

Exploring Identity in Transition for Adults Who Experience Physical Disability

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Abstract

The objective of this thesis is to gain a greater understanding of the components and processes that contribute to an optimal transition of identity in adults who experience physical disability subsequent to illness or injury. Disability experience is understood to include possibility for the full spectrum of negative and positive psychology, from posttraumatic stress to posttraumatic growth. Pre-disability identity, patient identity, and post-disability identity are considered within the themes of physical, psychological, social, and spiritual identity. Peer supported autonomy is believed to be a key element for establishing a positive post-disability identity. Therapeutic interventions informed by a narrative theory mindset can be employed to offer collaborative therapeutic support to peer supported autonomy in the identity transition process. These interventions can be optimally explored and enacted in a small group process. Using themes drawn from the research this study proposes a facilitated small group design in which identity in transition is considered in a collaborative, peer group environment that explores pre-disability identity, disability identity, autonomy, power, and peer witnessing.

Acknowledgements

The wisest teacher I have known once told me, “You will never write a good academic paper.” I looked at him with confusion. He smiled, and then went on to explain, “Oh, you can force yourself to meet the requirements of any academic establishment, but it will not be you, because you are not an academic, that is not where your heart is.”

This thesis has been written from within the context of my work at the G. F. Strong Rehab Centre in Vancouver, B.C. My heart has been informed through listening to and accompanying individuals in the construction of their unique and personal stories. These stories include an experience of physical disability, but the heart of the story is seen in the identity of the narrator.

This thesis has been written from within the context of a personal transition in which identity lost many of its familiar markers. Various names were given to this experience. My heart learned what it feels like to be assessed, observed through a therapeutic lens, diagnosed, treated, then discharged into the chaos of crossed boundaries, fictive projections, and limited emotional resources, and after all this to find it is still beating, alive, creative, forgiving, and eager to thrive.

This thesis has been written from within a context of healing realized in the generous kindness of friends who have time for coffee, intimacy, and humour. Friends have touched my heart, but it is my family who have held it with gentle love and care. There are not enough words with which to give heartfelt acknowledgement to the family I have been blessed with: Liana and Jesse, Aaron and Diedre with Susannah and River, and my husband Gerry who believes I matter. You are where my heart lives as you share with me hope and love and faith in God who is good.

Dedication

Remembering Elvira

December 8, 1952 to June 25, 2012

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Chapter 1: Introduction and Literature Review

Introduction

Whether acquired through the trauma of accident and injury, or through the process of sudden or gradual illness and disease, the diagnosis of a permanent physical disability shatters the life a person has known. Personal identity is significantly challenged. The process through which recovery and healing occurs includes physical healing, cognitive reordering, psychological resilience, social and family restructuring, and the meaning-making experiences of spirituality. Throughout this process the person is likely to ask, “Who am I now that this has happened?” For some the answer to this question may come quickly and easily, but for most, it is a longer transition, often involving many resources, both personal and professional, individual and societal.

Problem Statement

Identity is formed, in large part, in relationship: relationship to one’s physical body, relationship to one’s values, and relationship to others. Each of these relationships contribute significant components to identity formation. Illness and disability can turn one's own body into a stranger and force an unwanted reevaluation of prior values, beliefs, and relationships. Adult peer relationships in the transition following a disability experience are especially significant because illness and disability are known to increase isolation through loss of mobility and independence. New stresses are placed on pre-disability relationships. Decreased resources of energy and time limit opportunity for new relationships. These realities may result in a lack of meaningful peer relationships at a time when they are essential to an individual's well being.

The definition of “peer” may undergo a change when one transitions from health into disability. What are the choices in this circumstance where one’s identity and one’s “peer group” are challenged by the unexpected circumstances of adult acquired disability?

In this thesis I explore some of the recent research that seeks to understand what helps a person move through the identity transition brought about by a disability acquired in adulthood, towards affirming a preferred post-disability identity.

Research Questions

The following questions will be addressed:

- What happens to identity when an adult acquires a physical disability that results in impaired mobility and decreased independence?
- What might peer relationship attachment contribute to the process of restoring meaningful identity? Is disability a culture that has its own identity?
- Does narrative theory offer interventions which could support a group process for individuals within a disability transition experience?

Rational for the study: Purpose and significance

Exploring these questions will help the reader improve understanding of personal identity transition throughout the disability experience. This understanding can inform the choice of therapy interventions that facilitate coping, resilience, and posttraumatic growth for persons in such a life transition.

If identity is formed in relationship and disability increases isolation, could the establishing of a peer group defined by physical disability provide opportunity for a parallel peer relationship based in social circumstances, spirituality, and common interests to occur? I would like to suggest that both kinds of peer relationship are necessary for healthy and meaningful

identity transition to occur, and that a narrative theory informed therapy group could be a significant contributor to this process.

The collaborative foundation of narrative theory provides an environment of affirmation. Affirmation of the person's history and affirmation of the person's future allow the present experience of transition to be a place of significant meaning making where choices are identified and genuine opportunity emerges from the ashes of trauma and loss.

This process often involves re-education on many levels. As well as learning new physical skills for body management and mobility, new ways of thinking about disability often need to be learned. Many enter into the experience of disability carrying the dominant culture assumptions of diminished personhood and loss of personal agency as their new markers of personal identity. Establishing goals for the future is a difficult task if one carries an identity devoid of any sense of agency.

This paper explores ways in which a person's preferred identity can be chosen, named, affirmed, enacted, and strengthened. Gaining a better understanding of this process will allow those who work within the field of physical rehabilitation to offer collaborative plans that respect the identity, the autonomy, and the personal goals of the person living with an adult acquired physical disability.

Methodology

The research is presented in a Manuscript Thesis format in five chapters. The literature relevant to the topics of each paper will be reviewed within this introduction.

The format of each manuscript chapter will address the chapter topic in a manner consistent with the overall thesis topic.

In the concluding chapter a potential clinical application of the research findings will be considered. The design of a small group, based on the research findings in the manuscript chapters, will be offered as a therapy resource for consideration and application. Comments on the strengths and weaknesses of the thesis research will be included.

Literature Review

The literature reviewed for this research project addresses themes of identity in transition subsequent to adult acquired disability including: peer relationship in disability, autonomy, posttraumatic growth, and the benefits of a collaborative narrative theory informed perspective on identity and disability.

As this research project does not involve human participants it was important to use research referencing first hand experience with disability. The autoethnographic doctoral dissertation, *Storying Resilient Selves: Disability, Resilience & Narrative Identity* by Williams (2010) reports personal and peer experience of disability, and discusses identity, resilience, and transformational growth. Richards (2008) in, *Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing about Illness and Disability* considers the usefulness and validity of "the researcher as agent and researcher as object of research" (p. 1717). Both these documents identify the benefits to understanding issues of identity that can occur when the voice of lived disability experience responds to, and shapes, the questions of academic research.

Implementing a Client-Centred Approach in Rehabilitation: An Autoethnography. provides the research results of a co-autoethnographic study by Bright, Boland, Rutherford, Kayes and McPherson (2012), who describe the benefits of autoethnographic research as including, improved understanding of the context, nuances, and culture of disability, "it has made

us better clinicians" (p. 1003), and illustrate "that working alongside clients is potentially far more powerful than current dominant culture approaches recognize" (p. 1003).

These autoethnographic accounts affirm the need to expand the disability literature to include the research that promotes positive adjustment processes as legitimate and realistic outcomes following disability. "Prior to the 1990s, much of the research into adjustment following SCI tended to pathologize the adjustment process" (Dorsett, 2010, p. 85). In 1996 Tedeschi and Calhoun, published *The Posttraumatic Growth Inventory: Measuring the Positive Legacy of Trauma*. This publication is regularly referenced in the disability literature, and appears to represent the beginning of serious consideration of growth as a realistic identity outcome following trauma. The 2004 publication of *Posttraumatic Growth: Conceptual Foundations and Empirical Evidence* by Tedeschi & Calhoun is a comprehensive article presenting posttraumatic growth as a significant marker of positive identity transition.

Posttraumatic growth, also named adversarial growth, is described in varying ways in the literature. Some of the changes that describe this phenomenon include,

- 1) a change in priorities about what is important in life
- 2) development of new interests and opportunities
- 3) increased perception of competence and self-reliance
- 4) acceptance of one's vulnerability and negative emotional experiences
- 5) improved inter-personal relationships
- 6) increased compassion and empathy for others
- 7) greater appreciation of one's own existence
- 8) a greater appreciation for life
- 9) an increase in religious faith or spirituality (Rogan, Fortune & Prentice, 2013, p. 2).

The posttraumatic growth literature reviewed in this study includes accounts from researchers who have studied this occurrence in various disability and illness groups, including experiences of amputation, spinal cord injury, brain injury, stroke, cancer and other illnesses. A number of the studies are longitudinal studies considering the variations of posttraumatic growth and positive identity formation that occur over time.

A significant qualitative study based on interviews with 10 participants with visible impairments from chronic illness or serious injury is presented in *From Devastation to Integration: Adjusting to and Growing from Medical Trauma*. In this study, Salick and Auerbach (2006) ask the question, "What is the psychological impact of becoming disabled, and how does one get to the point of feeling better?" (p. 1025). They offer the following observation regarding the restructuring of "assumptive worlds, that is fundamental beliefs about the world" that are shattered by a traumatic event and the subsequent severe distress, "People who constructed positive identities following impairment were those who conceptualized their adversity not as a personal failure but as a socially mediated phenomenon that could be challenged and resisted" (p. 1022).

For the theme of relationship and identity in the disability experience, I have focused on the literature that discusses peer relationship, often in the form of peer mentorship. Virtually all articles that discuss disability and identity address the need for support in the form of meaningful personal relationship. "High levels of social support among persons with SCI are associated with higher life satisfaction, ... well being, ...quality of life, lower levels of depression, improved employment rates, and fewer health problems" (Veith, Pellino & Yasui, 2006, p. 289). There is, in the literature, evidence that sharing a disability experience, will create a bond of understanding and create a community of understanding: "support is most effective if provided by a *similar*

other - that is, a person who has successfully faced a similar situation" (Veith, Pellino & Yasui, 2006, p. 289). This assumption is discussed in chapter three and is considered within the options of adopting a "disability identity," and/or establishing a network that facilitates supported autonomy.

I begin the discussion in chapter four with the bias that telling one's story has therapeutic value. "The roots of psychosocial trauma imply an interactive phenomena induced by externally derived social situations that are internalized" (Andrade, 1996, p. 41). This internalization is often supported by societal circles of silence that believe denial equals protection, "rather than facilitating self disclosure and the "coached" resolving of traumatic experiences and subsequent psychological distress" (Andrade, 1996, p. 42). This basic premise is given a structure and a methodology in narrative informed theory and therapy that creates the possibility of a reproducible benefit in a wide variety of clinical practice situations.

The writings of Hedtke (2010) and Neimeyer (1999) question many of the assumptions practiced and promoted by dominant culture. The differences I found most compelling were the suggestions that the human response to loss, often called grief, is not a disorder or a pathology: "Recent research evidence fails to support cherished models that assume grieving is necessarily associated with depression" (Neimeyer, 1999, p.65); that death and loss do not require closure so much as integration into one's life narrative: "The need for a tidy ending before death is thus removed" (Hedtke, 2010, p.140); and that relationship is changed, but not ended, when death occurs: "death may be understood...primarily as an event in a relationship" (Hedtke, 2010, p. 304). Much of this thinking is relevant to the experience of loss through disability.

Hedtke's dissertation, *Folding Memories in Conversation: Remembering Practices in Bereavement Groups*, (2010) based on her narrative theory inspired group work with persons

dealing with life-death transition, prompted the question of whether a similar group process might be used in the disability community as people deal with their pre-disability to post-disability identity transition. Hedtke's work suggests narrative theory offers a framework from which the process of identity transition can be understood as an intentional exploration of preferred identity formation within an acquired disability identity experience.

In her PhD dissertation Hedtke (2010) writes, "The process itself is inextricably entwined with its purpose, which is to generate knowledge that can influence in preferred ways a person's relationship with the particular issue for which they have sought counselling" (p. 197). The goal of constructing a preferred identity following disability is a subjective preference that considers resilience and growth as possible outcomes.

Hedtke developed and facilitated a six week bereavement group series in which participants told their stories in a narrative therapy, facilitated conversation, format supplemented with journaling assignments. Hedtke identifies the pivotal question as, "Did the bereaved find their lives easier to live in the face of grief as a result of the bereavement groups?" One goal of this thesis is to ask the same question of disability therapy groups resulting from this research.

The much earlier work of Kleinman (1989) in *The Illness Narratives: Suffering, Healing, and the Human Condition* offers an in depth analysis of persons' experiences of illness as distinguished from the medical profession's diagnosis and treatment of the disease.

Kleinman, a medical doctor, focuses on stories emerging from his psychiatric practice. His book is not written from within a Narrative Therapy framework, but it upholds the Narrative Therapy precept of naming an alternative story in order to identify the unique meaning of the patient's experience of their story of illness and disability. Kleinman (1989) writes, "It is

clinically useful to learn how to interpret the patient's and family's perspective on illness. Indeed, the interpretation of narratives of illness experience, I will argue, is a core task in the work of doctoring ...an interpretation of illness is something that patients, families, and practitioners need to undertake together"(p.xiii-xiv). Kleinman explores the various levels of meaning that illness and disability have. In distinguishing these meanings from the clinical diagnosis of disease, he creates the possibility for a collaborative relationship between the professional who seeks to help and the individual who lives and owns the story of the disability experience.

Summary

The documents considered in this literature review indicate a shift in the psychology of trauma. Articles exploring incidence and characteristics of posttraumatic growth and resilience have sought to balance the predominance of a pathology focused exploration of disability. This shift is especially welcome in considerations of identity in transition as it informs clinicians and therapists of the realistic and positive vector of resilience and growth that can be hoped for following serious injury and illness. Establishing this realistic hope within the academic literature on disability includes the followings consequences:

1. People feel better. The goal of bringing comfort through hope for the future has traditionally been relegated to family, friends, and faith communities. The posttraumatic growth literature and the autoethnographies cited in this thesis offer hope for meaningful recovery and life experience following disability. This goal supports both the individuals who are experiencing the disability transition and those professionals who work with them. In her dissertation, Hedtke (2010) demonstrates that honoring this goal within the

therapeutic world can support other therapy goals of improved life functioning, resiliency, and emotional healing.

2. A more collaborative therapeutic relationship. Collaboration decreases resistance within relationship, so that therapy can focus on the concerns of the client rather than expending significant emotional energy on the maintenance of a more evidently power based relationship that presents a pathology informed "reality."
3. Builds independence from therapists. The brief therapy format of most Narrative Therapy focuses on the imparting of skills and the implementation of these skills in the client's real lived world.
4. Improves the status of a disability identity, encouraging development of authentic peer relationship.
5. Generative/Creative. Stories are art. When people are given the tools to hope, create, imagine and experience the concrete production of their story in the belief that it contains meaning, the sense of personal achievement encourages ongoing creative efforts.

Chapter 2: Disability and Identity in Transition

Introduction

When an adult acquires a physical disability that results in impaired mobility and decreased independence, one assumption often made, by that person and others, is that the individual is not the same person after this experience. Dickson, Allan, and O'Carroll (2008) speak of "biographic disruption and the notion of the 'disabled self'" in their discussion of the impact of spinal cord injury on a personal conception of identity. They observe, "The individual must identify which aspects of their identity or self have been lost through their injury, what aspects still remain and what aspects are part of their new identity based on their situation" (Dickson, Allan & O'Carroll, 2008, p. 409).

Whether acquired through the trauma of accident and injury, or through the process of sudden illness or degenerative disease, the diagnosis of a permanent physical disability shatters the life a person has known. This paper will ask questions about the impact of this event on the person's concept of self, and explore the factors that influence the transition process between the time of disability diagnosis and the time when the individual can positively affirm their own identity.

