shoe to drop. I keep waiting for the fall."

4.2.3 SELF-REINTEGRATION

Larry discussed how he had begun to come to terms with his disability by helping others in similar situations. "We have a desire to give, to the people we love, to our community, to our society…I think that's, when you feel that that's lost, that you've lost one of the bases of life….seeing a glimmer of what I could contribute rather than what I'd lost was the motivating factor (to) what I could get back." Bob spoke about how he forced himself to face his difficulties. "Every day was a challenge but it was enough that you met those challenges, overcame a lot of them. So you got more and more confident. Took a lot of work but still you did it." Dan referred to a motivational story about Sir Edmund Hillary who, when asked why he climbed Everest without oxygen, thereby putting his life in additional jeopardy, responded by saying that didn't go up there to die, he went up there to live. Dan concluded with "You have to live, you have to try to live or give up, well, you become an old person, right, who just sits in his seat and dies."

One of the most interesting points about all three of these references to self-integration was how each of the three moved back and forth between using the pronouns "I" and "you" to describe themselves when telling these stories. Perhaps this was a symbolic representation of an ongoing struggle with reintegration.

4.2.4 COMFORT WITH OTHERS WITH DISABILITIES

Each of the participants acknowledged a high degree of comfort in terms of associating and communicating with others with disabilities. Dan acknowledged that he

had given this issue considerable attention. "At first it's odd but when you start getting to know other people (with disabilities), it's cathartic. It's like, oh, thank God, someone else deals with this as well." Bob talked about his experiences during rehabilitation. "Everybody's in there, and you're all, sort of cohorts, just trying to cope with this devastating thing and, you know, you're talking." Larry also talked about his time during rehabilitation. "I guess my biggest rehab probably was with people who lived there long term… So, the biggest rehab was probably the peers, their attitude, you know, with life."

There was also another side to this discussion about levels of comfort with others. There was an acknowledgment that those who had not experienced disability could not fully appreciate the reality lived by these participants. Bob spoke about rehabilitation facility staff members who were able-bodied. "It doesn't matter how much they try and empathize, try and understand, they still haven't gone through the experience." Dan had a particularly pointed example to relate. When he returned to work following his rehabilitation period, he had a letter from his organization's disability support unit, advising his supervisor that Dan would require various accommodations. "So, (he) just laughed at this. I think it was a kind of genuine, you know, laugh. For him, it just seems odd, you know, whatever." He also noted that "no one understands this like, I'm sorry, like the people who have it."

This theme, and Theme 5 below, had the most coded phrases and statements offered by the participants. They are closely connected through the similarities of the concepts of support and understanding.

4.2.5 SUPPORT BY OTHERS

Larry, in particular, identified the support that he received from others during his rehabilitation, and in later times, as the most important factor in his eventually becoming independent. "My parents and friends, they valued me…I was included in everything… I was very fortunate that I had family and friends whereas other people there just didn't." After 16 years of living in an institution, Larry tells of his friends saying to him "You know, Larry, let's get together and, you know, you guys don't need to live in here. So we moved down to False Creek…Two years later I was married…I've got so many people to be thankful for, who contributed to my physical and mental health."

Dan also offered the other side of support. He talked about how his family withdrew their support when they believed he could cope on his own and how difficult that was for him. "It's, get on with it, man… You'll be smashing, don't wallow. By doing that, they minimized the support. The support lasts here. We have this much support for you, and then after that, you bet."

There appears to be a commonality between the theme of "Comfort with Others with Disabilities" and with this theme of "Support by Others". It may be that the former is actually a subset of the latter but that the assumptions held by the participants are somewhat different. Others with disabilities appear to have an inherent assumption of understanding attached to them. Those who are able-bodied need to earn at least a grudging acceptance through demonstration, albeit each of the participants commented that those who are able-bodied can never really understand. They can be empathic to a greater or lesser degree but, at least when it comes to disability, there is no substitute for experience.

