

The subjective experience of integrating paraplegia into one's life

L. Richter

20511795

Dissertation (article format) submitted in partial fulfilment of the requirements for the degree *Master of Social Science in Clinical Psychology* at the Mafikeng Campus of the North-West University

Supervisor: Dr D. K. Kirsten

Co-supervisor: Mrs. P. Kolobe

May 2016

It all starts here™

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Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

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Tel +27 18 299 4849
Email Ethics@nwu.ac.za

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ou=Vaal Triangle Campus,
email=linda.duplessis@nwu.ac.za,
c=ZA
Date: 2015.11.11 20:07:21 +0200

Prof Linda du Plessis
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We, as co-authors, hereby give consent that Louis Richter may submit the following manuscript for purposes of a dissertation (article format): *The subjective experience of integrating paraplegia into one's life.*

We also give consent that the manuscript may be submitted to the academic journal: *Qualitative Health Research* for possible publication.



Dr D. K. Kirsten

Supervisor

31 May 2016

Mrs P. Kolobe

Co-supervisor

31 May 2016

This manuscript was prepared according to the Authors Instructions of the academic journal: Qualitative Health Research.



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Director: CME Terblanche - BA (Pol Sc), BA Hons (Eng), MA (Eng), TEFL

22 Strydom Street
Baillie Park, 2531

Tel 082 821 3083
cumlaudelanguage@gmail.com

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Summary

Clinical psychologists in physical rehab units are likely to engage with spinal cord injured patients on a daily basis. They are not necessarily trained to guide these patients. Therefore a preliminary investigation that determines how people integrate paraplegia into their lives will lead to studies that are helpful to the development of more structured rehabilitation programmes in the future. This phenomenological study aimed at a preliminary investigation of the subjective experiences of integrating paraplegia into the lives of six individuals by means of a flexible phenomenological design and has potential for further investigation. Participants were not prompted towards positive self-reports or forced to choose between positive and negative outcomes. The researcher adhered to ethical considerations by obtaining ethical approval from the Human Resources Ethics Committee of the North-West University's Mafikeng Campus and taking measures such as voluntary informed consent; anonymity; the right to withdraw; beneficence and no maleficence.

The researcher utilised a purposive availability sample, recruited by means of snowball sampling. Data were collected by means of unstructured, in-depth individual interviews. These were audio-taped and analysed through thematic content analysis. The interview consisted of one primary open-ended question: *"Tell me about your experience of integrating paraplegia into your life."* Where participants found it difficult to understand the first primary question, follow-up questions assisted participants to elaborate on their answers: *"What had to happen and what was it like?"* and, *"What was it like to go through this process of integrating paraplegia into your life?"* The process allowed the researcher the flexibility to probe for clarification purposes. Trustworthiness was ensured by guaranteeing credibility and confirmability by means of triangulation and member checking. Dependability

was ensured by an independent psychologist who examined both the process and the results of the study.

During data collection and thematic analysis the researcher attempted to “bracket” his own preconceptions about adjusting to SCI. Reflections about the interviews assisted the researcher to analyse the data, and to comprehend that the integration of paraplegia into ones’ life mainly took place through a process of post traumatic growth for all of the participants. During thematic analysis, each data set was categorised into broad themes during a naïve reading and re-reading of the transcripts. Thereafter, common themes were identified and reviewed. Review involved the comparison, definition, naming and categorization of main and subthemes. Subthemes were identified based on the intensity they carried for participants and their significance within the context.

Eight main themes emerged during data analysis. First, *Outdoing adversity through posttraumatic growth* describes how the trauma of paraplegia compelled participants to adjust to, cope with and ruminate about trauma and its many losses. This directed them towards personal growth. The findings are consistent with Zoellner and Maercker (2006) and Tedeschi and Calhoun (2004; 2009), Calhoun and Tedeschi (2006) and Berger (2014) who found that intentional rumination results from personal crisis after a traumatic event. The second theme, *A unique life-long journey*, highlights how different the process of integrating paraplegia was for each participant. Third, *It takes time* demonstrates how the time element of the process holds patience, hope and strength. This third theme divides into four subthemes, namely *It’s a process*; *It’s not forever*; *In your own time* and *Time heals wounds*.

The fourth theme, *Initial negative reappraisal of life* is marked by the typical symptoms of psychological distress associated with trauma due to negative rumination. This theme subdivides into: *My life is over*; *This is not a life*; *Life makes no sense*; and *Life is out of*

control. Fifth, *A turning point* highlights the moment in time when participants took a conscious purposeful decision to make a cognitive shift towards positive rumination. The subthemes of theme five include *Wake-up call*; *Think again – affect balance*; and *Conscious decision*.

The sixth, seventh and eighth themes, *Positive reappraisal of life*, *Positive reappraisal of self* and *Positive reappraisal of relationships to others* are consistently highlighted in literature on PTG. In terms of these themes, the dynamics of posttraumatic growth include reliance on active emotion-focused coping strategies during experiences of turmoil. *Positive reappraisal of life* subdivides into the following themes: *My second chance in life*; *Life is still good*; *Life is meaningful and comprehensible*; *Life is manageable*; *You have rights* and *Holding on and letting go*.

The seventh theme, *Positive reappraisal of self*, unveils that participants managed to cope by refraining from identifying themselves with the shortcomings of disability. This main theme divides into the following subthemes: *Still me – but better*; *New roles in life*; *More than a body*; *Sexual intimacy remains important*; and *Living a new truth*. Overall this theme describes how participants' sense of self and identity and their roles developed after the trauma of paraplegia. The participants' beliefs and attitudes transformed from placing emphasis on their own needs to emphasis on people and relationships. Our study somewhat contradicts Picoraro, Womer, Kazak, and Feudtner's (2014) sixth component of PTG. These authors stated that a 'new body awareness, set of priorities and health behaviours,' is only applicable to children and adolescents and not to adults with a dramatic loss of body functions like we found in our study, or with serious illness, like in the study of Hefferon, Grealy and Mutrie (2010).

The eighth and last theme, *Positive reappraisal of relationships with others* shows the importance that all the participants attach to supportive relationships. The subthemes include *Partners for good*; *Blood is thicker than water – most of the time*; and *Leaving the abled and joining the disabled “family”*. Participants experienced increased meaning in their relationships overall, although they also had to join a new community of disabled people and in a sense leave behind the world of the able.

The limitations of this study include the generalisation to all paraplegics, especially the uneducated and socio-economic deprived paraplegics, is therefore unwise. Topics of sexual intimacy and bowel and bladder functions were not fully explored due to participants’ sensitivity about these topics. Data saturation was not obtained for these subthemes. Especially the manner in which they adjusted or coped with their physically normal partners’ sexual needs, remains unclear. Future studies differentiate by means of education, age, socio-economic status and the cause of the paraplegia. Focus group interviews may give a better description of the subjective lived experiences of participants. The input of caregivers and close family members regarding their lived experiences of the process of integration can be included to triangulate findings. The integration of bowel-bladder regulation and sexual intimacy into the lives of the paraplegic individual and his or her partner should be fully explored.

This investigation attempted to gain an understanding of how people integrate paraplegia into their lives by exploring the subjective experiences of six individuals. All participants have overcome lived adversity and have surpassed the quality of their lives prior to paraplegia by managing the challenges through personal and posttraumatic growth in the form of positive rumination, adjustment and active emotion-and problem-focused coping over time. What is outstanding, is that participants managed to refrain from identifying

themselves with the shortcomings of disability. This took a conscious purposeful decision to make a cognitive shift towards reappraisal and positive rumination.

Opsomming

Suid-Afrikaanse sielkundiges kom waarskynlik in aanraking met paraplegiese pasiënte wat unieke omgewings-, psigologiese en psigo-sosiale stressors ondervind as gevolg van hulle spesifieke omstandighede. 'n Begrip van hoe mense paraplegie suksesvol in hulle lewens integreer kan help om die toepaslike sorg te gee. Hierdie voorlopige ondersoek is gemik op die verkenning van subjektiewe ervarings rondom die integrasie van paraplegie in die lewens van ses individue deur middel van 'n buigsame fenomenologiese ontwerp. Deelnemers is nie aangehits in die rigting van positiewe self-rapportering nie en is nie gedwing om tussen positiewe en negatiewe uitkomst te kies nie. Die navorser het die etiese vereistes nagekom deur etiese toestemming te verkry van die Menshulpbronne Etiekkomitee van die Noordwes-Universiteit se Mafikengkampus en deur maatstawwe in te bou soos vrywillige, ingeligte toestemming; anonimiteit; die reg om te onttrek; weldadigheid en geen kwaadwilligheid nie.

Die navorser het 'n doelgerigte beskikbaarheidsteekproef gebruik wat gewerf is deur middel van sneeubal-steekproefneming. Data is versamel aan die hand van individuele gevallestudies deur middel van ongestruktureerde, in-diepte individuele onderhoude. Die onderhoude is opgeneem en transkripsie inhoude is tematies ontleed. Deelnemers het op 'n primêre oopeindigende vraag gereageer, naamlik: *“Vertel my van jou ervaring met die integrasie van paraplegie in jou lewe. Waar deelnemers gesukkel het om die vraag te beantwoord, is hulle aangemoedig deur verdere vrae soos: “Wat moes gebeur en wat het jy ervaar?” En: “Hoe is dit om deur hierdie proses te gaan om paraplegie in jou lewe te integreer?”* Die proses het die navorser toegelaat om duidelikheid te kry deur verder in te vra. Betroubaarheid is verseker deur geloofwaardigheid en bevestigbaarheid te waarborg.

Vetrouenswaardigheid is verseker deurdat 'n onafhanklike sielkundige beide die proses en die resultate van die studie ondersoek het.

Elke datastel is in breë temas onderverdeel na aanleiding van 'n nuwe lees en herlees van die transkrip. Daarna is algemene temas geïdentifiseer en dit is hersien. Hersiening het die vergelyking, definisie, benoeming en kategorisering van hoof- en subtemas ingesluit. Vanweë die klein steekproef is subtemas geïdentifiseer op grond van die intensiteit van die deelnemers se klem daarop en die beduidendheid binne die konteks.

Agt hooftemas het na vore gekom gedurende analise. Eerstens beskryf *Oorkoming van teëspoed deur posttraumatiese groei* hoe die beleefde trauma of paraplegie deelnemers gedwing het om aan te pas en die trauma die hoof te bied deur die trauma en die vele gepaardgaande verliese te oordink. Hierdie proses het hulle gelei na persoonlike groei. Die bevindinge stem ooreen met Zoellner en Maercker (2006) en Tedeschi en Calhoun (1996; 2004; 2006), wat bevind het dat doelbewuste oordenking die resultaat is van 'n persoonlike krisis na 'n traumatiese ervaring. Die tweede tema, *'n Unieke lewenslange reis*, beklemtoon hoe verskillend elke individu die proses om paraplegie te integreer, ervaar. Derdens demonstreer *Dit neem tyd* hoe die tydelement van die proses geduld, hoop en krag inhou. Hierdie derde tema onderverdeel in vier subtemas, naamlik *Dit is 'n proses; Dit is nie vir altyd nie; Op jou eie tyd* en *Tyd heel wonde*.