Better health care interventions have resulted in a growing population of individuals who have survived a trauma or illness crisis, and go on to live the remainder of their lives in bodies that have significantly changed. Chan, Chan, and Ng (2006) report, "as people live longer today, incidence of cancer and other degenerative diseases is currently on the rise ... a growing population is now living with chronic medical conditions" (p. 10) and Van de Velde et al. (2012) note the "increasing life expectancy after Spinal Cord Injury" (p. 491). The processes of moving from crisis, where one is the victim of unfortunate circumstances, through recovery and healing,

where one is a health care patient, to the status of chronic illness or permanent disability wherein one adopts or rejects a disability identity, occur within a variable time often called transition.

Transition is a time when significant changes occur in various realms: physical healing, cognitive reordering, psychological resilience-gathering, social and family restructuring, and the meaning-making experiences of spirituality are hopefully occurring simultaneously to bring the person through to a place of optimal health and functioning. The length of this time period varies considerably and will remain numerically unidentified for the purposes of this research. In the literature, transition can be categorized as the brief time between hospitalization and resettling at home (Van de Velde et al., 2012), or a number of months following injury (Hamill, Carson & Dorahy, 2010), or as long as 14 years following the event (Dickson et al., 2008).

In this transition process identity exhibits fluidity, vulnerability, and resilience, as questions such as, “Who am I now that this has happened?” are asked. Exploring the elements that contribute to positive identity transformation during this time of transition may increase the likelihood that therapeutic interventions and caregiver supports will be effective contributions to the efforts of the individual and their family/friend network.

Following a brief presentation of the concepts of disability and identity in transition that are relevant to this paper, this chapter will discuss transition within the four identity themes of physical identity, psychological identity, social identity, and spiritual identity.

Disability

Disability is a broadly used term within both society and the professional literature of many helping professions. Efforts to identify terminology that is respectful, accurate, and empowering of persons who live with the life experiences implied by this term, have not resulted in consensus. This paper will reflect the most recent terminology found in the literature without

attempting to evaluate its validity.

For the purposes of this thesis, the primary disability experience being considered is a loss of physical ability in adulthood, following illness or injury, resulting in decreased physical independence and mobility. These losses can be the result of sudden trauma through events such as motor vehicle accidents, falls, and work place injuries, or the gradual loss of physical ability through illnesses such as cancer, arthritis, and neuromuscular disorders such as multiple sclerosis (MS) or amyotrophic lateral sclerosis (ALS).

Much of the research literature cited in this thesis includes a wider array of disability experiences. It is recognized that experiences of disability resulting in losses of sight, hearing, speech, cognitive capacity, and mental health may share many of the consequences and experiences of identity in transition being considered in this paper. Future comparative studies may provide understanding that could establish differential insights. For this paper, inasmuch as a study includes considerations of some aspect of physical disability resulting in loss of independence and mobility, its findings will be considered a relevant contribution to understanding identity transition in the context of adult acquired disability.

There are numerous definitions of disability. A keen awareness, within the disability peer community, of the social significance and influence of these definitions, is reflected in the “Disability World” website that identifies eleven definitions or “models of disability.” These include medical, social, professional, tragedy/charity, moral, economic, and other models descriptive of disability experience within varying social contexts (Disabled-World Website, 2013). For the purposes of this paper the medical and social definitions will be highlighted.

The definition based on the medical model of disability continues to be widely used in both public and professional discourse. This definition includes viewing disability as “a problem

of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care” (Disabled-World Website, 2013). In this model physical impairment and its limitations are identified and treated by health care professionals, who carry the designation of experts in disability care and management. The medical attention given to the identified “disabled individual” results in the appropriate delivery of limited health care services and resources, nevertheless, the viewing of disability as “a problem of the person,” can create experiences of isolation, prejudice, discrimination, and rejection. Despite recent critique, the medical model of disability diagnosis and management within the Canadian health care system, remains an essential component for an optimal standard of living to be realized following disability. This apparently self evident statement, is at times a useful corrective when extreme frustration with medical institutions results in noncooperation, self defeating protest, or even refusal of essential care and services.

A definition based on the social model of disability asserts the understanding that the experience of disability is in large part socially determined. It sees the issue of disability as “a socially created problem and a matter of the full integration of individuals into society” (Disabled-World Website, 2013). The human rights issues of equal access and fair opportunity emerge as the major concerns within this model. The insights of this definition have benefited both the disability and the non-disability community through the construction of accessible buildings and city infrastructure, as well as providing meaningful social discourse for self and other advocacy.

The analysis of Alexander (2008) regarding the impact of free-market society on addiction experiences seems relevant to an understanding of disability experience. He states, “globalization of free-market society produces a general breakdown of psychosocial integration,

spreading dislocation everywhere. . . A free market society is one in which virtually every human activity is structured by competitive markets” (Alexander, 2008, p. 99). The priorities of a society have significant impact on the individuals of that society, and can actually contribute to and create disability in many forms.

A document produced by the World Health organization concludes, "A better model of disability in short, is one that synthesizes what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects" (Üstün, 2002, p. 9). Within this paper these two definitions, of the medical and the social models of disability, will be considered, questioned, and integrated into the discussion.

Identity in Transition

Transition occurs throughout every person's lifespan in developmental stages from childhood to early adulthood and through the aging process. It also occurs whenever choices are made in relationship, vocation, and location. Transition also occurs followed the crisis of trauma and illness. Both the natural and intentionally chosen transitions, as well as those that come as a shock, can be experienced as life crises. Transitions can contain experiences of disengagement, dismantling, disidentification, disenchantment, and disorientation (Bridges, 2004), as an individual moves from an ending to seek out an as yet unknown, new beginning. "Endings are, let's remember, experiences of *dying*. They are ordeals, and sometimes they challenge so basically our sense of who we are that we believe they will be the end of *us*" (Bridges, 2004, p. 131). This universal human experience of transition establishes a common ground from which understanding of the disability transition experience can begin.

On acquiring a physical disability, identity is thrust into such a transition. The individual seeks to find expression for the ordeal of the disability experience, looking to establish narrative

congruence with one's past identity, as well as identifying alternative forms of personal agency to replace the way of being and doing that has now changed. Sanders (1995), identifies "the telling of the tales of our souls" as "the most human of all our faculties," and goes on to say, "But talk alone does not necessitate change; talk must be coupled with action" (p. 48). Disability simultaneously impacts and threatens the realms of personal narrative, personal autonomy, and personal agency.

The degree of impact on one's identity, and the importance ascribed to the impact in each of these interrelated realms, will vary with each individual. It is significant to note that it cannot be assumed that disability experience contains only accounts of loss and suffering. Following after the early studies on posttraumatic growth by Tedeschi and Calhoun (1995), it has been noted that "resilience following trauma is more common than previously supposed and can result from multiple pathways" (Salick & Auerbach, 2006, p. 1022). Narratives of posttraumatic growth reveal that not only does the degree of impact vary, but the quality of the impact can include the full range on the continuum from shock, devastation, and hopelessness, through to resilience, integration, and beneficial personal growth. Until fairly recently academic exploration of the impact of disability on identity focused almost exclusively on the trauma and the subsequent possible pathologies.

In their research into disability identity, Dunn and Burcaw (2013) present an awareness of the fuller range of possible responses to disability under the umbrella of story. They note, "The term *narrative identity* refers to the personal evolving story of the self that an individual consciously and unconsciously creates to bind together many different aspects of the self" (Dunn & Burcaw, 2013, p. 148). A study focusing on identity changes in adults who experienced lower limb amputations observes, "most patients addressed their amputation as a potential break from

their past and what they were waiting for in the future. This break was not only with regard to body image, but also in patients' very identity, personality, functioning, sex life and relationships" (Senra, Oliveira, Leal & Viera, 2011, p. 188).

Identity is a holistic concept that is not easily defined or characterized to be one item on a list of human components. Four major themes will be drawn out and considered as significant to this discussion of disability and identity in transition: physical identity, psychological identity, social/cultural identity, and spiritual identity.

Physical Identity

Disability that decreases mobility and leaves an individual physically dependent on others for personal care is often publicly visible. This undeniable change in appearance and function is universally and deeply feared. From a very early age fear of "being hurt" is learned. It is not only the experience of physical suffering and discomfort that is feared, but also the realization that to be physically hurt to the point of disability will have a profound impact on identity. Publicly visible losses of preferred appearance and personal agency render an individual vulnerable in numerous ways. In *Writing the Othered Self: Autoethnography and the Problem of Objectification in Writing about Illness and Disability*, Richards (2008) comments, "People living with disabilities or illnesses are often reduced to the status of malfunctioning bodies ... They are also frequently the recipients of other people's expertise, not the contributors. This results in their being dehumanized and their unique situations generalized" (p. 1719).

People behave and speak differently towards one who is seen to be the victim of physical trauma, who now cannot move independently and requires physical assistance. If the individual is fortunate enough to survive the physical trauma or serious illness, a person can become a patient. At this point the person may or may not be aware of a potential future disability identity,

yet they are already aware that before is different from now.

Hence, the identity transition brought about by physical illness or trauma is not just a movement from pre-injury, able bodied identity to post-injury, disability identity. There is a transitional identity in between wherein the person is “the patient.”

In a patient identity a person can experience pain, humiliation, loss of autonomy, fear, and social segregation. In a medical emergency involving physical trauma, extraordinary trust is put into the hands of the strangers who provide essential, life saving interventions. The trauma to the body is paralleled by trauma to identity. This experience is vividly described in an autoethnographic dissertation, *Storying Resilient Selves: Disability, Resilience & Narrative Identity* (2010), by Williams. In recounting the events following her spinal cord injury Williams describes this experience of entering into a patient identity,

“They put me on the table ... One of them cuts open my shirt ... “Please don’t cut my bathing suit,” I plead. ... They don’t acknowledge me. My 21 year old body lies naked, fully exposed to perfect strangers. They seem not to notice. But I do. I’m horrified, frightened, and now humiliated. They treat me as though I am not even human. I feel like a piece of meat” (Williams, 2010, p. 2).

In such an experience identity is as shattered as the person’s physical body. In fact it could be argued that the physical becomes the identity. To experience oneself as “a piece of meat” is an identity metaphor implying death. Survival is threatened. Identity that resides in such physicality leaves an individual extremely vulnerable.

When physical reality is changed through sudden trauma, identity change is directed by the vector of fear and need into the identity of ‘the patient.’ Identity enters this transition following trauma and illness because it can no longer be sustained by identification with the

physical body now changed beyond recognition. The identification of self must expand beyond the traumatized physical body of the person. Persons who have prior well developed identity themes beyond the now threatened physical identity may more readily recover a positive post disability identity, through both their own resilience and the support of others. Kleinman (1989) recognizes both this "deeply private significance of illness" and the professional responsibility to provide support:

When the patient under examination disrobes to expose a body covered with the ugly scars of (the illness or disability) ...the practitioner should recognize that shame, hurt, anger, despair, or other constellations of feelings probably are present. As key ingredients of the illness experience, these feelings are likely to affect the patient's life experience in general, the illness per se, and the response to care. The role of the health care professional is not so much to ferret out the innermost secrets, as it is to assist the chronically ill and those around them to come to terms with - that is, accept, master, or change - those personal significances that can be shown to be operating in their lives and in their care. I take this to constitute the essence of what is now called empowering patients (Kleinman, 1989, p. 43).

This empowering describes the attitude and actions of therapeutic interventions aimed at producing what is now being called posttraumatic growth.

In a systematic review of posttraumatic growth (PTG) in persons living with serious medical conditions, Barskova and Oesterreich (2009) noted "no significant association of illness severity and PTG" (p. 1719), suggesting factors beyond the physical were the greater determinant of PTG. They did however also note that,

A moderately advanced disease may constitute an event that is serious enough to provoke

a re-examination of one's long held beliefs. In contrast to this, high life-threatening levels associated with a very advanced disease could lead to cognitive 'shutting down', whereby individuals are so threatened by the experience that they cannot bear to contemplate the consequences of the illness; therefore, the search for meaning and processes of personal growth are not supported (Barskova & Oesterreich, 2009, p. 1719).

This describes those who do not emerge from the physically determined patient identity forced upon them by their physical illness or trauma.

Being aware of this identity threat, the potentially accurate existential claim voiced by some patients that, "I am still the same person" can be understood as a statement of great courage. Unfortunately this statement is sometimes met with disbelieving but consoling nods, grief mingled with embarrassment, and poorly concealed pity. Traumatic physical reality can overwhelm identity. Perhaps what is more noteworthy is how often it does not. The threat to identity can also be met with an affirmation that personal identity resides in realms beyond the physical and the patient can be invited to explore an identity as a person in transition beyond the limitations of an identity that is primarily physically determined.

In her dissertation, *Storying Resilient Selves: Disability, Resilience & Narrative Identity* (2010), Williams (2010), begins with this quote from *Stigma: Notes on the Management of Spoiled Identity* by Goffman (1963).

While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind ... He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a

handicap (Williams, 2010, p. 1).

Williams (2010) cites this quote as an example of the “long accepted, deviance-informed depiction of disability as stigma” (p. 1) and notes the academic consensus that people with disabilities (PWD), have been negatively stereotyped. Her autoethnographic dissertation explores both her personal experience of sustaining and living with a spinal cord injury, and the accounts of six other women who like her, live with physical disability. Williams (2010) responds to the trend in “an academic literature saturated with accounts of women with physical disabilities whose stories tell tales of fear, rejection, and shame” (p. 7) with the assertion that this stereotype of identity being negatively determined by the physical differences acquired through disability does not tell her story. She states,

“my story may not be as uncommon as the scholarly reports of women with disabilities as stigmatized and oppressed – and depressed – might have us believe. It is true: women with physical disabilities face certain physical, emotional and social challenges that many able-bodied women do not. But it is the ability of these women to rise above those challenges, to pursue fruitful and successful lives and relationships, to face adversity and thrive that is recognized and celebrated in this paper. Unlike past scholarly accounts, this one is concerned with the oppressive forces that exercise her courage only to the extent that they illuminate her strength.” (Williams, 2010, p. 8)

In taking this stance Williams is relegating physical identity to a lesser status than the elevated status it is usually granted by a society obsessed with youth, beauty and health. She is acknowledging that identity is impacted by the physical realities produced by illness or trauma, but she states that personal identity is not appropriately determined, either positively or negatively, by the physical, in any ultimate identification of what it means to be a self.

The physically determined patient identity need never be one's permanent identity. In this assertion lies the conviction that thriving, rather than just surviving, is an appropriate post disability goal.

Psychological Identity

Just as the physical must be acknowledged, an individual's psychological constructs must likewise be considered in order to identify the components of identity transition. Previously held patterns of thinking and an individual's 'normal' affective responses enter into a state of transition of unknown duration. In this state the experience of identity being threatened can be overwhelming.

This psychological response is "recognized in the Diagnostic and Statistical Manual of Mental Disorders, which acknowledges a life-threatening disease as a serious stressor that can precipitate posttraumatic stress disorder (PTSD)" (Barskova & Oesterreich, 2009, p. 1709). PTSD is often anticipated, as a possible response to physical trauma and illness. In their phenomenological analysis of amputee adjustment, Hamill, Carson and Dorahy (2009) write, "Although each individual's response is unique, common psychosocial sequelae may include depression, anxiety, posttraumatic stress symptoms, body image issues, stigmatization and changes in self-identity and social functioning" (p. 729).

This generalization regarding the psychological consequences subsequent to the trauma of amputation reflects an accepted and common understanding of what can be expected. Alertness to the possible psychological distress subsequent to physical trauma has provided the benefit of appropriate and necessary psychological care to many. This necessary and beneficial contribution cannot be disregarded. However, recent autoethnographic, and other, research, has questioned the sufficiency of this list of "common psychosocial sequelae." In order to be

considered sufficient or complete, advocates of positive psychology claim a comprehensive list would need to include psychosocial responses to trauma such as coping, resilience, and posttraumatic growth.

