IDENTITY CONSTRUCTION FOLLOWING TRAUMATIC BRAIN INJURY: A CASE STUDY

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ABSTRACT

This construction of self-identity pre- and post-Traumatic Brain Injury (TBI) in a single case study is described. A life history research methodology was employed to explore the experience of a survivor of TBI, using a single case study design. The participant was a 31 year old White South African male who sustained TBI while on duty in the army. Multiple interviews were conducted with the participant to allow in-depth exploration of his self-identity formation pre- and post-TBI. Data analysis entailed transcribing the interviews, crafting a research story (narrative analysis) and an analysis of the narrative. The results illuminated the emergence and development of a resistance identity as a product of early pre-TBI experience, the loss of self following TBI as well as the emergence of a positive self-identity. The embedded issues of communication and self-identity are explained. The participant's narrative espoused a hopeful optimism, strongly challenging the dominant disability discourse. The specific strengths and limitations, and potential value of using life histories as both a methodological and clinical tool when working with TBI survivors is described. Implications for research and clinical practice in the field of Speech and Language Therapy (SLT) is also provided.

Key words: Traumatic brain injury, narrative life history methodology, self-identity, life experience, resistance identity, loss of self, communication impairment.

INTRODUCTION

Traumatic brain injury (TBI) exerts a profound impact on an individual's life. The effects are pervasive and devastating. A complex range of communication difficulties, including specific disturbances such as aphasia and dysarthria, are produced (Hilari & Byng, 2001). In addition, TBI also results in cognitive, physical, emotional, behavioural, and psychosocial sequelae (Hartley, 1995). Ultimately, the person who survives a TBI has to negotiate a series of life-altering experiences. This paper draws on the life experience of a TBI survivor to explore the development of self-identity pre- and post-TBI.

There is a burgeoning interest in exploring changes in identity following illness in the disciplines of psychology, sociology and medical anthropology (Frank, 1995). Within the narrative research tradition, the subjective experience of TBI (Nochi, 2000; 1998) has been explored. Speech-language therapy (SLT) professionals have also witnessed a transition in research orientation towards the use of qualitative research methods for exploring the consequences of communication disorders, such as aphasia (Pound, Parr, Lindsay & Woolf, 2000; Damico, Oelschlaeger, & Simmons-Mackie, 1999; and Parr, Byng, Gilpin, & Ireland, 1997). The current study is premised on the notion that knowledge of self-identity informs clinical practice. It is strongly aligned with the position taken by Hagstrom and Wertsch (2004), who assert that clinicians need to understand who the person is in order to help him/her with communication. Services would be more relevant if clinicians had the knowledge to understand the individual in the context of his/her life circumstances.

Self-identity formation is a complex process shaped by personal, social and temporal factors (Sarbin, 2000). Two subsystems underlie self-identity, namely personal identity and social identity. Personal identity refers to the unique constitution and biography of the individual, such as preferences and personality traits, whereas social identity refers to descriptions of self, based on membership and identification with a certain social group (de la Rey, 1991).

Identity is a theory of self that is developed and sustained through a process of inner concurrence about what the self is like (Schlenker, 1987).

The creation of self-knowledge relies on several components viz. personal memory of the past, conceptualising societal roles and interaction with the environment (Neisser, 1988). A TBI survivor's memory of pre-morbid experience shapes his/her self-identity, which often has undergone a critical change following the head injury. Following a marked life-altering event, new meanings are assigned to the individual's social interactions, thus re-shaping his/her identity development. Neisser's (1988) concept of the extended self has implications for a continuing life history in that individuals relate their past self during the construction of their present and future notions of their self-identity. As the meaning and status of a life event changes for an individual over time, so does his/her definition of the self, since a personal sense of self contains past and present experiences and expectations for the future (Brumfitt, 1998). Thus, as self-identity is continuously constructed and reconstructed, SLTs need to be sensitive to this process by understanding the individual as a dynamic social being (Hagstrom & Wertsch, 2004).

The experience of communication impairment is embedded within the process of self-identity formation. The irony lies in the problem itself, in that communication, which is required as a form of expression of self-identity, is compromised (Brumfitt, 1998). An individual who has sustained TBI has to negotiate new ways of communicating and engaging in various social activities, and renegotiate complex challenges with reduced fluidity and flexibility (Shadden & Agan, 2004). They are judged by those with whom they engage socially as either competent or not by virtue of the success of their communicative interactions. Their self-identity rests critically on how well they are able to negotiate these interactions, as their projected identities are subject to social evaluation. Communication is central in shaping self-identity formation as the individual with TBI contends with an altered self, as characterised by new ways of thinking, understanding, expressing and sense making.

What challenges may SLTs face when working with TBI survivors via a self-identity lens? Issues of identity construction post-TBI may seem daunting, since identity constructs have typically not been within the traditional knowledge base of SLTs. Self-identity is the traditional domain of psychology in clinical disciplines and the inclusion of self-identity in the SLT discourse creates the challenge of negotiating boundary crossing across disciplines. Furthermore, SLTs may be reluctant to take on more than they should due to large caseloads and limited healthcare funding (Shadden & Agan, 2004). Finally, identity loss and reconstruction in the aftermath of TBI is an elusive concept and may be difficult to target as a tangible therapeutic goal. However, given the inextricable link between communication and self-identity it is necessary to intervene within a framework that places the whole individual at centre stage. The notion that a sense of self is maintained in even the most impaired communicator (Brumfitt, 1998) supports the need to understand the preserved self of an individual with acquired communication impairment