Die vierde tema, *Aanvanklike negatiewe herwaardering van lewe*, word gekenmerk deur die tipiese psigologiese onsteltenis wat met trauma geassosieer word vanweë negatiewe oordenking. Hierdie tema onderverdeel in: *My lewe is verby; Hierdie is nie 'n lewe nie; Die lewe maak geen sin nie*; en *My lewe is buite beheer*. Vyfdens belig die tema *'n Keerpunt* die oomblik wanneer deelnemers 'n bewuste, doelgerigte besluit neem om 'n kognitiewe skuif te

maak in die rigting van positiewe oordenking. Die subtemas van die vyfde tema sluit in *Wekroep; Dink weer — affekbalans; en Doelbewuste besluit*.

Die sesde, sewende en agtste temas, *Positiewe herwaardering van lewe, Positiewe herwaardering van die self* en *Positiewe waardering van verhoudings met ander* word almal konsekwent in die literatuur oor PTG uitgelig. Met betrekking tot hierdie temas behels die dinamika van posttraumatische groei steun op aktiewe emosie-gefokusde hanteringstrategieë tydens ervaringe van beroering. *Positiewe herwaardering van lewe* onderverdeel in die volgende temas: *My tweede kans op 'n lewe; Die lewe is nog steeds goed; Die lewe is betekenisvol en verstaanbaar; My lewe is bestuurbaar; Jy het regte en Vasklou en laat gaan*.

Die sewende tema, *Positiewe herwaardering van die self*, toon dat deelnemers die situasie die hoof kon bied deur weg te bly daarvan om hulleself te identifiseer met die tekortkominge van gestremdheid. Hierdie hooftema onderverdeel in die volgende subtemas: *Steeds ek — maar beter; Nuwe rolle in die lewe; Meer as 'n liggaam; Seksuele intimiteit bly belangrik; en Leef 'n nuwe waarheid*. Oorhoofs beskryf hierdie tema hoe deelnemers se sin van hulle 'self', hulle identiteit en hulle rolle ontwikkel na die trauma van paraplegie. Die deelnemers se oortuigings en ingesteldheid het verander van 'n klem op hulle eie behoeftes na 'n klem op mense en verhoudings. Ons studie is effens strydig met Picoraro, Womer, Kazak, en Feudtner (2014) se sesde komponent van PTG. Hierdie outeurs voer aan dat 'new body awareness, set of priorities and health behaviours,' [nuwe liggaamsbewustheid, stel prioriteite en gesondheidsop tredes] slegs toepaslik is by kinders en adolessente en nie by volwassenes met 'n verlies aan liggaamsfunksies soos ons in hierdie studie gevind het, of by volwassenes met ernstige siektetoestande, soos in die studie van Hefferon, Grealy en Mutrie (2010) nie.

Die agtste en laaste tema, *Positiewe herwaardering van verhouding met ander* wys die belangrikheid wat alle deelnemers heg aan ondersteunende verhoudings. Die subtemas sluit in *Lewensmaats vir altyd; Bloed is dikker as water — meeste van die tyd*; en *Agterlaat van die liggaamlik geskiktes en aansluiting by die gestremde "familie"*. Deelnemers het oor die algemeen 'n toename in die betekenisvolheid van hulle verhoudings ervaar, alhoewel hulle ook by 'n nuwe gemeenskap van gestremde persone moes aansluit en in 'n sekere sin die wêreld van liggaamlik geskiktes moes agterlaat.

Die algemene beperkings van 'n voorlopige studie soos hierdie sluit in dat die aanvanklike verkenning 'n baie beperkte aantal deelnemers ingesluit het. Veralgemening na alle parapleë, veral die skolasies onopgeleide en sosio-ekonomies veragterde bevolking, is dus nie wys nie. Die onderwerpe van seksuele intimiteit en ingewands- en blaasfunksies is nie ten volle ondersoek nie vanweë die deelnemers sensitiwiteit rakende hierdie onderwerpe. Dataversadiging is nie bereik vir hierdie subtemas nie. Die manier waarop deelnemers aangepas het of hulle liggaamlik geskikte maat se seksuele behoeftes hanteer het, bly onduidelik. Toekomstige studies behoort te fokus op groter steekproewe en moet onderskei na aanleiding van skolasiese opleiding, ouderdom, sosio-ekonomiese status en die oorsaak van die paraplegie. Fokusgroeponderhoude kan 'n beter beskrywing van die subjektiewe ervaring van deelnemers bied. Die insette van versorgers en naby familieledede rakende hulle geleefde ervaring of die proses van integrasie kan ingesluit word om die bevindinge te trianguleer. Die integrasie van ingewands-blaas-regulasie en seksuele intimiteit in die lewens van die paraplegiese individu en sy of haar maat behoort ten volle ondersoek te word.

Nietemin bring hierdie fenomenologiese ondersoek begrip vir hoe mense paraplegie in hulle lewens integreer deur die subjektiewe ervaringe van ses individue te bekyk. Al die deelnemers het teëspoed oorkom en het verbeter op hulle lewens voor die paraplegie deur die

uitdagings die hoof te bied deur middel van persoonlike en posttraumatiese groei in die vorm van positiewe oordenking, aanpassing en aktiewe emosie- en probleem-gefokusde hantering wat met verloop van tyd ontwikkel het. Wat ongelooflik is, is dat deelnemers dit reggekry het om hulleself te weerhou daarvan om te identifiseer met die tekortkominge wat hulle gestremdheid meebring. Hierdie proses behels 'n bewuste, doelgerigte besluit om 'n kognitiewe skuif te maak in die rigting van herwaardering en positiewe oordenking

Introductory chapter: Literature review

Key terms: Spinal cord injury (SCI); paraplegia; subjective experience; psychological adjustment; coping styles / strategies; posttraumatic growth (PTG); resilience; positive psychology

Spinal cord injury – *paraplegia*: aetiology and prevalence

The spinal cord is a concentration of nerves that transfers signals between the body and the brain. It is vertically located in the middle of the back (Medline Plus, 2016). A spinal cord injury (SCI) disrupts these signals. Usually, it originates with a shock that fractures or dislocates the vertebrae (bone disks of the spine). Most injuries don't cut through the spinal cord. Damage is usually caused when parts of vertebrae cut into cord tissue, or compress the nerves. The term '*paraplegia*' refers to a SCI that results in a level of feeling and movement loss in the legs, ranging from impairment of leg movement, to complete loss of leg movement and functioning up to the chest (Medline Plus, 2016). The focus of this research study is specifically on patients who sustained a paraplegic SCI.

In general, statistics on the prevalence of SCIs in South Africa are difficult to locate. Globally, between 250 000 and 500 000 people sustain SCIs around the globe each year. Men are on average affected by SCI at a significantly higher rate than women, and most incidents occur before the affected person has reached the age of 30. The majority of individuals with spinal cord injuries are unemployed. The major causes of SCI are vehicular accidents and falls. More causes of SCIs and paraplegia are sports and recreation, medical causes or surgical procedures. General medical causes of SCIs include spinal cord compression, inflammation, infections and disk degeneration of the spine secondary to HIV and AIDS and tuberculosis, particularly among individuals from lower health care income groups. In

addition, violence is an increasing contributor to SCIs (SCI-info-pages, 2016; Seirlis (personal communication), 2016; World Health Organization, 2013).

An SCI with concurrent environmental, psychological and psychosocial stressors has a significant impact on the health care systems of South Africa as an emerging third world country. To relieve the pressure on the health care system, health care workers, like psychologists in physical rehabilitation units, should facilitate patients' efforts to successfully live with and triumph over paraplegia. Services provided as early as the rehab phase should provide a proper foundation with contingency plans. Patients have to own these plans so that they can elaborate on it in situations of conflict with the demands of the outside world, otherwise these health care users will re-emerge at health care facilities with mental illness, leading to increased overburdening of the system.

Studies revealed that persons who have sustained a spinal cord injury leading to paraplegia, have a significant risk of developing mental health problems. Post and van Leeuwen (2012) discovered that individuals with spinal cord injuries are on average subjected to higher levels of distress and lower levels of life satisfaction compared with the general population. The World Health Organization (2013) estimates the prevalence of depression among individuals with spinal cord injuries around the globe at 30 percent in comparison with the 5 percent among the rest of the population. Unfortunately, no reliable statistics are available in South Africa regarding the relationship between the broad population of individuals with spinal cord injuries and mental health problems. It is therefore important that health care workers, the clinical psychologist amongst others, and paraplegic patients in physical rehab work together to assist the patient with the integration of paraplegia into their lives.

Paraplegia and psychological adjustment

Psychological adjustment can be defined as a process of adjustment to paraplegia which entails equal indications of an accomplishment over and an acceptance of the consequences of the circumstances (Johnson, 2012). This implies constructive mental health despite the hardships, while the process refers to learning to effectively cope with the demands and its associated stress. The person with the spinal cord injury has to adapt to a sudden change of life with bodily limitations and consecutive challenges from a life where complete physical ability existed (Weiten, Dunn, & Hammer, 2014).

Pollard and Kennedy (2007) provides a description of adjustment among a group of individuals with spinal cord injuries. They contend that the majority of their sample (66%) presented with no signs or symptoms of depression and that the prevalence of anxiety and depression remained relatively stable over a 10-year period. Kennedy, Evans and Sandhu (2009) show a strong association between current cognitions (appraisals and hope) and psychological adjustment, as it accounted for 12 percent of the variance in anxiety and 34 percent of the variance in depression. Kaiser and Kennedy (2011) found that a group of individuals with spinal cord injuries made sense of their traumatic experiences, the impact of the SCI, coping and a reformed view of self and life.

These studies make some suggestions regarding psychological adjustment. They suggest the possibility of increased posttraumatic psychological growth from situations where increased levels of psychological distress could have otherwise been expected. In addition, cognitive processing, in particular primary appraisals of threat, were shown to be important in the process of psychological adjustment to SCI. This suggests that appraisals on SCIs are complex and relate just as much to context, life stages, roles and relationships, as to the individual.

An interesting South African-based study by Moodley (2010) focused on the neuropsychological functioning and adjustment of individuals with spinal cord injuries. Elevated levels of anxiety and depression was found on admission, and this lasted for a month. It was found that PTSD has a negative impact on cognitive functioning – a prime catalyst in adjustment. Overall, the results show a significant rate of improvement in psychological functioning over time. Besides Moodley's study, research in the field of psychology on SCI in South Africa, in particular on adjustment, is scarce.

Psychological adjustment to SCI received more attention in the literature elsewhere in the world. Chevalier, Kennedy and Sherlock (2009) argue that a gap in research remains due to the lack of longitudinal research on the process of adjustment to SCI and the contributory role of appraisals and coping strategies. They suppose that the concern could be addressed through the utilization of measurement tools that focus on the prevention of maladaptive adjustment issues; and which are specifically designed for administration on the population with spinal cord injuries. Able-bodied comparison groups will allow the identification of coping strategies unique to the spinal cord injured population influencing adjustment. Other studies on psychological adjustment includes that of Craig, Hancock and Dickson (1999), which studied long-term adjustment; Krause and Rohe (1998) on personality and life; and a dissertation of Claudio Peter (2013) on the role of psychological resources. Nevertheless, individuals with spinal cord injuries seem to be able to adjust to the circumstances of their disability, provided that coping strategies are applied and that cognitive processing is present.