McGrath and Linley offer a definition of posttraumatic growth which distinguishes it from other positive responses. "Posttraumatic growth entails incremental psychological change and should, therefore, be distinguished from coping and resilience, which are concerned simply with the endurance of stress and the ability to return to previous levels of function in its aftermath" (p. 772). In physical disability, there is often not a return to previous levels of physical function. Posttraumatic growth research acknowledges the possibility of, not only a return to previous levels of psychological function, but the opportunity to exceed that level through insight gained by the disability experience.

Williams (2010), an researcher living with a physical disability, describes the personal impact of discovering an exclusively negative expectation in her initial academic reading about psychological response to SCI. "Negative depictions of people with disabilities in mainstream media are easy to discount... Decades of academic research that supports the same conclusions, however, is not so easily regarded as myth. It is credible, and much harder to dismiss" (p. 34). She describes her experience of cognitive dissonance, "I struggled to resist internalizing the societal attitudes reflected in the literature ... that did not correspond with what I believed to be true. Such discrepancy places an individual in a state of psychological distress" (p. 35).

Williams (2010) began looking for literature that more accurately reflected her more positive experience of retaining and growing her personal identity subsequent to SCI. Her dissertation presents findings in the study of human resilience which contributed to filling in this gap: "The "gap" in the disabilities literature, as I see it, is that only part of the disability story has

been told” (p. 51).

Richardson (2008), another researcher with personal disability experience, similarly met with assumptions that did not match her experience, and writes, “The disability movement has been central in reminding us that there is a long history of people living with illness or disability—already othered by society—being othered further through the writings and research of outsiders in general, and health professionals in particular” (p.1717).

While acknowledging the contributions of “decades of scholars” who, in researching and describing the physical, psychological, and social consequences of disability, “have taken it upon themselves to expose these injustices with the spirited intent to ameliorate them, to foster awareness and understanding, and to enact social change in the direction of social justice” (Williams, 2010, p.51), Williams (2010) directs our attention to include the evidence brought forward by the positive psychology movement which challenges psychology’s “long history of serving a pathology focused agenda” (p. 53).

The recent literature examining posttraumatic growth has emerged in part from first hand autoethnographic research, such as the narratives documented by Williams and Richardson. The “symptoms” of resilience, courage, increased compassion, greater self understanding, and enlarged social awareness are now being added to the list of common psychosocial sequelae that may be in evidence within an individual’s response to traumatic experience resulting in physical disability.

The scale often used to evaluate posttraumatic growth is The Posttraumatic Growth Inventory (PGI) designed by Tedeschi and Calhoun (1996). This scale contains five subscales: Appreciation of Life, Relating to Others, Increased Personal Strength, New Possibilities, and Spiritual Changes (Powell, Ekin-Wood & Collin, 2007, p. 32).

One question underlying this paper is: What can influence a person, whose identity is in transition subsequent to the trauma of disability, towards gaining the psychological benefits of growth in the five categories listed in the PGI?

Social Identity

The observation that personal identity exists in relation to others, either totally or in large degree, is articulated by many. In the postmodern version of the self, "the self is largely defined through relationship" and "Gergen (1999) notes, there are: ...no independent selves; we are each constituted by others" (Hedtke, 2010, p. 124). Whether or not an individual consciously subscribes to this postmodern view of self, over the modernist view of the "rugged individual" in relationship to other rugged individuals, they will in all likelihood experience the significant impact of others on their self esteem, their resilience, and their post disability identity. The needs to belong, to be known, and to contribute within a meaningful community are all brought into question in a transition where the individual may not be able to return to their previous residence because of accessibility issues and may question their ability to continue in the relational and social roles they had assumed. Also, they may lose employment due to their extended absence from work, the reality that they cannot now do the work that had previously identified them, or the social perception that this is so.

Kleinman (1989) asks questions regarding the social meanings of illness and disability that lie beyond the meanings of physical symptoms and disorders. He notes that "information gained about the patient's behavior in the clinical setting is biased" and "patients learn to act as chronic cases; family members and care givers learn to treat patients in keeping with this view" (p. 180). Social and physical environments, as well as social relationships, contribute to our identity, especially when identity is in transition. As discussed earlier, the identity of "patient" is

assumed not only because a person requires health care services, but because a person is located in the social environment of a health care facility. When families take their loved ones home and individuals leave hospitals against medical advice, it may be that they are fleeing the felt identity threat within this social environment.

Clients and patients in health care settings react in varying ways to institutionally ascribed identities such as 'the patient,' 'the amputee,' 'the quadriplegic,' and other designations experienced in the course of receiving medical and rehabilitation services. The questions of disability identity, peer relationships, and social integration or reintegration usually emerge early on in the disability experience. These are some of the key questions encountered in the disability experience. As such they require more than a summary statement of their importance and will be dealt with more fully in chapter three.

Although Alexander (2008) is not discussing physical disability, his insights parallel some of the disability experiences of psychosocial reintegration. In considering the role of psychosocial integration in recovery from addiction, Alexander (2008) notes that individuals find "a renewed stake in conventional life and in their social relationships and a new identity to go with it...Often, the identity shift is so dramatic that it can be likened to a religious conversion experience" (p.160). The identity transition in disability can be likewise dramatic, but the vector is different, in that the individual is not released from the problem to return to normal, that is, the pre-problem way of life, but rather life is entered into it in a new way. Much of this reentry can occur through the restructuring of social identity, incorporating a reframing of the meaning and value of disability identity. "Disability identity entails a positive sense of self, feelings of connection to or solidarity with, the disability community" (Dunn & Burcaw, 2013, p.148).

Is disability a culture that has its own identity? Disability identity can be considered a

culture in that it includes a quality of protest against the dominant culture's assumptions regarding disability experience and identity. Tremendous social solidarity can result from this positive social identification with the disability community, however identification with the disability identity and culture is voluntary. Dunn and Burcaw (2013) observe that disability identity occurs on a continuum. "At least two groups on this continuum can be presumed to have no disability identity: Those individuals who are not disabled and those persons who possess a disability objectively but do not identify themselves as someone with a disability" (p. 149).

Cultural and ethnic meanings of disability may also play a significant role in identity transition. The meanings ascribed to the disability or illness are produced not only by the individual, but by their family and social network as well. "Each family must make sense of their experience, come to terms with it. In so doing, all the things that distinguish a family as unique are replicated in that process of imparting meaning to experience. Cultural and ethnic differences, social class and economic constraints, and a host of other factors will manifest themselves in this work of making illness a part of a family's construction of reality" (Kleinman, 1989, p. 185). Weingarten (2013) has observed the central role of identity in family functioning when living with chronic illness, "the most stressful losses are those that are ambiguous ... the loss of a family member as they once were may be more responsible for family dysfunction than the symptoms of the physical illness or condition itself" (p. 86).

This stressful ambiguity of identity in transition can be meaningfully acknowledged and addressed through the act of intentional witnessing. Sometimes called "outsider witnessing," or "re-membering conversations" this practice involves bringing together persons chosen by an individual, for the purpose of speaking to that person's identity. (Hedtke, 2010; Madigan, 2010; White, 2011). The act of witnessing another's experience and identity can provide the individual

and their social network with much needed markers in this time of transition. However, Weingarten (2013) describes the act of witnessing as consisting of four possible positions, with only one of the four being therapeutic. Both emotional awareness and effective responsiveness are required for a witness position to be realized as beneficial. Lack of, or low emotional awareness combined with high efficiency, or low efficiency combined with a high level of emotional awareness may be as unhelpful as the position that is neither aware, nor efficient. This, and other narrative theory interventions will be considered more fully in chapter four.

Disability and "illness is not simply a personal experience; it is transactional, communicative, and profoundly social" (Kleinman, 1989, p.185). This observation indicates an assumption that understanding disability through both the medical and social models is necessary. Disability and illness are personal issues for the individual who receives the treatments and resources of the healthcare system, they are also "a socially created problem" requiring "the full integration of individuals into society" (Disabled-World Website, 2013). In a social model of disability, disability is "a complex collection of conditions, many of which are created by the social environment. Hence, the management of the problem requires social action and is the collective responsibility of society at large ...The issue is both cultural and ideological, requiring individual, community, and social change" (Disabled-World Website, 2013).

Health care professionals, families, and individuals or groups who voluntarily intend to be part of the individual's future, will collaborate with the person to share and negotiate, shape and confirm, the preferred identity of the person who is entering that future. The identities of those families and groups are also likely to undergo a transition in their support of the individual. The ways in which they do this will be significantly impacted by enacted social/cultural beliefs and practices regarding illness and disability.

Spiritual Identity

Spirituality is an affirmed but less researched component of identity than the three previous themes. The concept of posttraumatic growth has relatively recently entered the academic psychology discourse. The expectation that identity may be positively shaped in a transition subsequent to suffering/trauma has a long history in the academic disciplines of spirituality and theology in many faith traditions. "The religious foundations of posttraumatic growth: Islam, Judaism, Christianity, Buddhism, and Hinduism all refer to the transforming power of trauma" (O'Rourke, Tallman & Altmaier, 2008, p. 719). One example of this is found in the somewhat unorthodox teachings of Irenaeus, the 2nd century bishop of Lyon, and a Christian theologian and philosopher. He believed all would "go to heaven" and considered this world to be a "vale of soul making" in which suffering held the potential for positive human development. One of his most quoted teachings can be translated from the Latin as, "The glory of God is a human being fully alive" (Regent College lecture, 1992). While there are numerous arguments regarding the theological implications of his teaching, in his view that suffering produced benefit, Irenaeus can be understood as anticipating a positive psychology wherein posttraumatic growth is an expected outcome of human suffering, albeit through divine action.

A more contemporary statement on the relationship of spiritual identity to trauma is found in Neimeyer (1999), "The reconstruction of a world of meaning is the central process in grieving" (p. 65). Likewise, Powell, Ekin-Wood & Collin (2007) state, "The basis of 'growing through adversity' is to re-attribute meaning" (p. 37). These claims would seem to presume that at least part of the answer to the "essential research question" of, "What is the psychological impact of becoming disabled, and how does one get to the point of feeling better?" (Salick & Auerbach, 2006, p. 1025), is found in the spiritual identity work of meaning-making.

It was noted earlier that one of the sub-scales of the Posttraumatic Growth Inventory (PGI) designed by Tedeschi and Calhoun (1996) is 'Spiritual Changes.' O'Rourke, Tallman, and Altmaier (2008) postulate, "Changes in spirituality and religiosity may play a vital role in understanding individuals' posttraumatic growth" (p. 719). Their evaluation of the PGI as an instrument to measure this growth notes that there were only two items loaded on a spiritual factor until a 2005 sample from Australia added three items to the PGI to strengthen the spiritual change assessment. In their assessment of this, and other instruments, measuring the constructs of the psychological aspects of spirituality, spiritual growth, or change in spirituality, and its relation to trauma, O'Rourke, Tallman, and Altmaier (2008) concluded that, "Traditionally, psychological research has either neglected the influence of spirituality or framed it in a negative light. While spirituality may occasionally contribute to negative outcomes as part of responding to traumatic stress, it has also been shown to open the doors for many benefits" (p. 726).

Defining spirituality is a subjective exercise. Within Canadian health care institutions, the role of spiritual care is increasingly being delegated to certified spiritual care professionals trained in the delivery of a spiritual care more broadly defined than the care traditionally delivered by religiously specific clergy. The Canadian Association for Spiritual Care self-defines as "a national multifaith organization ... concerned with a holistic approach to health care and personal development with a special focus on spiritual and religious care" (CASC website, 2013). The role of spiritual care practitioners in health care is to support individuals, and their family/friend networks, in their spiritual and religious practices, spiritual identity transitions, and spiritual crises of meaning making, such as those that may be experienced in trauma and disability.

While not exclusive to spiritual care, the work of supporting hope has been at the core of

the work of spiritual care practitioners when addressing spiritual identity in transition. In a 10 year, longitudinal study of 46 adults who had sustained spinal cord injury, qualitative data about hope is considered by a researcher who writes, "Traditionally, adjustment to a serious injury such as spinal cord injury has been conceptualized as staged grieving process. Hope, in this tradition, is commonly defined as denial and considered counterproductive to positive adjustment," but the researcher then presents the findings of the study and concludes, "It is recommended that interventions that support and facilitate hope need to be developed and tested" (Dorset, 2010, p. 83).

When identity is in transition, it is certain that individuals will need hope. Hope as described in this well known, but often abbreviated quote, contains many of the components required in the shaping and sustaining of a spiritual identity:

"Hope is a state of mind, not of the world. Either we have hope or we don't; it is a dimension of the soul, and it's not essentially dependent on some particular observation of the world or estimate of the situation. Hope is not prognostication. It is an orientation of the spirit, and an orientation of the heart; it transcends the world that is immediately experienced, and is anchored somewhere beyond its horizons ...Hope, in this deep and powerful sense, is not the same as joy that things are going well, or willingness to invest in enterprises that are obviously heading for success, but rather an ability to work for something because it is good, not just because it stands a chance to succeed. The more propitious the situation in which we demonstrate hope, the deeper the hope is. Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out." (Havel, V. <http://blog.gaiam.com/quotes/authors/vaclav-havel/67076>).

Spiritual identity is anchored to hope. A spiritual identity that is in transition has often lost its secure connection to the hope an individual requires in order to articulate confidently that their life has meaning, that "something makes sense." Spiritual identity in persons who do not practice a specific religion remains a core component of their lived experience. Who am I? Why am I? Where am I? Whose am I? Do I matter? These are all spiritual identity questions that can either build within an individual a certainty of meaning that constructs a life, or precipitate a descent into the despair that sometimes ends in death.

Dorset (2010) discusses the three aspects of Snyder's model of hope: pathways, goals, and agency, noting that hope is a cognitive, a behavioral, and an affective process. "Pathways are defined as the belief that one can find a way to reach a desired goal and involves being able to formulate at least one practical means to achieve the desired goal" and "agency is the extent to which people believe in their capacity to implement action to achieve the desired goal" (Dorset, 2010, p. 85). In this process "positive emotions flow from the perception of successful goal pursuit. Negative emotions ... flow from impeded or unsuccessful goal pursuits" (Dorset, 2010, p. 87).

The Snyder model suggests a cycle of hope where goal directed thinking leads to positive emotions leading to increased hope feeding further goal directed thinking. Entering the cycle at any point can result in a beneficial change. High hope has been linked to benefits in many areas. Dorset reports that 70% of the study participants clearly named hope as an essential factor in coping with their injury "in the early stages" (Dorset, 2010, p. 91). This would indicate that persons who enter into the experience of spiritual identity transition will realize some of the benefits of high hope such as clearer conceptualization of goals, better quality of life, more positive mood, and a broader range of problem solving skills (Dorset, 2010, p. 88).

It is significant that these benefits are realized independent of achieving the specific result being hoped for. These benefits occur even when the specific hoped for result does not occur, and they facilitate “the changing foci of hope” (Dorset, 2010, p. 93) over time that allows individuals to cope with what is. Often this new focus is described in spiritual terms, or assumes a significance that is adopted as a component of spiritual identity.

Until this spiritual identity can be named and known, “generalized hope provides a protective environment for the hoping person when particular hopes are compromised or no longer seem realistic” (Dorset, 2010, p. 95). Generalized hope describes a transitional spirituality that can sustain an individual who is restructuring meaning, and evaluating pre-trauma beliefs, values, and faith. One study notes that positive change takes many months to develop, “with spiritual perspectives being particularly slow to emerge, and that a degree of unpleasant engagement with the reality of the long term situation may be necessary” (McGrath & Linley, 2006, p.772).

