

**Experiences of Posttraumatic Growth in the Long-Term Phase of
Spinal Cord Injury: An Interpretative Phenomenological
Analysis**

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Introductory Chapter

Thesis Overview

Thesis Overview

A Spinal Cord Injury (SCI) is considered to be one of the most life changing injuries that an individual can experience (Van Leeuwen, Kraaijeveld, Lindeman, & Post, 2012). An SCI not only impacts on an individual's physical health (McDonald & Sadowsky), but also on their psychological wellbeing (Craig, Tran, & Middleton, 2009). SCIs are predominantly caused by a fracture in the spinal column causing motor neuron damage, which can result in paraplegia (loss of physical sensation and ability in the lower extremities) or tetraplegia (loss of functionality and sensation in all four limbs and torso). The most common causes of an SCI are road traffic accidents, violent assaults or through sport (McDonald & Sadowsky, 2002).

A growing body of literature has highlighted that individuals can experience positive life changes in the form of posttraumatic growth (PTG) following an SCI (Byra, 2016; Davis & Novoa, 2013; January, Zebraki, Chlan, & Vogel, 2015; Kalpakjian et al., 2014; Kennedy, Lude, Elfström, & Smithson, 2012; Kortte, Gilbert, Gorman, & Wegener, 2010; Kunz, Joseph, Geyh, & Peter, 2017; McMillen & Cook, 2003; Min et al., 2013; Pollard & Kennedy, 2009; Wang, Xie, & Zhao, 2018). Tedeschi and Calhoun (1996) described PTG as benefits that are perceived to have arisen through the struggle that ensues as the individual attempts to make sense of and adjust to their new reality following a traumatic life-event. To date, few SCI studies have been systematically reviewed and, when they have, they have been part of wider traumatic health conditions. However, it has been suggested that PTG may differ across health conditions (Barskova & Oesterreich, 2009; Bostock, Sheikh, & Barton, 2009). The first research paper therefore systematically reviews the literature on PTG following an SCI to narrow this gap in knowledge.

Quantitative literature has suggested that PTG reported in the early phase of recovery from trauma may represent coping mechanism rather than true growth, and therefore PTG

may be influenced by the passing of time (Helgeson, Reynolds, & Tomich, 2006). To date, qualitative research has provided valuable understanding on PTG following an SCI (Chun & Lee, 2008; Chun & Lee, 2010; Chun & Lee, 2013; de Roon-Cassini, de St. Aubin, Valvano, Hastings, & Brasel, 2013; Crawford, Gayman, & Tracey, 2014; Griffiths & Kennedy; 2012; Kennedy, Lude, Elfström, & Cox, 2013; Khanjani, Younesi, Khankeh, & Azkhosh, 2017; Wang et al., 2017; Weitzner et al., 2011). However, none have used Interpretative Phenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) to explore how individuals in the long-term phase of an SCI experience PTG or how they make sense of the PTG they have experienced over the years. The second study therefore employs IPA to explore how individuals in the long-term phase of their SCI experience and make sense of their positive growth.

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Chapter 1

Systematic Review

A Systematic Review of Posttraumatic Growth Following Spinal Cord Injury

Abstract

Purpose: A spinal cord injury (SCI) is a devastating and life changing trauma that can lead to long-term physical and psychological difficulties. However, research has shown that despite the life-changing nature of the injury, individuals can experience positive life changes known as posttraumatic growth (PTG). To date, no studies have systematically reviewed PTG only in the context of SCI. This study therefore aimed to review and synthesise the literature on PTG following SCI.

Methods: A systematic search was undertaken of six databases (Medline, PsycINFO, CINAHL Plus, Scopus, Web of science and PILOTS). Eleven relevant studies were identified as appropriate and were quality assessed.

Results: The prevalence rate of PTG ranged between 54% and 99% with participants experiencing a small to moderate degree of PTG. All of the five subdomains of PTG were also experienced to a small to moderate degree. Two longitudinal studies demonstrated that PTG scores stay relatively stable over a one and two-year period. This review uncovered many inconsistencies with regard to correlates of total PTG, especially anxiety and depression. Only one of three studies identified a significant correlation between time since injury and PTG. Trends were identified for significant correlations between PTG and positive coping strategies, with acceptance and positive reframing demonstrating medium effect sizes.

Conclusions: This review has identified that PTG is a reasonably common and stable experience following an SCI and is experienced to a small to moderate degree, comparable to other traumatic experiences identified in the literature. It has also highlighted significant relationships between positive coping and PTG and has identified important clinical implications and areas for future research.

Keywords: posttraumatic growth, spinal cord injury, tetraplegia, paraplegia, positive growth

Introduction

A spinal cord injury (SCI) is considered to be a traumatic and life changing event for the individual and their family (Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfström, 2012; Dreer, Elliot, Shewchuk, Berry, & Rivera, 2007). According to the National Institute for Health and Care Excellence (NICE), around 1000 people every year sustain an SCI in the United Kingdom (NICE, 2016). Motor vehicle accidents and falls are reported as the most common causes (NICE, 2016). Individuals with an SCI are at increased risk of secondary medical complications, such as autonomic dysreflexia (sudden uncontrollable high blood pressure), diabetes and chronic pain (Craig et al., 2013; Hulsebosch, 2005; Stillman, Barber, Burns, Williams, & Hoffman, 2017). In addition to the physical consequences, individuals may also experience significant levels of psychological distress, such as anxiety, depression and post-traumatic stress (Bonanno et al., 2012; Craig et al., 2013; Hatcher, Whitaker, & Karl, 2009; Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011; Kennedy & Rogers, 2000; Nielsen, 2003; Post, 2012). There is also growing research to suggest that from such trauma and adversity, some individuals can experience positive life changes (Tedeschi, Cann, Taku, Senol-Durak, & Calhoun, 2017).

A traumatic event can shatter an individual's beliefs about themselves, their world and their future (Tedeschi & Calhoun, 2004). Positive life changes are thought to occur through the struggle and suffering that individuals experience as they process the impact of a traumatic event and rebuild their lives (Tedeschi & Calhoun, 2004). The idea that individuals can experience positive life changes following adversity is not a new concept and has previously been described in religious teachings and by ancient philosophers (Tedeschi & Calhoun, 2004). This concept has various labels, such as post-traumatic growth (PTG;

Tedeschi & Calhoun, 1996), stress-related growth (Park, Cohen, & Murch, 1996), benefit-finding (Affleck & Tennen, 1996), perceived benefits (McMillen & Fisher, 1998) and adversarial growth (Linley & Joseph, 2004). Although there is no universally agreed label for this phenomenon, PTG has become the most accepted term (Shaw, Joseph, & Linley, 2008). The term PTG was first introduced by Tedeschi and Calhoun (1996), when developing the Posttraumatic Growth Inventory (PTGI) to measure this phenomenon (Tedeschi & Calhoun, 1996).

Posttraumatic growth, as measured by the PTGI, consists of three subcategories: i) a changed sense of oneself (e.g. noticing one's strength in the face of adversity); ii) a changed sense of relationships with others (e.g. noticing deeper connections with others); and iii) a changed philosophy of life (e.g. developing a new awareness and appreciation for life) (Calhoun & Tedeschi, 2013). Within these three domains, individuals are thought to experience growth in five areas: new possibilities, relating to others, personal strength, spiritual change and appreciation of life (Brunet, McDonough, Hadd, Crocker, & Sabiston, 2010; Kaler, Erbes, Tedeschi, Arbisi, & Polusny, 2011; Purc-Stephenson, 2014; Tedeschi & Calhoun, 1996; Taku, Cann, Calhoun, & Tedeschi, 2008). The PTGI produces an overall summed score of PTG (total PTG), which is the combined total of each of the five areas of PTG (new possibilities, relating to others, personal strength, spiritual change and appreciation of life).

A number of studies have shown PTG to occur across a range of populations, including individuals with cancer (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Schmidt, Blank, Bellizzi, & Park, 2011), HIV/AIDS (Milam, 2004; Milam, 2006), burns (Baillie, Sellwood, & Wisely, 2014), following motor vehicle accidents (Zoellner, Rabe, Karl, & Maercker, 2008; Wu, Leung, Cho, & Law, 2016), natural disasters (Holgerson, Boe,

& Holen, 2010; Xu & Liao, 2011) and interpersonal violence (Cobb, Tedeschi, Calhoun, & Cann, 2006).

The number of research articles exploring PTG within the area of SCI has grown over the last decade. Until now, only a small amount of these articles have been included in systematic reviews exploring PTG, and these reviews have included SCIs within a range of other traumatic health conditions (Barskova & Oesterreich, 2009; Helgeson, Reynolds, & Tomlich, 2006; Joseph & Linley, 2004; Livneh, 2016; Zoellner & Maercker, 2006). However, it has been suggested that PTG and its relationships with other variables may vary depending on the type of health condition (Barskova & Oesterreich, 2009; Bostock, Sheikh, & Barton, 2009). A greater understanding is therefore required of individual health-related traumas (Barskova & Oesterreich, 2009). Due to the life-long nature of an SCI and the extensive rehabilitation process the individual goes through, it is plausible to question whether their experience of PTG differs to other health-related traumas. As literature has grown in this area, it is now possible to undertake a systematic review exploring PTG in the SCI population. The aims of this study are to summarise the quantitative literature exploring PTG in individuals with an SCI in order to answer the following question: 1) To what degree is PTG experienced by individuals with a spinal cord injury?; 2) What factors correlate with total PTG following an SCI?

Methods

Search terms

Broad search terms were employed to capture the range of labels used to describe posttraumatic growth and spinal cord injury. Boolean operators were combined with search terms to maximise the search potential. The following search terms were used for

posttraumatic growth: ‘Posttraumatic Growth’, ‘Post-Traumatic Growth’, ‘Post Traumatic Growth’, ‘Psychological Growth’, ‘Perceiv* Growth’, ‘Benefit Finding’, ‘Benefit-Finding’, ‘Adversarial Growth’, ‘Flourishing’, ‘Meaning-Making’, ‘Meaning Making’, ‘Perceiv* Benefits’, ‘Stress Related Growth’, ‘Stress-Related Growth’, ‘Positive Growth’. The subsequent terms were used for spinal cord injury: ‘Paraplegia’, ‘Quadriplegia’, ‘Spinal Cord Injury’, ‘Spinal’.