Paraplegia and coping behaviour

Coping with a stressor requires an effort (application of skills), especially in situations that are potentially considered as harmful or stressful, such as paraplegia (Lazarus & Folkman, 1984). It implies planning and an effort, a process, and that a positive outcome is

not guaranteed. Coping can further be divided into problem-focused coping, where a problem is actively pursued in order to relief stress, and emotionally focused coping, where emotional anxiety associated with the problem situation is managed (Johnson, 2012).

Wang, Wang, Wang, Xie, Shi and Zhao (2015) identified several behaviours and mental processes in individuals with spinal cord injuries. This includes active emotion- and problem-focused coping in the form of religiosity; community reintegration; meaning-making by supporting disabled peers; obtaining knowledge regarding condition, treatment, rehabilitation and life thereafter; and redirected focus from present suffering to future victory with spinal cord injury. The sole intention of the participants was to cope with the strenuous or undesirable consequences of a life with the limits and adversity of spinal cord injury by applying these methods. The study of Kennedy, Evans and Sandhu (2009) among individuals with spinal cord injuries also examined coping. Here, the connection between the use of coping strategies, hope and appraisals, were explored. Hope was a better predictor of coping than appraisals. Coping variables did not explain more variance in depression than threat and challenge appraisals.

Munce, Webster, Fehlings, Straus, Jang, and Jaglal (2014) identified enablers of coping in individuals with traumatic SCI. It included physical and emotional support (problem resolution strategy) from the caregiver, peer support and feedback (obtaining cognitive solutions, information and advice; facilitating decision-making; accumulation of information), importance of positive perception and acceptance (cognitive reframing), and maintaining independence or control over care. Obstacles that interfered with participants' coping with regards to these coping methods were caregiver burnout, financing, lack of accessibility, physical limitations and secondary complications, and difficulty in the achievement of positive outlook or mood. This study especially validated that the mood or

outlook of the caregiver and the individual with spinal cord injury, among other enablers and obstacles, influenced the self-management of individuals with traumatic SCI significantly.

Paraplegia and posttraumatic growth

With resilience as a precursor in the field of positive functioning, researchers became interested in constructive psychological or personal transformation followed by trauma. Tedeschi and Calhoun (2004, 2009) and Calhoun and Tedeschi (2006) coined the term *'posttraumatic growth'* (PTG), which they developed from their predecessors as far from 1983. These researchers discovered requirements for beneficial changes to occur in the context of severe stressful incidences (Park, 1999). Generally, for growth to occur, the following fundamentals are suggested:

- self-enhancing appraisal or positive illusion (Taylor, 1983);
- coping as explained by the work of Lazarus and Folkman (1984) and the model of life crises and growth by Schafer and Moos (1992);
- stress-induced growth as a result of coping that leads to a meaning-making process (Park & Folkman, 1997).
- meaning-making by making a benefit attribution (Davis, Nolen-Hoeksema, & Larson, 1998);
- interpretive reality by means of information processing (Filipp, 1999).

Tedeschi and Calhoun (2004, 2009) and Calhoun and Tedeschi (2006) took these further in their comprehensive *'Model of Posttraumatic Growth'*, which is now the most accepted model to explain posttraumatic growth. It describes the experience of individuals who take personal positive modification further by surpassing the quality of their emotional health prior to the circumstances of the traumatic event. PTG occurs in the face of painful traumatic experience where ruminative activity that is initially automatic and often

distressing, takes place to challenge and rebuild a pre-trauma schema consisting of beliefs, goals and ways of managing emotional distress. This ruminative activity consists of coping behaviours, usage of support networks and making sense of a traumatic occurrence and its aftermath. It refers shortly to the accomplishment of a positive and meaningful self-transformation in the face of traumatic experiences; thriving after adverse circumstances that otherwise may have caused lasting and unpleasant psychological responses; and a fuller, richer and perhaps more meaningful life with improved wellbeing (Berger, 2014; Calhoun & Tedeschi, 2006; Clinciu, 2013; Folkman & Moskowitz, 2004; Tedeschi & Calhoun, 2004, 2009).

Adjustment, unlike PTG, is the outcome of coping methods aimed at balancing distress with well-being with the aim of adaptation. Therefore, growth and emotional distress are able to coexist (Calhoun, Cann, Tedeschi & McMillan, 2000; Tedeschi & Calhoun, 2004, 2009; Zoellner & Maercker, 2006).

Positive outcomes typically associated with posttraumatic growth

Subjective experiences of constructive personal transformation in the context of a struggle with trauma form part of the reports on PTG (Berger, 2014; Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2004, 2009; Zoellner & Maercker, 2006). Traces of a constructive personal positive transformation include an amplified appreciation of life; developing new life priorities; enlarged personal strength; recognition of new possibilities; expanded intimacy or proximity in relationships; and constructive spiritual change (Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2004, 2009; Zoellner & Maercker, 2006). Wang et al. (2015) discovered interesting effects of PTG among a sample of individuals with spinal cord injuries. Value and meaningfulness of life; an increase in new meaningful relationships with people who shared experiences; happiness with achievements; and enhancement of wisdom and a deep insight

into life that resulted from the hardships of spinal cord injury, were positive outcomes of SCI that emerged in the study.

Link between posttraumatic growth and psychological wellbeing

PTG has clinical significance for mental health as confirmed by research. McMillen, Smith, and Fisher (1997) discovered that PTG may be predictive of fewer PTSD symptoms, while Schorr and Roemer (2002) found a low to moderate correlation between PTG and PTSD symptoms of lesser severity. In the longitudinal study by Frazier et al. (2001), participants who gained positive changes, or who always experienced benefits, were significantly less depressed 12 months after they have been sexually assaulted.

The majority of research on PTG has focused on *either positive or negative* results only, utilizing quantitative methods. This has not really illuminated the complexity involved in the experience of posttrauma recovery: the integration of trauma, especially SCI (in this case paraplegia), into one's life. The exploration of paraplegics' approaches in application of their resources in order to outgrow the demands of their circumstances (subjective experience of integrating paraplegia), should similarly be of value within the parameters of wellbeing and positive psychology as a science, and it has not received sufficient attention in the past. The effectiveness of psychological support during and after physical rehabilitation of an individual with a spinal cord injury, such as injuries that cause paraplegia, depends on success over adversity.

The research questions of this phenomenological study were: What is it like to integrate paraplegia into one's life and what do people do to integrate paraplegia into their lives? The aim of this qualitative and flexible phenomenological study was to investigate the subjective experience of integrating paraplegia into one's life. The relevance of this preliminary study is that an understanding of the experience of integrating paraplegia could possibly focus future

research efforts may assist psychologists and possibly other health care workers, such as trauma counsellors and social workers to support those battling with integrating paraplegia into their lives, both in the public and private health sectors of South Africa. New information can become available to these health care workers that may assist with improved health care to paraplegic individuals.

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Note to Examiners

This article manuscript will be submitted to *Qualitative Health Research*, but to aid reading and examination, the following changes have been made to the journal's requirements:

- The pages of the article are numbered starting at the title page and following chronologically after that.
- Tables were placed into the article and not in an addendum as required by *Qualitative Health Research*. When the article is submitted to *Qualitative Health Research*, the tables and figures will be placed as required.

Manuscript: “Subjective posttraumatic growth experiences by paraplegic individuals”

Louis Richter¹, *Doret K. Kirsten² and Patricia Kolobe¹

Louis Richter¹ and Patricia Kolobe¹

1 – Human and Social Sciences: Department of Psychology (Mafikeng Campus)

North-West University (Mafikeng Campus), Private Bag X 2046,

Mmabatho, 2735, South Africa

louisrich@webmail.co.za

patricia.kolobe@nwu.ac.za

*Doret K. Kirsten²

North-West University School of Education Sciences

Private bag X6001, Internal box 34

Potchefstroom, 2520

*doret.kirsten@nwu.ac.za

* Corresponding author

Abstract

This phenomenological study aimed to explore the subjective experience of integrating paraplegia into the lives of individuals who have sustained injuries causing paraplegia. Semi-structured, in-depth individual interviews were conducted with six participants with paraplegia. The researcher utilised an availability sample by applying the snowball sampling method. Interviews were audio-recorded and transcribed verbatim. Transcripts were analysed using thematic content analysis. Initially a descriptive approach was followed and then an interpretive approach. The main themes that emerged, are: *Outdoing adversity through posttraumatic growth; It is a unique life-long journey; It Takes Time; Initial Negative Appraisal; A Turning Point; Positive Reappraisal of Life; Positive Reappraisal of Self* and a *Positive Reappraisal of Relationships with Others*. The findings suggest that all the participants have overcome adversity and have surpassed their lives prior to paraplegia by managing the challenges through personal and posttraumatic growth in the form of positive rumination, adjustment and active emotion- and problem-focused coping. The limitations of the study included the absence of in-depth investigation of sexual intimacy and bowel and bladder issues, and the need for the inclusion of uneducated and socio-economic deprived paraplegics. Future studies may focus on differentiation by means of education, age, socio-economic status and the cause of paraplegia, the integration of bowel and bladder regulation and sexual intimacy into the lives of the paraplegic individuals, their partners, caregivers and families.

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Short Title: Subjective posttraumatic growth experiences in paraplegic individuals

(Keywords: subjective experience; spinal cord injury; paraplegia; posttraumatic growth; coping styles; adjustment; reappraisal of life; re-authoring life story)

Introduction

Sustaining a spinal cord injury such as those that cause paraplegia, is a distressing event that has lasting consequences. Life as the person knows it, changes forever. The immediacy and unanticipated changes associated with the complete or partial loss of sensation and motor regulation of the legs and lower body (paraplegia), pose a significant challenge to a person's psychological resources and lifestyle (Smith, Marcillo, & Norenberg, 2004). During the acute recovery phase in rehabilitation facilities, patients are possibly overly focussed on facing the physical and functional challenges of becoming as physically independent as possible. In this process and despite psychological support, the real challenge of integrating the traumatic incident with its concurrent psychological and lifestyle complexities may only dawn upon patients after discharge from physical rehabilitation. It is at this point that they have to start integrating it into their lives.

Despite making adjustments, many inevitable life-changing outcomes of paraplegia are subjectively experienced as loss. Subjective experiences of loss are, amongst others, related to additional time required to prepare for and engage in self-care and activities of daily living; less independence in activities (or extended activities) of daily living; changes in individual identity and the person's view of self in relation to others, body-image and sexuality; loss of a job and income; perceived changes in quality of life and social status; and also perceived

losses such as rejection and stereotyping (Langer, 1994; Hastings, Horn, deRoon-Cassini, de St. Auben, & Valvano, 2009). Concurrently, experiences of loss could well manifest itself as a grief process characterised by various phases such as denial, anger, bargaining, depression, which will ideally end in acceptance and progress to normal functioning (Kübler-Ross 1969). If paraplegic individuals fail to integrate paraplegia into their lives successfully, they may develop lasting psychological disorders such as depression, anxiety, and at its worst, even posttraumatic stress disorder (Martz, 2005; Craig, Tran, & Middleton, 2009), although not all individuals with paraplegia develop psychopathology.