It must be noted that spirituality does not stand in opposition to physicality. Nor does it splinter identity into separate compartments. Healthy spiritual identity integrates the physical, spiritual, and psychological realities of the individual into a known, and knowable, person. When this holistic goal of spiritual identity formation is understood, it is not surprising to read that persons who were recovering from traumatic brain injury identified the advice to act as if nothing had happened, to rest, to take it easy, as the worst advice they received. Rumination is often psychologically painful and sometimes assumed to be an undesirable, obsessive cognitive pattern. However, some individuals experienced the advice that discourages rumination to be advice that denies their desire for wholeness and health, and promotes passivity, pessimism, and a lack of hope (Powell, Ekin-Wood & Collin, 2007). It may be that rumination serves a creative

purpose and does not deserve the negative labeling it traditionally attracts. Calmness does not necessarily indicate a healthier spirituality than struggle. Tedeschi and Calhoun (2004) note, "It is the individual's struggle with the new reality in the aftermath of trauma that is crucial in determining the extent to which posttraumatic growth occurs" (p. 5). Prayer and meditation are stereotypically depicted in popular culture as activities of serene bliss. The experiences reported by serious practitioners of these disciplines indicate struggle is often a significant component in the attaining of spiritual wellness. The cognitive and affective processes that are utilized in prayer and meditation may have more similarity to the struggle that has been called rumination, than has been widely recognized.

Active engagement in problem solving is a spiritual exercise as much as it is a behavioral, affective, or cognitive one. This perhaps "unpleasant engagement with the reality of the long term situation" (McGrath & Linley, 2006, p.772) may occur over many months before producing growth and insight. "The research literature suggests that a degree of rumination or, 'turning over in the mind', is a factor associated with, if not necessary for, posttraumatic growth" (Powell, Ekin-Wood & Collin, 2007, p. 36). In the language of spirituality, this describes the spiritual identity forming actions of contemplation, meditation, grateful compassion intentionally directed towards self and others, all directed towards the soul building conviction that life has meaning.

Summary

Disability impacts and changes identity in complex and multifaceted ways. To say that identity is impacted or changed is not to say the individual has lost something irretrievable in terms of their personhood. The influence continuum of disability experience ranges from posttraumatic stress through to posttraumatic growth. Recent work in positive psychology emphasizes the importance of including research regarding positive growth outcomes following

disability, in order to gain a more balanced view of what can be considered realistic and achievable in a circumstance that presents considerable barriers and obstacles to well being.

The expectations of those supporting the individual during a disability transition can significantly influence the vector of recovery. Continuity of identity is often primarily retained through relationship. Individuals usually adapt well to alternative means of mobility so long as their close relationships and social structures remain intact. Sometimes, even when such apparently essential supports are not, or only minimally, available, drawing on meaning-making resources can disclose resilience and hope that will sustain a person who appears to have "lost all." These are the stories of courage and inspiration that we sometimes name as "larger than life." It is the survival of identity that inspires.

The period of transition, during which an individual deals with the physical, psychological, social, and spiritual identity impacts of trauma or illness that result in physical disability, is an especially significant time. Over these months, and often years, collaborative interventions which promote goal setting, self reflection, meaning-making, cognitive restructuring, social advocacy, and relationship appreciation, can contribute to positive identity growth wherein physical disability does not define the whole of a person, but is one fact among many that describe who this individual is.

Future research which analyses the structure of transition, the time over which transition occurs, the possible positive or negative impacts of transition occurring in a very short time period or over a protracted time, all raise questions. Researching these questions has the potential to enhance the understanding of how identity changes and which interventions might act as catalysts or supports for desirable changes that promote posttraumatic growth and strengthen an individual's preferred identity.

Chapter 3: Peer Relationship in Disability

Introduction

Aristotle's declaration, "In poverty and in other misfortune men think friends are the only refuge" (Nicomachean Ethics 8:1), and the simple adage "there is strength in numbers" both speak to the felt need for relational support when facing trauma. Perhaps more than anything else, relationships can determine the quality of the transition between the occurrence of disability diagnosis and the positive affirmation of post disability identity.

The word peer refers to "a person who belongs to the same age group or social group as someone else" (<http://www.merriam-webster.com/dictionary/peer>). There is, in this definition, an understanding that peers are not necessarily a group an individual chooses to be in relationship with. Peers may become, but usually do not start out as, friends. Traditional nuances of social class structure and privilege still inform our understanding of the word. However, in contemporary Canadian society, there is an assumption that one has the right to seek out like minded peers through engaging in pursuits of self improvement through educational, recreational, and social activities based on interest, rather than inheritance or political engineering. In defining "peer" for the context of this paper, questions are asked regarding, "Who gets to decide who is included in the word peer?" and "What are the specific factors in peer relationship that can contribute to the process of confirming or restoring meaningful identity following adult acquired physical disability?"

The definition of peer within the experience of disability acquires nuances unique to the disability context. The meaning of the word peer changes to refer to those whose personal narratives include physical trauma or illness with a subsequent disability outcome. This understanding of peer assumes that persons with spinal cord injuries, or brain injuries, or

arthritis, will now consider those within their diagnostic category as their primary peers, over and against the usual peer groups of age, social circumstances, preferred lifestyle, or interests in recreational and cultural activities. Peer becomes a category based, not on choice, not on demographics or social categories of class or achievement, but rather on a similar experience resulting in similar need. Part of identity transition in disability includes considerations and choices regarding who will be understood to be a peer. This process dovetails with complex questions of personal autonomy.

In identity transition the key questions of relationship, disability identity, and social integration or reintegration usually emerge early on in the physical rehabilitation experience. These questions are answered, in part, according to how the word peer is understood and enacted. This dynamic will be considered by exploring the three themes of Peer Relationship and Autonomy, Therapeutic Relationship and Peer Relationship, and Disability Identity.

Peer Relationship and Autonomy

The dictionary definition of the word peer as "a person who belongs to the same age group or social group as someone else" implies natural selection and social restrictions to be the limits to autonomy in the selection of peers. However, the common current social practice of choosing a preferred group as a peer group implies an individualistic view of society wherein persons engage and identify with a group by choice. In such a society "autonomy is a prerequisite for experiencing participation" (Van de Velde et al., 2012, p. 492).

In a culture that highly values autonomy, choosing to participate may well determine membership or exclusion. This aspect of choice significantly strengthens an individual's attachment to a peer group. Exercising autonomy to proclaim such voluntary participation becomes the necessary prerequisite for belonging. It must be noted that many non-western

cultures would not understand autonomy as the prerequisite for participation, in fact they would find this an incomprehensible and contradictory denial of the family, social class, or the community one is born into and finds belonging within. Much like the social model of disability, discussed in chapter 2, that states, "the experience of disability is in large part socially determined," the definition of peer is, at least in part, a sociocultural creation.

Autonomy, as one of the pillars of western health care ethics, is routinely and often cited as a primary principle of ethical care and client/patient rights. "The role of personal choice ... has become more important since the concept of autonomy has been adopted by the disability rights groups as a primary right" (Van de Velde, 2012, p. 492). Autonomy, as used in health care, is understood to mean being "free from external control and constraint. Applied to individuals, it consists primarily in a person's ability to look after oneself without help from others" (Van de Velde et al., 2012, p. 492). Autonomy is the unencumbered decision making ability of the individual. Although conceived to protect individual rights and choices, this ideal of autonomy can become problematic in the disability context where decision making during acute crisis, trauma, stress, and distress often cannot be said to be unencumbered.

The social ideal of autonomy as individual "capacity to judge, decide, and act on the basis of their own attitudes and reasoning" (Van de Velde et al, 2012, p. 492) is made complex, and even paradoxical, when an individual experiences a physical disability. "Having a disability means being in a vulnerable position because of the explicit needs and assistance from others and therefore autonomy is often a goal and plays an important part in the genesis and maintenance of the illness...overvaluing autonomy can be detrimental for people with disabilities" (Van de Velde et al, 2012, p. 492-3). Individuals can readily experience themselves as having no capacity to enact autonomy when physical independence is compromised or lost and may

conclude, not only have they lost autonomy as they once knew it, they have also lost any value as a peer in relationship.

In an insightful evaluation of the role of autonomy in a disability context, Van de Velde et al (2012) summarize this complexity and expand the understanding of autonomy beyond merely a state of individual independence.

There is critique on this individualist-liberal view on autonomy because (1) it doesn't consider other cultures... (2) it raises numerous ethical issues concerning cultural, social and political restrictions for absolute autonomy (3) there have been different views concerning autonomy influenced by demographical factors such as age, gender, level of education and the individual's cognitive capabilities. Collopy and others have tried to capture these critiques when distinguishing autonomy in six polarities: decisional versus execution; direct versus delegated; competent versus incapacitated; authentic versus inauthentic; immediate versus long range and negative versus positive autonomy. This means that autonomy is more complex than just decisional and executional autonomy" (p. 492).

These six autonomy polarities provide a helpful way to enlarge the autonomy experience to include concepts and practices of inter-dependence and agency enacted through others. When inter-dependency is recognized and valued the opportunities for meaningful, voluntary peer relationship increases (Van de Velde, 2012).

Williams (2010) presents an example of this connection between inter-dependent autonomy and peer relationship in this dialogue between a sister, Tamara, and her brother, Keith, who supported her following her paralyzing motorcycle accident,

"I would cry and then Keith would say, "I love you, but this happened, and it really is going to be okay." ... he would get in my face and say, "Do you want to rot in bed?" And I would go. "No!" And then he would say, "Well you're going to have to do this, they have to move you, which I'm sure you know..." And then he would go outside and cry himself and then come back in" (p. 128).

Tamara's autonomy was supported by Keith, who articulated decisions and choices too difficult for Tamara to choose in a time when pain weakened her will and threatened to obscure her authentic wish to work towards long term, positive benefit. Keith was not only Tamara's brother, he became an emotional peer, who wept with her. In this inter-dependent role he could enact an autonomy Tamara could claim. She could not have done this alone.

Relational-Cultural theory (RCT) also offers insight into the dynamic between autonomy and relationship. RCT is a feminist informed theory of human development and psychotherapy which suggests individuals "become increasingly relationally complex, rather than more individuated and autonomous over the lifespan" (Comstock, 2005, p. 26). Relegating autonomy to a lesser status would appear to be a significant departure from the dominant culture imperative to establish identity by 'becoming your own person.' RCT suggests becoming a self is done in relationship, and in times of stress "resilience be seen as a relational dynamic" (Jordan, 1992, p. 1) evidenced through the establishing of intentional peer relationships, rather than merely the result of an autonomous personality style or the successful construction of a social network that protects the individual from the adverse consequences of stress. In RCT a mutual empathy, of differentiated but connected individuals in relationship, is the goal.

The exploration of identity through the establishing of intentional peer relationship, however peer may be defined, contributes significantly to a positive identity transition.

"Transformation through relationship also suggests not just a return to a previously existing state, but movement through and beyond stress or suffering into a new and more comprehensive personal and relational integration ... And in moving beyond personal resilience to personal transformation and social change, the relational context is central" (Jordan, 1992. p. 1).

Therapeutic Relationship

When one enters the health care system therapeutic relationships are established with numerous health care professionals. Some individuals living with disability find, that over time, a high percentage of all their relationships are with persons who are paid to be in the role they hold in order to serve the physical, psychological, social, and spiritual needs of persons living with disability (personal conversations, G. F. Strong Rehabilitation Centre, 1998 - 2013). The ages old observation that "knowledge does not equal understanding" (Heraclitus, c. 535-475 BCE) warrants serious consideration and hints at the need to acknowledge the limits of these professional and therapeutic relationships. As much as professionals know, in the great majority of instances, they do not identify with their clients as peers. This professional boundary, while ethically appropriate, has therapeutically limiting consequences that it can be helpful to acknowledge and explore.

Does one need to 'identify with' in order to claim understanding? Not necessarily. But for someone who holds professional power to assume, 'Yes of course I understand you' can be an emotionally painful dismissal that overlooks the knowledge acquired only through 'identify with' shared experience. Most therapists and health care practitioners do not share the experience of the individual they are serving. They understand through years of study, the practice of diagnosis and treatment, observation, empathy, and research, but for the most part, they do not 'identify with.' Understanding without identification offers significant and much needed

connection with the person towards whom the understanding is directed, however its value for building relationship has limits.

It is both the ethical and the pragmatic responsibility of the professional to recognize and respect these limits. Diagnosis, treatment, research, and empathy are great benefits, but these knowledges do not guarantee understanding. Understanding can be said to have occurred when the client states, "You understand me" not when a therapist says, "Of course I understand you." Even then, this understanding falls short of identification with, such as is experienced in a peer relationship.

The relationships that contribute medical knowledge, psychological support and education, resource management expertise, and physical therapy become intimate relationships in the lives of many individuals who experience physical disability. These relationships can create an experience of community that sustains individuals in a time of transition. Hamill, Carson, and Dorahy (2010) note, "Health professionals were also in a position to provide credible advice and support, provided that they were appropriately experienced, and, even more importantly, that their interactions with patients were personal rather than merely functional" (p. 734). This suggests a quality of understanding that is inclined towards attempted identification is preferable to a merely clinical or medical understanding.

It would be easy to assume that a person's pre disability sources of relational support will continue to be available, but sometimes that pre disability community never existed or, in response to the trauma and disability, has ceased to exist. If it exists, the community of family and friends is itself often impacted and overwhelmed and cannot offer supportive and understanding relationship during the time of transition. Even in optimal circumstances, where an individual has an understanding and supportive peer community, the individual may

recognize the need for a group with whom they identify through exploring and sharing their experience of trauma and disability. In all of these circumstances the felt need for peer relationship with a person who has undergone a similar trauma, resulting in a similar disability experience can be intense.

In recognition of this, peer mentor positions have been created in a variety of clinical disability situations as a way to support individuals in their identity transition.

Peer mentors are paid or volunteer members of the healthcare/rehabilitation team who "promote optimal health and social reintegration of persons with disabling conditions" (Ljungberg, Kroll, Libin & Gordon, 2011, 351). Peer mentors can be key people in the lives of adults who have acquired a physical disability. Peer mentoring has been described as a unique relationship that "bridges professional, lay, and client perspectives" (Young, 1999, p. 1) for the purpose of assisting clients in their transitions to the community. This assistance is unique in that the peer mentor identifies with the individuals experiences of trauma, disability, and identity transition, by virtue of personal experience.

A peer mentor can offer an individual their first opportunity to consider accepting someone as a peer on the basis of shared disability experience. In contrast to other professional relationships 'identification with' is a factor central to the peer mentor relationship. The therapeutic value of this was noted in a study researching psychosocial adjustment in the transition period following amputation, "Ultimately, however, the strongest support connection was made with other individuals who had undergone the same experience" (Hamill, Carson & Dorahy, 2010, p.734). Disability peer relationship can introduce the individual to consider adopting a positive disability identity as they transition from a pre disability identity to a post disability identity.

Disability identity

The term disability identity is not a term which is widely used or well understood outside of the disability community. It arises from individuals living with disability who choose to participate in a narrative identity known as disability identity which can be described as:

- "an important and adaptive psychosocial construct" (Dunn & Burcaw, 2013, p. 148)
- containing "relevant content and goals linked to disability" (Dunn & Burcaw, 2013, p. 149)
- a guide as to "what to do, what to value, and how to act in various circumstances" (Dunn & Burcaw, 2013, p. 148)
- one of many identities a person possesses (Dunn & Burcaw, 2013, p. 149)
- something claimed over time (Dunn & Burcaw, 2013, p. 152)
- "an authentic and important aspect of the social psychology of disability" (Dunn & Burcaw, 2013, p. 155)
- "a positive sense of self, feelings of connection to, or solidarity with, the disability community" (Dunn & Burcaw, 2013, p. 148).

Relationship choices amongst individuals who can be identified by disability vary widely. To assume every person living with SCI, brain injury, or amputation acknowledges as peer every other person who shares this experience would be a naïve generalization. Some persons who can objectively be said to possess a disability, actively deny an identity defined by this disability and refuse membership in a disability community. Others, who can be said to have adopted a disability identity, intentionally pursue relationship within the disability community and view what is called disability, as something that has led to personal growth and invaluable insight. Often the word disability is sidelined for another preferred term, such as differently abled.

Individuals tell their story with a focus on overcoming difficulties in the same manner that able bodied persons speak of their victories and achievements.