Therapeutic intervention may be enhanced by understanding the relationship between therapeutic outcome and self-understanding. Pound (1993) explored the attitudes of aphasic speakers and their therapists to aphasia and found that SLTs who were interviewed focused almost exclusively on what they deemed the devastating consequences of impaired communication following stroke. On the other hand, people with aphasia reported both the negative and positive aspects of their altered lives and equated the importance of communication in their lives with other major life issues, such as driving, employment and the ability to execute activities of daily living. Therefore, if clinicians are to provide a service that is person-centred, it is critical to acknowledge that it is not sufficient to focus exclusively on the individual's communication impairment but to gain a deeper understanding of other pertinent life issues that feature robustly in his/her reality. Clinicians therefore should attempt to understand who the person is in order to effectively manage the consequences of communication difficulties.

Traditionally, research on the psychosocial issues pertaining to TBI has been amassed within quantitative research frameworks. As a consequence of the methodological choices, the understanding of TBI has been relayed from an etic (or outsider) professional perspective. Many of these studies have utilised quantitative positivist research designs to explore complex concepts such as the chronic physical, emotional, and social changes post-TBI; quality of life following TBI; functional performance after TBI; and rehabilitation outcome following TBI (Corrigan, Bogner, Mysiw, Clinchot & Fugate, 2001). The process of knowledge production in the field is therefore likely to benefit from an epistemological shift which creates understanding of the personal experiences of people who live in the aftermath of TBI.

The inclusion of the experiential domain may assist in creating knowledge to support the current paradigm shift in the rehabilitation field from the medical model toward the social model of disability, which emphasises the interaction of disease and disability within the larger ambit of society (Jordan & Bryan, 2001). While the medical model has centralised the focus on impairment, the social model requires a deeper understanding of disability within a social context of disabling barriers. Social barriers must be removed as an essential prerequisite for empowering people with disability (Pound et al., 2000). The significance of generating an integrated understanding of disability has lead to the blurring of boundaries between SLT, sociology and disability theory (Pound et al., 2000).

In light of the foregoing discussion, a life history research methodology was utilized in this study to explore self-identity formation. The personal biography highlights the issues most important to the individual in his or her context (Atkinson, 1998). The life history narrative allows participants to engage in a process of self-reflection, thus enabling them to explore and construct self-narratives about themselves located within a broader social, political, and historical milieu, thus generating broader contextual meaning from the individual's experience (Cole & Knowles, 2001). Life history research allows the opportunity for the individual to ably foreground the self in relation to impairment over time (Kathard, 2003).

Life history research offers a heightened sensitivity to the complexity of TBI by adding a human dimension to the experience of TBI and is particularly valuable in understanding the changing dynamics of individuals who experience fluctuating performance as they recover (Hartley, 1995). The story of a TBI survivor purveys not only what the disability means to the individual along a temporal continuum, but also conveys the rich personal meaning that s/he has attached to it. Critically, life history methodology has the potential to generate knowledge which SLTs can apply to their practice especially when working in a culturally and linguistically diverse context, such as South Africa.

This study responds to the following question: *What is the nature and the process of self-identity construction in an individual who has sustained traumatic brain injury?*

METHODOLOGY

Aims of the study

1. To explore the nature and process of self-identity construction pre- and post-TBI
2. To consider the implications of the findings for research and clinical practice in the field of SLT

Research design

A qualitative, life history research methodology was utilized (Cole & Knowles, 2001) to explore the participant's self-identity formation using a single subject case study design. Life history research values depth over breadth, thus the aim is not population representativeness (Cole & Knowles, 2001). Single-subject methodologies are widely accepted and relevant as a legitimate technique for exploring the depth of experience of aphasia and dysfluency (Kearns, 1999) and therefore also have applicability for TBI. Importantly, single case study designs used in qualitative research can contribute to practice, theory, social issues and action and thus hold value in facilitating a deeper understanding of the complex process of self-identity construction post TBI.

Participant selection criteria

Purposeful sampling was implemented to select an information-rich case for in-depth study. This strategy is useful when the purpose is to gain a deep understanding of the particular case, in the absence of any desire to generalise the findings to all cases (McMillan & Schumacher, 2000). The participant was selected on the basis of his experience and understanding of TBI in his lifeworld. The participant was required to:

- Be an adult who would have sustained a closed head injury at least two years prior to the interview and needed to have lived with TBI in order to relate pre- and post-TBI experience

- Have adequate cognitive ability that would enable him/her to provide a narrative account of his/her experience of TBI via a series of in depth interviews (Nochi, 1998)

- Have an information-rich story to share (Nochi, 1998)

- Have a degree of self-awareness and insight into the fact that s/he had sustained TBI in order to provide useful information for theory-building (Nochi, 1998)

- Voluntarily participate in the study because life history methodology necessitates a personal sharing of life experience and sustained engagement with the research process (Cole & Knowles, 2001)

- Be able to share his/her experience in English so that researcher and participant could communicate in a common language for the purposes of facilitating an in-depth exploration of his/her life experience

- Be able to share his/her story with adequate verbal competency or via alternative or augmentative communication if considered appropriate

Method of data collection

Multiple in-depth interviews were conducted to enable the researcher to obtain meaningful insights that reflected how the individual made sense of the event of TBI in his/her life. The content of the interviews was shaped by focussing on topics of interest or significance to the participant (Clandinin & Connelly, 2000). See Appendix A for the interview schedule used during data collection. The interview schedule was developed using Atkinson's (1998) guidelines.