Some people recover from traumatic experiences and arrive close to a former degree of well-being, a notion that is called resilience. Resilient individuals can return to a similar level of functioning to life before the incidence of trauma (Carver, 1998). Some individuals even surpass previous levels of functioning and well-being after trauma, which is even more remarkable. These individuals report that they have adjusted and live fuller, richer and perhaps more meaningful lives with improved well-being after the traumatic event, despite the pain of tragedy and loss (Kennedy, Lude, Elfström, & Cox, 2013; Kennedy, Lude, & Taylor, 2006; Hefferon & Boniwell, 2011). This notion reflects what numerous positive psychologists have proposed: some people who suffer significant trauma do not only recover from their trauma, but they surpass the level of functioning they had before the occurrence of the trauma (Hefferon, Greal, & Mutrie, 2009). In fact, they thrive and use the traumatic experience as an opportunity for further individual growth and development (Zoellner & Maercker, 2006). This notion is a principle known as posttraumatic growth (PTG), which suggests that people find means to integrate trauma into their lives to thrive after adverse circumstances that otherwise may have caused lasting and unpleasant psychological responses (Berger, 2014; Calhoun & Tedesch, 2006; Sparkes & Smith, 2013; Tedeschi & Calhoun, 2004; 2009).

Research in the field of PTG has expanded significantly over the past years. Researchers studied mostly the positive gains of PTG. They also paid attention to the relationships between coping, cognitive processing, meaning making and adjustment and PTG within the background of various traumatic incidences – including anything from natural disasters other chronic physical conditions, such as cancer, and sexual assault (Berger, 2014; Calhoun & Tedeschi, 2006; Davis, Hefferon, Grealy & Mutrie, 2009, 2010; Nolen-Hoeksema, & Larson, 1998, Tedeschi & Calhoun, 2004, 2009; Zoellner & Maercker, 2006). However, studies specific to paraplegia or SCI are scarce.

Previous studies among individuals with SCIs show various designs and have studied: coping and coping strategies, psychological adjustment; barriers to self-management, emotional impact, posttraumatic growth and the process of posttraumatic growth. The results show that many people living with spinal cord injury manage the consequences of their disability without significant levels of psychopathology by making use of active coping strategies (Pollard & Kennedy, 2009). In addition, researchers found that current cognitions, in particular primary appraisals of threat, are important in the process of psychological adjustment (Kennedy, Evans & Sandhu, 2009). Another study found that appraisals and coping is significantly linked with adjustment (Chevalier, Kennedy & Sherlock, 2009). Not surprisingly, some research shows that caregiver burnout, limited accessibility, physical limitations and secondary complications, lack of a positive outlook and mood, and financial issues are barriers to self-management of SCI. Researchers also examined the various stressors of SCI and how affected individuals overcame them.

The majority of the research focused mostly on *either* positive *or* negative outcomes of PTG, utilized quantitative methods, and did not really illuminate the complexity involved in the experience of post-trauma recovery from SCI and paraplegia, i.e. the integration of

paraplegia into one's life. The exploration of paraplegics' subjective experience of integrating paraplegia should be of value within the parameters of supporting paraplegic patients during and after physical rehabilitation. This preliminary investigation was therefore intended to capture the comprehensive stories of paraplegic individuals that reflect day-to-day subjective experience and living with paraplegia and how the participants have made it part of their lives. The main research question in this phenomenological study was therefore: What is the subjective experience of integrating paraplegia into one's life? Because only people with SCI can answer this question the aim of the research was to explore the subjective experience of integrating paraplegia into one's life and to explore further research themes for the future. Phenomenological research is ideally suited for investigating the inner experiences of participants' awareness that only they can give you (Groenewald, 2004).

Methodology

Phenomenological design

A phenomenological design was used which allowing the researcher to capture the complex and subjective nature of six participants' lived experiences of integrating paraplegia into their lives without prompting them towards positive self-reports or forcing a choice between positive and negative outcomes. Therefore, the meaning of the subjective experiences of participants provide an understanding of how a group of individuals integrated paraplegia into their lives (Creswell, 2007; Maree, 2010; Richards & Morse, 2012).

Participants

A focused and purposive availability sample consisting of 1 black Xhosa female, 3 white Afrikaans females and 2 English Indian males was used (see Table 1). A purposive sample was used because only individuals who sustained paraplegia will be able to answer

our research question (Maree, 2010). The participants were recruited by means of a snowball sampling method. Sampling continued until data saturation was reached, except in the thematic field of sexual intimacy and bowel-bladder regulation. These themes were targeted as fields of interest and importance for future studies in this field due to its highly sensitive nature and relevance. All participants were South African citizens and had tertiary qualifications. They were recruited by an independent psychologist who identified one participant. Thereafter participants were asked to suggest the name of someone else they knew with paraplegia that could be contacted to take part in the study, should they consent and meet the inclusion criteria (Maree, 2010). Eligible participants had to have sustained an injury resulting in paraplegia and at least six months should have elapsed from the time they had sustained it to be considered as part of the study. Comfortable communication in English or Afrikaans was a specific requirement for participation.

Table 1

Biographical Information of Participants

	Age	Race	Gender	Language	Occupation	Time that has elapsed since the SCI in years
N=6						
1	33	White	Female	Afrikaans	Director	12
2	65	White	Female	Afrikaans	Pensioner; Former midwife	4
3	42	White	Female	Afrikaans	Technical officer	18
4	34	Black	Female	Xhosa	Entrepreneur	8
5	25	Indian	Male	English	Postgraduate student	4
6	34	Indian	Male	English	Information technologist	11

Procedure

The study received ethical approval from the Ethics Committee of the North-West University (Mafikeng Campus: ethics number NWU-00438-15-A9). The researcher adhered to the regulations of the Health Professions Council of South Africa (2008) and the North-West University's guidelines for ethical research practices as provided in the Manual for Postgraduate Studies (North-West University, 2010). No particular site was identified for data gathering, as data gathering took place under circumstances that was convenient for the participants. Prior to the voluntary individual interviews, participants were informed verbally and in writing of the voluntary nature of participation, their freedom to withdraw, intentions of no harm and the aim, rationale, research process, availability of psychological support afterwards, and the intention of publishing the data in an academic journal (see Appendix A). Participants were allowed to ask clarifying questions prior to signing written informed consent. Anonymity, privacy and confidentiality were ensured by protecting the database with a password to which only the researcher and supervisors have access. None of the participants indicated a need for psychological debriefing after the interviews.

Data gathering

Qualitative data was gathered from six paraplegic individuals to obtain a comprehensive understanding of the day-to-day subjective experiences of living with paraplegia and integrating it into one's life. Audiotaped in-depth individual interviews were conducted and eventually transcribed verbatim. Participants had to explain to the researcher their subjective experiences of integrating paraplegia into their lives. The interview guide consisted of 1 primary open-ended question: "*Tell me about your experience of integrating paraplegia into your life.*" Where participants found it difficult to understand the primary question, follow-up questions assisted participants to elaborate on their answers: "*What had*

to happen and what was it like?” and, *“What is it like to go through this process of integrating paraplegia into your life?”* The aim was to capture the essence of the lived experiences of the participants, while the flexibility to remain open and to probe for new questions for clarification, was maintained. Participants was guided back to the focus of the interview when they got side-tracked by trivial aspects that were not related to the study (Creswell, 2007; Maree, 2010).

Data analysis

Analysis was conducted by three interpreters: one independent psychologist; the research supervisor; and the researcher himself. The three parties met afterwards to reach agreement on the findings (Brocki & Wearden, 2006; Creswell, 2007; Koch, 2006; Smith & Osborn, 2003; Willig, 2001). The thematic content analysis was mainly inspired by the procedures, Groenewald (2004), Maree (2010) and Vaismoradi, Turunen, and Bondas (2013) and was aimed at compiling a final report . The process started with familiarisation with the data by categorising each data set into relatively broad themes. This entailed a process of bracketing the investigators’ preconceived ideas and a naïve reading and re-reading of transcripts. Themes that occurred across the data sets were identified, reviewed and reflected upon (Groenewald, 2004; Vaismoradi, M., Turunen, H., and Bondas, T. (2013). Reviewing involved the comparison of themes across the data sets and defining and naming the themes. It further allowed for specific categorisation into main and subthemes, and elaborated on insight into those areas where responses and perceptions were relatively consistent, while potential negative cases were identified. Subthemes were defined according to the intensity it had for participants. The intensity of subthemes is linked to how significant they are within the context of the data set and how closely related they are to the themes. These qualities

were judged by consulting the available literature (Maree, 2010). After interpreters reached consensus on the findings, it was combined and illustrated in a table (See Table 2).

Trustworthiness was ensured in this study by paying attention to credibility, confirmability and dependability (Lincoln & Guba, 1985). Credibility and confirmability was established through the application of triangulation and member checking. A psychologist that was not involved in the research process examined both the process and results of the study in order to ensure dependability.

Results

The interviews resulted in eight predominant themes, of which the first is *Overcoming adversity through PTG*. The growth and integration process is described in the second theme, titled *It is a unique life-long journey* and the third, *It Takes Time*. It is implied that an initial *Negative Reappraisal of life* (Theme 4) precedes the *Positive reappraisal* (Theme 6) component; and that a *Turning point* (Theme 5) was needed for the negative reappraisal to transform to positive reappraisal. The integration of paraplegia requires a process of rumination, which starts with the *Reappraisal of life* in theme 6, and continues with the last two themes, namely *Reappraisal of Self* (Theme 7) and *Reappraisal of Relationships with Others* (Theme 8). The success of this reappraisal process seems to be determined by adjustment, appraisals and the coping strategies of participants. Coping strategies are not discussed separately as a theme, but are rather integrated in the discussion of the other main and subthemes. The main findings are illustrated in Table 2

Table 2

Summary of main findings

Resulting themes

Theme 1	Outdoing adversity through PTG
Theme 2	It's a unique life-long journey
Theme 3	It takes time
Subthemes:	It's is a process
	It's not forever
	In your own time
	Time heals wounds
Theme 4	Initial Negative Reappraisal of Life
Subthemes:	My life is over
	This is not a life
	Life makes no sense
	Life is out of control
Theme 5	A turning Point
Subthemes:	Wake-up call
	Think again – affect balance
	Conscious decision
Theme 6	Positive Reappraisal of life
Subthemes:	My second chance in life
	Life is still good
	Life is meaningful and comprehensible
	Life is manageable
	You have rights
	Holding on and letting go

Resulting themes

Theme 7	Positive reappraisal of self
Subthemes:	<ul style="list-style-type: none"> Still me – but better New roles in life More than a body Living a new truth Sexual intimacy remains important
Theme 8	Positive reappraisal of relationships with others
Subthemes:	<ul style="list-style-type: none"> Partners for good Blood is thicker than water – most of the times Leaving the abled and joining the disabled family

Overcoming adversity through Posttraumatic Growth

All the participants felt that they have surpassed the quality of their lives prior to paraplegia. Their subjective experience was that the trauma of paraplegia compelled them to ruminate on life and to adjust their ways of coping. It redirected them to personal achievements that wouldn't otherwise have been possible. Accomplishments such as a positive, meaningful self-transformation and a fuller, richer and perhaps more meaningful life and relationships were all part of their personal experiences of trauma. Participant 6 gave an example of how he managed to overcome adversity by emphasizing his strengths:

Most people will say that I am very strong. When people speak, they use the word 'inspiring' a lot of times and that I never give up ... it's just – when you are put through the test – that they come out, you know. I always had

fortitude. I always had strength. It wasn't as amplified as it were after the accident. After the accident, you are taken into another dimension.