These disability narratives are "first-person accounts (that) disclose and promote appreciation for the common and unique factors that shape the experience of disability" (Dunn & Burcaw, 2013, p. 148). In providing some normalization through shared experience, the telling of these stories communicates to the narrator the highly therapeutic realization, "I am not alone." These narratives highlight issues of disability experience and become valuable resources for understanding the social psychological experience of disability.

In their research Dunn and Burcaw (2013) noted that "a positive disability identity is apt to appear prior to adulthood" (p. 150), yet they included references to adult acquired SCI in the study. It seems likely that adopting the disability identity defined above would promote and support posttraumatic growth in individuals whose disability experience occurred during adulthood. The primary benefit of affirming a disability identity is communal attachment characterized by "favorable feelings toward and a desire to affiliate with a broad community of people with disabilities" (Dunn & Burcaw, 2013, p. 149).

Autonomy is a significant factor in the development of disability identity. It is not clear whether choosing a disability identity comes before affiliating with a disability peer group or results from such affiliation, but both the adoption of a disability identity and the designation of others as peers within a disability community are significant autonomous actions that contribute to positive identity formation. Researchers have reported that choosing a disability identity has become so meaningful that, in certain instances, potentially curative treatments were refused because "living with a disability was perceived to be a valuable experience, one that provided a positive source of personal and political identity" (Dunn & Burcaw, 2013, p. 149). These

choices can result not only in personal benefit for the individual, but in significant contribution to advocacy for social reforms and attitudinal shifts.

Summary

The question "Who gets to decide who is included in the word peer?" is not as rhetorical as it may appear. Autonomy compromised by loss, pain, and isolation may render the individual unable to participate in relational decision making and activity for a period of time. It may not be possible for the individual to consider new relationships from within an identity transition, especially if loss of pre-disability relationship is felt to be occurring. Contributions to this decision are made not only by the individual as they reevaluate their post disability relational network, but also by therapists, caregivers, employers, disability groups, family and friends, faith communities, cultural groups, and special interest groups in the client's life. Some individuals may choose to have no or minimal or occasional contact with their physical disability peers, and in fact may have no sense of being a peer within such a group. Others may find a network of new relationships, that become their most essential relational experience such that they claim and promote disability identity.

"What are the specific factors in peer relationship that can contribute to the process of confirming or restoring meaningful identity following adult acquired physical disability?" Supported autonomy appears to be a key factor in the identity decision an individual makes regarding the peer network they reaffirm or construct subsequent to disability. The choice of who is named as peer has a significant impact on the identity narrative told by the individual. This can result in an identity continuum that ranges from the disavowing of disability as a determinant of identity, to the embracing of disability identity as the primary shaper of an individual's preferred identity. An individual's place on this identity continuum is only

significant insofar as it determines the presence of significant peer support while the individual constructs a meaningful identity following adult acquired physical disability.

Chapter 4: Narrative Theory Contributions

Introduction

Interventions informed by narrative theory can offer collaborate therapy methods supportive of the identity transition process in the experience of disability. The use of the term "narrative theory" in this paper requires some explanation beyond mere definition. The term is used to describe a complex of attitudes rather than a specific grouping of therapy methods.

Narrative theory, within the world of psychotherapy, is not owned by any one author, but has been contributed to by many. Significant contributors to the understanding of the so-called 'narrative theory' being considered in this thesis include Kleinman (1989), White and Epston (1990 and 2011), Sanders (1995), Neimeyer (1999), Alexander (2008), Hedtke (2010), Madigan (2010), and Weingarten (2013). Much of the literature chosen for consideration in this research exhibits evidence of being narrative informed, even when not self identified as such. An example of this includes the work produced collaboratively in the 1990's by the Stone Centre writers, Jordan, Kaplan, Miller, Stiver, and Surrey (1991, 1992, 1997). These writers nowhere reference "narrative" as their model of therapy or their underlying theory, yet they present concepts, and ways of being as therapists, that seem to encompass a similar mindset, complimentary to those who name narrative theory as their presupposition.

Concepts

A narrative theory mindset relevant in considerations of the disability identity in transition experience includes the following concepts:

- awareness of dominant culture power and entitlement
- intentional welcome of "subjugated knowledges" (White & Epston, 1990, p. 25)
- understanding therapy to be a meaning making, "spiritual", process

- prioritizing story as the context for therapy
- a collaborative process of problem identification within a therapeutic relationship
- sharing ownership of the title "expert" with clients and family/friend networks
- understanding problems as contextual to relational and lived experience
- the belief that identity is constructed through self-in-relationship over time
- intentional affirmative witnessing through the client's local/peer community

Dominant Culture

The members of the dominant culture who are called “white” can think of themselves as having no, or a neutral ethnicity and culture. They often consider themselves to represent the norm and remain unaware of the power they participate in. Research into this phenomenon has demonstrated that when a white person develops a keener awareness of themselves as having a racial identity, discrimination and prejudice decrease (Sue, 2003). Similar increases of awareness can occur whenever entitled statuses are acknowledged and named, whether those arise from gender, participation in social class and relational networks, financial or educational privilege, or from the privileged status of "health."

In Sue and Sue's list of eight statements that define the culturally competent counsellor, statements 3 and 4 address the needs for an awareness of dominant culture entitlement: “The culturally competent counselor is aware of his/her own racist, sexist, heterosexist, or other attitudes of oppression” and “The culturally competent counselor has a clear knowledge of sociopolitical and institutional barriers that prevent some diverse clients from accessing services” (Sue & Sue, 2003).

In working with persons who have recently experienced disability, it is crucial that a therapist develop self awareness as to the many societal attitudes and interpretations of disability

they have assumed within their role as a professional in the dominant culture of western health care.

Subjugated Knowledges

"The insurrection of the subjugated knowledges" is a phrase from Foucault used to describe the process of empowerment persons experience when they reconstitute their lives and relationships through appreciation of their unique struggles and strengths (White & Epston, 1990, p. 32). The world of illness and disability has necessarily privileged the knowledge of medical experts and the system that supports this essential knowledge. Kleinman, a medical doctor and psychiatrist reflects on this,

Let us consider the health care system, then, as an enterprise centered on the care of illness experiences. ... Remarkably, most health care is delivered not in biomedical institutions or by professional practitioners but by family. ... Viewing the patient as a colleague and therapy as collaboration would, I believe, greatly improve the quality of the patient-doctor relationship....

Though it sounds simple, this type of medical reform is hedged in with thorny questions. It would require coordinated political, legal, and medical change - thus it can easily be dismissed as utopian. But I think this would be a sad error.... The professional sector's institutions are profession - rather than patient - centered" (1989, p. 259-263).

The word 'insurrection' sounds extreme and reflects the depth of despair that may occur when individuals experience the silencing of their story and the loss of their voice in a profession centered therapeutic conversation.

Honouring other knowledges need not imply a rejection of the medical system that is essential to the delivery of much needed and valued care for all those living with physical

disability, but rather can be heard as an assertion that personal and cultural knowledge must be honoured for care to occur. These knowledges can be easily suppressed in dominant culture discourses. In narrative theory informed therapeutic conversations subjugated knowledges are highlighted and invited to participate, contributing to the knowledge utilized by the client and their professional health care providers. These knowledges are understood to be the rich resources from which both problems and preferred identities can be named, and re-authored futures chosen and collaboratively constructed.

Meaning Making

Hope is a necessary component for the work of reconstructing and re-authoring a chosen future. In disability experience, hope, which is sometimes enacted as a personal knowledge standing in opposition to the "reality" of expert medical opinion, becomes an even more essential component for integrating what such an event means in a person's life. The "deeply private significance of illness" (Kleinman, 1989, p. 43) may call for an affirmation of human spiritual experience as central to human identity and personhood.

Spiritual experience is often described within subjective and personal criteria that likely cannot be replicated. Historically, this departure from objective empirical data has been cause for dismissing this realm of human experience as relevant to research within the field of psychology. "There is no question that religion is often used in the way Freud saw it, or that many religious beliefs have served as substitutes for facts ... Some would extend this criticism into the full-fledged conviction that every religious belief and experience will eventually disappear as scientific knowledge continues to grow" (May, 1987, p. 28).

Rather than continuing this science versus religion debate, May proposes the development of a contemplative psychology. He observes, "contemplation offers the most

fundamental meeting ground for psychology and religion; it is at once a psychological condition and a religious attitude” (1987, p. 25). This contemplative psychology has the potential to include all ways of knowing:

A contemplative psychology is an approach to human experience that maintains that wisdom depends upon the full cooperation of all ways of knowing: observation, logical inference, behavioral learning, and intuition. It acknowledges that the purest form of knowing is intuition, and it seeks to expand the innate human capacity for intuitive perception. The goal of a contemplative psychology is not the separate autonomy of the individual but the realization of one’s essential rootedness in God and relatedness in creation. Its means are not wilful mastery but willing surrender. Its resources lie in the comparison of modern psychological understandings with the insights of ancient spiritual traditions of both East and West. And its laboratory is the stillness of the human mind in silence (May, 1987, p. 26-27).

The time of transition after crisis holds potential as a place and time of meaning making, meaning discerning, and personal transformation. All the resources available to an individual need to be encouraged and supported. A contemplative psychology can be one such resource.

Narrative theory implicitly supports a contemplative psychology mindset in its invitation to meaning making through the “performance and circulation of their preferred stories and knowledges” (White & Epston, 1999, p.76). While social constructionist theories are not known to affirm the big picture stories and doctrines of world religions (Madigan, 2010, p. 66), in their affirmation of local knowledges (Madigan, 2010, p. 45-46) they invite those affirmations of the sacred that are integral to many personal narratives. This tension, that would dismiss the dominant culture of powerful religious organizations, yet affirm the spiritual beliefs and

practices of the individual, has not been significantly addressed in any of the narrative theory literature I have reviewed. This presents an opportunity for future research into the relationship between a spiritual narrative story and preferred identity outcomes following disability.

The construction of narrative identity is founded on convictions in which, "the issue of valid or verifiable truth is less important than the beliefs storytellers develop and rely on to understand, navigate, and share their life experiences with others" (Dunn & Burcaw, 2013, p. 151). Although narrative theory does not address the function of faith (i.e. beliefs that may or may not be identified as religious by the person holding them), "spirituality" or "faith" is implicitly affirmed in so much as it contributes to this meaning making process that story tellers develop and rely on.

Narrative theory has been embraced by numerous people groups, who are in part identified by their spiritual community affiliation, and who have communally, as well as individually, experienced socially and politically sanctioned trauma. These include Aboriginal Australians working with the Dulwich Centre Foundation, individuals from the Six Nations Reserve near Caledonia Ontario, survivors of the Rwandan national genocide through Ibuka Association, the Ugandan Mt. Elgon Self-Help Community Project, and "Palestinian therapists at the Treatment and Rehabilitation Center in Ramallah are similarly developing forms of narrative practice that are culturally resonant" (White, 2011, p, 164-166).

It is hopeful that discussions which more directly address the significance of human spiritual transformation will emerge from the work of these people groups as they develop these culturally resonant forms of narrative practice. The centrality of the spiritual dimensions of human identity within cultures that are not focused on the promotion of individualism and free market society, holds hope for all cultures, including what some call the disability culture.

Meaning making through relationship is an inherently universal human activity. Dominant cultures that have minimized or disregarded the knowledge of spiritual identity expressed in, and experienced in, community stand to learn much from the research that may emerge from Dulwich, Ibuka, Mt. Elgon, and others who tell their stories.

Prioritizing Story

"Narrative therapy finds no cause or reason to diagnose and/or label a person's lived experience" (Madigan, 2010, p. 8). Naming of experience occurs through a process of construction and re-membering of the personal story that emerges through therapeutic conversations, rather than through a pronouncement of professional diagnosis. What gets to be said in therapy, who gets to say it, and with what professional influence it is said, is challenged by one of the primary questions in narrative theory: "Who has the storytelling rights to the story being told?" (Madigan, 2010, p. 9). Removing the story of disability experience from the story of the medical file is a symbolically and clinically powerful gesture. It establishes the client/patient and their family in the role of owner (of both the personal story and the medical/therapeutic file), and the roles of medical and other practitioners as the employed professionals who work in service of the owner's needs. The client's right to access their medical and clinical files supports this mindset in theory. In practice, it is often difficult for to attain this access.

Collaborative Problem Identification

The narrative mindset is deeply collaborative and intimately conversational. The core of the therapeutic relationship resides in a conversation. This conversation is facilitated by the therapist, who adopts a stance of curiosity and not knowing akin to the Socratic stance of "one thing only I know, and that is that I know nothing" (Shelley, 2013, p. 84). This collaborative

stance is not unique to narrative theory. "Socrates and Adler, modeled cooperation in the role of a warm, gentle, humble co-thinker who stimulated others through skillful and sometimes playful questioning" (Shelley, 2013, p. 84). From this stance the therapist and client co-construct the conversation in which the problem is named, identities chosen and communities of support are re-membered. The quality of the relationship becomes evident in the quality of the conversation. Such mutuality necessitates a therapist perception of the client in which "neither the person nor the relationship between persons is the problem. Rather the problem becomes the problem, and then the person's relationship with the problem becomes the problem" (White & Epston, 1990, p. 40). This practice of externalizing the problem allows an authentically collaborative therapeutic relationship to develop.

An example of collaborative problem identification is found in the work of Dunn and Burcaw (2013) in their account of Joan, who initially responded to her amputation of one arm with self loathing, isolation, and substance abuse. In working with a therapist Joan was able to get past her need to "dis-identify myself with the image or label of being a cripple" (p.153) and join a therapy group for women with disabilities. In this process she learned to identify perfectionism, rather than the disability, as the problem that was creating her rage and unhappiness. She describes her insights: "Imperfection is the essence of being organic and alive. ... Cardboard ideals of perfection are flat and pale by comparison" (p.153).

In Relational Cultural Theory (RCT) this mindset is called Mutual Empathy. RCT posits that personal identity grows in, through, and toward an attitude of relatedness and mutuality, becoming increasingly complex over the entire human life span. This prerequisite for healthy human development is described as "the experience of mutual responsiveness and influence" (Comstock, 2005. p. 26) that can only occur in relationship. RCT sees this as essential to mental

health and well-being. Relational movement is the process of working through the distress of disconnection towards reconnection, using Mutual Empathy for relational transformation and enhancement. The work of Mutual Empathy includes constructive conflict, respect for differences, supported vulnerability, authentic expression, differentiation of self, and empathetic resonance resulting in mutual growth within the collaborative relationship (Jordan, 1992). In chapter three of this paper the observation was made that identification with another individual who has experienced a similar physical trauma, is a central factor in the peer mentor relationship. Identification with, is a strong component of Mutual Empathy.

An example of this can be seen in the reports of success of peer mentor programs that seek to re-establish connection following the perceived “loss of identity” (Dickson, Allan & O’Carroll, 2008, p. 416) experienced by some individuals recovering from spinal cord injury, and other physical trauma.

Jordan describes the benefit of Mutual Empathy for persons who are recovering from trauma, “the movement towards helping others often becomes the key to the transformation of private pain and isolation into compassion for the suffering of all human beings” (1992, p. 7). One study reported on the impact of a peer mentor leadership training program, for individuals recovering from acquired brain injury. In becoming a peer leader one individual reported becoming, “more confident in myself to be able to go out and be an advocate for people with acquired brain injury and stroke” (Kennedy, Turner & Kendall, 2011, p. 162). Another participant in the same study described the benefits in their peer mentoring as, “It was a bit of a boost for them that there is someone that has had the same problems, that is there helping them so it’s sort of a win, win situation really, it helps me go forward as well so you see that there is benefit for yourself and also for those who do it” (Kennedy, Turner & Kendall, 2011, p. 162).