Search strategy

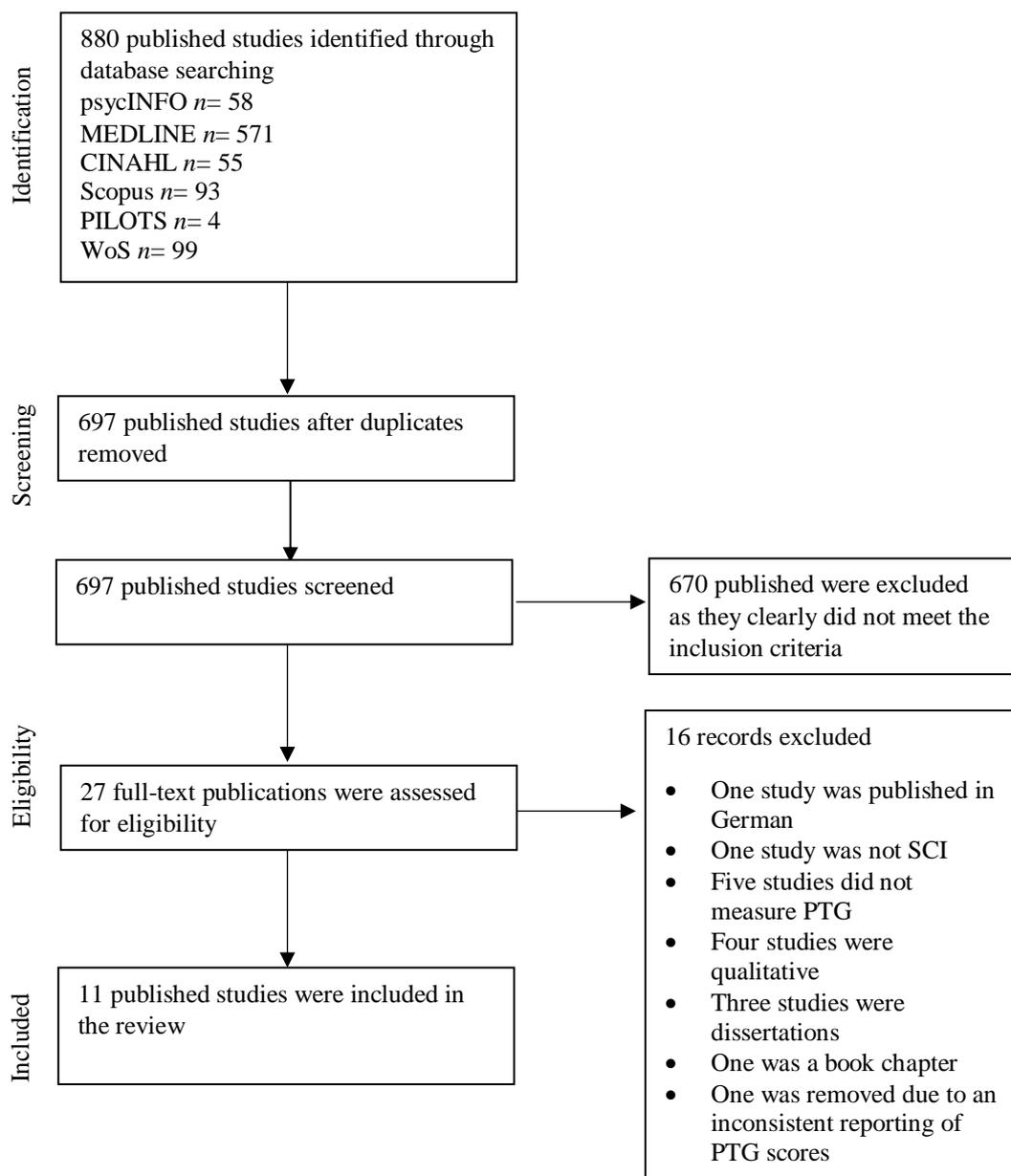
This review has been undertaken and reported in adherence to the Preferred Reporting Items for Systematic Reviews (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). Following a series of scoping searches, six electronic databases (Medline, PsycINFO, CINAHL Plus, Scopus, Web of Science and PILOTS) were searched individually for published studies that met the inclusion criteria for this review, from their inception up to April 2018. The search strategy was developed through consultation with a systematic review specialist and did not include filters that would limit search results. Hand searches of the references and citations of the included studies were also undertaken. The stages of study selection are reported using PRISMA guidelines (Figure 1) (Moher et al., 2009).

Study selection

All studies identified through searching the databases were transferred into Endnote. All duplicates were removed, and the titles and abstracts of the remaining articles were initially screened for eligibility. The full-texts of potentially relevant studies were then comprehensively screened. An independent reviewer (MH) cross-checked and verified selected studies and studies that were to be excluded. On occasion, the wider research team were consulted when there was doubt regarding the eligibility of a study. The inclusion criteria for this review stipulated that studies must have: 1) explored PTG in individuals with

SCIs; 2) used a valid measure of PTG where PTG was the sole focus of the measure; 3) been written in English; 4) reported quantitative data; 5) included participants over the age of 16 years (who can legally consent to their own treatment) and 6) been published in peer reviewed journals.

Figure 1.
PRISMA flow diagram of included studies



Data extraction

A data extraction table was used by LG to capture demographic, methodological and outcome data. Relevant data were then extracted from each paper by LG and checked for accuracy by MH. Two authors were contacted requesting further data in order to gain additional information on the outcomes of their findings. Total mean scores, and mean scores for subdomains of PTG were extracted. Correlations between total PTG and other variables were extracted, and effect sizes were reported for Pearson's correlation coefficient ($r = .10$ - small effect; $r = .30$ - medium effect; $r = .50$ - large effect; Cohen, 1988). Data were tabulated and narratively synthesised.

Results

Study Characteristics

The details of each included study and their participants are presented in Table 1. The 11 studies utilised a variety of designs (longitudinal, cross-sectional and observational), and were conducted across nine different countries. The Posttraumatic Growth Inventory (PTGI) was the main measure of choice and was employed by eight studies. Standardised and translated versions were used by three (Byra, 2016; Min et al., 2013; Wang et al., 2018) of the eight studies, a reliable and valid short form version was used by one study (Kunz et al., 2017) and another study used a single item from each subdomain of the PTGI (Kalpakjian et al., 2014). The remaining three studies used the Stress Related Growth Scale (SRGS-15) (Kennedy et al., 2012), the Benefit Finding Scale (BFS) (Kortte et al., 2010) or the Perceived Benefit Scale (PBS) (McMillen & Cook, 2003) to capture PTG. Participants were recruited within medical settings as either inpatients or outpatients. Data were reported for a total of 1,636 participants, of which 1,245 (76.10%) were male. Mean ages reported by the studies ranged between 33.2 to 53.54 years, and time since injury ranged from a matter of days to over 15 years.

Table 1.

Characteristics of included studies

Author	Design	Location	Sampling Method	<i>n</i>	Male, <i>n</i> (%)	Age, mean (SD)	Ethnicity, <i>n</i> (%)	Cause of Injury, <i>n</i> (%)	Time since Injury
Byra (2016)	Cross-sectional	Poland	Convenience sampling - Participants were recruited through rehabilitation centres, and services running social inclusion and professional activation programmes	169	129 (76.33)	49.44 (13.79)	n/r	Traumatic onset = 169 (100) (no descriptive information given)	15 years and over (mean not reported)
Davis & Novoa (2013)	Longitudinal – PTG measured on 3 occasions over the first 13 months of injury	Canada	Convenience sampling - Participants recruited through two regional rehabilitation centres (first two assessments were undertaken in the rehabilitation centre)	67	54 (80.6)	44.7 (17.2)	n/r	Traumatic injury = 50 (74.63) & Non-traumatic onset = 17 (25.37) (no descriptive information given)	n/r
January et al. (2015)	Cross-sectional	USA	Convenience sampling - Participants were recruited from an ongoing study and were currently participating or had previously participated in a paediatric SCI program	161	103 (64)	33.2 (7.3)	White ethnicity 130 (87.7)	Vehicular/pedestrian 80 (49.7) Violence 11 (6.8) Fall/flying object 12 (7.5) Sports 43 (26.7) Medical/surgical 13 (8.1) Other/unknown 2 (1.2)	Mean = 17.6 (SD = 7.6) years

Kalpakjian et al. (2014)	Cross-sectional	USA	Convenience sampling – Participants were recruited through an existing multicentre pharmaceutical study	824	632 (76.70)	43.67 (13.7)	n/r	Traumatic onset = 824 (100) (caused by violence = 15.53%; no further descriptive information given)	Mean = 10.75 (SD = 9.4) years
Kennedy et al. (2012)	Longitudinal multi-wave panel design	Britain, Switzerland, Germany & Ireland	Convenience sampling – Participants in the early stages of recovery from their SCI were recruited from British, Swiss, German and Irish spinal centres	232 (12 weeks) 44 (1 year) 90 (2 years)	184 (79.3) (12 weeks) 114 (79.2) (1 year) 71 (78.9) (2 year)	40 (n/r)	n/r	Traumatic & Non-traumatic onset (no descriptive information given)	n/r
Kortte et al. (2010)	Prospective observational design	USA	Convenience sampling – Participants recruited through in-patient, acute rehabilitation for SCI	87 (Baseline) 76 (3 months)	59 (67.8)	47.28 (18.5)	White: 48 (55.2) Hispanic: 2 (2.3) African-American: 36 (41.4) Asian/Pacific Islander: 1 (1.1)	Traumatic onset = 50 (57.5) & Non-traumatic onset = 37 (42.5) (no descriptive information given)	New SCI, admission to 3-months after admission
Kunz et al. (2017)	Cross-sectional	Switzerland	Convenience sampling – Participants recruited from a Swiss SCI Cohort Study who were admitted for their first SCI rehabilitation	141	94 (66.7)	53.54 (17.19)	n/r	Traumatic onset = 82 (58.2) Non-traumatic onset = 59 (41.8) (no descriptive information given)	Mean = 160.96 (SD = 92.41) days

McMillen & Cook (2003)	Cross-sectional	USA	Convenience sampling – Participants (accessing rehabilitation services) were recruited due to their involvement in a preceding research study	42	34 (81)	43.29 (13.86)	African Americans: 10 (23.81), Caucasians 30 (71.43) Other: 2 (4.76)	Motor vehicle crashes = 26 (62%) Gunshot = 8 (19%) Falls = 8 (19%)	18-36 months
Min et al. (2013)	Cross-sectional	Republic of Korea	Convenience sampling - Participants were recruited during their annual health check-up at the National Rehabilitation Hospital	37	29 (78.4)	41.5 (10.8)	n/r	Traumatic (e.g. traffic accident work related, sports accident, fall from height) = 34 (91.9) Non-traumatic (e.g. inflammation and tumour) = 3 (8.1 %)	Mean = 100.2 (SD = 82.2) months
Pollard & Kennedy (2009)	Longitudinal/ Cross-sectional	UK	Convenience sampling – Participants were recruited from a preceding study as part of a longitudinal design	37	30 (81.1)	40.9 (range 25–73 years)	n/r	Traumatic onset = 37 (100) (no descriptive information given)	Mean = 9.9 years (SD – not reported)
Wang et al. (2018)	Cross-sectional	China	Convenience sampling – Participants were recruited at the start of undertaking a rehabilitation programme and at a rehabilitation centre.	300	180 (60)	45.81 (12.89)	n/r	Traumatic onset = 300 (100) (no descriptive information given)	Mean = 12.06 (SD = 14.35) years

Note: n/r = not reported

Quality Assessment

The quality of each of the 11 selected studies was independently evaluated by two of the researchers (LG and MH), using an adapted version of Bostock and colleagues' quality assessment tool, which was specifically developed from numerous tools in order to assess studies exploring PTG (Bostock et al., 2009). This tool enabled a thorough assessment of the validity of each study across six domains (see Table 2), and was chosen due to its specific focus on PTG and its ability to capture validity across the various aspects of each study. Lower scores suggest threats to the validity of the study and a score of zero on any item demonstrates a considerable threat to that criteria (Bostock et al., 2009).