The interviews were video- and audio recorded, thus enabling the researcher to observe the kinesics and non-verbal communication of the participant, lending greater depth to the information shared. Audio tape-recording of the interview sessions allowed both the researcher and the participant to cross-check the data gathered, thus enabling a means of validating the data. The interviews were supplemented by sources of information from the participant's personal journal, photograph albums and medical records.

Research procedure

The procedure comprised three main phases, namely, a screening phase, a pilot phase, and main study (Table 1). All phases were implemented at a rehabilitation institution in KwaZulu Natal, South Africa for individuals who have sustained strokes and head injuries. Three participants were interviewed during the screening phase. Two participants met the criteria for selection as they had information-rich stories. One participant was chosen for the pilot and the other as the main case study. During the pilot phase, the interview schedule, interview process, logistics of data collection and analysis procedures were refined.

In the main study the participant was interviewed on three occasions. Each interview was approximately ninety minutes. The interviews were audio and video recorded. The participant narrated his life story to the researcher. It was critical to establish a comfortable rapport with the participant, in light of the sensitive and intensely personal nature of the interviews. Exposure of oneself during the research process involves issues of respect, trust, fairness, truth telling and justice (Cole & Knowles, 2001; Clandinin & Connelly, 2000). A semi-structured interview approach was adopted, thus promoting flexibility during the interview process (Atkinson, 1998). The participant was able to move backward and forward along a temporal dimension as part of the storytelling process (Clandinin & Connelly, 2000).

Description of the participant

The participant selected was a 31 year-old white South African male, Paul Carstens (name changed to protect identity), who sustained TBI on November 4, 1991 while on duty in the South African army. He was 18 years old at the time when he was involved in an explosion causing him to sustain a head injury and killing his friend who was assisting him. Paul was in a coma for six months following the accident, having sustained severe brain injury.

Prior to the accident, Paul had just completed secondary school and embarked on military service. He described himself pre-morbidly as a relaxed, fun-loving, unconventional individual who possessed good communication and interpersonal skills. At the time of the interviews, which were conducted in September 2003, at least 12 years post injury, Paul was receiving psychotherapy and speech-language therapy to address cognitive and communication difficulties. In terms of cognitive abilities, Paul was experiencing subtle memory, attention, concentration and organisational difficulties. He also presented with moderate dysarthria, thus his speech intelligibility was compromised. Other conditions included arthritis; restricted mobility (he was using crutches); impaired vision in his left eye due to optical nerve damage; and permanent dental misalignment caused by injury to his mandible.

Table 1: Outline of research procedure

PHASE 1: SCREENING	PHASE 2: PILOT STUDY	PHASE 3: MAIN STUDY
✓ Three participants were interviewed. Since they fulfilled the selection criteria employed, two were randomly selected for participation in the study. From these two participants, one was chosen for the pilot study and one for the main study.	✓ The participant was interviewed over one one-hour and one two-hour sessions. The interviews were audio_ and video recorded. The participant narrated his life story to the researcher. *The following aspects were pilot tested:* interview schedule, interview process, logistics and data analysis procedures.	✓ The participant was interviewed over three one-and-a-half -hour sessions. The interviews were audio- and video recorded. The participant narrated his life story to the researcher. The data collected were qualitatively analysed.

Ethical considerations

Qualitative researchers can be considered as guests in the private spaces of the participants' world (Stake, 1994). Therefore, it was imperative to adhere to a strict code of ethics. Ethical Clearance was obtained from the University of KwaZulu Natal Ethics Committee prior to the study. Informed consent was obtained from the participant and ethical issues of anonymity, confidentiality, withdrawal and the role of researcher and participant were highlighted. The participant was treated with fairness by promoting open discussion and negotiation. He was also informed of the intended (video and audio) recording of the interview sessions. Written informed consent to record the interviews was obtained from the participant at the outset. In order to ensure an authentic representation of the participant's story, he was provided with the storied (recorded) representation of his narrative to enable him to validate the information shared (Stake, 1994).

Rigour and trustworthiness

The researcher's reflexive position during the research process is valued as a critical technique for establishing trustworthiness (Cole & Knowles, 2001). In order to achieve this, numerous strategies of trustworthiness were employed. *Prolonged and persistent fieldwork* involved the use of multiple in-depth interviews and ongoing contact with the participant over the course of the process spanning two years. The interviews were conducted in the *participant's language* to ensure that the situation was conducive to storytelling. *Verbatim accounts* of conversations in the form of direct quotes were representative of the participant's meaning of his experience. *Low inference descriptors* refer to literal descriptions used and understood by the participant, as opposed to the abstract language used by the researcher. These add more depth to the data (McMillan & Schumacher, 2000). Therefore, in portraying Paul's account of his life experience, accurate descriptions from the interviews were used to enhance trustworthiness of the data.

Furthermore, while in-depth interviews formed the core data collection technique, triangulation or multi-method strategies of data collection were also employed to increase validity (medical records, journals and photo albums). Multimethod strategies increase the credibility of findings by yielding different insights around the central topic (McMillan & Schumacher, 2000). Member checking was also employed. This entailed returning the recorded version of his story to the participant for validation and verification. Member checking is an important aspect of life history methodology, as it indicates respect for the individual and enhances the truth-value or fidelity of the narrative (Frank, 1997; Atkinson, 1998).