Expert

In a collaborative therapeutic relationship the designation of expert loses relational relevance, even while it retains relevant implications of responsibility. Sharing ownership of the title of expert in the therapeutic relationship with clients, and family/friend networks, allows the collective work of therapy, rather than the reputation, skill, or personality of the therapist, to remain the focus of the relationship. It also recognizes "the centrality of the insider voice: The expert on the lived experience of disability or illness is not the clinician, but the person experiencing disability or illness" (Richards, 2008, p. 1717).

An alternative view to sharing the title of expert, is to consider expertise to reside within the relationship, rather than in any particular person. This frees all parties from the burden imposed by the expert designation. This diminishes the danger that successful therapy will primarily contribute to the status of the therapist, and place the client in the position of being required to support that status by being "the good client." Placing expertise within the relationship allows for the dignity of sharing success.

Responsibility to offer appropriate professional knowledge, in an ethical manner, at the right time, for the identified problem, remains with the therapist, who benefits financially from the relationship, and, in many instances holds the power and privileges of higher education, professional accreditation, and societal esteem.

In the context of physical disability the therapist may also be the person who holds the status of health. In such instances, recognition of the knowledges gained through the experiences of trauma, illness, and disability, where posttraumatic growth has occurred, will contribute towards authentic sharing of expert status. (It is also important to note that physical disability does not mean the person is ill. Wheel chair athletes exhibit high levels of health and fitness.)

Balancing these sensitive realities within a therapeutic relationship is perhaps where the greatest expertise, on the part of the therapist, resides. In the work of supporting a person in identity transition, it may be that saying, "I don't know" and inviting conversation becomes the marker of the truly professional expert.

Problem Context

Problems are contextual to lived experience. Lived experience includes not only the narrative of the person experiencing disability, but also consists of the social, political, cultural, economic, and relational components beyond the immediate control of the individual client and their family. Acknowledging this larger context without being overwhelmed by it can be a significant therapeutic contribution.

Individuals who are required to be in partnership with the health care system benefit from both community and professional advocates who can educate and assist in "navigating" the medical and rehabilitation world. The social model of disability that asserts an understanding of disability experience as, in large part, socially determined can be helpful in managing feelings of powerlessness. To see the issue of disability as "a socially created problem and a matter of the full integration of individuals into society" (Disabled-World Website, 2013) includes the individual and their family in a community of shared responsibility.

The human rights issues of equal access become opportunities for participation in a social project that benefits both the disability and the non-disability community through the construction of accessible buildings and city infrastructure, as well as providing meaningful social discourse for self and other advocacy. When the identified problem looks beyond the mind and body of the individual, and considers the social context, meaning making and motivation to change societal and personal barriers, are enhanced.

Self in Relationship

Narrative theory sees the formation of identity as socially situated. This is especially relevant in the experience of disability. "Although we live in singular bodies, illness makes visible that we become intelligible through continuous processes of social negotiation" (Weingarten, 2013, p. 83). An individual experiences a painful threat to identity when they see reflected back them, in the eyes of their family/friends, a person they do not wish to be. Their family and friends are also persons struggling to maintain identity in a shifting context, requiring they now renegotiate many details of a relationship no longer intelligible to them. In this context of relational renegotiation, "The self is dialogically constructed. The other is already from the outset part of the self. I am who I am in relation to the other ... a tension between the self and the other is built into the very desire for identity" (Volf, 1996, p. 91). Disability cannot be considered an identity transition of only one individual, as its impact is inherently communal.

The reality of being a self in and through relationship is demonstrated at many levels of complexity in the disability context. "Witnessing a loved one struggle with self-loss, truly taking in the magnitude of suffering can be excruciating" (Weingarten, 2013, p. 91). If individuals in a disability experience, attempt to spare loved ones such grief by ending the relationship through divorce, or emotional withdrawal both persons undergo significant distress and the threat to identity is a real crisis for everyone in the family/friend network. The threat to identity clearly extends beyond the individual.

To recognize this sharing of pain, and to accept these painful bonds of affection can involve trust, humility, and resilience. Weingarten proposes the promotion of "reasonable hope" stating, "I deliberately work so that more often than not couples leave a session believing that there are actions to take - however small- that will lead to a preferred outcome" (Weingarten,

2013, p. 94). Rebuilding or reaffirming identity in the transition after disability is often accomplished within a relational renegotiation process.

Three forms of disruption to the self-narrative are described as "Narrative disorganization occurs when events or experiences, like sudden or chronic illness, make it difficult to sustain a stable sense of oneself. Narrative dissociation, ... results in a thinning of the self-narrative, the self-narrative lacks both voice and audience... In the case of narrative dominance, one narrative takes over and in effect "colonizes" the self-narrative, "crowding out" all other versions. As therapists we need to understand how all three forms of narrative disruption operate relationally, contribute to experiences of self and other-loss, and can shift" (Weingarten, 2013, p. 94) over time.

Disability renders the socially situated formation of identity complex and painful, even as it remains an essential and positive component for recovery. It may be that a client and/or their family will retreat into isolation, not only to protect themselves, but also to protect those they care for. This retreat from relationship may create increased anxiety within the relational system. Non-anxious, professional presence can offer a relational bridge between the individual and their friends and family. Professionals are often trusted with the raw emotion individuals attempt to shield their loved ones from. Weingarten (2013) comments on this, "while couples do better when both share feelings, partners of people living with chronic illness may inhibit themselves or even keep secrets under the mistaken idea that they are "protecting" their loved one" (p. 85).

Community

A community that affirms an individual in their preferred identity can come together from unlikely places. Narrative theory recognizes the benefit for the individual to intentionally choose a witnessing community as part of the process of re-authoring their story and affirming

the identity that emerges from the transition following disability. In disability experience the community an individual would prefer may no longer be available to them. Loss of employment, recreational involvements, and limitations in mobility can significantly limit choices. These are some of the realities that have given rise to the emergence of "the disability peer community" through which some individuals may find affirmative witnessing to their present identity.

Interventions

The narrative theory mindset that adopts the above convictions gives rise to specific therapeutic interventions. Three interventions relevant to the experience of disability include re-authoring narrative identity, externalizing the problem, and the witnessing of transitioned identities.

Re-authoring Narrative Identity

“The term *narrative identity* refers to the personal evolving story of the self that an individual consciously and unconsciously creates to bind together many different aspects of the self” (Dunn & Burcaw, 2013, p. 148). One of the achievements of posttraumatic growth is the construction of a narrative identity the individual comfortably inhabits. One study "looked at a small number of TBI (traumatic brain injury) patients 'at ease with themselves' and found that they all had a 'positive self narrative' about the event" (Powell, Ekin-Wood & Collin, 2007, p. 37).

Re-authoring is the process of re-storying: restoration of the story that evolves subsequent to the disability experience. This may involve the process of reinterpreting pre-disability experience in the light of what the individual has learnt through the disability experience. Previous aspects of the self will be consciously and unconsciously bound together within the

present self. In their study examining posttraumatic growth in persons with visible disability Salick and Auerbach identified five stages in the adjustment and growth process subsequent to trauma/illness: Apprehension, Devastation, Choosing to Go On, Rebuilding, and Integration (2006, p. 1034). Re-authoring occurs on some level at each stage, but is often not articulated fully until the final stage of integration in which "participants reported the integration of their pre and post trauma lives" (2006, p. 1032).

It is significant to note that "The trauma itself remains a distressing event. It appears that few people consciously and systematically intend to make meaning out of trauma or to benefit from it. Posttraumatic growth is most likely a consequence of attempts at psychological survival, and it can coexist with the residual distress of the trauma" (Tedeschi & Calhoun, 2004, p. 5). The process of re-authoring can emerge from the initially automatic and largely intrusive rumination that follows trauma. As rumination, which is in itself painful and distressing, is channeled into various forms of storytelling such as writing in journals, letters or email, posting on facebook, speaking, praying, creative expression in visual arts, drama, or electronic media, and spoken therapeutic conversations, posttraumatic growth emerges. "The degree to which individuals engage in self-disclosure about their emotions and about their perspective on their crisis, and how others respond to that self-disclosure, may also play a role in growth... cognitive processes of the traumatic event, particularly the process of ruminative thought, is related to growth" (Tedeschi & Calhoun, 2004, p. 5).

To re-author identity following trauma appears to be an almost instinctual need, akin to an obsession, that for some is linked to psychological identity survival. There is a need to know, 'Who am I now that this has happened?' "Supportive others can aid in posttraumatic growth by providing a way to craft narratives about the changes that have occurred and by offering

perspectives that can be integrated into schema change" (Tedeschi & Calhoun, 2004, p. 8).

Peers, family, and professional therapists each have a role to play in this support of re-authoring identity. Support is best received when offered at the time, and in the manner, identified as preferred by the individual. The research that describes the benefits of engaging in cognitive and affective self disclosure would also suggest group therapy as a potentially significant contributor to healthy identity transition.

Externalizing the problem

Circumstances resulting in disability can be highly problem saturated, and are most often experienced as fixed, and thus, overwhelming. This can lead to the internalizing of a problem identity such that individuals will describe themselves in negative and derogatory language. Changing the language of the conversation and allowing the person to examine their relationship to the problem, rather than examining themselves as the problem, can be a powerful identity changing intervention.

The process of externalizing the problem "is an approach to therapy that encourages persons to objectify and at times, to personify the problems that they experience as oppressive" (White & Epston, 1990, p. 38). Externalized problems can be more objectively addressed than self loathing, or an identity informed by despair.

When a person, who now lives with a physical disability, changes the focus from what has been lost and what they can't do, to what they can do, it is not only a change in their thinking. It is a change in their identity. This change from "can't" language to "can" language marks a significant change wherein the disability is no longer perceived to be the problem in every situation. It is not uncommon for those outside the disability experience to miss the

significance of this change in perception. They may be confused that individuals can live with disability and sometimes not consider disability as the problem.

Therefore, it cannot be assumed that disability will be considered a problem, and even when it is, it may not be the problem the client wishes to address at the time. It also cannot be assumed that the transition of identity is experienced as a problem. In reflecting on his experience following a leg amputation one individual reported, "it was not the amputation per se that conferred this new identity, but rather the manner in which others behaved towards him" (Hamill, Carson & Dorahy, 2010, p. 734). In this example, it is neither the disability nor the new identity that is the problem. Further conversation with this client would allow the client to give a name to the problem such as "stigma" or "isolation" or "rejection" or "feeling different." This naming could help to direct a therapist's understanding of the client experience, and allow for a collaborative exercise of identifying the influence of this problem on the person, as well as discovering the influence the person might gain over this problem.

The benefit of this process of externalizing the problem, for individuals in the disability experience, resides in freeing the individual from a felt need to assume an identity arising from the disability experience. Externalizing the problems arising from the disability experience allows for an experience of greater identity choice. To believe one is not defined by "the problem" is to gain empowerment and freedom. In an experience where power and freedom are often named as the greatest losses, this significant realization can generate autonomy and confidence.

Witnessing Transitioned Identities

Identity in transition can be meaningfully acknowledged and affirmed through the act of intentional witnessing. Sometimes called "outsider witnessing" (White, 2011), a "definitional

ceremony" (Madigan, 2010) or "re-membering conversations" (Hedtke, 2010) this practice involves bringing together persons chosen by an individual, for the purpose of naming and speaking to that person's identity. Regarding this definitional ceremony Hedtke (2010) quotes Myerhoff (1992), "A story told aloud to progeny or peers is, of course, more than a text. It is an event" (p. 141). This event of having disability experience and identity intentionally witnessed can provide the individual and their social network with much needed markers from which to move forward. Although Hedtke is writing about bereavement following death, many of her observations are relevant for the bereavement following disability, especially her observation that "Discussion of loss alone is of dubious merit and potentially painful for the bereaved. ... I contend that when we focus on stories of benefit, while acknowledging the painful aspects as well, we construct more useful ways of living with the experiences of death and grief" (Hedtke, 2010, p. 149). These stories of benefit and growth, strength and love, reside in the relational community as well as in the individual. This relational community can consist of family, friends, professional therapists, disability peers, or any combination of persons who come together for the purpose of affirmative witnessing and appreciative inquiry. When these stories of benefit are shared in a group, identity is positively witnessed.

Weingarten (2013) describes the act of witnessing as consisting of four possible positions, with only one of the four being therapeutic. The four positions each describe the two components of emotional awareness and effective responsiveness as either present/high or absent/low.

In witness position one, emotional awareness and effective responsiveness are both present/high. The witnessing person is emotionally present, attuned, aligned, and their responses are useful, appropriate, and timely. This is the only fully functional witness position.

In witness position two, emotional awareness is absent or low and responsiveness is high. In this position the witnessing responses may well be efficient, competent, capable, organized, and even useful, but they are rendered into clumsy, intrusive advice-giving lacking in empathy to the point of berating the individual they are "trying to help." The witnesser is emotionally distant, and unaware of the impact of their insensitive efficiency. The individual who is the recipient of such efficiency may feel obligated to "be grateful" because they fear losing the relationship if they complain.

In witness position three, emotional awareness and effective responsiveness are both low or absent. In this situation the witnesser is numb, seemingly emotionless, unaware, hopeless, disempowered, and withdrawn. The disabled individual may "take care of" family and friends who assume this position as a way to maintain relationship, hoping that eventually they will receive empathy and response in return.

In witness position four, empathy and emotional awareness are high to the point of overwhelming the witnesser. They cannot think of or mobilize any useful action and effective responsiveness is low or absent. The witnesser may cry every time they see the individual, or simply be so aware of their own painful emotions that they cannot respond. Again, the individual who should be receiving support may find themselves giving it.

Although "Witnessing positions are not static or stable" (Weingarten, 2013, p. 92), the benefit of a witnessing community, is that personal variations can be ameliorated so that there is always at least enough empathy and efficiency available. When such a level of support is realized through a witnessing community, the individual will have available to them resources for affirming or reconstructing identity.

Summary

The collaborative mindset of narrative theory allows for many voices to contribute to the transition of identity following disability. The medical model priorities assume their appropriate place alongside acknowledgments of socially determined disability experiences and barriers. The community of discourse is enlarged to include all of the expertise available. Individuals experiencing the disability transition may benefit from bringing together or participating in a witnessing community wherein their expertise of experience can contribute to this enlarged conversation.

The mindset and therapy methods explored in this chapter, indicate a facilitated peer group format may be an inherently therapeutic tool that provides a venue in which transition can be appropriately supported. Such a group would model a practical manifestation of a witnessing community. Chapter five will present a group design that incorporates these theoretical and practical considerations and benefits.

Chapter 5: Small Group Design and Summary

Introduction

The term ‘disability’ has been used throughout this document to describe the circumstance of the population being considered. It must be acknowledged that there is no consensus, and considerable discussion, regarding the terminology that is used to describe the persons and the experience. One recent term suggested as a replacement for the label of ‘disabled,’ or the more commonly used ‘person with disability,’ is the term ‘differently abled.’ The decision was made to not use the ‘differently abled’ term in this paper as it does not recognize the loss and/or trauma that has occurred. In personal conversations with persons living with physical disability there was mixed response to ‘differently abled’ and in many therapeutic conversations some recognition of impairment is required. However, this recognition of impairment can carry an implied exclusion from the norm of human experience that creates the unwelcome and harmful stigma historically associated with disability experience.

The World Health Organization document on the International Classification of Functioning, Disability, and Health (ICF) seeks to correct this:

In ICF the term functioning refers to all body functions, activities and participation, while disability is similarly an umbrella term for impairments, activity limitations and participation restrictions. ... Previously, disability began where health ended; once you were disabled, you were in a separate category. We want to get away from this kind of thinking. We want to make ICF a tool for measuring functioning in society, no matter what the reason for one’s impairments. So it becomes a much more versatile tool with a much broader area of use than a traditional classification of health and disability. This is a radical shift. From emphasizing people’s disabilities, we now focus on their level of

health. ICF puts the notions of ‘health’ and ‘disability’ in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity. ICF thus ‘mainstreams’ the experience of disability and recognizes it as universal human experience (Ustun, 2002, p. 2-3).