The overall scores of the quality assessment are presented in Table 2. There was a great degree of variation in study design. One noticeable area that varied in quality was the internal validity of the studies. This was partly due to studies assessing PTG at a timepoint that may not have allowed individuals to fully develop PTG. The current literature is inconclusive on the amount of time considered appropriate for PTG to occur (Barskova & Oesterreich, 2009; Bostock et al., 2009; Helgeson, Reynolds, & Tomich, 2006). Therefore, studies were scored low if they had assessed PTG within 12 months of the SCI, as PTG could be considered a coping mechanism during the early stages of recovery (Helgeson et al., 2006). None of the studies controlled for trauma that was unrelated to the SCI, and the majority of studies failed to fully control for injury type and severity, which together could impact the internal validity of the studies. The statistical validity of the studies was another problematic area as all but one study reported the results of their power calculations, and the majority of studies were underpowered and at increased risk of Type 1 error.

Table 2.
Results of quality assessment

	Byra (2016)	Davis & Novoa (2013)	January et al. (2015)	Kalpakjian et al. (2014)	Kennedy et al. (2012)	Kortte et al. (2010)	Kunz et al. (2017)	McMillen & Cook (2003)	Min et al. (2013)	Pollard & Kennedy (2009)	Wang et al. (2018)
<i>Hypothesis</i>											
<i>Validity</i>											
Relevance to review	3	3	3	3	2	2	3	3	3	3	3
Clear hypothesis / aims	2	2	3	3	2	3	3	3	3	3	2
<i>Internal</i>											
<i>Validity</i>											
Appropriate time since injury onset	3	1	3	3	3	1	1	3	3	3	3
Controlled for trauma unrelated to SCI	0	0	0	0	0	0	0	0	0	0	0
Controlled for SCI severity / type	3	1	2	3	3	2	1	3	2	1	1
<i>Construct</i>											
<i>validity</i>											
Appropriate definition of PTG	3	3	3	3	2	3	3	3	2	3	2
PTG assessed with a valid / appropriate measure	3	3	3	2	3	3	3	2	3	3	3

Measurement											
Sensitivity of PTG measure	3	3	3	2	2	2	3	2	3	3	3
Specificity of PTG measure	3	3	3	3	2	3	3	2	3	3	3
Reliability of PTG measure	3	3	3	3	3	3	3	2	3	3	3
Validity of PTG measure	2	2	2	2	2	2	2	1	2	2	2
Statistical conclusion validity											
Power reported	0	0	0	3	0	0	0	0	0	0	0
Appropriate statistical power	2	2	2	3	2	1	2	2	1	2	2
Type 1 error	2	2	2	3	2	1	2	2	3	2	2
External validity											
Conclusions consistent with result	3	3	3	3	3	3	3	3	3	3	3
Limitations acknowledged	2	2	2	2	2	2	1	2	2	2	2
Findings generalisable	2	2	1	2	2	1	1	1	1	2	2
Totals (maximum score = 51)	39	35	38	43	35	32	34	34	37	38	36

Note: 0 = Considerable risk to validity (criteria not considered); 1 = Moderate risk to validity (considered to a small degree, but criteria not met);

2 = Partial risk to validity (considered to a reasonable extent, and criteria partially met); 3 = No risk to validity (fully considered and criteria has been met).

Prevalence of PTG

The prevalence estimates of PTG were reported by five studies (January et al., 2015; Kalpakjian et al., 2014; Kunz et al., 2017; McMillen & Cook 2003; Wang et al., 2018). The studies stated that between 54% (Kalpakjian et al., 2014) and 99% (Wang et al., 2018) of participants experienced PTG. These prevalence scores should be interpreted with caution, as they were obtained using a variety of PTG measures, and only three studies stated their cut off for determining whether PTG was experienced. Two of the studies interpreted a score of three (moderate amount of growth) or above on any item of the PTGI (January et al., 2015; Wang et al., 2018) as indicative of PTG, and McMillen and Cook (2003) required a score of over three on any item of the PBS. Furthermore, the reported prevalence scores were obtained across a range of factors, such as nationality, age of SCI onset (childhood and adulthood) and time since SCI onset. However, they do provide evidence that PTG is potentially a common experience following an SCI.

Total PTG

Total PTG scores were reported by 10 of the 11 studies reviewed (Table 3). The range of measures used prevented meaningful comparisons of total PTG across all of the studies, however, five studies (Byra, 2016; Davis & Novoa, 2013; January et al., 2015; Min et al., 2013; Pollard & Kennedy, 2009) used the 21-item version of the PTGI (which produces a score between 0-105). Taku et al. (2007) suggests that cut off scores can be calculated from the PTGI and its six-point Likert scale. For descriptive purposes, cut off scores were calculated (see Table 4). Total mean scores ranged between 45.73 (Pollard & Kennedy, 2009) and 66.82 (Davis & Novoa, 2013), suggesting that following an SCI, individuals experienced a small to moderate amount of PTG.

Table 3.
Outcome of included studies

Author	Measure of PTG	PTG Total and Subdomain Scores Mean (SD)	Variable	PTG variable	Bivariate association	Effect size
Byra (2016)	PTGI (Polish version)	Total PTG 66.57 (19.69)	Age of participants	Total PTG	$r = -0.12$ (n/s)	
		Changes in self-perception 28.26 (10.13)	Age at trauma	Total PTG	Non-significant (no data reported)	
		Changes in relations to others 23.23 (7.22)	Hope	Total PTG	$r = 0.44^{**}$	Medium
		Appreciation of life 11.20 (3.18)	Focus on the problem (coping)	Total PTG	$r = 0.47^{**}$	Medium
		Spiritual changes 6.66 (2.90)	Focus on emotions (coping)	Total PTG	$r = 0.01$ (n/s)	
			Seeking emotional support (coping)	Total PTG	$r = 0.16^*$	Small
			Acceptance	Total PTG	$r = 0.32^{**}$	Medium
			Religion	Total PTG	$r = 0.61^{**}$	Large
			Humour	Total PTG	$r = 0.17^*$	Small
	Denial	Total PTG	$r = 0.06$ (n/s)			
	Alcohol/drug use ideation	Total PTG	$r = -0.18^{**}$	Small		

Davis & Novoa (2013)	PTGI	Time 1 (2 months after injury)	Depression	Total PTG at Time 2 only	$r = 0.31^*$	Medium
		Total PTG 60.1679 (23.09)				
		Relating to others 22.90 (8.43)				
		New opportunities 11.12 (6.25)	Subjective wellbeing	Total PTG	Non-significant (no data reported)	
		Personal strength 11.36 (5.88)				
		Spiritual change 4.33 (3.56)				
		Appreciation of life 10.42 (4.28)				
		Time 2 (5 months after injury)				
		Total PTG 66.82 (24.37)				
		Relating to others 24.61 (7.89)				
		New opportunities 14.37 (6.56)				
		Personal strength 12.82 (5.62)				
		Spiritual change 4.38 (3.58)				
		Appreciation of life 10.63 (4.18)				
		Time 3 (13 months after injury)				
		Total PTG 60.62 (27.79)				
		Relating to others 22.30 (9.35)				
		New opportunities 12.72 (7.48)				
		Personal strength 11.87 (6.02)				
		Spiritual change 3.98 (3.78)				
		Appreciation of life 9.74 (4.55)				
January et al. (2015)	PTGI	Total PTG 61.68 22.23	Behavioural coping	Total PTG	$r = 0.29^{***}$	Small
		New possibilities 15.35 (5.92)				
		Relating to others 20.13 (8.46)	Cognitive coping	Total PTG	$r = 0.39^{***}$	Medium
		Personal strength 11.86 (4.91)				
		Appreciation of life 9.84 (3.93)	Increased life satisfaction	Total PTG	$r = 0.18^*$	Small
		Spiritual change 4.48 (3.59)				
			Happiness	Total PTG	$r = 0.27^{**}$	Small
			Current age	Total PTG	$r = -0.18^*$	Small
	Age at injury	Total PTG	$r = -0.07$ (n/s)			
	Injury duration	Total PTG	$r = -0.15$ (n/s)			

			Depression	Total PTG	$r = 0.04$ (n/s)	
			Anxiety	Total PTG	$r = 0.10$ (n/s)	
			Avoidance coping	Total PTG	$r = 0.03$ (n/s)	
Kalpakjian et al. (2014)	PTGI (A single item from each domain was chosen)	Total PTG 12.40 (6.8) Relating to others 2.59 (1.90) (r/g = 61%) New opportunities 1.72 (1.85) (r/g = 38%) Personal strength 3.00 (1.96) (r/g = 67%) Spiritual change 2.11 (2.10) (r/g = 47%) Appreciation of life 2.99 (1.83) (r/g = 68%)				
Kennedy et al. (2012)	SRGS-15	Total SRG Time 1 (12weeks) 12.66 (6.84) Time 2 (1year) 13.27 (7.40) Time 3 (2 years) 13.38 (7.80)	Perceived manageability (at 12 weeks)	Total SRG (at 2 years)	$r = 0.30^{***}$	Medium
			Positive reinterpretation (at 12 weeks)	Total SRG (at 2 years)	$r = 0.37^{***}$	Medium
			Acceptance (at 12 weeks)	Total SRG (at 2 years)	$r = 0.39^{***}$	Medium
			Fighting spirit (at 12 weeks)	Total SRG (at 2 years)	$r = 0.29^{**}$	Small
			Sense of coherence (at 12 weeks)	Total SRG (at 2 years)	$r = 0.10$ (n/s)	

			Appraisal of life events:			
			Threat (at 12 weeks)	Total SRG (at 2 years)	$r = -0.26$ (n/s)	
			Challenge (at 12 weeks)	Total SRG (at 2 years)	$r = 0.22$ (n/s)	
			Loss (at 12 weeks)	Total SRG (at 2 years)	$r = -0.08$ (n/s)	
			Behavioural disengagement (at 12 weeks)	Total SRG (at 2 years)	$r = 0.07$ (n/s)	
			Planning (at 12 weeks)	Total SRG (at 2 years)	$r = 0.23$ (n/s)	
			Social reliance (at 12 weeks)	Total SRG (at 2 years)	$r = -0.07$ (n/s)	
Kortte et al. (2010)	BFS	Total BFS 58.51 (15.68)	Life satisfaction	BF (baseline – prior to 3 months)	$r = .32^{**}$	Medium
			Life satisfaction	BF (3-month follow-up)	$r = .23$ (n/s)	Small
Kunz et al. (2017)	PTGI-Short form (10 items)	Total PTG 20.89 (11.72) Relating to others 4.90 (2.93) New possibilities 4.01 (3.14) Personal strength 4.65 (3.23) Spiritual change 2.02 (2.82) Appreciation of life 5.30 (3.02)	Global distress	Total PTG	$r_s = 0.24^{**}$	Small
			Posttraumatic depreciation	Total PTG	$r_s = .47^{***}$	Medium
			Anxiety	Total PTG	$r_s = 0.28^{***}$	Small
			Depression	Total PTG	$r_s = 0.10$ (n/s)	