4.2.6 SHATTERED REALITY

Each of the participants spoke about their injury or accident and its immediate aftermath as though it had happened yesterday. Two of them, Dan and Bob, still maintain an internal distinction between their pre-injury and post-injury selves. Bob commented that "Even though it's been 30 years I can still see myself as the 'pre' Bob, the able-bodied Bob and the post-injury Bob, this disabled person and, too, I've never completely integrated those two pieces and it's not in the negative, it's just the reality." Dan stated that "I don't know the other guy (his pre-injury self). I know me now. My parents know who the other guy was. I get flashes of him and I think he's stupid, sure, I do. Wake up you fool. I am this guy, I don't have a choice in that."

There was a clear relationship between the three participants and the degree to which they described themselves as having two internal representations of themselves, as still being "shattered". Larry, who has lived with his disability the longest, made no reference to having this circumstance. Bob, who was in the middle with regard to the duration of his disability, spoke about not being 'completely integrated'. Dan, the most recently disabled, spoke about himself as being two distinct people. Within the framework of this study, it is impossible to comment on whether the degree of "shattering" is related

to the duration of the disability or whether it is more a function of a different variable such as the nature of the disability or connected to the specific personality of each of the individuals.

4.2.7 INSTITUTIONAL/BUREAUCRATIC BARRIERS

All of the participants spoke about the impediments introduced into their rehabilitation processes through unnecessary regulations maintained through institutional or bureaucratic processes. Larry demonstrated considerable emotion when he recounted events from over 20 years ago when he was still institutionalized. "When I first went to Pearson (Hospital) you were in bed by 7:00 p.m. because why would anybody, because why would anybody want to be up past that time? 'Well, Doctor, have you ever been up past 7:00 p.m.?' I was known as a real troublemaker. I mean, I'd bring beer in and…I wasn't…they threatened to send me to Winnipeg. As a problem of the state."

Dan talked about his ongoing struggle as a person with an invisible disability. "The university says that it is an open space for everyone that has a disability, a different gender, and so on. You must hold them accountable. They are not, the university doesn't go out of its way to make that real…Your experience is up to you…I'm always fighting for things."

4.2.8 OPPORTUNITY FOR GROWTH

Larry addressed this issue directly as he discussed his early efforts to provide support to others with disabilities. "I started to see some value in what I was able to do rather than focus on what I couldn't do." He also talked about how he began to accept the attention he attracted due to his disability. "And at first that was a fear, and then I was able to understand that it doesn't have to be a negative. It could be a huge positive because why would you be interviewing me except for the fact that I'm in a chair?"

Bob talked about how he was able to see his life experience from two points of view, providing him with a much richer perspective. "If you get out and experience (the world) from a whole bunch of people's different view, including able-bodied, you're going to see it quite differently and you're going to tackle things in a different manner."

4.3   A CULTURAL SHIFT

In this study, the participants' descriptions of their experiences all began with graphic and detailed, but somewhat detached, illustrations of the events leading up to their acquiring a disability. There was very much a sense of these events being described as though by third parties who witnessed a tragic accident. However, as this opening part of our conversations moved to a description of their cognitive and emotional states following the precipitating event, the tone of the discussions changed dramatically. It was as if each of the participants had been able to come to terms with the event of the disability much more readily than with its aftermath. As can be seen above in Chart #2, the theme of a "Shattered Reality" was coded significantly more frequently than any other.

Although this concept of a "Shattered Reality" may have some relationship to the first stages of shock and anxiety found within many of the stage theories of psychosocial adaptation to disability as described by Livneh & Antonak (1997), the sentiments expressed by the participants appeared to be related more to bewilderment and confusion. They stated, both implicitly and explicitly, that they did not know what to do or how to act. As noted above, Bob spoke about feeling as though he had been transported to another country where a different language was spoken.