However, despite the shared outcome, the rumination of trauma and adjustment of coping skills was unique to each individual. The element of uniqueness is described by the next theme.

A unique life-long journey

The process of integrating paraplegia into one's life was clearly different for each participant. Two of the participants initially did not cope very well, as opposed to the other four who really coped well from the start, although it was not easy for them either. Participant 6 said: *Every story is different and everyone's journey is different.* Another female, participant 4, commented: *With spinal cord injury, there is no two patients that are alike.* This difference was apparent in how they initially appraised their loss and their lives, themselves as humans and their relationships with others, as well whether they utilised avoidant coping skills, or active problem-focused and emotion-focused skills. Participants described this unique life-long journey as a slow one in the next theme.

It takes time

With time, healing gradually emerges as patience, hope and strength escalate. This is the result of several personal resources, like coping, adjustment and positive reappraisal, which develop gradually over time. The following subthemes demonstrate how the time element of the process of integrating paraplegia holds patience, hope and strength:

It's a process

Participant 3 reported that “*it is actually a loooong road*”, which was supported by another participant (4) who said that “*you have to wait it out and see ...*” and that it “*is tough waiting it out.*” This was confirmed by the 34-year-old male (Participant 6):

Once they told me and the news was broken to me that was it. I wouldn't say I accepted it, there and then ... but what I did accept was that this is the situation right now. I need to do what I need to do to move forward.

The time-consuming nature of this process requires a strength from patients in that they have to maintain a certain psychological perseverance and hope over a long period of time.

It's not forever

Paraplegia brings a persons' life to a halt for a certain period of time before the participants can progress towards ruminating their paraplegic lives for the better, as participant 2 expressed: “*That entire period was as if an entire part of your life just came to a standstill and later went on again.*” The thought that the tragedy of paraplegia only lasts for a while, provides the hope that life will become good again and that one should utilise strength and patience to work through this halt successfully.

In your own time

The adjustment process also takes a different amount of time for different people. As participant 1 explained: “... it may take a while. It does not take everyone the same time. It takes longer for some than for others, but you will be okay”. Participant 4, who initially used distraction unsuccessfully as a coping attempt after becoming paraplegic, abused alcohol and prescribed medication. He said that “you will get out of it on your own time ... you do get out

of it.” This means that health care workers have to be sensitive to the individual’s pace of development.

Time heals wounds.

The importance of time and the healing benefits of gaining perspective associated with time was underscored by participant 3:

Time was actually the most important factor with me. Time made a pretty big difference for me... I think that any ‘time’ brings healing. I think that you cannot just turn over any trauma or something that effects your soul and spirit...The circumstances begin to grow on you, you adapt bit by bit”

Participant 1 was severely depressed initially with suicide ideation and one attempt due to ineffective coping. She commented on how bad it was for her and that it took almost a year for her to adjust. She further elaborated:

I think a year is a good time to give yourself time to feel sorry for yourself and to feel bad and to work through all the negative things for you to realise: ‘All right, no, you are not going to get better, no you are not going to walk again...so come, let me make the best of what I still have. Yes.

Participants felt that it is important to take the time to mourn the loss brought about by paraplegia and to work through the grief. They indicated that the right psychological resources – like coping, adjustment and positive rumination – does emerge over time by being patient, hopeful and strong. Health care workers can normalise this tendency in patients.

Initial negative Reappraisal of Life

All participants initially experienced the typical psychological distress associated with trauma: shock, confusion, fear of the unknown, loss, frustration, self-doubt, pain and shame. Participants who utilised avoidant coping strategies – avoidance, repression and distraction – did not initially cope effectively with their psychological distress. They appraised their lives much more negatively than the others and devalued it, and therefore initially tended to participate predominately in negative rumination. This entailed discounting their lives, as demonstrated by the subthemes. Being aware of this tendency can help health care workers to expect these reactions and to deal with them proactively.

My life is over

Some participants failed to cope and felt that their lives are over. Some expected to die and prepared themselves accordingly. Participant 4 explained that he “*was under the impression that it is still only a matter of time*” before he dies and that it is “*just a short while.*” Participant 1 attempted suicide and thought about it constantly. The following quote from a young female participant (1), illustrates this: “*Oh, I was like: ‘I cannot go on with this, now I have to get pills, now I am going to drink pills ... Suicide! Yes!’*”

The perception that life is over also entailed difficulty to comprehend the permanency of their changed lives. Participant 2 explains:

My husband kept on saying to me: ‘My Wife, our lives are going to be different now.’ I could never comprehend it, because nobody ever pertinently told me that I am now paralysed. Or maybe I just never made it my own. I don’t know ... Just always that we are going to have a different life.

This is not a life

Participants initially devalued their lives as disabled persons. Participant 4 said that he felt that “*even if I do live, this is not a life*”. Patients discount life and do not appreciate being alive, like this participant said: “*... in the beginning of paraplegia you take everything for granted.*” Devaluation also had to do with unexamined self-perceived stigma and stereotypical ideas about people with paraplegia. Participant 5 felt that “*being dead is better than being disabled basically. So I think I was one of that people who has felt like I should have rather just died than live like this.*”

Life makes no sense

Participants experienced an existential void where they experienced a temporary loss of a sense of meaning in life and an inability to make sense of the trauma. Participant 1 said: “*Why in this life do I have to get up? I am anyway not going to do anything today. Why do I do it?*” Difficulties to comprehend their situation and to make sense of it were further highlighted by Participant 5:

not knowing what's going on. It took me a while to understand what's going on. So when I finally caught on to what was going on, that's then when I thought I would rather die than live like this.

Life is out of control

Life was initially characterised by intense uncertainty. Participant 1, narrated:

It is as if you are walking into a relationship for the first time, but you don't ask too much questions and you don't talk too much, because you first want

to check things out...Because you don't know: will I be okay? Will I be able to get up in the mornings? ...It was just that uncertainty...

She further expressed her initial anxiety and uncertainty:

For me in the beginning it was... you go with the flow, understand? A person does not think too much about it. In the beginning, uhm, you do not know what to expect. You do not even know what to think.

A sense of surreality followed the uncertainty and confusion. The elderly lady (2) tells about her experience as follows: “There was also this sense of life being unreal ... initially it was really so unreal ... No, I never denied it. I just did not realise exactly what was going on.”

Participants had a clear sense of a loss of control in that they will no longer be able to manage their lives or do things. Participant 1 said: “*So, initially when you get injured you start looking at all the things that you can't do and which you are able to do the easiest*”. participant 2 narrated the following:

It will never again be the way it was. I am no longer in control...initially it was a frustration because it felt so out of control... this [baking biscuits] was something I thought I would never do again. I gave away a lot of my ingredients before the time. I gave away some of my clothes and my handbags. I don't know what went on in my mind.

Participant 5 elaborated on this notion:

Because of what is portrayed mostly...or what I had seen – in my eyes – was the inability of disabled people. Yeah, so I dwelled a lot thinking about

the inabilities of disabled people thinking that I may not be able to do all sorts of other things.”

However, the participants all reached a point where they changed this around, which brings us to the next theme.

A turning Point

In each case, there was a moment in time that the participant took a conscious purposeful decision to look at their trepidation differently. They made a cognitive shift of positive rumination. The realisation of the need to ruminate positively, are described in the subthemes below. These subthemes are of value in that they provide a window into the turning point, which could help researchers find out how to guide patients to this point.

Wake-up call

The turning point refers to the moment in time where the decision to step out of the “problem-saturated story of the paraplegic life”, into an alternative story of “overcoming adversity”, was taken. Participants 1 and 4 initially coped destructively after becoming paraplegic until they each reached a turning point after a wake-up call. Participant 4 vented by means of alcohol to desensitise the difficult emotions of paraplegia, instead of coping actively with the emotions. He even caused a motor vehicle accident in his adapted car while driving under the influence of alcohol. Participant 4 said:

I was drunk behind the steering wheel and I smashed my car ... I did not have any visitors this time around ... the first time around, there were hundreds of visitors – and that gave me some food for thought. Then I realised that I should stop feeling myself sorry ... A lot of people were upset with me ... That was a wake-up call. That's when I decided ... no more

sleeping pills, no more anti-depressants, no more feeling myself sorry. From that point onwards, my studies was going good and my life was going good again. I was thinking clearly again.

While in hospital after the accident, Participant 4 realized that he had less support from visitors than he had before when he was in hospital for the paraplegia-inducing accident. This became a wake-up call, as he felt that he was losing the people close to him with his behaviour. He realized that he had to make the decision of ruminating his life positively. Therefore, he incorporated an active coping approach into the concurrent emotional challenges of paraplegia.

Likewise, participant 1 found it extremely difficult to cope with the negative emotions of paraplegia and attempted suicide. She relates that the suicide attempt was her wake-up call to ruminate her life with paraplegia positively. Like participant 4, she consciously and deliberately transformed her coping approaches from destructive-avoidant coping to active emotion-focused coping. She disclosed:

So when I could not reach those pills, then I realised: 'But you know what?...this is not destined for you. So, come let's see what I can do.' Then I decided that I am going to study ... Yes, so when I made that decision and I had something to do in the mornings when I get up...then it was like a 360 degree turn around.

Think again – affect balance

All participants emphasised the importance of a positive reappraisal and positive rumination to outbalance the negative affect. Participant 1 emphasised:

So, I think the biggest thing that anybody can do is to get your head straight. You must be able to know: 'I am still young ...' So, you must really think about all the things that scares you, you must really think it through well. Pull the threads open a bit ... pull things apart. Ask: 'What if?' ... And with the answers that you get, you start to realise: 'But my goodness! I am going to be okay!'

Reaching the turning point involved a conscious purposeful decision.

Conscious decision

Participant 4 disclosed how he deliberately had to re-ruminate to have a life change:

If you do not try ... or if you are not willing to improve, you will not. I think that's it...nobody can do it for you. It is impossible. So you need to 'want to do it. You need to get your mind in the right place.

Once the participant could make the turn described above, they could arrive at a positive reappraisal and take control. This forms the next theme.

Positive reappraisal of Life

Participants relied on active emotion-focused coping strategies during experiences of turmoil, such as focusing on personal strengths, virtues and spirituality. Their lives gradually became well worth living for. Even those who initially did not cope effectively after becoming paraplegic, became able to cope with paraplegia by relying on transformed coping and thinking styles. They initiated positive appraisal of their lives and therefore tended towards the dynamics of PTG, namely positive reappraisal of life, self and their relationships

with others. Knowing what this positive reappraisal looks like, can assist researchers and health care workers on their journey towards finding ways to stimulate this thought process.