			Life satisfaction	Total PTG	$r_s = -0.03$ (n/s)	
			Physical functioning	Total PTG	$r_s = -0.13$ (n/s)	
			Pain intensity	Total PTG	$r_s = 0.15$ (n/s)	
McMillen & Cook (2003)	PBS	Total PBS 14.35 (n/s) Increased self-efficacy 2.25 (0.83) (r/g = 26%) Increased community closeness 1.23 (1.04) (r/g = 5%) Increased spirituality 2.11 (1.43) (r/g = 43%) Increased compassion 2.76 (0.96) (r/g = 50%) Increased faith in people 2.38 (0.98) (38%) Increased family closeness 2.92 (1.09) (r/g = 62%) Material gain 0.70 (0.94) (r/g = 5%)	No correlations were undertaken with total PBS scores			
Min et al. (2013)	PTGI (Korean version)	Total PTG 52.3 (27.9)	Resilience	Total PTG	$r_s = 0.59^{***}$	Large
			Depression	Total PTG	$r_s = -0.48^{**}$	Medium
			Age	Total PTG	Non-significant (no data reported)	
			Time since injury	Total PTG	Non-significant (no data reported)	
Pollard & Kennedy (2009)	PTGI	Total PTG 45.72 (21.50) Relating to others 14.97 (8.78) New possibilities 11.00 (5.63) Personal strength 9.78 (5.31) Spiritual change 2.54 (2.77) Appreciation of life 7.00 (4.14)				

Wang et al. (2018)	PTGI (20 items; Chinese version)	Total PTG 59.05 (18.07)	Post-traumatic Stress Disorder Symptoms	Total PTG	$r = -0.12^*$	Small
			Resilience	Total PTG	$r = 0.57^{**}$	Large
			Anxiety	Total PTG	$r = -0.27^{**}$	Small
			Depression	Total PTG	$r = -0.40^{**}$	Medium
			Duration since injury	Total PTG	$r = 0.23^{**}$	Small
			Extent of environmental barriers	Total PTG	$r = -0.16^*$	Small
			Age	Total PTG	$r = 0.10$ (n/s)	
			Age at injury	Total PTG	$r = -0.02$ (n/s)	
Categorical data (religion, gender, marital status, education, level and completeness of injury and employment) were reported to have been analysed through Pearson correlation and will therefore not be reported.						

Note: (n/s) = non-significant; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; r/g = percentage of people reporting growth that was moderate or greater; PTGI (Posttraumatic Growth Inventory); SRGS-15 (Stress-Related Growth Scale); BFS (Benefit Finding Scale); PBS (Perceived Benefit Scale); The Polish version of the PTGI has incorporated new opportunities and personal strength into one factor called changes in self-perception.

Table 4.
Calculated cut-off scores for the PTGI

Domain	Cut-off scores
Total PTG	1-20 small amount of growth; 21-28 moderate growth; ≥ 28 large amount of growth
Relating to others	1-20 small amount of growth; 21-28 moderate growth; ≥ 28 large amount of growth
New possibilities	1-14 small amount of growth; 15-19 moderate growth; ≥ 20 large amount of growth
Personal strength	1-11 small amount of growth; 12-15 moderate growth; ≥ 16 large amount of growth
Spiritual change	1-5 small amount of growth; 6-7 moderate growth; ≥ 8 large amount of growth
Appreciation of life	1-8 small amount of growth; 8-11 moderate growth; ≥ 12 large amount of growth

Subdomains of PTG

Although PTG is a unique experience to each individual, Tedeschi and Calhoun (1996) suggest that, generally, PTG occurs across five factors: new possibilities, relating to others, personal strength, spiritual change and appreciation of life. As a variety of PTG measures were utilised by the studies in this review, only studies that used the PTGI (21-item) were used to demonstrate the range of scores for each of the five factors of PTG. The Polish version of the PTGI incorporated new opportunities and personal strength into one factor called changes in self-perception, which prevented the comparison of this subdomain. Mean Scores for relating to others ranged from 14.97 (Pollard & Kennedy, 2009) to 24.61 (Davis & Novoa, 2013); new possibilities ranged from 11.00 (Pollard & Kennedy, 2009) to 15.35 (January et al., 2015); personal strength ranged from 9.78 (Pollard & Kennedy, 2009)

to 12.82 (Davis & Novoa, 2013); spiritual change ranged from 2.54 (Pollard & Kennedy, 2009) to 6.66 (Byra, 2016); and appreciation of life ranged from 7.00 (Pollard & Kennedy, 2009) to 11.20 (Byra, 2016). For descriptive purposes, cut off scores were calculated from the PTGI Likert scale (see Table 4). Studies demonstrated that, overall, individuals experienced a small to moderate degree of PTG across all of the PTGI subdomains.

Kalpakjian et al. (2014) used a single item from each subdomain of the PTGI and found that new opportunities was the least reported item with only 38 percent of participants reporting moderate to very high levels of growth. A change in priorities (appreciation of life) was the highest reported item of growth with 68 percent of participants reporting moderate to very high levels of growth in this area. McMillen and Cook (2003) employed the PBS and identified that increased family closeness was the most reported area of growth and was reported by 62 percent of participants. Increased community closeness was found to be one of the lowest reported areas of growth with only five percent of participants experiencing growth in this area.

Correlates of Total PTG

Demographic factors. Four studies explored correlations between PTG and age of SCI onset (Byra, 2016; January et al., 2015; Min et al., 2013; Wang et al., 2018). None of the studies found a significant correlation between age of onset and total PTG (Byra, 2016; January et al., 2015; Min et al., 2013; Wang et al., 2018).

Five studies explored participant age and PTG. Three studies found no significant correlation between the two variables (Byra 2016; Min et al., 2013; Wang et al., 2018). January et al. (2015) found that participant age and total PTG significantly and negatively correlated but the effect size was small. This finding may differ to the other three studies as the participants had all experienced SCI onset during childhood and were adults at the time of

the study. Overall, there appears to be no support for a correlated relationship between total PTG and age at SCI onset, and very little support for a relationship between total PTG and participant age.

Injury-related factors. There were mixed findings regarding PTG and time since injury. Wang et al. (2018) found a significant, positive but small relationship between time since injury and PTG. Contrastingly, two studies found that time since injury was not significantly correlated with PTG (January et al., 2015; Min et al., 2013). It therefore appears that there is little evidence for a relationship between time since injury and PTG.

One study explored the relationship between physical functioning and PTG, and pain intensity and PTG (Kunz et al., 2017). No significant relationship was found between either variable and total PTG. Kennedy et al. (2012) did, however, find a significant positive relationship between perceived manageability (at 12 weeks) and PTG using the SRG-15 (at two years post injury), and this relationship had a medium effect size. Wang et al. (2018) also identified a significant and negative relationship with a medium effect size between perceived environmental barriers and total PTG (Wang et al., 2018). These findings suggest that there does not appear to be a correlated trend between physical pain or functioning and total PTG. However, they tentatively suggest a potential relationship between how individuals perceive they can manage following their SCI and overall PTG. There is a suggestion of a negative relationship between environmental barriers and total PTG.

PTG and psychological factors. Three studies explored the relationship between life satisfaction and PTG (January et al., 2015; Kortte et al., 2010; Kunz et al., 2017). January et al. (2015) found life satisfaction to be significantly and positively correlated with total PTG, but the effect size was small. Kortte et al. (2010) used the BFS and found a significant and positive relationship between PTG and life satisfaction during participants' acute inpatient

stay. Again, the effect size was small. Interestingly, the correlation was no longer significant at the three-month follow-up (Kortte et al., 2010). Kunz et al. (2017) also found no significant relationship between life satisfaction and PTG. General happiness was also found by one study to positively and significantly correlate with total PTG, and the effect size was small (January et al., 2015). Another study found no correlation between total PTG and subjective wellbeing (Davis & Novoa, 2013). These mixed findings may suggest a possible trend between the relationship of life satisfaction, happiness and total PTG, but the magnitude of their relationship appears to be small.

Two studies explored the relationship between PTG and resilience (Min et al., 2013; Wang et al., 2018) and both reported that they correlated significantly and positively and that the effect size for both studies was large. This demonstrates a trend in the relationship between resilience and total PTG.

Only one study explored the relationship between hope and total PTG and found that the two variables correlated significantly and positively, and the correlation produced a medium effect size (Byra, 2016).

PTG and psychological distress. Five studies reported correlations between depression and PTG (Davis & Novoa, 2013; January et al., 2015; Kunz et al., 2017; Min et al., 2013; Wang et al., 2018). Two studies found that depression significantly and negatively correlated with total PTG and the effect size was medium (Min et al., 2013; Wang et al., 2018). Another study found that depression significant and positively correlated with PTG at a five-month follow-up and the effect size was small (Davis & Novoa, 2013). However, the correlation was not significant at baseline or at the 13-month follow-up (Davis & Novoa, 2013). Two other studies found that depression was not significantly related to PTG (January et al., 2015; Kunz et al., 2017). These mixed findings paint a confusing picture of the

relationship between depression and PTG hindering any meaningful conclusions from being drawn. All mean depression scores reported by the studies suggest mild levels of depression (January et al., 2015; Kunz et al., 2017; Min et al., 2013; Wang et al., 2018). One study did not report their mean scores (Davis & Novoa, 2013). However, both the studies that found a negative relationship between depression and PTG (Min et al., 2013; Wang et al., 2018) reported slightly higher mean scores for depression, which may explain the variation in the findings.

Three studies examined the relationship between anxiety and PTG (January et al., 2015; Kunz et al., 2017; Wang et al., 2018). Only two studies reported a significant correlation (Kunz et al., 2017; Wang et al., 2018). Kunz et al. (2017) found a positive but weak correlation between anxiety and total PTG. Wang et al. (2018) found that anxiety negatively correlated with PTG and the effect size was small. In addition, Kunz et al. (2017) investigated for correlations between PTG and global distress and found that global distress significantly and positively correlated with total PTG, but the relationship was weak. Similar to depression, Wang et al. (2018) appeared to report slightly higher levels of anxiety than the other studies (January et al., 2015; Kunz et al., 2017), which may again explain the inconsistency in the findings.

One study explored the relationship between PTSD and total PTG and found a significant, negative correlation, and the effect size was small.