Methodological challenges

The participant was able to narrate his story with considerable ease, despite the presence of dysarthria and subtle cognitive difficulties. Organizational and memory problems were mildly evident during the narration. For example, at certain points in the narration, he reached a blank and was unable to continue with a certain thread of thought and had to be prompted. At other times his narrative tended to be tangential and he thus needed to be redirected to the focus of the question that was asked. Fortunately, memory blanks were rare as reliance on good memory is a critical aspect of identity construction (Shadden & Agan, 2004; Neisser, 1988).

Interviews were audio_ and video recorded to facilitate the transcription process. The participant and researcher negotiated methods of clarification, which included requesting repetition and/or elaboration of a spoken word(s) if they were unclear to the researcher and speaking at an increased vocal intensity to increase the clarity of his speech. The option of communicating graphically or via the written mode in instances of communication breakdown was also available. However, the participant did not find it necessary to use these alternatives. In life history research, particularly when working with people experiencing communication disorders, it is critical that the researcher is a skilled listener to allow the personal story to unfold meaningfully.

Data analysis

The data analysis was conducted at three levels. The first level of analysis entailed *generating transcripts* from the interviews conducted. This was followed by *narrative analysis* (Polkinghorne, 1995), which produced the research story through meaningful interaction with the interview data (transcripts). The third analytical level involved an *analysis of the narrative* (Polkinghorne, 1995) in which the research story was examined for common themes and concepts in relation to the critical research question. During this process the researcher steered clear of imposing prior theoretically derived concepts on the data. Instead, careful inspection of the narrative facilitated the generation and development of new concepts from the research data via an inductive analysis. The emerging themes were then discussed in relation to available literature.

RESULTS AND DISCUSSION

For the purposes of this paper, the results are presented as excerpts from the research story, as well as verbatim excerpts from the transcripts. The results and discussion are integrated. The emerging themes listed below describe the evolution of the participant's self-identity:

1. Developing a resistance identity as a product of early pre-TBI experience
2. Moving from loss of self to reconstruction of self post-TBI
3. Constructing a positive self-identity post-TBI

Developing a resistance identity as a product of early pre-TBI experience

In attempting to understand the process of identity formation and the shifts in self-identity, it was critical to explore the role that early childhood experiences have played in shaping Paul's self-identity. His early life experiences reflected a childhood characterised by disappointment, sadness, confusion and a sense of abandonment. Paul experienced resentment and deep pain at being separated from his parents at an early age when he was sent to boarding school:

> 'We were sent up to Eshowe. I begged and pleaded for her (my mother) to take me back. I think I was causing her more pain than anything else. She drove all the way to Eshowe with us in the car, which made her happy. She drove back alone and she cried all the way home ... going to school, leaving home ... that had to have been the saddest experience of my childhood.'

Paul's feelings of loneliness and sadness were further intensified

by the reality that his family unit had been split by his parent's divorce when he was four years old. This was clearly a traumatic experience for him, as reflected in the following excerpt:

> 'My parents were divorced when I was four years old. I was too young to understand what was happening. I didn't even know it was happening. But soon enough, the reality of It was etched into our lives. Forever. We worked around it though. My parents made sure of that.'

Paul could not seek solace in his relationship with his older brother, as they were not close. As a result, he needed to adopt a strategy that would enable him to survive at boarding school away from all that was familiar and safe. He depended on himself. Paul developed a firm sense of individuality that became central to his quest for survival at such a tender age, where parental love and support is so critical to one's feelings of safety, security and acceptance:

> Six year-old boy wants his mommy. Alone in a strange place. Begged and pleaded, please take me back. I hated being away from mom. I felt hurt, rejected, abandoned. I cried. I waited. They didn't come back for me. This was it. I had to be strong, smart, independent. Fight my own battles. Be my own person. Chris, my brother, and I weren't close. I couldn't depend on him. We fought all the time. I built a protective wall around me. I needed to feel safe, in control. I needed to be Me.'

His experience at school was challenging and mingled with a sense of longing for his parents. Paul also had a dire need to prove his worth to a father who undermined his ability:

> 'Life at school was full of challenges, especially when mum and dad were so far away...my dad and I just never clicked... it was a strange relationship that we shared. I think my dad just demanded too much from me. I couldn't deliver and he used to give me these lectures about not being good enough at anything.'

Paul's initial reaction of withdrawing into a silent safe space within himself to help him deal with the feelings of abandonment he was experiencing, led to him developing a firm sense of self-identity. Defining one's self-identity is critical to determining how one acts in a given environment and relates to others (Schlenker, 1987). Paul was determined to be different; to affirm his individuality:

> 'I was a rebel, especially in high school. The anti-trendy, anti-groupie. Chris, on the other hand was very much a groupie. I did my own thing. Made my own rules. And broke them! That didn't win me too many friends but I had two really good friends who understood me. If we did anything we would do it three different ways. Each to his own. I didn't care for convention. I still don't. I broke all the rules!'

Paul's need to adopt a strong persona and not to succumb to peer-pressure and group convention was his way of negotiating this challenge. It was never important to him to fit in. His outspoken defiance of social convention is reflected in his discourse and ultimately linked to who he was. Paul's strong sense of independence was further reflected in his assertion that he did not have many heroes growing up. He cited himself as his source of inspiration, indicating a certain lack of wonder and perhaps even trust in the adults in his lifeworld. Paul has attributed the person he has become to his own effort:

> 'That's where I developed all my independence from

(boarding school) because I had to stand on my own two feet...I was never brought up by my parents...what I am now is basically self-created...I was never around my parents that much...my inspiration to do anything had to come from me.'