My second chance in life

Participants cultivated positive emotions by becoming grateful for having a second chance to make a difference and to do things differently. Participant 2 relied on her virtue of gratitude to think differently about her life: *“I have a second chance ... it is wonderful to have a second chance, it could have been so final.”* She further highlighted her realization that she is alive and has a second opportunity to live a proper life:

There is still a lot of work for me....they told me that we are going to bake some biscuits something I never thought I would do again. They showed me that I can lead a normal life, I am only slower, I can no longer do things quickly-quickly.

For Participant 5, the realization dawned that *“there is life after disability.”*

Life is still good

This subtheme reflects gratitude, benefit-finding and a new appreciation for participants' changed lives. Participant 4 stated: *“You don't take things for granted any more”* and he continues: *“Look in the beginning it was very bad, right. But as I am thinking of it, there is actually more positives than negatives.”* He emphasizes the importance of appreciation of life and benefit-finding and the realization that the situation could have been worse:

There is always something more severe or someone worse off than you. So if you can identify and recognize that you will be able to appreciate what

you have ... So, if you are alert and not only looking at yourself, you will find people around you that are worse off – but they are making a life for themselves. They are not sulking. They are living and appreciating their lives.

Participant 2 suggested gratitude as she gave touching life advice:

You must focus. You must focus on the things that you do have, not moan about the things that you cannot do. Be thankful in all things. Because now you have opportunities again which you would not have had if you still had your normal life ... I can honestly say it [paraplegia] has definitely influenced my life positively.

Life is meaningful and comprehensible

Participants reappraised their lives after resolving their existential crises of finding meaning in the suffering and pain of paraplegia. They realized that they have a purpose, are able to attribute positive meaning to their trauma and that life and suffering makes sense. There was an improved sense of coherence after trauma and a sense of spirituality that surpassed their former levels of functioning. Participant 4 said: “*So, if you do something, you want it to be meaningful and you want it to count for something ... Yeah, you want to do more meaningful things.*”

Participant 5 said:

“Later I joined the disability sector ... I thought it would give meaning to me ... so that I can understand about disability ... for me it was about awareness, but there was a lot more that came out of it.

Participant 6 revealed that “I had to lose my body so that I could find my soul.”

Life is manageable

The manageability of life refers to the adjustments people made, as well as knowing their rights as disabled people. Participants made positive and even ingenious practical adjustments or alterations. They wanted to live their lives as normal as possible. This raised a new sense of security, peace and control. Participant 1 disclosed how adjusting her car made a significant contribution towards her experience of independence and mobility:

a very big positive thing that happened to me, was when I could drive my car after the accident, because if you are not mobile, how will you be able to get to places? Independence is a very big thing to me. I don't want someone to pick me up and drive me around all of the time. I would like to do things by myself.

Simple adjustments and practical solutions empowered Participant 2 to continue doing the things she loved to do: “My husband adjusted the gardening tools so that I can still be able to work in the garden.” Participant 3, currently a middle-aged lady, does gardening in pots so that she is still able to do gardening like before. She also engaged more in creative expression to compensate for the loss of physical activity: *I was a very active person – a sport fanatic. Now I am a craft-kind of person. I do art. I implemented my hands creatively.*

Adjustments to one’s living and work environment is another important way of coping with paraplegia. Participant 6 relied on financial resources to make adjustments to his house.

You have to build ramps, the floor needs to be level and easier to push, so removing carpets and that type of things. The bathroom needed to be redone so I was able to shower and do everything, we had to make a few

changes around my room, the bed that you sleep on so it was a few changes here and there to kind of help the situation, but I was fortunate enough to financially afford all of those things.

Involvement of social support or, for instance an assistant in their living environment, also made participants' lives more manageable (also see main theme: Reappraisal of Relationships with Others). It helped participants to adapt to paraplegia. Participant 4 appointed an assistant, who also became his friend, to stay with him. Participant 3 showed in her example how social support helped her to adapt.

I just decided to do this thing and from there onwards I changed the house for the first time to make it more comfortable to me. It was also then that I got a stay in housekeeper for the first time and so forth. From there the things came slowly into place. It was then that I got a female friend that could live with me. At the end, we were about 4 people that lived together. After that, my parents decided to sell their house and to go smaller, because I also had a big house. And then they moved in with me and from there onwards there wasn't really time for going downwards.

You have rights

Knowing their rights as a disabled person, not becoming a victim of stigma associated with physical disability, and advocating for the rights of the disabled, added to a positive reappraisal of life, self and relationships to others, as well as environmental mastery. Participant 5 felt empowered by knowing her rights:

I needed to be empowered ... because focusing on your impairment can make you think, that what is disabling you is really your impairment ... It

[knowing their rights] can free them from thinking that the problem is my legs, because once a person is freed ... that they know what their rights are, then they know what they are entitled to ... So, they see themselves as equals...

Holding on and letting go

Participants accepted that some matters are within their control and others are ultimately uncontrollable. This realisation helped them to overcome their initial perceived helplessness. They have accepted their fate, either by calling upon a higher power, or themselves. They decided to pursue the matters that can be controlled instead. Participant 2 expressed that “*God made all things work out for the best,*” versus the report of Participant 4:

... but when I hit the 18-month mark, I said to myself: 'If I walk, it is a bonus, but it is now out of my hands. If it comes, so be it. Then it will come by a surprise, but I will not sit every day waiting and even praying for it, because there are other important things as well.'

The frustration of being unable to perform various tasks, such as cooking, was out of the control of participant 2. She accepted that it was God’s way of making it “*work out for the best.*” She regained control by accepting His goodwill. Participant 4 accepted that walking is beyond his control. He focused on other important matters within his control, such as his studies.

Positive reappraisal of Self

The most striking contribution of self-reappraisal was that participants managed to cope in such a way that they refrained from identifying themselves with the shortcomings of disability. Participants realized that they are still human, regardless of their limitations. It is

confirmed by a report by participant 1: *“Remember, you do not become your accident. You are still a human being.”* This became evident in the following subthemes: *still me – but better; new roles in life; more than a body; sexuality remains important; The new truth*

Still me – but better

Participants’ sense of self and identity developed after the trauma of paraplegia. These developments are evident in the beliefs, evaluations, personal characteristics and perceptions of participants (Baumeister, 1999; Corsini & Wedding, 2011). Participant 2 mentioned: *“Before my accident, I was a ‘Mary’ ... So, I changed from a ‘Mary’, to a ‘Martha’* [characters of the Bible] *and I don’t feel guilty to be a ‘Martha’ ...”* Participant 4 tells how he improved his sense of self and identity:

Before the accident, I was very proud, conceited and egoistic. I used to fight a lot and solved problems by fighting. I took hasty decisions and were very impulsive... Bragged ... typical guy. I lived my flashy life. Fast cars were important to me ... money and materialistic things ... I had to work on myself and look at life differently, changing my way of thinking and how I approach or treat people...

Previously, participant 4 was arrogant and found worth in his possessions and friends. He realized that that was superficial. Like the other participants, paraplegia changed his view of who he really is, as well as his values. With paraplegia, he lost most of his worldly possessions according to which he had previously defined himself: *“Before, I was the guy with money and the nice car. Now, I don’t have those things.”* He was left with the question: *“Who am I then?”* He felt that taking the ambitious and challenging journey of redefining himself, is his only option: *“I needed to define myself differently and to find out who I am and what I have to offer to somebody else.”* The new person he became is humble,

appreciative and associates himself with people who will always be there, regardless of the circumstances:

When you lay there thinking of dying, none of those things are there, but what is there is the people around you and you look at them and asking yourself about what good you did to them so that they are standing by your side and in a few months it is still those same faces. Those are the things that you will take with you ... the images of your loved ones or those who stood by you.

New roles in life

Participants' roles have changed with their identity as a result of the new responsibilities, positions and statuses that arose because of adjustment to disability. A prominent finding was that participants tend to serve people more directly in their new roles of life. Where they used to be more focussed on their own interests and needs, they became much more focussed on the needs of others and to play a supportive role. Participant 2 used to be a housewife and mother. She was constantly so occupied with household tasks, which she deemed as important at the time, that she actually was not in touch with the real needs of her family and other people. Now that she is unable to enter many rooms in her house, she relinquished the domestic role to her husband and feels "*at peace with my husband who has absolute control.*" She has grown into a role where she serves people, a role where she inspires and encourage individuals of the disabled and paraplegic community:

Before, I've never given a thought when I see someone in a wheelchair. Now, if I see someone in a wheelchair, I make an effort to ride to that person and touch him and to speak with them

Participant 5 found meaning by accepting a new role as an activist for the rights of disabled persons. Participant 6 entered the role of a helper where he “*helps people with their blockages.*” He reported:

Where I can give back my time and motivate and inspire, then I do that. I also go and visit people and give back in this manner, whether it's at home or at work, or whatever it is, you try to just make it easier for someone else.

The working participants made adjustments to be able to fulfil their occupational roles. They either performed different tasks, or made it less straining physically. The work environment was also adjusted to become more accessible. Participant 3 reflected that, “*I am still in the same profession. I just can't do the physical aspects any more. I can now only do the computer part of it.*” Participant 1 held a management position after achieving an honours degree. Adjusting work demands to their abilities, and leniency from work, made the work environment more friendly and accessible. Participant 6 reported that:

With work it's been great all the time, they have been very accommodating, they allow me to work twice a week from home, they allocated toilets on all the floors, so a lot of changes have happened.

The experiences described above ultimately made participants realise that they are more than a body.

More than a body

This subtheme highlights the importance of body awareness and health behaviours in paraplegic patients. Health workers should keep these factors in mind when supporting such individuals. Participants came to a point where the physical features of their bodies no longer defined their self-worth and identity, and they came to greater appreciation and awareness of

health through proper bodily care. Participants ultimately gained a new familiarity with and awareness of their bodies with its abilities and a dramatic change in body functions.

However, reaching this point is a process. Participant 6 provided an example:

So, initially ... when you get injured ... You start looking at all of the things that you can't do and which you are able to do the easiest ... the most important that you should do, is to focus on what you can do, because the more you focus on what you can do, the easier those things become and then slowly you add to that arsenal ... the more you realise that you are not this body, the more you realise your true nature.

The inabilities of participants' bodies initially contributed towards a negative representation of themselves after becoming paraplegic. Loss of a good appearance was a significant issue that participant 4 had to overcome and cope with when he saw his broken spine: *"After the session with my family, I broke again. I told them that I look like a monster. There is no use in living.* Participant 2 also raised the concerns about loss of control over bowel and bladder functioning:

Only two days before I was discharged, I received the information that I don't have control over my bladder and digestion any more, and that was a huge shock to me. For me, it was a disgrace to know that I am dependant.

The dramatic change of the body's ability to control a bowel movement, was a topic that some participants shied away from by only mentioning it briefly, while others chose not to raise the topic at all. The researcher decided against further exploration to show respect for the participants' sensitivity about the issue. Some paraplegics need assistance to extract faeces or to be cleaned. Others may need to carry stoma bags to keep their faeces and urine,

which is embarrassing. Participant 1 reported that wearing a catheter is one of the most negative changes of paraplegia:

You are not able to control your bladder and stomach. So, the big problem about that is when you have to go somewhere that does not have a paraplegic bathroom, you have to carry a catheter. The catheter is just a plastic little pipe and urine in a plastic bag. That does not work well always. Actually, it is just a creepy story.