PTG and coping. Four studies (Byra, 2016; January et al., 2015; Kennedy et al., 2012; Pollard & Kennedy, 2009) explored correlations between PTG and coping in individuals with an SCI. Byra (2016) found that use of humour and seeking emotional support were both significantly and positively correlated with total PTG and their effect sizes were small. Both problem focused coping and acceptance were also shown to be significantly

and positively correlated with total PTG, and demonstrated medium effect sizes (Byra, 2016). Kennedy et al. (2012) also found significant and positive correlations between acceptance (12 weeks post injury) and PTG (two years post injury), and positive reframing (12 weeks post injury) and PTG (two years post injury) using the SRG-15, which yielded medium and small effect sizes respectively. These findings were also supported by January et al. (2015) who reported a significant and positive correlation between PTG and cognitive coping strategies (acceptance and positive reframing), which demonstrated a medium effect size. These findings demonstrate a consistent theme for the correlation between acceptance and PTG and highlight a potential theme for the correlation between positive reframing and PTG.

January et al. (2015) also identified a significant and positive correlation between PTG and behavioural coping (active coping and use of tangible support), which produced a small effect size. Another study found a positive correlation between fighting spirit (12 weeks post injury) and PTG (two years post injury), demonstrating a small effect size (Kennedy et al., 2012). Planning (12 weeks post injury) and social reliance (12 weeks post injury) were not found to be significantly correlated with PTG (two years post injury) (Kennedy et al., 2012).

Collectively, these findings suggest a trend between positive coping styles and PTG. Specifically, acceptance appears to have gathered the most interest and support as a correlate of PTG and consistently demonstrated medium effect sizes. A possible trend was also identified for positive reframing as a correlate of PTG.

Studies found little to no support for negative coping styles and total PTG. Byra (2016) found that alcohol and drug use negatively correlated with total PTG, but the effect size was small. Contrastingly, January et al. (2015) found no significant relationship between PTG and avoidance coping (substance use and behavioural disengagement). Behavioural

disengagement (12 weeks post injury) was also found to be unrelated to PTG (two years post injury) by Kennedy et al. (2012). Byra (2016) explored for a correlation between denial and total PTG and found no relationship. Overall, these findings suggest little to no support for negative coping styles as correlates of total PTG.

Discussion

The main aim of this review was to systematically collate the quantitative literature exploring PTG in individuals with an SCI. The results to the following questions were synthesised: 1) To what degree is PTG experienced by individuals with a spinal cord injury?; 2) What factors correlate with total PTG following an SCI? As the literature exploring PTG in SCIs has grown over the last ten years, this review was able to include 11 published journal articles, which were located across six databases. Although all of the studies examined PTG in SCIs, their aims, designs and outcome measures varied greatly, and there was a significant degree of diversity across demographic factors and injury characteristics. This therefore hindered the task of comparing studies, precluded meta-analysis, and should be taken into consideration when interpreting the results of this review.

To What Degree is PTG Experienced by Individuals with a Spinal Cord Injury?

The overall prevalence rates of PTG for individuals with an SCI broadly ranged between 54% (Kalpakjian et al., 2014) and 99% (Wang et al., 2018), which is similar to the rates of PTG reported for other health-related traumas where the PTGI was the measure of choice, such as HIV (59%; Milam, 2004), coronary artery disease (71.2%; Bluvstein, Moravchick, Sheps, Schreiber, & Bloch, 2013) and breast cancer (93%; Schroevers & Teo, 2008).

Five of the studies (Byra, 2016; Davis & Novoa, 2013; January et al., 2015; Min et al., 2013; Pollard & Kennedy, 2009) in this review used the PTGI and demonstrated that

participants' total PTG scores ranged from 45.73 (Pollard & Kennedy, 2009) to 66.82 (Davis & Novoa, 2013). Overall, the range of scores in this review were similar to the degree of PTG reported for many other traumatic physical health conditions, such as stroke (mean= 50.33; Gangstad, Norman & Barton, 2009), advanced breast cancer (mean= 43.76; Mystakidou et al., 2008), amputation (mean= 59.62; Stutts and Stanaland, 2016), HIV (mean= 61.14; Nightingale, Sher, & Hansen, 2010), and cancer at various stages (mean= 73.12; Schroevers & Teo, 2008). Broad ranges of PTG have also been reported in two other reviews exploring PTG following traumatic injury, such as acquired brain injury (Grace, Kinsella, Muldoon, & Fortune, 2015) and burns (Martin, Byrnes, McGarry, Rea, & Wood, 2017). Linley and Joseph (2004) suggest that variations in PTG may not be due to the nature of the event itself, but due to individual differences, such as how individuals experience the event (for example, their degree of control and sense of threat). Linley and Joseph (2004) and McMillen (2004) also question the degree to which PTG is culturally influenced based on how society believes it should respond in the aftermath of trauma, which may also lead to fluctuations in reports of PTG.

Interestingly, the two studies exploring PTG using a longitudinal design over a 12-month and two-year period demonstrated that PTG scores remained relatively stable over time (Davis & Novoa, 2013; Kennedy et al., 2012).

When total PTG scores were broken down across the five subdomains of PTG, four studies (Davis & Novoa, 2013; January et al., 2015; Min et al., 2013; Pollard & Kennedy, 2009) demonstrated that a small to moderate amount of growth was experienced for all the subdomains of PTG. One study reported that a change in priorities (appreciation of life) was the most reported item of growth (Kalpakjian et al., 2014). Using the PBS, McMillen and Cook (2003) identified that increased community closeness was the lowest reported area of

growth, which may add support to Wang and colleagues' finding that environmental barriers negatively correlated with PTG (Wang et al., 2018).

What Factors Correlate with Total PTG Following an SCI?

As discussed, there were many conflicting findings between the studies, and few trends emerged in the reported correlations. There are many potential reasons for this, such as the varying degree of quality between the studies and differing timeframes in which PTG was captured. It may also be due to the variety of measures used and the diversity of participants.

One interesting finding was that no correlation between age of SCI onset and total PTG was identified, and only one study demonstrated a significant, yet small, correlation between participant age and PTG (January et al., 2015). This is surprising as a meta-analysis and two systematic reviews exploring PTG across a range of contexts identified that younger aged individuals were likely to experience greater growth (Barskova & Oesterreich, 2009; Helgeson et al., 2006; Linley & Joseph, 2004). As the studies exploring age as a correlate of PTG were cross sectional studies, this suggests that the area would benefit from further exploration using longitudinal designs.

It is commonly assumed that PTG requires a significant passing of time in order for individuals to process the trauma and identify positive growth (Barskova & Oesterreich, 2009). It was therefore interesting to find that only one out of the three studies found a significant correlation between time since injury and total PTG. Other systematic reviews exploring PTG also have mixed findings for this belief (Barskova & Oesterreich, 2009; Linley & Joseph, 2004). Two meta-analyses identified that time since injury may play a role in moderating the relationship between PTG and psychological adjustment, suggesting that as more time passes, the relationship between PTG and psychological wellbeing becomes stronger (Helgeson, Reynolds, & Tomich, 2006; Sawyer, Ayers & Field, 2010). The findings

in this review highlight this as another area that requires further investigation, especially given the clinical importance of understanding the trajectories of PTG.

Tedeschi and Calhoun (2004) suggest that PTG occurs through the process of rebuilding schemas that incorporate the person's new and potentially unrecognisable reality. Taking this into consideration, it was noteworthy that the one study that explored for correlations between physical functioning and pain intensity did not find a correlation between these two variables and total PTG (Kennedy et al., 2012). However, they did report a significant and positive relationship between perceived manageability and total PTG (using the SRGS-15) (Kennedy et al., 2012). This may suggest that it is how the individual perceives that they can manage following an SCI, rather than their actual physical functioning level, that correlates with total PTG. It has been suggested that perceived manageability influences how people cope and appraise distressing life events and the degree to which they experience psychological difficulties (Kennedy, Scott-Wilson, & Sandhu, 2009). Associations between physical functioning, perceived manageability and PTG would benefit from further exploration and aid clinical understanding.

Both studies exploring resilience and total PTG (Min et al., 2013; Wang et al., 2018) found a significant and positive correlation between the two variables. This was an unexpected finding as Tedeschi and Calhoun (2006) suggest that resilience and PTG are two different constructs, as resilience provides a protective factor that enables individuals to go on living their life following adversity, where PTG is a transformative process resulting from the disruption of cognitive schemas following adversity. Therefore, highly resilient individuals should experience less opportunity for PTG following traumatic life events (Levine, Laufer, Stein, Hamama-Raz, & Solomon, 2009; Westphal & Bonanno, 2007). The reason for this interesting finding may be due to variations in the literature on how resilience is defined and measured (Min et al., 2013).

There were contrasting findings for the relationship between depression and PTG. This may be due to differences in populations and research design. The general theme reported by systematic reviews is that most studies do not find a relationship between depression and PTG, but when they do, it is generally inversely related (Helgeson et al., 2006; Linley & Joseph, 2004; Martz & Livneh, 2016; Pascoe & Edvardsson, 2013).

Anxiety was found by two studies to be significantly correlated with PTG. One study identified a positive relationship (Kunz et al., 2017) and another found a negative relationship (Wang et al., 2018). It is difficult to conclude the reasons for the variation in the two studies, but it may be due to the variability of time since injury between the two studies. Kunz et al. (2017) recruited participants within their first year of rehabilitation, where Wang et al. (2018) explored PTG in participants up to 10 years or more post-injury. Extraneous variables, such as time since injury, may therefore have influenced these findings, as time since injury has been shown to moderate the relationship between anxiety and PTG (Helgeson et al., 2006). Only one study explored a correlation between PTSD and PTG and the relationship was shown to be significant and negative, which may reflect a potential curvilinear relationship between PTSD and PTG (Shakespeare-Finch & Lurie-Beck, 2014). More studies in this area would be needed to draw any firm conclusions about trends in the relationship between the two variables.

A clear trend was shown across five of the studies for the relationship between PTG and positive coping strategies. Acceptance was found by two studies to be significantly correlated with PTG, with both studies demonstrating a medium effect size (Byra, 2016; Kennedy et al., 2012). Another study identified that cognitive coping, which included acceptance and positive reframing, also significantly correlated with PTG and produced a medium effect size (January et al., 2015). Positive reframing was also found by Kennedy et al. (2012) to be significantly correlated with PTG, and problem focused coping was identified

by Byra (2016) to be significantly correlated with PTG. These findings suggest a key theme between positive coping and PTG. In addition to the current review, a systematic review exploring PTG in serious medical conditions found acceptance coping from a positive perspective, rather than resignation, to be related to greater PTG (Barskova & Osterreich, 2009). Acceptance has also been shown by other studies to be related to greater PTG, further emphasising its significance as a coping response from a positive perspective (Park et al., 1996; Armeli, Gunthert, & Cohen, 2001).