Paul's experience as White, English and middle-class unfolded within a broader socio-political context. His experiences unravelled in South Africa during a turbulent social and political period (1980 to 1991). During this time military service was still compulsory for young White males under the previous apartheid regime. The imposition of military service was not always met with enthusiasm especially since at the critical age of 18 years, one is usually looking forward to travelling and furthering one's education. In this particular case, Paul indicated a strong dislike for the army:

> 'I hated the army like hell!'

Ironically, his life-altering event occurred in this very context (the army). His sentiments could be understood within the context of his tendency to challenge authority and live life by his rules.

Paul's narrative thus spoke resolutely of his need to locate himself in a world that he often encountered as unfriendly and cold. What Paul viewed as being different from the rest was later to become his way of adapting to lifestyle changes as a person living with an acquired disability. His sense of self-identity was thus valued as a means of claiming his place in a hostile world. It was within this protective space that he retreated in order to feel safeguarded against sources of pain and disappointment. Clearly, initial experiences had created a resistance identity; that is, negative experiences produced a sense of resistance to convention and anything that undermined his self-worth. This resistance was ultimately embedded pre-morbidly in Paul's sense of identity . This was his way of surviving.

Although Paul retreated into a protective space, he developed skills that helped him survive in the face of adversity. His encounter of life as a young person fashioned a resilience that was going to prepare him for a greater challenge later in life. In a sense, Paul's resistance identity harboured strength of spirit that led to the critical shift in the way he was to view his world and his place in it: with further intent to resist the restraints and inherent expectations imposed by society on one who has a disability. Paul's process of self-identity formation is thus best understood within the context of his early life experiences. The emerging transition of his self-identity was "normal" and expected, however it may not have taken the trajectory it did, had his life circumstances been different.

Moving from loss of self to reconstruction of self following TBI

Paul's initial experience following TBI was characterised by a sense of loss - a loss of many functions, including his speech:

> 'all my movements in the mouth, like moving my tongue from side to side were very slow there was absolutely nothing coming out'

He experienced the frustration at not being able to project his voice:

> the stupid nurses, they used to run a cold bath and put me in. I couldn't talk. I couldn't say anything. I used to try and hit them!'

Paul endured a transition at this stage from having a strong and

boisterous voice to support his personality and define his sense of self, to momentarily losing that voice. At a broader level, Paul's sense of self experienced a shift which was defined by loss following the TBI. Other losses included a certain degree of loss of mobility, partial loss of independence and economic empowerment, loss of former friendships as friends were uncomfortable about Paul's acquired disability and loss of a certain public image that he always tried to project.

Sense of self is dramatically affected by TBI and is experienced by survivors of TBI as a complex, multi-layered phenomenon (Nochi, 1998). Individuals with TBI often experience conflict in trying to reconcile the disparity created by the self-image they maintain and society's perception of who they really are. The dominant public narrative has the tendency to impose negative labels on people with TBI. This creates conflict within the individual, leading to a sense of loss of self. Nochi (1998) has identified this phenomenon as loss of self as perceived by others. Labels generally imply negative images of disability and promote a deficit-based, pathologically oriented view of people with disabilities, thus discounting their individuality and casting them into pre-existing categories. This perspective of people with disabilities is espoused by the medical model, which perpetuates the notion that illness is a form of social deviancy. Paul's resistance identity then gradually resurfaced as his recovery progressed and he began to challenge the public narrative. He regained his speech, his voice, which was a critical step in the transition. He spoke strongly of his need to be acknowledged as an individual with unique traits that preclude any form of categorisation:

'I am priceless. I am unique. Everything about me marks who I am. My thumbprints. My voice. I am an individual. And no one can take that away from me.' [emphasis mine]

Paul thus once again asserted his identity foremost as an individual who has never blindly followed convention. The fact that he was physically challenged did not feature resolutely in his self-appraisal. He spoke of his frustration due to the limitations incurred by his injuries, such as not being able to drive or surf anymore. Interestingly, he did not cite his remaining communication difficulties as a constraint imposed by the head injury. Instead, he chose to value his voice and saw it as instrumental in affirming his identity. Paul's communication difficulties and the utility of speech-language therapy were raised by the researcher. However, he did not attribute much significance to these aspects, choosing to talk about other critical aspects which concerned him e.g. his limited mobility. Whilst his speech may have had a dysarthric quality, rendering it unclear at times, what mattered to Paul was that, ultimately, he was able to communicate his message. Despite the consequences of his impairment/s he did not view himself entirely as defined by a disability. The way that society perceived him however, was apparent to him and to this end, Paul experienced the effects of this negative perception, which conflicted with his own understanding of himself and what he was capable of achieving:

'Life isn't always smooth sailing when you have a disability. People treat you differently. The trick is learning how to deal with prejudices. It's not easy. Sometimes I get really angry like when I go to the till to pay and my fiancé is with me and they ask her for the money. It is as though I don't exist! Talk to the man! ... I have a short fuse! I do try to be patient sometimes. But I just get so angry when people talk over me! I wish they would see me and treat me like they would anyone else. I know that my body has been injured but my brain is still happening!' [emphasis his]

Paul faced the challenges of societal prejudice during his daily course of events. It was perhaps because of his perceived communication (dis)ability and marked physical impairments, such as his unsteady gait whilst walking which necessitated the use of assistive devices like crutches, and his injured eye, that the cashier in the above exchange treated him as described. However, Paul used his voice once again to speak out against the prejudice. He used his ability to communicate to his advantage. His experience of disability and the subsequent restrictions it imposed on his movement was exacerbated by the discrimination displayed towards him, embodied in a form of social prejudice that exists against people with disabilities:

'I see that I fit in perfectly into society. But society, I feel, has a problem with me. I am a person! I think that people need to give us a chance. They have to learn to accept and adapt to people with disabilities. Society limits itself by limiting us.'.