This imagery supports the conceptualization of an acquired disability as forcing a cultural shift from that of the culture of the able-bodied to one of disability. Culture, in this context, could be described not so much as a way of life or learned behaviour, but, as described by Geertz (1973), as an interpretive process, where each individual searches for the meanings inherent in those "webs of significance" (p. 4) that he or she has created. In the case of an acquired disability, those new "webs of significance" have been created for the individual by external forces but are no less in need of a new interpretation. It is this need for re-interpretation, demanded by the new environment created by those external circumstances, that creates the bewilderment and confusion described above as a first response to an acquired disability. It is Rogers' (1956) *incongruity*, Gergen's (1980), *shifting socio-historical circumstances*, Manis & Meltzer's (1972) *effective environment,* and Goffman's (1959) *discrepancy* at play here. Each points to the Symbolic Interactionist concept of *making meaning* out of the interrelationship between the individual and the objects of his or her environment (Mead, 1925).

As I described in the first section of this paper, I believe that the newly-disabled adult can become "stuck" in this period of cultural transition. I use the term "stuck" to represent both a time and a place that is between two cultures; it is a state of limbo where the injured worker, by definition, has been ejected from his or her membership in the culture of the able-bodied but is not yet prepared or learned how to join a new culture of disability. It is a period of psychological trauma that, like the physical trauma of an accident or injury, may not necessarily heal itself without professional support. That state of trauma, or "shattered reality" as discussed in this study, is the impetus that causes some individuals to become "stuck".

What causes only some to become "stuck" remains speculative at this juncture. However, as noted above, one would be tempted to examine the psychosocial variables associated with acquired disability. Tan (1997), in a study that examined goal setting as a predictor of return to work in a group of individuals with chronic pain, noted that "nonorganic factors were better predictors of return to work status than the organic findings…patients who returned to work had fewer job, personal, or family-related problems" (p. 162). Of equal interest, there were no significant differences in various pain evaluation measures between those who returned to work and those who did not. Aronoff & Feldman (2000), refer to Strang (1985) in noting the term *chronic disability conviction* as one that applies to individuals who are "capable of returning to work but choose to be disabled" (p. 158). The authors also note that there appears to be no positive relationship between the severity of the injury or disability and the *chronic disability conviction*; rather, this conviction or syndrome is more closely related to an inability to cope with other life problems.

4.4   WHAT DID I LEARN?

Several of the specific themes that emerged from this study support the concept of a traumatic transition that is necessary for my concepts of *cultural shift* and *disability addiction* to serve as models for the process undergone by those who acquire a disability. Although each of the respondents has cleared the bar of successful rehabilitation, as illustrated by being employed and, to a large degree accepting their present circumstances, the issues associated with the imposed duality of the *self* have not been completely extinguished. If we assume that these issues and those raised within the other

themes are less assimilated in those who have not yet moved this far along the dimension of success, it becomes more credible to see that an unrepaired Shattered Reality can lead to an inability or unwillingness to let go of the personal meanings that had been established prior to the onset of a disability.

The balance of the themes derived from the participants' conversations fall into two categories. The first is that which contains the process through which each of the participants has progressed, each to a somewhat different degree. These include Fear of the Unknown, Self-reintegration and Opportunity for Growth. The second category includes the forces that have been at play to help or hinder that progress. These include Comfort with Others with Disabilities, Support by Others, and Institutional/Bureaucratic Barriers. These two dimensions, the internal and the external, align with the Symbolic Interactionist concept of the self and the environment (Mead, 1925). The manner in which they are interpreted is how each of the individual participants *makes meaning* of the relationship in order to reach a new state of equilibrium or self-reintegration.

As noted above, the themes of Comfort with Others with Disabilities and Support by Others are closely related. The principal difference is that a positive relationship with the former group is assumed and that this same relationship with able-bodied supporters must be earned.

The stories told by the participants in the above study do not directly address the concept of *disability addiction*. However, there appears to be a correlation between the repercussions that were described as being associated with a Shattered Reality, the degree of recovery from that state, and the tendency to look forward within one's new life as a person with a disability rather than back at one's old, able-bodied life as a source of meaning. Although I acknowledge that this is at present a speculative relationship, it could help to explain the phenomenon of *disability addiction* and offer direction for a psychotherapeutic counselling protocol.