A potential trend was also highlighted between life satisfaction and PTG. As one study identified a positive correlation (January et al., 2015) and another only found a correlation at baseline (acute phase), and not at the three-month follow-up. A third study found no relationship (Kunz et al., 2017). January et al. (2015) focused on individuals who experienced their injuries during childhood, and therefore had a longer duration since injury than participants in the two other studies (Kortte et al., 2010; Kunz et al., 2017). Time since injury may have been a factor for the variation in findings, as a longitudinal study exploring PTG 13-years after a traumatic brain injury found that life satisfaction at 13-years was associated with PTG (Powell, Gilson, & Collin, 2012). Further studies employing a longitudinal design are needed to improve understanding of the relationship between life satisfaction and PTG following an SCI and the role of potential mediators and moderators.

Finally, hope was identified by one study as a significant correlate of total PTG and demonstrated a medium effect size (Byra, 2016). Higher levels of hope have been shown to be associated with greater growth and meaning making in cancer (Ho et al., 2011; Kolokotroni, Anagnostopoulos, & Tsikkinis, 2014; Casellas-Grau, Ochoa, & Ruini, 2017). This demonstrates another important area for further study as it may have significant clinical implications.

Limitations of Reported Studies

Many of the studies varied in their methodology with the majority using cross-sectional designs and varying measures, therefore inhibiting the understanding of PTG over time and leading to many inconsistencies. To reduce the overwhelm of inconsistencies, this review focused only on correlations of total PTG, and therefore did not report correlations with PTG subdomains, such as spirituality and appreciation of life. This enabled a more focused comparison between studies, but provides a limitation in terms of unreported relationships between PTG subdomains and variables. Only studies employing a valid measure that exclusively captured PTG were incorporated as this enabled meaningful comparisons between studies and the wider literature. Future studies should aim for consistency in how they measure PTG, so that more meaningful comparisons can be made. None of the studies incorporated control groups and few gave details of participants lost to attrition, making it very difficult to generalise the findings. Future research should utilise consistent measures of PTG and address these issues with increased methodological rigour so that the understanding of PTG can be advanced.

Clinical Implications

The findings of this systematic review have many clinical ramifications. Overall, this review identified that it is somewhat common for individuals to experience a small to moderate degree of PTG following an SCI, and that PTG appears to remain relatively stable over a two-year period. Clinically, this is important as it offers hope to individuals living with an SCI and their families. However, PTG should be discussed tentatively with individuals, as PTG is a unique experience to each individual, and not everyone will experience it. Clinicians should remain aware that positive coping responses, such as acceptance and positive reframing were shown to significantly correlate with PTG, and may therefore play an

important part in the process of PTG following an SCI. An awareness of this could support clinicians to normalise experiences of positive coping in the aftermath of a SCI.

Conclusion

This review has highlighted that PTG is possible following an SCI, and is a relatively common experience. It has also shown the importance of individual differences, such as coping responses and psychological factors, that are correlated to PTG. The findings of this review have important implications clinically, as health care providers need to be aware that PTG is possible so that hope can be instilled in individuals, while also remaining aware of potential barriers to PTG. This review has summarised the current literature on PTG following an SCI and reported correlations between demographic factors, psychological distress, coping responses and total PTG. Areas requiring further research have been described and emphasis has been placed on the need for more longitudinal designed studies to capture the trajectory of PTG and better explain its relationships over the long-term phase of an SCI. Qualitative studies exploring how individuals experience PTG over the long-term phase may also generate further understanding of this phenomenon, so that important clinical questions can be answered about how individuals experience PTG over time following an SCI.

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Chapter 2

Research Paper

Experiences of Posttraumatic Growth in the Long-Term Phase of Spinal

Cord Injury: An Interpretative Phenomenological Analysis

Empirical paper to be submitted to the British Journal of Health

Psychology

Abstract

Purpose: Research has demonstrated that a spinal cord injury (SCI) can have devastating physical and psychological consequences. Accumulating research has also identified that individuals can experience posttraumatic growth (PTG) following an SCI. Studies suggest that PTG is a phenomenon that may unfold and vary over time and to date no qualitative studies have focused solely on PTG in individuals during the long-term phase of an SCI.

Methods: Six participants engaged in semi-structured interviews to capture their experience of PTG in the long-term phase of their SCI. Their interviews were analysed using Interpretative Phenomenological Analysis.

Results: Three master themes encapsulated how participants experienced PTG; ‘The earthshattering consequences of injury’, ‘Determination to reclaim one’s life’ and ‘Roses (PTG) and thorns (Injury and struggle)’.

Conclusion: Participants’ narratives revealed the shattering impact the injury had on their lives as they were immediately plunged into a cruel new world. They demonstrated tenacity and purposefully chose to see the positive as they fought to reclaim their lives. Through their positivity and their determination their lives flourished in new ways. Their struggle with the SCI continued as they aged, but alongside this, positive growth continued.

Keywords: long-term phase; spinal cord injury, posttraumatic growth, interpretative phenomenological analysis, positive growth

Introduction

According to the National Institute for Health and Care Excellence (NICE) (2016), there are approximately 40,000 individuals living with a Spinal Cord Injury (SCI) in the United Kingdom. SCIs are predominantly caused by a fracture in the spinal column, which can result in paraplegia (loss of physical sensation and ability in the lower extremities) or tetraplegia (loss of functionality and sensation in all four limbs and torso). SCIs are associated with further physical and neurological complications (El Masri & Kumar, 2011) and can have a devastating impact on an individual's physical and psychological wellbeing (Craig, Tran, & Middleton, 2009). However, despite the traumatising impact of an SCI, research has accumulated showing that individuals with SCIs can experience Posttraumatic Growth (Byra, 2016; Davis & Novoa, 2013; January, Zebraki, Chlan, & Vogel, 2015; Kalpakjian et al., 2014; Kennedy, Lude, Elfström, & Smithson, 2012; Kortte, Gilbert, Gorman, & Wegener, 2010; Kunz, Joseph, Geyh, & Peter, 2017; McMillen & Cook, 2003; Min et al., 2013; Pollard & Kennedy, 2009; Wang, Xie, & Zhao, 2018).

Posttraumatic Growth (PTG) describes the positive psychological transformation that is experienced by individuals as they struggle in the aftermath of a traumatic life-event (Tedeschi & Calhoun, 2004). The term PTG was coined by Tedeschi and Calhoun (1996), and although there are a variety of alternative titles for this phenomenon, such as stress-related growth (Park, Cohen, & Murch, 1996) and benefit-finding (Affleck & Tennen, 1996), PTG has become the most frequently used (Shaw, Joseph & Linley, 2008).

Tedeschi and Calhoun (1996) suggest that although the experience of PTG is personal to the individual, positive growth falls mainly under five domains: new possibilities, relating to others, personal strength, spiritual change and appreciation of life (Tedeschi & Calhoun, 1996). These five domains are further encapsulated by three overarching categories: a changed sense of oneself; a changed sense of relationships with others; and a changed

philosophy of life (Calhoun & Tedeschi, 2013). Calhoun and Tedeschi state that PTG is uniquely different to other positive psychological traits related to challenging life-events in the literature, such as resilience and hardiness, as PTG distinctively describes the transformation individuals experience as they positively grow beyond who they were pre-trauma (Tedeschi & Calhoun, 2004).

The quantitative literature has demonstrated that between 54% (Kalpakjian et al., 2014) and 99% (Wang et al., 2018) of individuals will experience some degree of PTG following an SCI. Qualitative studies exploring PTG in individuals with an SCI have identified appreciation of life as a consistent theme (Chun & Lee, 2008; Chun & Lee, 2013; Crawford, Gayman, & Tracey, 2014; deRoos-Cassini, de St. Aubin, Valvano, Hastings, & Brasel, 2013; Kennedy, Lude, Elfström, & Cox, 2013). These studies suggest that following an SCI, individuals gained a new perspective on life and no longer took it for granted as they developed an appreciation for its value and fragility. In addition to appreciation of life, Chun and Lee (2008) found in their thematic analysis that growth was also experienced in meaningful family relationships, where individuals experienced greater intimacy, trust and mutuality. Growth was also experienced through meaningful engagement in activities, as individuals identified new strengths and abilities, experienced positive emotions and developed stronger relationships.

Weitzner et al. (2011) found through their modified grounded theory approach that individuals viewed their disability as a facilitator of positive growth in their life, particularly in the area of self-discovery and self-improvement, as several participants felt they had developed new abilities, experienced a change in their attitudes and developed deeper family relationships since their SCI.

In addition to Weitzner et al. (2011) and Chun and Lee (2008), Kennedy et al. (2013) found through thematic analysis that individuals experienced a change in attitudes and

personality, stronger and more intimate relationships with family and friends, and developed new skills and abilities. Participants also described experiencing a new understanding of disability, which gave them greater empathy for others living with a disabling condition. Participants also reported developing greater understanding and knowledge of their SCI and their body, and a greater appreciation for their health and health care services. A small number of participants also reported growth in acceptance, either of themselves or receiving help from others. Other themes were identified in the area of spirituality, re-evaluating their lives and living life in line with new goals and priorities. Finally, a small number of individuals reported their SCI as an opportunity for them to turn their life around, such as changing careers or discontinuing risky behaviours.

Qualitative studies have also identified facilitators for PTG (Chun & Lee, 2010; Crawford, Gayman, & Tracey, 2014; Griffiths & Kennedy, 2012; Khanjani, Younesi, Khankeh, & Azkhosh, 2017). When exploring experiences of positive outcomes following an SCI using IPA, Griffiths and Kennedy (2012) found that individuals described a close link between growth and ageing. This suggests that maturing with age was an important facilitator of growth (Griffiths & Kennedy, 2012). Through thematic analysis, Chun and Lee (2010) identified that individuals engaging in leisure activities experienced opportunities to make sense of their injury, develop personal strength and new skills in areas such as art and sport. They also reported having the opportunity to form new meaningful relationships, experience positive emotions and find meaning in everyday life. Crawford and colleagues used a phenomenological approach to identify how parasport athletes perceived and experienced PTG following their SCIs. Like Chun and Lee (2010), they found that participants reported experiencing new relationships through their sport. They found parasport facilitated greater health, fitness and psychological wellbeing. Participants also reported that parasport offered an opportunity to establish their previous identity or forge a new one. Finally, they also

reported that participants reported greater self-efficacy and problem-solving abilities (Crawford et al., 2014).

Using content analysis, Khanjani and colleagues (2017) discovered that two of the most significant facilitators reported for promoting PTG were having appropriate support and resources available following their SCI, such as family and friends to support them to overcome new obstacles, and having appropriate wheelchairs and aids to increase independence. Having regular contact with SCI associations and an active presence in society were also considered important facilitators of PTG, as they promoted empowerment and a sense of purpose. A positive attitude about the injury and their futures instilled hope and facilitated growth, and having spiritual beliefs helped find meaning in their lives which supported PTG (Khanjani et al., 2017).