The underlying assumption for this academic work is that it is primarily valuable insofar as it is helpful to those individuals who are experiencing identity transition in the context of disability. Disability, a physical impairment that affects functioning, is only one of many factors that influence identity. The insight that the majority of humanity experience decrement in health, as well as other losses, provides a place of identification in which client and therapist can potentially meet as human experience peers. The ICF mainstreaming of the experience of disability as a universal human experience confirms collaboration as an essential mindset of any therapy seeking to address disability experience.

As noted in the chapter one literature review, “Fervor for the dominant models of grief led therapists . . . to turn their listening more to what the models predicted than to what people were saying to them” (Hedtke, 2010, p. 17). This loss of focus from the ideal of client centered care, has at times also held true within the systems of organized health care that serve individuals living with disability. Structures that allow for people to be heard can benefit both the individuals and the organization. One such structure is the small group.

Small Group Design

The provision of a clearly designated sacred space, library, art room, or simply a comfortable room with some natural light, within a health care setting, is in itself a therapeutic intervention. This simple provision of a safe, accessible environment can be a major

contribution towards achieving the therapeutic benefit realized when people meet. However, even within health care facilities, physical venues that accommodate the needs of individuals with physical disabilities can be surprisingly difficult to find. Spaces designated for treating what is “wrong” are clearly identified in health facilities, but space can be lacking for the seemingly less pressing needs of supporting what needs to grow. Hedtke (2010) notes, “miracles of relationship were happening everywhere in the hospital, largely unnoticed because of the pull of pathologizing discourse” (p. 17).

As well as the provision of an appropriate physical space, the designation of time for listening also confers a respect for the process of transition that can have a therapeutic benefit. Chapter two’s considerations of pre-disability identity, patient identity, and post-disability identity in transition, within the themes of physical, psychological, social, and spiritual identity, suggest that the time of transition can provide significant opportunities for the facilitation of posttraumatic growth and the development of a positive post-disability identity. Providing an event that gives time for these developments to be named, recognized, and discussed is essential for their affirmation and encouragement. In chapter three, it is noted that client identified peers who support client autonomy, in collaboration with the resources of family, friends, and professional therapists, can offer a psychological context in which social connectedness becomes a therapeutic intervention that promotes the development of a positive disability identity. This development also requires intentional time designated for the building of relationship.

The articulated intention, by professionals who hold both power and privilege, to work collaboratively is also inherently therapeutic. Chapter four’s considerations of therapeutic interventions informed by a narrative theory mindset suggest that these narrative concepts can benefit individuals during the identity transition phase of the disability experience. Bringing

together the observations drawn from the research, this study proposes that therapeutic interventions intended to support a positive identity subsequent to disability, can be optimally explored and enacted in a small group process, facilitated within a rehabilitation or health care setting. The facilitator can be a Spiritual Care Practitioner, Social Worker, Psychologist, Counsellor, or any other Health Care Professional willing to work collaboratively. Collaborative, client-centered care is a key element in the construction of many physical and occupational therapy rehabilitation programs, however, Spiritual Care Practitioners are often in the best position to provide a venue in which the physical, psychological, social and spiritual aspects of identity can be integrated. In such a health care context, goals are mutually formulated, worked towards and achieved. Narrative theory offers a psychological parallel congruent with, and complimentary to, this ideal of physical rehabilitation.

A therapy group offered in this context, has the opportunity to support positive identity development within a facilitated, yet collaborative, group process that offers opportunity for peer group formation. The research in this thesis is biased towards the conviction that client autonomy, peer relationship, and collaborative process contain inherently therapeutic possibility and therefore warrant the explicit validation given to scheduled events and structures. The design of a structured, collaborative, therapy group is one instance of such an event.

Rationale

Issues of loss and identity deeply affect the human spirit. These issues require intentional meaning-making involving the reframing of an individual's worldview in the context of their ultimate values, beliefs and their sense of trust or faith. Persons experiencing identity transitions subsequent to disability can feel a profound sense of dislocation and social isolation.

“The reconstruction of a world of meaning is the central process in grieving” (Neimeyer, 1999). The structure of a small group can create a space wherein the values, beliefs, faith, and practices of meaning making that sustain who a person is, can be restructured, reaffirmed, and shared for mutual benefit.

Reconstruction of meaning and identity following trauma/disability begins with “a starting point of ‘being with’ rather than ‘doing to’ (through) mindful listening, allowing time, supporting clients to prioritize what is meaningful and viewing the therapists’ role differently” (Bright, et al, 2012, p. 997). The philosophical assertion affirming client-centered collaboration, in the rhetorical narrative theory question, “Who has the story telling rights to the story being told?” (Madigan, 2010, p. 9) invites guided conversations that linger over questions of meaning and identity, past, present, and future.

A small group format invites a dialogue that is well suited to a narrative therapy process that listens, reflects, and makes meaning in the context of trauma and disability. Michael White (2011) observes, “It is invariably the case that efforts to directly address people’s experiences of trauma are unproductive at best, and in many circumstances, deleterious” (p. 123) and goes on to suggest,

The primary therapeutic task in addressing the effects of trauma on people’s lives is then to provide a context for the development or redevelopment of the sort of personal reality that gives rise to a sense of self that is referred to as ‘myself.’ This development or redevelopment of this sense of an inner life can be achieved through a therapeutic inquiry that brings together a person’s diverse experiences of life into a storyline that is unifying of these experiences and that provides a sense of personal continuity (2011, p. 123-124).

A group facilitator who brings this mindset into a group experience is less likely to fall into the

temptation to rescue individuals from intense emotions, and more likely to retain the differentiation of non-anxious presence that promotes comfortable communication about emotional issues (Kerr, 1988). Holding this mindset in a group context welcomes the resources of personal wisdom, spiritual contemplation, family and community tradition, cultural understandings, and ongoing cognitive restructuring into a relational conversation where people are heard, challenged, and affirmed by a group of peers.

Structure

A group of 5 to 7 participants would meet once a week, for six meetings of 1 ½ hours each. During each meeting every participant would be given the opportunity to respond to the theme of that week.

The emotional intensity and felt isolation experienced in disability, have many similarities to the bereavement experience. This proposed group structure considers the data from the research done by Hedtke (2010). This research gathered data from bereavement groups using the practice of “remembering conversations” (p. 20), a research exercise founded on narrative practices of inquiry. This narrative perspective recognizes the significance of telling and analyzing one’s stories. The multiple stories of an individual contain meanings that are useful to those in identity transition. These multiple stories reference the communal and cultural histories of the individual’s past, they acknowledge the recent experience of crisis as well as the present disability. Perhaps most importantly these stories can be the maps that lay out future life vectors.

The group would be a closed group that meets for a limited number of sessions. Part of the rationale for this emerges from the physical realities of disability. Public transportation limitations, issues of chronic pain, schedules for medical treatments and appointments, issues of

wheelchair maintenance, are some of the additional complications of disability that can make regular attendance over a long period of time challenging for some individuals. The session time was limited to 1 1/2 hours because sitting tolerance for some clients is limited to around 2 hours.

Additional rationale for this format is found in brief group therapy research, “Remoralization can occur quickly, and eight sessions or fewer are sufficient to return many clients to their precrisis level” (Yalom, 2005, p. 288). The possibility for a second phase of an open group for aftercare maintenance is a follow-up plan that may be of additional benefit. This option “reinforces the gains made during the intensive phase and helps clients apply their gains more broadly in their own social environment. This model has worked well in the treatment of substance abuse, trauma, and depression” (Yalom, 2005, p. 283).

Selection

Participants would include clients from the community, and the out-patient and in-patient populations of physical rehabilitation centers. Individuals still in acute care hospitals would generally still be dealing with medical needs that would prevent their participation. Clients with complete aphasia or significant memory loss would usually not be suitable for this group, however, as each client would be interviewed before the first group meeting, this would allow assessment for everyone who expresses interest in participation. Ideally the client group would begin and end the group together. Group membership would be voluntary. Consent, establishing confidentiality limits and expectations, as well as potential benefit and risk would be transparently presented in these individual pre-session meetings.

The primary admission criteria would be the identification of a transition from an identity of “being well” to “disability.” Some clients who have lived with a diagnosis over many years, may none-the-less clearly identify a specific time in their lives when they experienced such a

transition. The identification of this experience resides in the story of the individual, not in the medical diagnosis. The diagnoses represented by participants may include a variety of illnesses, such as stroke, cancer, or arthritis, as well as the disability resulting from injury caused by accident, self harm, or violence. Both men and women, of all ages would be considered. A heterogeneous mix represents an alternative to the medically designated peer groups formulated on the basis of diagnosis. This can have the beneficial impact of implicitly confirming experience with disability as a “universal human experience (Ustun, 2002, p. 2-3).

Process

Group participants will be encouraged to look beyond the medical model paradigms of diagnosis, treatment, and cure, so as to allow them to give priority to their core identity and the unique meaning of their experiences. Mindfulness, a meaningful sense of being, and personal experiences of transcendence, are incorporated into an expanded appreciation of health, healing, and care, lending a holistic understanding to the experiences of illness and disability.

The facilitator, after ensuring a safe environment through the provision of an appropriate physical space, and the initial screening at intake interviews, would establish the agreements for confidentiality and respect necessary for personal story sharing and disclosure in the group. At the start of each session opportunity would be given for the introduction of a concept relevant to the topic of the week, followed by facilitated discussion. In the initial meeting the concepts of feedback and disclosure could be clarified by presenting the Jo-Hari Window (Yalom, 2005, p. 529) as a cognitive guide demonstrating the desired outcome of group conversation. Clients would be reminded that their participation is voluntary and intended for personal and group benefit.

Each session would be simply structured so that the facilitation required is minimal and client discussion is the primary activity. Following a welcome and a brief summary of the previous session the theme for discussion would be introduced by the facilitator, who then ensures each participant is heard in the ensuing conversation. It is important that time be given to wrap up the session with each participant being given opportunity to reflect on what has made an impact and/or what they will take away from the session.

Themes

This outline describes a possible implementation of the themes. The issues identified are both implicitly and explicitly addressed in the discussions arising from these themes. The questions listed for each session are intended to indicate the mindset of the facilitator, although they may be selectively used as explicit tools for directing the session. They form an array of possible questions. One or two questions could be used in a session, either asked as a question or stated as a concept. Their use will depend on the unique dynamics of the group at any given moment. If one question is all that is needed to invoke reflection and interaction, then there would be no need to use others. Some of these questions may be inappropriate to one group, but well suited to another.

The process of formulating and using questions such as the ones suggested here emerges, in part, from my reading of Madigan (2010). Some of the questions listed are similar to those given as examples in his book, *Theories of Psychotherapy Series: Narrative Therapy*, but most have been adapted or created for the specific group being presented in this paper.¹ Although

¹ I learnt the tone and nuances for formulating these questions from three Narrative Therapy workshops attended over the past two years. I had opportunity to listen to Stephen Madigan and Lorraine Hedtke in therapeutic conversations that modelled the use of questions. As I listened to them, I jotted down notes that have evolved into the list of questions presented here. I have also incorporated questions arising from conversations with Doug Longstaffe, Director of Spiritual

they have been formatted through narrative informed language for this thesis, many of the questions emerge from nearly twenty years of work as a health care chaplain. They come from collaborative conversations with spiritual care professionals, health care staff, clients who are recovering from illness and trauma, and their families, and friends who assist them in making sense of the disability experience. I have gathered these questions because they have facilitated meaningful conversations, supporting emotional and spiritual healing for the persons with physical disabilities I have met with in my work as a Health Care Chaplain. I anticipate they will contribute to the same goal when utilized within a therapy group.

The questions coordinate with the six themes that shape the weekly group sessions:

Session 1: Identity without Disability

Session 2: Disability Narrative

Session 3: Transition

Session 4: Power

Session 5: Help

Session 6: Seeing Each Other

In Session 1, The Jo-Hari window is briefly introduced to demonstrate the concepts of disclosure and feedback in group process. Participants are then invited to introduce themselves with no reference to illness or disability. For participants who have carried a diagnosis over many years and for those who have been recently focusing on the trauma of their circumstances, this invitation provides a unique, and perhaps unexpected, opportunity to consider their personal identity outside of the context of disability. This narration of identity is followed by a dialogue

Care at Vancouver General Hospital, and Dr. Patrick J. Ducklow, Psychologist and Professor, in Vancouver, B.C. The lack of specific citation in these question lists does not diminish my indebtedness to the teaching I have received.

regarding what contributes to identity formation. The facilitator can record the key points in this, and any other, discussion on a chart visible to all participants. The notes belong to the group.

This session will invite participants to reflect on their belief histories and relational histories, rather than their trauma histories, establishing a strengths based model for future group discussions, and beginning the process of retroactive meaning making in the present, that projects into a preferred future.

Questions:

- Do you remember a time when you decided you believed something to be true?
- What did it feel like to make a decision about what you would believe?
- What Value or Virtue has had the greatest influence on you in the decisions you have made?
- What influence did the people who were important to you have on your beliefs?
- Was there a time in your life when your beliefs were influenced by an event or a new idea that caused you to change them?
- How do you decide what is important to you?
- When you decide something matters, how do you respond?
- How does your belief that something matters influence your feelings?
- How does your belief that something matters influence your thinking?

In Session 2 the individual disability stories are told. The “problem” of disability is viewed as external from personal identity. This is primarily communicated by the externalizing language the facilitator chooses to use.

Questions:

- What influence has the disability had on your identity?
- What influence has your identity had on the disability?

- Is there something unexpected that is valuable to you now?
- Is there something you need to say to the disability?
- Is there something you need to say “No” or “Yes” to?
- Has disability taught you anything valuable?
- What or Who in your life prepared you for today?
- Is it worth it or not worth it to maintain the practice of your spiritual beliefs?
- What belief or value have you chosen to retain, despite it being threatened by the disability?
- What belief or system of meaning making is sustaining you today?
- What behaviors help you remember this belief?
- What thoughts will support this belief so that it continues to support you?
- If you were to continue in this belief that you have today, where will it take you?
- What dream or purpose do you aspire to, and hope for?
- What commitment, to a person or to a way of being in the world, do you intend to keep?

In Session 3 the experience of transition is explored through consideration of continuity and discontinuity of identity. Continuity and discontinuity are presented as value neutral. Any value placed on them is attributed by the individual who has lived the experience. The facilitator explicitly references the past and future in the context of the decision making present time.

Questions:

- What does your self from the past tell your self today?
- How would you introduce the person (the self) you lost?
- How could you introduce the person (the self) you have found?
- How will you introduce the person (the self) you will discover?
- What does your experience tell you about yourself that you might otherwise not have known?

- Where did you learn what disability means? Are these your words?
- How would you define disability now?
- How do you hope to define disability in the future?
- If disability could speak to you, what would it say?
- In which situations does disability speak the loudest?
- Are you satisfied or dissatisfied with the person you are right now?
- What happens to your dreams for your future when you are satisfied/ dissatisfied with who you are?
- Who do people say you are?
- Which people will you believe? Why?
- How does what you value/believe influence who you see yourself to be now?
- Which value/belief will define you in the future?

Session 4 considers decision making, change, choice, power, and identity. While employing care to avoid jargon, the facilitator briefly introduces the narrative concepts of the techniques of power such as organizing persons in space, classifying persons, exclusion of persons, ascriptions of identity, and self surveillance (White & Epston, 1990, p. 30-31).

Participants are invited to recount the various impacts of power in their experience. Different types of power such as persuasion, coercion, force, and influence, are identified with an effort made to view power as morally neutral. The possibility of establishing a preferred identity is discussed in the context of personal experiences of power.

Questions:

- What decision do you need to make today?
- What will make it possible for you to make that decision?

- Who will you invite to make the decision with you?
- What metaphor best depicts the change you wish to make?
- Will the decision help you feel more like yourself? Less like yourself?
- What does this decision tell you about who you want to be?
- What will prevent you from acting on your decision?
- How does (anxiety/depression/pain/other problem...) solicit your support in sabotaging yourself?
- Who has the power to decide what needs to change in your life?
- What influence does perfectionism have on disability?
- What is required for perfectionism to be satisfied?
- What influence does your belief about power have?
- What would it take for you to make the decision to feel differently?
- What influence will you employ to manage your emotional pain?
- How will life be different once you have made the decision you wish to make?
- Who is observing you?
- Who is evaluating/judging you?