5.0   WHERE DO WE GO FROM HERE?

If we accept that the individual may become "stuck" between two cultures due to a *disability addiction* brought about by her reaction to the trauma of the disability itself and

its relationship to underlying psychosocial issues, what can we do about it at a practical level? The answer may lie in an examination of Motivational Interviewing as a method of psychotherapeutic support for these individuals.

5.1 MOTIVATIONAL INTERVIEWING

As a practice model, Motivational Interviewing (MI) acknowledges its debt to Carl Rogers' notion of "reflective listening" and "accurate empathy". These terms are collectively renamed by Miller & Rollnick (2002), as "acceptance" (p. 37). This does not imply agreement, rather, that the counsellor is able to empathize with the client's current position and understand his circumstance from the client's own point of view. MI also distinguishes itself from Rogers' methods by adopting a "consciously directive" (p. 25) approach to counselling, which Miller & Rollnick (2002) define as an effort to "enhanc(e) intrinsic motivation to change by exploring and resolving ambivalence." (p. 25).

Also inherent to MI is the notion of the Transtheoretical Model (TTM) of change, first developed by Prochaska, DiClemente & Norcross in 1982 and subsequently modified into its current form, (Prochaska, DiClemente & Norcross, 1992). This model asserts that "behavior (sic) change involves a process that occurs in increments and that involves specific and varied tasks" Miller & Rollnick (2002), p.201. These stages of change are described by (Prochaska, DiClemente & Norcross, 1992) as follows:

- Pre-contemplation – the earliest stage where there is no current intention to change;
- Contemplation – where the individual is aware that a problem exists but he or she is not yet ready to seriously consider acting upon that awareness;
- Preparation – occurs when the individual is ready to take action within the next short period of time;
- Action – is the period when the individual has begun to modify his or her behaviour to overcome the specific problem;
- Maintenance – is the period during which efforts are made to prevent relapse.

A recognition of these stages of change, and the different approaches required to meet clients at their particular stage, provides MI with a framework within which to apply its central tenet of developing an increasing level of ambivalence within the client between his or her current state of behaviour/addiction and those deeply held ideals or goals

which, according to MI, are what each of us also want. This increased ambivalence, and the recognition that it engenders, in turn, leads to an increased level of motivation to reach these goals.

5.2   THE VALUE OF MI TO DISABILITY ADDICTION

Two elements of Motivational Interviewing may be of particular value to those with a *disability addiction*. The first is that MI acknowledges that individuals may be within a specific stage of change and that each stage carries with it certain common and anticipated behavioural characteristics. For example, what would otherwise be considered conduct that was defiant or even intended to sabotage a therapeutic process is seen as natural and anticipated behaviour. This acceptance by MI of behaviour that may otherwise be considered to be somehow deleterious to the counselling process actually lies at the heart of MI theory. By making use of the resistance to change offered by the client as a counterpoint to his long-term, core goals, the MI counsellor begins to create a feeling of ambivalence between the client's current actions and the future that he wants to reach (Miller & Rollnick, 2002).

The second element of MI that will be of value to those with a *disability addiction* is that it accepts the client at whatever stage of change she may be within when beginning a program of psychotherapeutic counselling. Along with this acceptance come different strategies for developing the required ambivalence needed to proceed towards the goal of accepting one's reality and developing a solution. Even within a particular stage, such as pre-contemplation, MI offers several strategies to help the client develop ambivalence, depending on the nature of the pre-contemplator's circumstances. Miller & Rollnick, (2002) describe four distinct categories of resistance that may be offered. These include reluctance, rebellion, resignation and rationalization. By carefully examining the circumstance and needs of each client, the MI model offers tailored processes within which to proceed.