Another recent study used an interpretative phenomenological analysis (IPA) to explore the process of PTG in individuals with an SCI in China (Wang et al., 2017). Wang and colleagues (2017) identified three super-ordinate themes that encapsulated the process of PTG, which were struggling in hopelessness, disentangling from disability, facing challenge and achieving positive growth (Wang et al., 2017). Along with the other qualitative literature described here, this study has important clinical implications as it highlights the process of growth for people with an SCI.

To date, the qualitative literature on PTG following an SCI has increased understanding of what PTG is experienced following an SCI, how it is facilitated and the process individuals go through. However, there is little information on how affected individuals make sense of their experience and the meaning they ascribe to this over a much longer period of time. Furthermore, the qualitative studies described here did not report controlling for age of SCI onset or time since injury, resulting in a heterogenous sample for both factors.

These are important methodical considerations in terms of homogeneity, as individual experiences of PTG may vary over time (Tedeschi & Calhoun, 2004). This is significant when considering that an individual's stay in hospital could have ranged from months to years, and therefore reduced their opportunity to have fully experienced PTG at point of interview. Furthermore, PTG following an SCI may differ depending on whether SCI onset was during childhood or adulthood, as individuals experiencing an SCI in childhood are likely to have more opportunities for growth than an individual experiencing an SCI later in life (January et al., 2015). To date, none of the qualitative studies exploring SCIs and PTG have taken these factors into account and, therefore, none have focused solely on the experience of PTG in adults who sustained their injury during adulthood and are in the long-term phase of their SCI. Therefore, the overall research question aimed to explore how individuals experience and make sense of PTG during the long-term phase of their SCI.

Principal Aim of the Study

To explore the experiences of Posttraumatic Growth in individuals during the long-term phase of their spinal cord injury.

Secondary Aims of the Study

- To understand how individuals experience Posttraumatic Growth in the long-term phase of their spinal cord injury.
- To gain insight into how individuals with a spinal cord injury make sense of their experiences of Posttraumatic Growth.

Method

Research and ethical approval

This study was granted approval from the Doctorate in Clinical Psychology Research Committee (see Appendix A), and awarded University Sponsorship (see Appendix B). Ethical approval was then granted by the National Research Ethics Service (see Appendix C) and the Health Research Authority (see Appendix D).

Design

This qualitative study used in-depth interviews to elicit detailed narratives of the participants' experiences. The transcripts were individually analysed on a case-by-case basis, using IPA, to explore and interpret how the participants experienced and made sense of their PTG (Smith, Flowers and Larkin, 2009).

Participants

As recommended by Smith et al. (2009), this study aimed to recruit between four and ten participants, which, depending on quality of data, is considered the appropriate sample size for a professional doctorate. In total, eight individuals responded to the recruitment adverts distributed through a Regional Spinal Injuries Centre in England, and through a local spinal injuries charity. One individual did not meet the eligibility criteria and another felt too unwell to participate. Six eligible participants were therefore recruited. Two of the participants were female and four were male, and their ages ranged from 44 years to 59 years of age. All participants were British. Time since injury ranged from 10 years to 36 years. Four participants had incomplete SCIs (a varying degree of motor and/or sensory functioning had been maintained below the injury site) and two had complete (complete loss of function below the injury site) injuries (see Table 1 for participant demographics).

Inclusion criteria

Individuals were eligible to take part in this study if they were fluent in English, under the care of the regional SCI unit, living in the North West of England, had an SCI and self-identify as having experienced PTG following the injury. They must have experienced an acute (sudden and unexpected) SCI at age 18 or older and at least 10 years prior to interview.

Exclusion criteria

Individuals were excluded if they did not meet the inclusion criteria. Individuals were also excluded if they had known difficulties that would prevent them from giving informed consent or successfully engaging in the interview, such as significant mental health problems or substance misuse, as these issues may have reduced their ability to accurately recall historical experiences or meaningfully engage in the interview (King et al., 2003).

Table 1.
Participant demographics

Pseudonym	Age	Cause of SCI	Type of SCI	Time since injury in years
Mark	51	Road traffic accident	Incomplete tetraplegia	20
Julie	59	Sport injury	Incomplete paraplegia	36
Sarah	47	Road traffic accident	Incomplete fractures of the spine	25
Frank	56	Road traffic accident	Incomplete paraplegia	10
James	44	Fall	Complete tetraplegia	24
Thomas	49	Sport injury	Complete tetraplegia	31

Procedure

Participants were recruited through a Regional Spinal Injuries Centre and spinal injuries charity using purposive sampling (Smith et al., 2009). The spinal injuries charity

promoted the research by circulating an email to their members, which included an electronic copy of the poster (Appendix E). The study was promoted throughout the Spinal Injuries Centre using research flyers (smaller versions of the poster) and posters in the outpatient department. Clinical staff at the Spinal Injuries Centre also identified potential participants prior to their routine clinical appointments, and offered them research flyers when they attended their appointments.

Individuals who wished to take part in the study either completed an advert reply slip (Appendix F) permitting the lead researcher to contact them, or contacted the lead researcher via the contact details provided on the posters and flyers. They were then sent or e-mailed a Participation Information Sheet and opt-in form (Appendix G) by the researcher. The Participation Information Sheet provided information about the study, including details about informed consent, confidentiality and anonymity, and interview recording and transcription process. Potential participants either returned the opt-in form to the researcher (using a provided stamped addressed envelope), or opted-in via email.

The lead researcher telephoned all individuals who expressed an interest. This enabled the researcher to formally check that individuals met the inclusion criteria and provided an opportunity to answer questions. Individuals who did not meet the inclusion criteria were informed straight away and were thanked for their time and their interest in the study. Their information and contact details were destroyed immediately. Individuals who met the inclusion criteria and requested to take part arranged their interview during the telephone call. Interviews were arranged for at least seven days after point of telephone contact.

At interview, the researcher refreshed participants on the contents of the Participation Information Sheet and gave them the opportunity to ask any questions. Once participants were ready to continue and had read and signed the consent form (Appendix H), they were asked to complete a demographic information sheet (Appendix I). The researcher reminded participants of the risks involved in discussing distressing information and encouraged them to share what they felt comfortable with, and reminded them they could stop the interview at any point. Participants were also encouraged to take breaks as and when required.

Interviews were undertaken by the researcher and took place at a suitable location chosen by the participants. Four participants were interviewed at their home, one was interviewed at the university, and another was interviewed at the Spinal Injuries Centre. Interviews were between 60 and 90 minutes in total and followed a semi-structured interview schedule (Appendix J). The schedule was flexibly followed in order to support the natural flow of conversation (Smith et al., 2009). Following the interview, each participant was given a debrief sheet (Appendix K) thanking them for taking part and explaining what to do if they became distressed at any point as a result of the interview.

Interviews were audio-recorded anonymously on a digital voice recorder. The first two interviews were transcribed by the researcher and the remaining interviews by a University-approved transcriber. Once transcribed, the recordings were erased, and any identifiable details deleted or anonymised for each transcription. Each participant was given a pseudonym to protect anonymity. The first two interviews provided pilot information to enable the opportunity for changes to be made to the interview schedule if needed. No changes were necessary, and both pilot interviews were included in this study. The transcripts were then analysed using IPA.

Data analysis

Interview transcripts were analysed using IPA, as it enabled a focus on the rich and individual experiences of each participant (Gibson & Hugh-Jones, 2012). IPA enabled interpretations about how participants made sense of their experiences, and the association between their narratives and their actual experience (Shaw, 2010). The theoretical underpinnings of IPA stem from phenomenology, hermeneutics, and idiography (Smith, 2011).

Phenomenological philosophy has been shaped over the last century by writers such as Husserl, Heidegger, Merleau-Ponty, and Sartre (Smith et al., 2011). Their writings suggest that human beings make sense of their world through their own unique perspective, which is shaped by the context within which they live, and through their personal and embodied relationship with the world (Smith et al., 2011). Based on this philosophy, the IPA researcher acknowledges that they can only attempt to make sense of another person's experience through the filter of their own unique viewpoint and presumptions (Brocki & Weardon, 2006). The researcher therefore takes a phenomenological stance by knowingly setting aside their own preconceptions, which is known as 'bracketing', in order to ascertain the lived experience of the individual (Tuffour, 2017).

Heidegger articulated phenomenology as a hermeneutic (interpretative) activity rather than a descriptive process (Smith et al., 2011). Through IPA, the researcher attempts to interpret how the individual makes sense of their experiences. The researcher therefore engages in a 'double hermeneutic' process (Smith et al., 2011). The philosopher, Gadamer, suggests that through the interpretation process, the researcher's unconscious preconceptions may surface, requiring the researcher to consciously and reflexively 'bracket' their prior knowledge (Smith et al., 2011). The practice of reflection and interpretation is cyclical and flowing which exemplifies the hermeneutic circle (Tuffour, 2017). The hermeneutic circle provides understanding of the non-linear process of IPA, where the researcher reflexively engages with

the data (Smith et al., 2011). This activity is ideographical and therefore, each case is analysed anew, with all preconceptions 'bracketed' (Tuffour, 2017).

The idiographic nature of IPA enables the unique and subtle offerings of each individual to be captured, before exploring for convergence, divergence and recurring themes between individuals (Smith et al., 2011). Researchers are required to follow the idiographic framework throughout the analysis (Tuffour, 2017).

In line with the IPA framework set out by Smith et al. (2011), the researcher immersed themselves in the data by reading and re-reading each transcript, then engaging in initial coding at a descriptive level while also making linguistic and conceptual comments (see Appendix L for an example). These exploratory comments were developed into emergent themes and grouped into super-ordinate themes, based on shared characteristics and meaning. This was repeated for each person separately, before combining the super-ordinate themes across all participants and grouping them into higher order master themes (see Appendix M). As IPA is an iterative method, the researcher renamed and reorganised themes to develop more concise accounts of participants' experiences throughout the process (Smith et al., 2009).

Quality and validity

As IPA is a subjective and non-prescriptive methodology, it allows itself to be adapted flexibly, as long as the researcher maintains a move from descriptive to interpretative (Brocki & Weardon, 2006). To ensure transparency and maintain quality and validity, the researcher worked closely with their academic and clinical supervisors by sharing all transcripts, initial coding, emergent and super-ordinate theme development for each participant as they were completed, as well as the final master themes which were reflectively discussed.

Reflexive Statement

Throughout the process of IPA, the researcher reflects on participants' narratives and their interpretations of participants' accounts (Smith et al., 2009). It is therefore important for the researcher to be aware of their own position and bias and to remain transparent throughout the process (Smith et al., 2009). The researcher was aware of how their keen interest in clinical health psychology and positive psychology, especially PTG, influenced their decision to research this area. They remained conscious of this and reflected on how their knowledge and interest of this field may have had an influence on their interpretation of participants' accounts. An example of this was when the researcher found themselves using labels from the literature to interpret text and themes. The researcher reflected on this and raised it in supervision to ensure that what they were interpreting was actually the participants' experiences and not the researcher's preconceptions.