Session 5 examines the nature of help. The felt experience of being powerless is inherent to the experience of trauma/disability that includes long periods of hospitalization and living in a residential rehabilitation centre. Reconstructing a belief in personal agency is a significant component in the reconstruction of meaning and identity. The directing of others who assist with physical care is an important skill to acquire when living with a disability. In this session consideration will be given to how an individual can learn to direct those who assist in one's

emotional care. Participants are invited to describe and define the Where, When, Who, What, and How of “Help.”

Questions:

- What/Who was it that helped you come here today?
- Where have you found help before?
- How do you decide when you need help?
- Do you look for help because you identify a problem or because you identify a goal?
- How does felt helplessness tell you to think of yourself?
- Does disability have an opinion about what you need? Do you agree?
- Does where the help comes from make a difference to you?
- How do you decide if the help is helping?
- Can you decide when the time is right for the help available to you?
- Do you feel you have the right to accept or refuse the help offered to you?
- What institutional discourses or practices help you to experience hope?
- What institutional discourses or practices support hopelessness?
- How perfect does the help need to be?

Session 6 will seek to affirm the relationships within the group through an exercise called Seeing Each Other. In the last session each participant will have the opportunity to speak to each other participant. At the end of session 5 participants are instructed to think of a word, a phrase, or an image that depicts for them, the identity of each of the others in the group (including the facilitator). The intention is that each person will hear an aspect of their identity affirmed by every other person in the group. The hope is that this will have been modeled in previous sessions. In the first five sessions the language of genuine affirmation within the process of

meaning making and identity reconstruction/reaffirmation will have become familiar to group participants.

Summary Conclusion

To be in conversation with individuals in the significant life transition following adult acquired disability is often a privilege fraught with the mixed anxiety and hope of both unknown fears and unknown opportunities. It requires courage to sit with clients who want things to be different, and to empathetically, but with a well differentiated calmness, listen to the rage, the despair, the fear, the great pain of loss and grief - all the emotions found in the disability experience that create anxiety. Seeing the identity of the person in the turmoil of crisis and the uncertainty of transition requires intention, faith, and hope. It requires seeing what is not yet visible and believing that posttraumatic growth will emerge because someone is looking for it and because it has happened before.

The term identity may at times seem undefined in this paper because we can never be certain we know who we are looking for when it is ourselves we seek. We do not know our identities until we see them, sometimes after losing them, sometimes after choosing them, and sometimes being gifted with them. It is not the definition of the thing that is significant, but the process of seeking, working, believing, communicating, arguing, ruminating, hoping, and believing again. This process requires that others participate through establishing relationship that validates and challenges and confirms and says, explicitly or implicitly, "you matter."

One obvious limitation of this research project is the lack of human participants. Persons living with disabilities are needed for future research, not only as the subjects of the studies, but perhaps more importantly as the experience informed researchers who know what questions are most pressing. Also, considerations of the disability experience within a geriatric population

may require responses informed by considerations and priorities other than those presented in this paper. Likewise, academic inquiry that asks these questions within gender or culture specific populations will offer important insights through future research.

Small groups focused on identity in transition need to be trialed and critiqued, and doubtless, adjusted to meet the real needs of real individuals. The question, “Did individuals living with disability find their lives easier to live, in the face of the losses they have experienced, as a result of their participation in facilitated small groups focused on the topic of identity?” needs to be asked and answered. To have such groups led by researchers who share the experience of disability could provide much opportunity for all forms of qualitative research data to emerge. The best case scenario is when the research is also the therapy.

As noted, more consideration could be given to the variables of culture, gender, age, economics, and also the varying degrees of impairment that are found grouped under the term disability. It is likely that therapeutic interventions and trajectories may be helpful for some populations but not others. Research that determines such specifics can only be beneficial, both in appropriately delivering care that is helpful to the clients, and in the optimal utilization of health care resources by the therapists and professionals who facilitate care.

The expression and development of identity through a variety of art forms is a discussion inherently related to this topic, yet left completely unexplored in this paper. The ongoing potential for creative growth to emerge from post traumatic growth is one of the wonders of human overcoming, and requires at least the acknowledgement that people are not only meant to survive, but to thrive in the many and varied forms of human expression and experience open to all persons.

References

- Alexander, B. K. (2008). *The globalization of addiction: A study in poverty of the spirit*. NY: Oxford University Press.
- Andrade, Y. (1996). The psycho-cultural context (PCC) model of trauma: Understanding experiences of émigré children. *Estuos de Psicologia*, 1(1), 36-49.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- Barskova, T. & Oesterreich, R. (2009). Posttraumatic growth in people living with a serious medical condition and its relation to physical and mental health: A systemic review. *Disability & Rehabilitation*, 31(21), 1709-1733.
- Bowen, M., (1985). *Family therapy in clinical practice*. Northvale, New Jersey: Jason Aronson.
- Bowen Theory (n.d.). The Bowen Center for the Study of the Family. Retrieved from <http://www.thebowncenter.org/pages/theory.html>
- Bridges, W. (2004). *Transitions: Making sense of life's changes*. 2nd Edition. Cambridge, MA: Da Capo Press, Perseus Books Group.
- Bright, F. A. S., Boland, P., Rutherford, S. J., Kayes, N. M. & McPherson, K. M. (2012). Implementing a client-centred approach in rehabilitation: An autoethnography. *Disability & Rehabilitation*, 34(12), 997-1004.
- British Columbia Association of Clinical Counsellors (2011). *Ethics Code and Standards of Practice*. Accessed from: <http://bc-counsellors.org/wp-content/uploads/2011/02/2011-11-22BCACC-CodeGuidelinesApprovedOct16.pdf>
- Catalano, D., Chan, F., Wilson, L., Chiu, C. , Muller, V. R. (2011). The buffering effect of resilience on depression among individuals with spinal cord injury: A structural

- equation model. *Rehabilitation Psychology*, 56(3), 200–211.
- Chan, C. L. W., Chan, T. H. Y. & Ng, S.M. (2006). The strength-focused and meaning-oriented approach to resilience and transformation (SMART): A body-mind-spirit approach to trauma management. *Social Work in Health Care*, 43(2/3), 9-36.
- Comstock, D. (Ed.). (2005). *Diversity and development: Critical contexts that shape our lives and relationships*. Belmont, CA: Brooks/Cole, Cengage Learning.
- Dickson, A., Allan, D. & O'Carroll, R. (2008). Biographical disruption and the experience of loss following a spinal cord injury: An interpretative phenomenological analysis. *Psychology and Health*, 23(4), 407-425.
- Disabled-World Website: *Disabled World towards tomorrow: Definitions of the models of disability*. <http://www.disabled-world.com/definitions/disability-models.php>
- Dorsett, P. (2010). The importance of hope in coping with severe acquired disability. *Australian Social Work*, 63(1), 83-102.
- Dunn, D. S. & Burcaw, S. (2013). Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology*, 58(2), 148-157.
- Hamill, R., Carson, S. & Dorahy, M. (2009). Experiences of psychosocial adjustment within 18 months of amputation: an interpretative phenomenological analysis. *Disability and Rehabilitation*, 32(9), 729-740.
- Hanks, R. A., Rapport, L. J., Wertheimer, J. & Koviak, C. (2012). Randomized controlled trial of peer mentoring for individuals with traumatic brain injury and their significant others. *Archives of Physical Rehabilitation*, 93, 1297-1304.
- Hedtke, C. L. (2010). *Folding memories in conversation: Remembering practices in bereavement groups*. (Doctoral dissertation). Retrieved from

<http://www.taosinstitute.net/carol-lorraine-hedtke>.

- Hibbard, M. R., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., Ireland-Knight, L., Gordon, W., Avner, J. & Gartner, A. (2002). Peer support in the community: Initial findings of a mentoring program for individuals with traumatic brain injury and their families. *Journal of Head Trauma Rehabilitation*, 17(2), 112-131.
- Hoff, L. A. (2009). *Violence and abuse issues: Cross-cultural perspectives for health and social services*. New York: Routledge.
- Jordan, J. V. (1992). *Relational resilience*. Wellesley, MA: Stone Center Colloquium Series.
- Jordan, J. V. (Ed.). (1997). *Women's growth in diversity: More writings from the Stone Center*. New York: The Guilford Press.
- Jordan, J. V., Kaplan, A. G., Miller, J. B., Stiver, I. P., Surrey, J. L. (1991). *Women's growth in connection: Writings from the Stone Center*. New York: The Guilford Press.
- Kennedy, A., Turner, B. & Kendall, M. (2011). Growth in a 'new world': Case studies of peer leadership experiences in the STEPS program for people with acquired brain injury. *Brain Impairment*, 12(2), 152-164.
- Kerr, M. E. (1988). Chronic anxiety and defining a self. *The Atlantic Monthly*, Sept., 35-58.
- Kleinman, A. (1989) *The illness narratives: Suffering, healing and the human condition*. USA: Basic Books.
- Kroll, T. (2005). *Peer mentoring: Tap the experience of others with spinal cord injury*. (Chapter 6). In Groah, S. L. (Ed.). *Managing spinal cord injury: A guide to living well after spinal cord injury*. Washington, DC: NRH Press.

- Lieberman, J. A. & Stuart, M. R. (1999). The BATHE method: Incorporating counseling and psychotherapy into the everyday management of patients. *Primary Care Companion Journal of Clinical Psychiatry*, 1(2), 35-38.
- Ljungberg, I., Kroll, T., Linin, A. & Gordon, S. (2011). Using peer mentoring for people with spinal cord injury to enhance self-efficacy beliefs and prevent medical complications. *Journal of Clinical Nursing*, 20, 351-358.
- McGrath, J. C. & Linley, P. A. (2006). Posttraumatic growth in acquired brain injury: A preliminary small scale study. *Brain Injury*, 20(7), 767-773.
- Madigan, S. (2010). *Theories of psychotherapy series: Narrative therapy*. Washington, DC: American Psychological Association.
- May, G. G. (1987). *Will and Spirit: A contemplative psychology*. New York, NY: HarperCollins.
- Miller, W. R., Rose, G. S. (2009). Toward a theory of motivational interviewing. *American Psychologist*, 64(6), 527-537.
- Miller, W. R., Rose, G. S. (2010). Motivational interviewing in relational context. *American Psychologist*, May-June. DOI: 10.1037/a0019487
- Miller S.D., Duncan B.L. & Hubble M.A. (1997). *Escape from Babel: Toward a unifying language for psychotherapy practice*. New York, NY: W.W. Norton & Co.
- Morgan, A. (2000). *What is narrative therapy? An easy-to-read introduction*. Adelaide, South Australia: Dulwich Centre Publications.
- Neimeyer, R. A. (1999). Narrative Strategies in Grief Therapy. *Journal of Constructivist Psychology*, 12:65-85.
- O'Rourke, J. J. F., Tallman, B. A. & Altmaier, E. M. (2008). Measuring posttraumatic changes in spirituality/religiosity. *Mental Health, Religion & Culture*, 11(7), 719-728.

- Pollard, C. & Kennedy, P. (2007). A longitudinal analysis of emotional impact, coping strategies and posttraumatic psychological growth following spinal cord injury: A 10-year review. *British Journal of Health Psychology*, 12, 347-362.
- Powell, T., Ekin-Wood, A. & Collin, C. (2007). Posttraumatic growth after head injury: A long-term follow-up. *Brain Injury*, 21(1), 31-38.
- Powell, T., Gilson, R. & Collin, C. (2012). TBI 13 years on: factors associated with posttraumatic growth. *Disability & Rehabilitation*, 34(17), 1461-1467.
- Reynolds, V. (2002). Weaving threads of belonging: Cultural witnessing groups. *Journal of Child and Youth Care*, 15(3), 89-105.
- Richards, R. (2008). Writing the othered self: Autoethnography and the problem of objectification in writing about illness and disability. *Qualitative Health Research*, 18(12), 1717-1728.
- Rogan, C., Fortune, D. G. & Prentice, G. (2013). Posttraumatic growth, illness perceptions and coping in people with acquired brain injury. *Neuropsychological Rehabilitation*, 2-19.
- Rowan, J. (1990). *Subpersonalities: The people inside us*. London and New York: Routledge.
- Salick, E. C. & Auerbach, C. F. (2006). From devastation to integration: Adjusting to and growing from medical trauma. *Qualitative Health Research*, 16, 1021-1036.
- Sanders, C. (1995). Soul making. *Family Therapy Newsletter*, 5(2), 44-49.
- Senra, H., Oliveira, R. A., Leal, I. & Vieira, C. (2011). Beyond the body image: A qualitative study on how adults experience lower limb amputation. *Clinical Rehabilitation*, 26(2), 180-191.
- Shelley, C.A. (2013). The life tasks revisited. In: P. Prina, A. Millar, C. Shelley & K. John (Eds.). *Adlerian Yearbook 2013*, (pp. 70-90). London: Adlerian Society (UK) and

Institute for Individual Psychology.

Struchen, M. A., Davis, L. C., Bogaards, J. A., Hudler-Hull, T., Clark, A. N., Mazzei, D. M.,

Sander, A. M. & Caroselli, J. S. (2011). Making connections after brain injury:

Development and evaluation of a social peer-mentoring program for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 26(1), 4-19.*

Sue, D. W., Microtraining Associates. (2003). White racial identity development.

<http://ctiv.alexanderstreet.com.proxy.cityu.edu/View/529681/play>true>

Sue, D. W. & Sue, D. (2003). *Counseling the culturally diverse* (4th ed.) New York: John Wiley & Sons.

Tedeschi, R. G. & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9(3), 455-471.*

Tedeschi, R. G. & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological inquiry, 15(1), 1-18.*

Ustun, T. B. (2002). Towards a Common Language for Functioning, Disability and Health: International Classification of Functioning (ICF). *World Health Organization, Geneva.*
<http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>

Van de Velde, D., Bracke, P., Van Hove, G., Josephsson, S., Devisch, I. & Vanderstraeten, G. (2012). The illusion and the paradox of being autonomous, experiences from persons with spinal cord injury in their transition period from hospital to home. *Disability & Rehabilitation, 34(6), 491-502.*

Van der Kolk, B. (1994). The body keeps the score: Memory and the evolving psychobiology of stress. *Harvard Review of Psychiatry, 1(5), 253-265.*

Veith, E. M., Sherman, J. E., Pellino, T. A. & Yasui, N. Y. (2006). Qualitative Analysis of the

- peer-mentoring relationship among individuals with spinal cord injury. *Rehabilitation Psychology*, 51(4), 289-298.
- Volf, M. (1996). *Exclusion and embrace: A theological exploration of identity, otherness, and reconciliation*. Nashville: Abingdon Press.
- Website: No identified author. (2013). Disabled World: Definitions of the models of disability. <http://www.disabled-world.com/definitions/disability-models.php>
- Weingarten, K. (2013). The “cruel radiance of what is”: Helping couples live with chronic illness. *Family Process*, 52(1), 83-101.
- White, M. (2011). *Narrative practice: Continuing the conversations*. Denborough, D. (Ed.). New York: W.W. Norton & Co.
- White, M. and Epston, D. (1990). *Narrative means to therapeutic ends*. New York: W.W. Norton & Co.
- Williams, J. (2010). *Storying resilient selves: Disability, resilience & narrative identity*. (Doctoral dissertation). Retrieved from UMI Dissertation publishing. 3407130.
- Yalom, I.D. & Leszcz, M. (2005). *The theory and practice of group therapy* (5th ed.). New York, NY: Basic Books.
- Young, J. M., Lawrence, W. & Quick, P. (1999). A unique role: The peer mentor on the spinal cord team at G. F. Strong Rehab Centre. *Healthcare Management Forum*, 12(1), 51-53.