6.0   A COUNSELLOR WITH A DISABILITY

If we accept the notion of Rogers (1956) that the individual has an innate propensity to strive towards self-integration, what value may a psychotherapeutic counsellor with a disability bring to this equation? The answer may be that he or she will

be of assistance by modelling and supporting those positive attributes of the external side of the relationship between the *self* of the client with an acquired disability and the environment, especially if the counsellor adopts a Rogerian model of counselling, which includes the three mainstays of his technique – congruency, unconditional positive regard and empathic understanding (Rogers, 1956). A counsellor with a disability, especially a visible disability, would then meet the criteria for what I refer to as Rogerian Show and Tell. He or she would *be* supportive and *be seen* to be supportive by the client with an acquired disability.

It is my proposition that several benefits may accrue to the client with a recently acquired CID through engagement in a psychotherapeutic process with a counsellor who is experienced in and living with a visible disability. First, such a counsellor will already be a member of the cultural group of which the injured worker has recently become a member, thereby offering a visible demonstration of the potential to function successfully as a member of this group within a vocational setting. Second, the counsellor will more easily be able to demonstrate an empathy that will be credibly received on the part of the injured worker. Third, a trusting and caring relationship necessary for therapeutic advancement will be more readily attained than would otherwise be the case. By bringing these variables to bear, the disabled individual may more readily learn about the concept of a safety net and that, indeed, one is in place waiting for him.

In an attempt to categorize this form of therapeutic engagement, I recognize from my own experience in providing support to individuals as described above, that I have blended the core principles of Person Centred Therapy with a set of visual and verbal support cues incorporated into my presentation of myself as a counsellor with a disability.

To encourage participants in my qualitative study to offer their experiences starting from the time of their injury, rather than merely a self-analysis of their present circumstances, I needed to be aware of the effects that my own appearance as a person with a visible disability could have on the discussions. Through my experience as a vocational counsellor, I have seen situations where a client has chosen to diminish his or her own past or present difficulties in the face of my more apparently challenging circumstances as a wheelchair user. The converse has also been true, when a client has presented as being much more affected by disability. In addition, I needed to be aware of

my own long history with disability, both personally and professionally, and the potentially distracting or conversation-shaping effects that my own perceptions or comments could have on the stories told by the participants.

I attempted to take these concerns into account by incorporating two distinct elements into my approach. First, I began our discussions by asking each of the participants to tell me about the events and circumstances that led to their acquiring a disability. My intent was to help each of them focus in an inward manner and to travel back in time from their present, analytical perspective to one where they were reliving past events. Second, as our conversations progressed, I asked as few questions as possible, trying only to clarify points or concepts, and not to lead the discussion.

My intent, with all of these efforts, was to provide the participants with a Rogerian-like environment that would encourage them to be "in" their stories and, therefore, be able to offer as realistic a sense of their own reality as was possible within the constraints inherent to the circumstances associated with participating in an interview.

7.0   IMPLICATIONS FOR THE FUTURE

The final issues to be addressed are whether the data generated and the conclusions drawn from this paper may serve as a basis, or at least an incentive, for future research and whether there are issues of policy and practice that may be affected.

7.1   RESEARCH

Several of the themes outlined align themselves with current work being carried out on better understanding post-traumatic growth. This has variously been described as positive psychological outcomes following stress, going beyond the original level of thriving following a traumatic state, and feeling greater self-efficacy and strength following an originally negative response to trauma (Cadell, Regehr & Hemsworth, 2003). In that same study, in which the authors looked at caregivers of those living with AIDS, they found that spirituality, social supports and high levels of distress can lead to post-traumatic growth.

The research that may be of interest to readers is the potential relationship between post-traumatic growth, the related variables as outlined by Cadell et al (2003) and others, and the effect of psychotherapeutic support provided by counsellors with disabilities. A positive correlation between these factors could serve as the basis for an effective model of support to those with acquired disabilities who were still "stuck" between cultures. As early as September, 2008, I will begin a study of Workers Compensation Board clients with acquired disabilities who will be receiving psychotherapeutic counselling making use of the Motivational Interviewing model, which will be provided by myself, a counsellor with a disability. Data will be gathered over a two-year period and, with the assistance of the Yukon Workers Compensation Health and Safety Board, the effects of this service will be compared to a control group who have not received similar supports. Although the study will not be large enough to allow for two counsellors, one able-bodied and one with a disability, clients will be administered questionnaires following completion of the counselling period and asked to rate the program, including the value of having a counsellor with a disability.