If Paul accepted the labels and associated expectations that society imposed upon him and his disability, then he would have to relinquish the validation of his self-image as a unique individual (Nochi, 1998). His narrative resonated with the sentiment that he was not willing to accept society's labels and was clearly determined to carve out a positive self-identity, and receive acknowledgement for the person that he is; a determination historically rooted and linked to his resistance identity. Paul's construction of self-knowledge and ultimately the reconstruction of his self via new experiences is a deeply complex concept. Attempting to engage with this complex process can only serve to deepen an understanding of the lived experience of TBI in all its multifarious components.

Constructing a positive self-identity post-TBI

In exploring the process of positive identity construction post TBI, issues of attitude, hope and illness as moral re-awakening were central features. Moral re-awakening refers to a renewed sense of spirituality that is drawn from an experience of illness or disability (Frank, 1997).

Attitudinal dimensions

Paul's story resonated with courage, hope and an ultimate acceptance of all that has occurred in his life thus far, with specific reference to the accident and resulting injuries. He acknowledged, after an ongoing period of grieving (at least four years post injury), that life goes on. With this acceptance of the way his life unfolded, Paul chose to adopt an attitude that would facilitate his transition into a new life with optimism and strength of spirit:

'I have two choices: I can either be happy and accept what is happening and look forward to the future, or be sad and regret what is done'

Paul's attitude was infused with hope. He chose to use the experience of the accident in his favour. Instead of allowing himself to be paralysed with sadness, resentment and regret at the course his life has taken, Paul resolved to pursue his challenges with courage and hope. Remarkably, the very event that had caused his life to be steered in a direction he did not anticipate, had also enabled him to discover certain truths about himself:

'I used to be very naive and carefree. But the accident has transformed my life, the way I see things. I feel more grounded. I'm able to see the lighter side of things. I used to

be a very negative guy.'

Evidently, the accident had changed Paul's life transforming the way he saw and experienced his world. He had been thrust from complacency to an appreciation of life with all its complexity and contradiction. Paul felt that the accident had granted him the opportunity to reconstruct himself positively. Moreover, while Paul was initially plagued by feelings of insecurity and loneliness fostered by a less than ideal family dynamic, he later (post-TBI) experienced greater stability due to improved personal relationships.

Paul's reaction to the accident, resultant injuries and the pervasive impact it had exerted on his life and sense of self clearly contradicted the conventional notion that traumatic experiences produce an ongoing sense of loss and devastation (Schlenker, 1987). He chose to communicate his responses in a positive way, thus constructing a positive social identity, which in turn influenced his actions and responses to certain life events. While the experience of loss is a real part of the experience, Paul's story highlights the fact that it does not continue indefinitely, thus contradicting the medical notion that people live in a continual state of loss.

Moral re-awakening

Paul's self-narrative echoed with hope and optimism for the future. His plans included sharing his life with his significant other and creating vocational opportunities for himself. He emphasised the role of spirituality in his positive reconstruction:

'The one and only thing I can remember from my coma is saying God, please don't let me go. I was literally begging God just to let me live, especially for my mother. Since then religion has become so important to me. It's brought my life into perspective. It has made me realise what is really important to me. I value my mom and my fiancé equally. And my religion supersedes them. I have also learned to take good care of myself, to value my general well-being. And family is the most important thing to me.'

In this vein, Paul's narrative is closely aligned with Frank's (1995) quest narrative, which encounters suffering boldly, accepts illness and uses it heroically. Quest narratives involve perseverance and are oriented toward the future. Illness is thus not viewed as an interruption that must be overcome but rather as a challenge that must be met and from which the individual can gain something meaningful. Illness is seen as a critical event that becomes an occasion to turn an inner gaze and to engage in a moral questioning of who we are (Frank, 1997).

Paul's narrative reflects the polyphonic nature of a quest narrative where multiple voices echo complex, interwoven and often contradictory values and stories and represent an affirmation of identity (Frank, 1995). Thus, in Paul's life story, living with an acquired disability was not viewed entirely as fatalistic but was embraced as part of his complex life experience. The sense of hope that Paul fostered represented new meanings that he created of himself through the experience of trauma. Kleinman (1988) contends that the experience of a critical event need not be experienced as a self-defeating exercise but can be used as a conduit to deeper and better things. Hope is born from the personal and cultural dilemmas that are induced by illness, forcing one to turn to sources of meaning that are already present in our lives (Kleinman, 1988). Although Paul was often plagued by despair and repeatedly questioned his fate, there was an overriding sense of resolution and motivation:

'I believe that God is supreme. He is in charge of absolutely everything. And if He wanted this to happen, there had to be a Way. It had to be His Will. If God is willing, who am I to question that? He has helped to improve my life. Things can only get better. I believe that God gives us gifts. If we don't use them, he takes them away and in so doing takes a chunk of our lives away. My gift from Him is to help people by sharing my experiences with them and I'm trying to put back into society what I've taken out. To search within myself and make a difference to others' lives. That's why these motivational talks that I give are so important to me. Sharing my experiences also helps me come to terms with where I am right now.'