Participants needed to realise that they should not define themselves by how they may appear to society. They realized that they can only try not to be overly concerned about what the body cannot do, but rather on what they have to offer as individuals. They had to accept that it will remain a lifelong difficulty that they'll have to cope with – hence they tolerate it.

Sexual intimacy remains important

Three of the participants did not mention the topic of sexual intimacy at all. The others volunteered cursory information, except for participant 4, who spontaneously offered information on his own experiences. Not one mentioned how their disability affects their partner's needs of sexual intimacy, or how they address the needs of their partners or their own. Due to participants' reluctance to speak about sexual intimacy, it was not fully explored. However, participant 4 made it clear that sexual intimacy remains an important need in the life of a young person with paraplegia: *"Will I be able to have sex and what would it be like? It was also one of the most important things – talking from a guy's perspective."* However, participant 4 also reveals how he coped with the unknown of the future with regard to sexual activity and experiences. He remained optimistic and decided to discover how his body will react, regardless of the scientific opinions of physicians. He mentioned:

They said that I may or may not have children. Okay, and that it won't be the natural way. Up until two months ago, I did not know. We are busy having a baby right now and it happened on the natural way. What I am saying is, that you can't accept everything the doctor says. So, don't worry about something, unless you've tried and tried and seen it for yourself.

For participant 4, it was possible to resolve challenges related to sexuality and intimacy. He was even able to conceive children naturally. Yet, this topic remains hugely unexplored.

Living a new truth

With the disability came new priorities, adjusted values and more wholesome beliefs and attitudes. In the past, many of the participants made their own needs the highest priority. Participant 2 said: *"I do my thing like I want and whenever I want."* With paraplegia, people and relationships became the most important priority in life. They consider other people in their decisions. Situations arise where participants are in need of support. It redirected priorities more towards people, like in the example of participant 2:

With the accident, I realized once again how much my husband loves me and that he wants to make the way as easy as possible for me. He literally crucified himself to meet my needs.

Participants expressed gratefulness towards the people who took the effort in supporting them. They compensate by paying more attention to people and their needs. Meaning were added to their lives this way. New attitudes were formed. The focus was placed on the *"can do's"* instead of the *"cant do's."* They had cultivate this view in order to build on their abilities. Participant 6 reported: *"The more you focus on what you can do, the*

easier those things become and then slowly you start adding to that arsenal.” Participant 5’s belief of a paraplegic individual being primarily unable to contribute to life, changed:

The responsibility is not only on the person, it’s also on society. Society also needs to change. The attitudes from society. They pose a barrier, they pose an attitude and a barrier. The physical infra-structure, it poses a barrier. So it is disabling in itself. So society also disables people. The attitudes disable people.

Participants reappraised their relationships with their partners, families, the broader community and the disabled community. Re-appraisal of relationships are discussed in the following theme.

Positive reappraisal of Relationships With Others

The importance of supportive relationships emerged clearly throughout all interviews. Participant 2 explains that she realized the new value of relationships: *“Before the accident, I’ve never invested in relationships and since the accident, I am so grateful that I can say: ‘Now, I live.’... what is the most important in life – relationships.”*

Partners for good

All the participants reappraised their relationships with their life partners positively, except for the middle aged lady who divorced 1 year after she became paraplegic. She decided that she would be better off to separate from him because their relationship was already burdened before the paraplegia: *“Well, if I only think about the emotional conflict that we had it couldn’t just disappear. It would have, on the contrary, just become worse.”*

The other participants' relationships became more meaningful, closer, more loving and supportive. The expression of patience, support and gratitude contributed towards their coping successes. An example from participant 2 follows:

My husband is my carer, since the accident until this present moment and since the accident happened, he was with me early, as early as he could, sometimes 5 'O clock in the mornings already. He stood by me for the entire day until approximately 10 'O clock at night ... He [husband] is not a man of many words, but his deeds shouts to the heavens. And he was a witness in that hospital and for as far as we came, praise comes to our heavenly Father, because where do you still find an old man and woman who love each other so much.

Initially, Participant 5 had preconceived fears regarding intimate relationships and her disability. Therefore, she abstained from it for a while in fear of being rejected and embarrassed:

I still shied away from dating. Because I mean when you're dating someone, you have to expose yourself to much deeper things you know. And you yourself, not understanding what is going on at the time, and anybody, any girl is shy anyway to start dating or to open up to any guy to begin with. And now with the impairment, it being different, and society painting all these pictures, you think I don't want to embarrass myself, let me rather just stay away, you know, withdraw from it.

However, she managed to reappraise her perception on relationships when she became involved with someone who proved the opposite of her assumptions and her self-perceived societal stigmatization. She reported:

I met someone who showed me that it's really not about that [society's stigmatization regarding paraplegia and assumptions of participant], and made me realize that most of it is in my mind ... showing me that it's not all there is, you know, about you as a person. And he made things easier for me, because he could see that I was holding back. So then he was a lot more patient, he was like, 'okay I'm here, I wanna be with you, I find you attractive' and what not.

Blood is thicker than water – most of the time

All participants reappraised their relationships with their families, most with more positivity. In cases of positive reappraisal, experiences that include positive acts and emotions of love, care, empathy, encouragement, unconditional acceptance and support increased in the families. It contributed towards an increase in proximity and meaning among family members. Participants in turn showed appreciation. Participant 5 reported:

Well, I had a great support system, which is my family. Who actually saw it differently from what I thought was gonna be. Who tried to show me in the best way that they can, that paraplegia means nothing to them.

Participant 2 said the following:

The children acted unbelievable. Support! Support! And they have started to organize prayer groups immediately. The family, distant relatives, became involved again as a result of the accident. Emotionally, financially and spiritual support.

However, the opposite unfortunately also happens in some instances. Participant4 was disappointed in certain family members that faded away with their support as the time went

by. He feels that they don't provide the support that one will expect from family. He shows a negative appraisal of the relationships with those family members:

My mom carried on with her life. My brothers carried on with theirs. So, basically... it's you. That is the difficult part and then you sit and think how different you would have reacted if they were in your position.

During the tough times, he learned that there are a few family members that he can rely on during times of need. They supported him throughout. "There is that one or two, like my dad and my late sister who stood all the way." He shows appreciation and gratitude for the connections with them, which helped him to cope with paraplegia.

Participant 6 reveals what support means to a paraplegic:

"Just to be there. I knew that at any point of time if I needed any assistance and up till today, eleven years later, they're still there. If I pick up the phone, if I need assistance, my mom, my dad and my sister are around and all my friends. So when I say assistance it's the presence that is there, it's the very important thing. Yes, it brought the family closer together, not that we were not close, but now I tend to spend a lot more time with my family than I probably would have spent if I wasn't injured.

Leaving the abled and joining the disabled "family"

Participants redefined their relationships in that they grew closer to the disabled community and felt a slight separation from some of the people in the "normal" society. Participant 1 gave an example of a commonality between paraplegic individuals that created a bond or connection:

There is this unspoken rule ... for example, if you are in a wheelchair and somebody else are also in one and you pass each other in the mall ... you just nod your head ... because you know what he is going through.

Two young female participants (1 and 5) grew away from the able community where they once belonged and where they no longer felt welcome. These experience raised their awareness of the stigma attached to the disabled population, and it contributed towards a negative reappraisal of the able-bodied community. They had to learn to come to a positive appraisal of both communities, and to find meaning by creating awareness of fellow disabled persons. Participant 6 explains this development well by saying:

Where I can give back my time and motivate and inspire then I do that. I also go and visit people and give back in this manner, whether it's at home or at work or whatever it is, you try to just make it easier for someone else..

Discussion

The aim of this study was to explore the subjective experiences of six individuals with integrating paraplegia into their lives. All participants have overcome adversity and have even surpassed the quality of life they had before through PTG (*see Overcoming adversity through posttraumatic growth*). According to the interviews, comments of participants, and the reflections of interpreters, it appeared that the integration of paraplegia was described by the modal of PTG (Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2004, 2009). Therefore the subjective lived experiences were described according to PTG.

The subjective experience of integrating of paraplegia is that it is a time-consuming process (*see It takes time*) and it is unique to each individual (*see A unique life-long journey*) (Barskova & Oesterreich, 2009; Tedeschi & Calhoun, 2004, 2009). This notion is in line with

the description of Zoellner and Maercker (2006), who state that, “It is quite probable that the adaptation processes to these different kinds of traumatic events differ from one another.” They note that when PTG is subjectively experienced as positive “The constructive side of self-perceived PTG is correlated with healthy adjustment, with its adaptive effects showing in the long run.” (p. 640). Studies on various kinds of trauma, including SCI, found that growth can be subjectively experienced after the initial trauma (Kalpakjian, McCullumsmith, Fann, Richards, Stoelb, Heinemann & Bombardier, 2014; Davis, Wortman, Lehman & Silver, 2000; Frazier, Conlon & Glaser, 2001). However, unlike the participants in the studies mentioned above, our participants are faced with a permanent change (disability), which makes their PTG a life-long journey. In this study, some participants experienced growth faster than others. Some issues of paraplegia require more adjustment, which results in slower growth. With new issues that are constantly arising, participants continually need to adjust, cope and grow. Therefore, in the light of our findings and that of literature, it was participants subjective experience that each paraplegic individual should take his own time to adjust to challenges that emerge after the injury.

In some cases, the initial subjective experiences of ‘*Negative reappraisal of life*’ was marked by unsuccessful, avoidant coping. For the participants who chose avoidance, the devaluation that followed this coping approach gave rise to negative rumination. This resulted in the following lived experiences: for instance the impulses of suicide (participant 1) and negative emotions caused by a loss of autonomy, distress from complications, and isolation from society. Wang et al. (2015) refer to these issues as an initial experience of ‘*struggle in hopelessness*’ among individuals with SCI. Those participants who did not make use of avoidance, could experience growth through this phase with more ease. Active emotion- and problem-focused coping approaches will therefore be beneficial to adjust to or cope with the challenges of paraplegia

The theme of a '**Turning point**' is in line with the transformational model of Tedeschi and Calhoun (2004; 2009), the work of Zoellner and Merck (2006) and Hefferon, Grealy and Mutrie (2010). Like these authors, we found that intentional rumination brought about by a personal crisis after a traumatic event added to PTG and it should be encouraged. Zoellner and Merck (2006) described positive ruminations as follows:

Initially, rumination is more automatic than deliberate. After the first coping success (e.g. reduction of emotional distress), ... rumination transforms into more deliberate thinking about the trauma and its impact on one's life (p. 630).

The '**Turning point**' that we identified in our study, is also in keeping with the work of Frederickson (2002, 2003), and Frederickson and Losada (2005). They stated that the subjective experiences of positive emotions influence one's momentary thought-action repertoires to render opportunities for the construction of enduring personal resources. These enduring personal resources lead to experiences of personal growth and transformation. Our participants seemed to use positive ruminations as a way to outweigh their emotional distressing experiences with positive emotional experiences obtained from positive events and positive rumination (see '**Think again – affect balance**' - subtheme of '**Turning point**'). Paraplegic individuals should therefore be guided to use crises or traumatic circumstances secondary to paraplegia as an opportunity to ruminate positively to foster experiences of growth and positive emotions.