A second area of research will be required to investigate the availability and interest of counsellors with disabilities in delivering similar services. There will also be a need to consider the effects of introducing both this service concept and an increase in counsellors with disabilities into the world of generic counselling services.

7.2   POLICY

At a policy level, an acceptance of the central tenets of this paper will require a reconsideration of the services available to those with acquired disabilities. This will be of particular issue if the above mentioned research study indicates a positive relationship between MI counselling by a counsellor with a disability and a selection of qualitative and quantitative variables, including Quality Of Life and periods of Return To Work respectively. Processes and funding to provide these services will need to be incorporated into Workers Compensation Boards, insurance programs and other services intended to provide rehabilitation supports to those with acquired disabilities. Of particular need will be the requirement to provide training on MI and its relationship to *disability addiction*.

7.3   PRACTICE

At a practice level, there will need to be considerable dissemination of information to counsellors and prospective counsellors, especially those with disabilities. This information will include available data on the efficacy of this model and structured training opportunities. In the longer term, there will be need to work with other practitioners to create and standardize data gathering tools that can be used to further confirm and develop this counselling process and technique.

8.0   FINAL COMMENTS

In summary, I believe that I have met the purpose of this paper, which was initially described as an attempt to develop a process of support for individuals who have acquired disabilities and who have exhibited difficulties in re-establishing a psychosocial balance. Through a consideration of the meanings made of an acquired disability, I have demonstrated the potential for the development of a *disability addiction*, exhibited as a response to an inability of some individuals to successfully transit through a *cultural shift* brought on by the trauma of an acquired disability. Finally, I have been able to recommend a psychotherapeutic counselling process intended to support those individuals who have developed a *disability addiction*.

I believe that the arguments and model presented within this paper lay the groundwork for further investigation into the efficacy of providing a Motivational Interviewing counselling program for individuals with acquired disabilities who have become "stuck" between two cultures to the point of *disability addiction*. I recognize that much of the argument put forward within this paper has been by analogy and through qualitative methods of data gathering. However, the development of every new theory is faced with a paucity of quantitative information from which to spring. What I am putting forward is a leap of intuition based on my own personal and professional experience and the use of as much peripheral and circumstantial information as I have been able to discover to serve as underpinnings for these ideas.

I believe that, conceptually, I have successfully made use of the rule of parsimony as compared to the several stage theories of rehabilitation as were discussed above. I believe that I have also offered a model of treatment that is easily comprehensible to the

prospective client and which has been proven successful with other forms of addiction. I can only speculate that these characteristics will allow for increased participation in therapy than has otherwise been the case for those with acquired disabilities and, ultimately, in improved outcomes for those in need of this support.

9.0   APPENDIX "A"

DEFINITION OF DISABILITY

A disability(1) is a physical condition, a mental condition, or a health problem that restricts the performance of one or more of a person's significant life activities (2) for an extended period(3)."

1. This would include examples such as: hearing, seeing, communicating, mobility, agility, pain, learning, confusion/memory, development, emotional/psychological, other.
2. This would include examples such as: school, work transportation, recreation, housing, family, relationship, other.
3. This would be for periods longer than six months or on a recurring or intermittent basis.

Note: This definition was developed by the Yukon government for internal census purposes. It is aligned with the current World Health Organization definition and has been positively reviewed by Statistics Canada with regard to its ability to generate data that can be directly compared with disability-related data generated by the 2006 post-censul Participation and Activity Limitation Survey (PALS). The PALS (2006) is a follow-up survey to the federal census. It gathers data on disability across the country.

The Yukon definition was reviewed throughout its development by Statistics Canada research staff to ensure that it would capture information that was capable of being directly compared to national PALS data.

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