Through his spiritual growth, Paul was able to reach out to others, sharing his experiences with them and strengthening his self-identity. Paul saw his ability to do this as a divine gift and in so doing recognised that his own life experiences could be used as valuable lessons not only to others but to himself as well. His desire to help others resonates with Kleinman's (1988) suggestion that illness heightens one's awareness of other people's suffering, thus making one more inclined to behave in ways that would help to reduce the suffering of others and allow one to assume responsibility for others. The motivational talks Paul presented, provided a valuable opportunity for his personal growth following the accident. In giving to others, Paul's feelings of self-worth were reaffirmed. He used his communication skills positively and to his benefit, despite the dysarthria. Paul was able to view the events of his life as meaningful and purposeful, thus empowering him with hope and the ability to perceive and maintain an important role in society. It is almost as if, in living a post-traumatic life, Paul's trauma has become the source of his work, which in turn has become a source of community, nurturing possibilities of new role-taking and meaning-making (Frank, 1997).

IMPLICATIONS, RECOMMENDATIONS AND LIMITATIONS

The study holds significant implications at various levels. The contributions of life history research are linked to its intellectual and moral purpose and its potential to provide insight into individual lives (Cole & Knowles, 2001). The present study holds the potential to provide a research methodological tool for exploring in greater depth the lives of the people with whom clinicians work. Life history research can be utilised to engage at deeper levels with individuals who experience TBI and its consequences, as illustrated in Paul's case.

Importantly, the study has also shown that even when people present with communication impairment they have stories to tell and as such should be granted the opportunity to be heard. Life history research has the potential to provide a platform upon which discourse around individuals with disabilities, who have been marginalized from the dominant research dialogue, may be informed. Paul's story highlighted this notion and illuminated the complexity of issues underlying self-identity and communication.

The use of life histories as a clinical method can be explored within SLT contexts. While communication is the focus of intervention, it is also pivotal to creating self-identity. Therefore, when applied to the understanding of an individual who has survived a TBI, communication is the instrument used to generate a life story account of experience. By understanding the critical dual role of communication as both an intervention need, as well as in constructing self-identity, clinical interventions can become more client-centred. The knowledge produced in this study can thus encourage clinicians to understand their clients' communica-

tion needs as they relate to the individual's sense of self in his/her life context. When communication is viewed in this way, it may assist the clinician in thinking through intervention goals for the individual and to understand the types of intervention that are necessary.

Clinicians who have read Paul's story at a general hospital in Johannesburg, South Africa and Sandwell, England have indicated that life history has potential as a clinical tool. Whilst clinicians often use a case history, this tool traces the history of the disorder while the life history interview offers potential to understand how individuals live with disorders. By developing client-centred therapy goals, the clinician is able to generate relevant functional communication intervention. They also reported that using life histories in therapy would highlight the importance of other life issues (employment, housing, relationships, physical mobility, inability to drive) which are important to consider when setting intervention goals and strategies. Although communication was an important issue, it remained embedded within an identity frame. However, time constraints were cited as a concern and limitation to the clinical implementation of life histories.

Furthermore, the SLTs reported that reading this particular narrative challenged their perceptions of people with disabilities as they acknowledged that positive experiences could emerge from an event such as TBI. This notion resonates with Pound's (1993) assertion that it is critical for SLTs to develop a heightened awareness and deeper understanding of the multi-faceted nature of individuals' responses to disability, in order to appreciate a different perspective and to cultivate positive attitudes amongst professionals. She maintained that if therapists adopt negative attitudes to disability by focusing on impairment, it is likely to lead to negative stereotyping of people with disabilities. This attitude hinders the recognition of the potential of people with disabilities to take control over their changing lives. Clinicians are encouraged to critically evaluate their own beliefs and attitudes to ensure that their practice removes, rather than creates, disabling barriers. When applied to Paul's case, it would have been easy to interpret Paul's experiences in general, and his communication difficulties in particular, as negative events. His narrative, however, proved otherwise.

In the field of TBI particularly, SLTs must be cognisant of what role they can play in strengthening the positive self-identity trajectory. The communication intervention program therefore depends on the clinician's ability to consider issues of the client's potential and his/her understanding of disability. In Paul's story for example, his optimistic appraisal of experience could well be overlooked in a therapy program that is not sensitive to the complex processes underlying the construction of his positive self-identity post TBI. It would be imperative to engage with Paul's affirming attitude and inner self if relevant therapy goals and intervention plans are to be produced. The intimate link between his communication and self-identity would be the key to fostering optimal intervention.

Life history research also engages with the spiritual and moral dimensions of the individual. As discussed, Paul's story resonated with a sense of moral awakening. His experience of TBI has ignited a deeper life meaning and spiritual awakening that forms the basis of how he lives, communicates and interacts with people. Through understanding these deeper dimensions of the individual, clinicians may be able to sharpen their insight into the multifaceted nature of human experience. While the body/impairment aspects of interventions have received primary attention in the Speech-Language Pathology literature, issues of spirituality would appear to have received marginal coverage (Jordan

& Bryan, 2001). However, Paul's story implies that clinicians should understand and interact with issues of spirituality where they are apparent if they are to engage with personally meaningful interventions.