Furthermore, our study shows that transformed coping styles and reappraisals, together with constructive environmental factors, deliver experiences of success over adversity through PTG (see '**Positive reappraisal of life, self and relationships with others**') (Byra, 2015; Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2004, 2009; Zoellner & Maercker,

2006). Financial wellbeing, education and social support were some of the environmental factors that contributed towards adjustment to adversity in our specific group of participants. Zoellner and Maercker (2006) indicate that constructive environmental factors and positive rumination are coping strategies that contribute to benefit-finding – a fundamental component of PTG.

Our study unveils that it was the subjective experience of paraplegic individuals that they could see the benefit of the trauma once they experience meaning from suffering and pain after positive rumination. This pertains to the *'realization of additional opportunities'* in the comprehensive model of PTG (Calhoun & Tedeschi, 2006; Tedeschi & Calhoun, 2004; 2009). Participants experienced gratitude for the new opportunity to make a difference. Their subjective reappraisals that life are meaningful, manageable and comprehensible, were also evident in this study. This notion refers to the components of Antonovsky's (1993) sense of coherence as underlying experiences of PTG and emotional wellbeing (Zoellner & Maercker, 2006).

Tedeschi and Calhoun (2004) and Calhoun and Tedeschi (2006), identified an experience of *positive personality change* as part of their theme *'overall advanced appreciation of life'*. In this study it relates to *'Still me – but better'* - a subtheme of the subjective experience of a *'Reappraisal of self'*. Some of our participants' sense of self were experienced as a positive change and this became evident from thought patterns, affect, beliefs, judgement, characteristics and perceptions. The theme *'Reappraisal of self'* further reveals the *'development of spirituality and religiosity'* and an *'increased awareness of strength'*, something that is also present in Tedeschi and Calhoun's (2004) and Calhoun and Tedeschi's (2006) comprehensive model of PTG. This main theme explains the subjective experience of building emotional strength, meaning, and an improved life perspective.

Tedeschi and Calhoun (2004; 2009) understate the development of spirituality and religiosity as a component of PTG. Like Caserta, Lund, Utz, and de Vries (2009), our study suggests that religious growth (or spirituality) is not only a minor beneficial experience of PTG, but also an important contributing experience of adjustment to paraplegia.

Returning to more physical factors, our adult participants attached more importance to certain aspects of body awareness and bodily functions after paraplegia (see *'More than a body'*). The prominence of this sense impression seemed to depend on the nature of the trauma and included awareness of disability, remaining abilities, and a dramatic change in body functions. Ultimately, once the participants had adjusted, physical features of the body defined participants' experiences self-worth and identity to a lesser extent after paraplegia, while greater appreciation and awareness towards health is achieved by proper bodily care (see *'More than a body'* - subtheme of *'Reappraisal of self'*). Hefferon, Grealy and Mutrie (2010) and Picoraro, Womer, Kazak, and Feudtner (2014) also emphasize an increase in body awareness among people with chronic illness. Picoraro, Womer, Kazak, and Feudtner (2014) classify this phenomenon as a sixth component of PTG, namely: *'new body awareness, set of priorities and health behaviours.'* However, Picoraro and his team view this as an experience that is unique to children and adolescents who have experienced physical trauma, unlike our study and the one of Hefferon, Grealy and Mutrie (2010), which revealed that adult participants also experienced an increased awareness of their dramatic loss of body functions and serious illness (paraplegia). This matter is in our view not addressed adequately in other research on PTG.

The subjective experiences of loss of independent bodily functions such as functions of the bowel and bladder (see *'More than a body'*) remains negatively appraised. Our participants merely endured these experiences of loss, and did not truly accept it, although

they accepted that they have to live with it. Zoellner and Maercker (2006) refer to the idea of living with something that a person cannot accept as “a form of coping effort in the face of enduring distress” (p. 638). The various individual experiences of our participants relate to experiences of PTG that is in keeping with this notion: lasting subjective experiences of distress caused by bowel and bladder concerns is conquered with the strength to cope in the face of adversarial growth experiences (Zoellner & Maercker, 2006). Health care workers could play a positive role in helping patients adjust to managing their bodily functions.

In addition to the above, many paraplegic individuals still experience sexual intimacy as important after injury (Singh, Rohilla, Siwach, Dhankar & Kaur, 2012; Fritz, Dillaway & Lysack, 2015) and this was clearly important in our study as well. Some participants, like participant 4, managed to reappraise and reintegrate sexuality into his life, at least partially (see ‘*Sexual intimacy remains important*’). He even conceived children naturally. Participant 4 adjusted to altered sexual intimacy by overcoming the challenging experiences through PTG in two ways, namely through emotion-focused coping and long-term cognitive reappraisal of sexual intercourse (Barskova & Oesterreich, 2009; Zoellner & Maercker, 2006; Ducharme, 2010); and long-term cognitive reappraisal (Ducharme, 2010; Zoellner & Maercker, 2006; Blix, Hansen, Birkeland Nissen & Heir, 2013). Emotion-focused coping and positive reappraisal was evident from participant 4’s optimistic subjective experiences (an emerging strength in the face of adversity) and decision to discover how his body will react (learning new abilities). Most other participants of our study did not discuss their sexual intimate experiences. Due to participants’ hesitation to speak about this, it was not fully explored. As a result, the following question remains: How does the paraplegic individuals and their partners adapt to altered sexual intimacy?

The available literature does provide guidelines for dealing with experiences of sexuality, such as that there should be proper education and information regarding altered sexuality and needs of intimacy (Consortium for Spinal Cord Medicine, 2010; Kreuter et al., 2010); there should be open and honest communication (Beauregard & Noreau, (2009); and couples should be guided towards an initial focus on sensational experiences, such as being touched or kissed (Ducharme, 2010). These techniques usually reduce the negative experiences of performance anxiety that may have a negative impact on sexual function and sexual intimacy. The sexual intimacy of women has been explored in the study by Kreuter, Taft, Siösteen and Biering-Srensen (2010). These women valued a partner's effort with "taking time and being considerate of their needs when making love. They also pointed out that memories and fantasies helped to enhance their pleasure" (p. 159). Beauregard and Noreau (2009) indicate that women rather preferred experiences of inter-partner proximity above physical sexual activity with their spinal cord injured spouses. In many ways, psychological research refrains to address male subjective experiences on sexual intimacy. Men, in general, are less likely to speak about it, which highlights the importance of this topic.

The theme of positive '*Reappraisal of relationships*' is in keeping with the findings of most researchers in the field of PTG, who mark quality interpersonal relationships as a very important contributing factor to the experience of PTG. Our participants subjectively experienced an increased sense of proximity to and meaning from existing relationships. Support from partners and certain family members assisted participants to overcome the difficulties. Tedeschi and Calhoun (2004, 2009) and Calhoun and Tedeschi (2006) identify this subjective experience as very important for the experience of PTG and for the integration of paraplegia. Our participants benefited from the comforting experiences of relying on others, like an improved self-esteem and lower relationship anxiety (Zoellner & Maercker,

2006). All our participants gave and received social support, which enabled the subjective experiences of growth (Caserta, Lund, Utz & de Vries, 2009). However, the realization that some significant people will be emotionally unavailable or even completely absent during important times of their lives, compelled them to become more independent and to select the individuals they want to include into their support networks with greater care. The disabled community in general became significant to our participants, while some of the able-bodied became less significant over time due to the subjective experiences of stigma and its misconceptions. Most spinal cord injured patients experience obliteration at first. The clinical psychologist as part of the multidisciplinary team is to support and prepare patients to add new adjustments to their lives by providing psychological intervention during physical rehabilitation.

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Declaration of Conflict of Interest

The authors declare that there is no conflict of interest whatsoever that could have had an impact on the findings of this article.

Concluding Summary

What is remarkable, is that it was participants subjective experience that they have surpassed the quality of their lives prior to paraplegia by managing the challenges through personal and posttraumatic growth in the form of positive rumination, adjustment and active emotion- and problem-focused coping. In the light of our findings, in addition to the literature, the integration of paraplegia is a time-consuming process that is a unique experience to each individual. Each paraplegic individual takes his own time to adjust to challenges that emerge after the injury. Interesting questions remains for future research: First, what does the experiences of paraplegic individuals and their partners regarding adjustment to altered sexual intimacy entail? And second: How does one integrate the life-long concern of bowel-bladder regulation?

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Appendix A: Research Participant Consent Form



Research Participant Informed Consent Form

Research Participant Information Statement

Your voluntary participation in this research project (*"The subjective experience or integrate paraplegia into one's life"* - approved by the Ethics Committee of the North-West University Mafikeng campus: ethics number: NWU- 00438-15-A9) of Mr. L. Richter for purposes of his master's degree in Clinical Psychology with Dr DK Kirsten as the main supervisor and Mrs. P. Kolobe as co-supervisor at the North West University's Mafikeng Campus, is appreciated. Please keep in mind that publication of results may take place in an academic journal, should the application be successful, but will be completely anonymous. By signing this document, you will voluntarily agree to participate in the study.

Purpose and rationale of the study: The purpose of this study is to obtain rich, descriptive information regarding an individual's experience of integrating paraplegia into his or her life.

Research Process: After you have consented to participate in the study by signing this document, an individual interview will take place and be audio-recorded. Thereafter the interviews will be transcribed and analysed by the researcher.

Voluntary participation means that you may withdraw at any stage of the process, without having to give explanations and without suffering any negative consequences. You are further entitled to ask any questions you wish before you agree to participate in the study. No physical or emotional harm is foreseen as a result of participation to the study. Should unforeseen emotional reactions occur, debriefing will be made available after your participation by the principal researcher (Mr. Richter). If deemed necessary a referral to a psychologist will be made for ongoing psychological support, at your own cost. Your anonymity, privacy and confidentiality is assured. The necessary steps will be taken to protect

your identity and the information gathered from you with a password on a database saved on a computer. Only the principal researcher and the supervisors will have access to it.

Participant consent:

I, _____, agree to participate in this research. I have read the Research Participant Information Statement and had any questions I have about the research answered for me by the researcher.

Name of research participant (first name and surname):

_____ Date: _____

Signature Research Participant

_____ Date: _____

Researcher / Witness name: _____ Date: _____

Witness relationship to research participant (friend, spouse, partner)

Appendix B: Biographical information of participant

Your voluntary participation in this research project ("The subjective experience or integrating paraplegia into one's life") of Mr. L. Richter for purposes of his master's degree in Clinical Psychology with Dr DK Kirsten as main supervisor and Mrs. P. Kolobe as co-supervisor at the North West University, is appreciated. Now that you are aware of the ethical aspects, the purpose, rationale and research process of the study, it will be expected of you to complete the following personal, non-identifiable, biographical information that is part of the information required for the study.

Age _____

Highest level of education _____

Marital status _____

Gender _____

Race _____

Home language _____

Nationality _____

Career (before and after the injury)

Cause of impairment _____

Type of impairment _____

Date of injury responsible for the impairment _____