The use of narratives in aphasia therapy is endorsed by Pound et al. (2000) who encourage SLTs to sharpen their listening skills and hone in on their ability to facilitate storytelling, as the value of narrative medicine can be used as a powerful tool for fuelling therapeutic interventions and measuring outcomes. The very act of telling one's story has potential to produce a therapeutic and cathartic effect for the storyteller. Empirical research that has been conducted on the use of narrative constructions with diverse populations experiencing chronic conditions has indicated that narratives of emotional experiences have produced positive changes in these individuals (Nochi, 2000; Parr et al., 1997).

Practically, for the individuals whose lives were irrevocably affected by the experience of TBI, this study could be used to inform and educate the public about the issues raised. Societal notions of disability need to be challenged to facilitate the successful integration of people with disabilities. Again, intervention should encompass the gamut of the personal experience of disability, extending beyond a focus on the personal to the social creation of disability. The study has social and political implications in that the issues of disability that have been raised have the potential to influence the way society perceives people with disabilities. Instead of viewing "pathology" and "normal" as disparate entities, they can be seen and appreciated as varieties along a continuum of modes of being-in-the-world (Papadimitriou, 2001, p.10), thus encouraging clinicians as well as the public to appreciate disability as a continuum of human diversity.

At a theoretical level, the issues raised in the study are congruent with the move toward embracing the social model of disability and procuring subjective perspectives on the experience of disability (Hilari & Byng, 2001; Frank 1997; Nochi, 2000; Nochi, 1998; Parr et al., 1997). The study contributes to a growing body of research on the personal meaning ascribed to certain life experiences, such as acquiring a disability. Furthermore, the study has highlighted issues of communication that are embedded within a self-identity development.

The strengths of the study include the data collection method, namely a series of multiple, in-depth interviews, thus yielding value laden, information-rich data. Furthermore, by virtue of the life history methodology implemented, an emic (insider) perspective is provided, as the narrator was able to construct his self-identity and life via the narrative process. A pilot study was conducted in order to evaluate the efficacy of the interview schedule (data collection tool), interview process, data analysis, and the overall logistics of the interview procedure, thus enhancing the trustworthiness of the main study. A single case study design facilitated an in-depth exploration and understanding of what it means to be a survivor of TBI. Moreover, the research story was analysed qualitatively, facilitating insight and a deeper understanding of the experience of TBI within the broader landscape of the participant's lifeworld.

As described under participant selection criteria, the participant was required to have sufficient cognitive and communicative ability to be included in the study. These were not stipulated as exclusionary criteria, but rather to facilitate the process and provide relevant knowledge about the particular case. Since this is still a developing methodology, future research could look to including people with severe cognitive and communication difficulties to expand the knowledge base. This would require refining the current methodology considerably. For example, encour-

aging the narrator to employ Alternative and Augmentative Communication (AAC) devices, drawing, symbols, and gestures to convey a meaningful story. The stance of the researcher in this instance may also change. Instead of using open ended questions, s/he may need to use forced alternative questioning in order to procure information from the narrator.

A limitation worth noting is that imposed by the constraints of language and text. However, even within linguistic and textual restrictions, it is possible to provide a meaningful representation of one's life within the text (Clandinin & Connelly, 2000). Memory also imposes restrictions on the narrative, as events are selectively revealed, thus despite prolonged engagement with the participant, his/her revelations will always be constrained. This is, however, the nature of retelling experience but should be considered particularly when interviewing participants who have memory problems.

CONCLUSION

This study explored the process of self-identity construction pre and post TBI, using a life history methodology. The results highlighted the interaction of complex variables underlying the process of self-identity formation in a survivor of TBI. The self is seen as central to action. The role of communication in negotiating and representing self-identity is illuminated. The participant's narrative highlighted his life experience in the period preceding and following a head injury. The story revealed how critical early life experiences, fashioned through interaction with significant others (family, peers), shaped self-identity and the ability to negotiate significant life changes incurred by the head injury. The evolution of a positive self-identity is traced. Paul's self-identity was constructed via his dialogue. His communication was entwined with all aspects of his life and served to present a particular social persona. Paul used his communication strengths positively in constructing and affirming his altered post injury self-identity. Illness as an experience of moral awakening is highlighted, as Paul's deep spirituality enabled him to nurture hope for the future, to look forward to living and sharing his life with his significant other. In this regard, Paul has become the ultimate architect of his own social reality.

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APPENDIX A

INTERVIEW SCHEDULE

The following questions were used as a guide during the interview. The interviews unfolded in the direction the participant took, with some guidance being offered by the researcher.

- ❖ Where / when were you born, earliest childhood memories, what was your family like, describe your parents, siblings, grandparents?

- ❖ Tell me about your linguistic, cultural, social and racial background

- ❖ Tell me about the most significant events in your life

- ❖ What academic qualifications do you have?

- ❖ Tell me about your earliest childhood memories

- ❖ What were your experiences like at school?

- ❖ Do you see education as playing an important role in one's life?

- ❖ Who were your role models?

- ❖ What did you want to become on graduating from school?

- ❖ Describe the political climate when you were growing up

- ❖ Tell me more about the accident

- ❖ How has having sustained a head injury changed your life?

- ❖ How do you view disability?

- ❖ What are the challenges you face as a person with a disability?

- ❖ How has the accident impacted on your relationships with family and friends

- ❖ Did you find the rehabilitation services rendered to you following the accident effective?

- ❖ What are your hopes for the future?

- ❖ Is there anything we may have omitted from your life story?

- ❖ Do you have any comments about the interviews and all that has been discussed?

- ❖ Did you find that talking about your life was a therapeutic experience?

- ❖ Did it have a cathartic effect on you?