The researcher did not have any prior experience of working with individuals with SCIs before this research. However, they had worked in physical health settings as an Assistant Psychologist and on three placements during their clinical psychology doctoral training, during which they had witnessed examples of PTG. The researcher reflected on how their prior experiences arose in their memory as they made interpretations of participants' experiences. For example, they questioned whether they were looking for PTG based on their prior clinical experience. Again, this may have taken the researcher away from the unique voice of each account. Reflecting throughout this process enabled the researcher to identify unexpected preconceptions as they arose (Smith et al., 2009).

Results

The aim of this study was to explore the experiences of PTG in individuals during the long-term phase of their SCI. Three master themes were identified through the analysis and are presented with their corresponding subthemes in Table 2.

Table 2.
Master themes and sub-themes

Master Themes	Subthemes
The earthshattering consequences of injury: <i>“I’d gone from this very busy, happy, fun, with everybody on holiday lifestyle to this, boom”</i>	<ul style="list-style-type: none"> • Carefree and the world at one’s feet • Plunged into a cruel new world • Life changing impact for family
Determination to reclaim one’s life - <i>“You know you, you either sank or swam... it was a case really of, I’m in this situation, there’s no going back”</i>	<ul style="list-style-type: none"> • Survival is a choice • Grieving and accepting the permanence of the injury • Protecting the fragile self • Support as a salvation
Roses (PTG) and thorns (injury and struggle) - <i>“there are times I wish it had never happened. But... what I also got is an incredible journey, and an experience, and a growth and depth that I don’t think I would have had otherwise.”</i>	<ul style="list-style-type: none"> • Injury as a catalyst for growth • Self-actualisation • The continuous struggle with the injury

Master theme one: The earthshattering consequences of injury

“I’d gone from this very busy, happy, fun, with everybody on holiday lifestyle to this, boom.” (Sarah). This master theme illustrates the traumatic, sudden and unexpected nature of participants’ injuries, how their lives and dreams were instantly shattered, and the devastating impact on their families. It encompasses three subthemes, discussed in more detail below: 1)

Carefree and the world at one's feet; 2) Waking up to a cruel new world; 3) Life changing for family.

Carefree and the world at one's feet. Participants' narratives created a sense that, pre-injury, their lives were 'happy-go-lucky'. They lived in their own carefree worlds, with their own hopes, dreams and desires as their only focus. Anything beyond that was rarely given a second thought. *"I was a happy person and that was what I did. And I got out of bed so that I could get to work and get to the beach in the afternoon, and there wasn't much more than that."* (Sarah). Julie described that *"everything was just geared up to enjoy myself basically, it was just a happy-go-lucky life."* (Julie). They suggest that life was fun-filled and free, and far from adversity.

Most of the narratives revealed a shared similarity, suggesting participants were already successful in their careers, sport or academia, or had promising careers mapped out. James had just achieved his qualification for his new job before his injury. How James spoke about this unearthed a sense of continued grief for the trajectory his life may have taken if he had been able to pursue his aspiration. Sarah's account implied that, prior to her injury, she was admired by others, as they saw her as *"jammy [...] charmed and bright and funny and happy"* (Sarah). Her narrative intimates that, prior to the injury, a bright future was waiting for her; *"I spoke lots of languages [...] Bright, smart, and charming. Always with top results in this, that and the other"* (Sarah). Thomas was competing at a very high level in sport and was hoping to go to University; *"I was aiming to go to the Olympics, that was my intention. So, everything was kind of geared towards that. I was also hoping to go to University"*. These narratives reinforce that participants had a sense that the world was at their feet and their future was bright. However, their futures were changed forever in an instant.

Plunged into a cruel new world. Participants described how their world immediately changed following their SCI. Mark's account of waking up to his injury gave a powerful illustration of how control and independence was stripped from him as he woke to his new reality.

"I woke up erm in Halo traction with er, and er, with er a tracheostomy done.

Wondering quite, erm, what had happened in the meantime [...] as soon as I woke up, the nurse explained to me where I was, and I thought nah. No, no I don't remember that. That can't have happened. And the consultant came over and, and er, seemed to confirm what she was telling me." (Mark)

Mark experienced shock and disbelief as he awakened to hearing the news. He struggled to make sense of his new existence as he found himself trapped in his own body *"I'm just existing in this space behind my eyeballs"* (Mark), which gave a sense he was existing but without a functioning body, as if he was 'disembodied'. Mark had nothing but the injury as proof that the accident had taken place. Other participants also described feeling shock and disbelief, and struggled for control following their injury. *"I didn't believe them. Like most people, you know [...] I didn't think that anybody had any right, or, any, you know, no right I suppose, to say you will not walk again"* (Julie). Julie's quote suggests a feeling of anger as a cruel new world was forced upon her. Thomas further illustrates how participants felt stripped of independence and control and experienced utter powerlessness as the new cruel world dawned upon them. *"You lose all the activity and all of the physical independence and immediately you're completely physically depending on everyone else. Erm, the sporting career obviously comes to an end immediately as well. It was sort of an immediate change"*.

Life changing impact for the family. The lives of the participants' families were also changed forever as nearly all participants needed to move back in to their parents' homes. Many homes had to be modified or extended to accommodate the participants. For example, *“the ramp went gently around the back and to [...] a conservatory, which had been built purposely around the back, erm, so that it provided [...] an extra room [...]”* (Mark).

Moving back in with family was a difficult time for all participants as family homes were not yet fully accessible when they left hospital; Julie describes it as: *“a flipping nightmare. That was horrendous erm, [...] their home wasn't adapted, but dad, you know [...] he made a ramp, then he altered the downstairs utility into a bathroom as well. Erm, did everything.”* (Julie).

In addition to the changes parents made to their homes, they also suddenly found themselves in a new role as a carer:

“they didn't really have big care packages at that time which, you know 20 years ago now, there was a lot more family involvement in the care rather than formal support, so your family were sort of the main carers.” (Thomas)

Participants acknowledged the sacrifices their parents and family had to make and the devastating impact it had on them, as Frank explained:

“And it's not just the person whose accident it is as well, it's the person who lives with you, like it's your parents or your partner, and they have to change their lifestyle too. It's not just my injury, it was everyone around me. As I said, it causes a lot of problems.” (Frank)

There was a sense that participants' families were also injured and were suddenly placed in a carer's role; furthermore, they modified their homes as best as they could to provide an accessible space for loved ones. Without a doubt, this was also a lifechanging injury for participants' families.

Master theme two: Determination to reclaim one's life

"Spinal cord injury is the type of injury where you-, you sink or swim." (Mark). The second master theme reflects the strength and determination participants demonstrated to flourish, despite the devastating injury they had sustained. This master theme captures how participants made sense of this process, which will be expanded upon over four subthemes: 1) Survival is a choice; 2) Grieving and accepting the permanence of the injury; 3) Protecting the fragile self; 4) Support as a salvation.

Survival is a choice. Most participants indicated a turning point in their recovery, where they appeared to make a conscious decision to change their mindset and fight to reclaim their lives. Sarah gave an account of the psychological struggle she experienced and the moment she chose to fight for her future, *"I could have made the choice to be really depressed at that point and, erm, and end up in a wheelchair anyway because the fight would have been too difficult"* (Sarah). Frank also reported a turning point in his recovery, where he was faced with a choice to either dwell on his tragedy or see the positive and move his life forward in a valued direction.

"[...]when you come out of hospital it's totally different. You're basically left on your own and that's where you've got to make the decision then. 'I've got to do this' and

'I've got to do that', and try and think positive [...] you can either get depressed and sit there feeling sorry for yourself or you can turn around and say 'well alright, I've got this injury, let's do the best we can.' (Frank)

Some participants reported that their choice was inspired by seeing the alternatives to not fighting against the overwhelming tide of the injury.

"spinal cord injury is the type of injury where you-, you sink or swim [...] You see it in other people around the unit, you very quickly learn, erm, just by watching other people around and the way they react to their injury." (Mark)

The narratives provided rich information offering the opportunity to interpret how they made sense of their PTG. The choice to turn their lives around appeared to have been a significant moment in their journey to experiencing PTG, and participants reflected on this as a critical point of time in their life.

Grieving and accepting the permanence of the injury. *"However much you want to wish it away it's not going to happen."* (Mark). All participants conveyed a sense that there are aspects of the injury they have accepted over time, while continuing to mourn for elements of their previous lives.

"There are things that I still wished I'd done, that I didn't have an opportunity to do, or didn't think I wanted to do them as much. Now whether that's because I can't do them in the way that I want to do them? So it's another bit of that grieving thing, because I'd love to have skied, proper ski. You know standing up." (Julie)

Acceptance of the injury and themselves appeared to be an important stage of moving towards PTG, as illustrated by Frank: *“There’s a lot of stuff I can’t do, obviously, and a lot of stuff you’ve gotta accept you can’t do.”* (Frank). Acceptance of the injury appeared to open up opportunities for participants to pursue new activities that were in line with their strengths and interests, and in turn provided an opportunity to experience growth rather than continuing to dwell on what they could no longer do:

“Whatever happened was going to have to be a kind of new beginning really. And a new me in some ways, but in other ways not. I think that’s how I thought of it [...] The sense of almost having to get interested in new things, perhaps, and find new ways of stimulating the mind.” (Thomas)

Participants also accepted themselves for who they were, and many things that used to trouble them became insignificant as they developed a new perspective on themselves and life.

“That was something that bugged me beforehand, you know I always wanted to be thinner, or, or have different hair, or whatever. And afterwards, I haven’t got time to worry about that [...]this is the new me and this is me being comfy in who I am.”

(Julie)

Protecting the fragile self. All participants demonstrated the importance of keeping a positive mindset throughout the long-term phase of their injuries. The function of this positive mindset was surprising as it seemed not just to be a way of coping, but for survival.

Many participants gave a sense that ongoing grief remained and, overall, the past and the negative aspects of the injury were best not thought about.

“I wouldn’t dwell on it because, do you know what I mean, it’s a negative. I always try to keep a positive on all of the stuff that I think of. Because if you think negative stuff you start thinking ‘well what happens with this?’, and ‘what happens with that?’.” (Frank)

Mark’s account below illuminates how some participants felt their new positive outlook not only protected them from their internal negative struggle, but also protected their relationships.

“you need all the people on your side as you can possibly get, because of the nature of the injury and how profound, how profound an effect it has on your life. So dare I say for a bit of self-preservation, you note how other people split up from their partners and friends and suddenly, all of a sudden they stop coming to visit them and you think, I can’t afford to be in that situation. If people are coming to visit me, the last thing they want to see is me full of doom and gloom.” (Mark)

Participants’ positive mindsets may have represented a protective armour around their fragile inner core. They made sense of this positivity as a way of sustaining and improving their relationships and as a way to facilitate growth by embracing new goals and dreams.

“Instead on concentrating on the (laughs) 99.9% that you’ve lost, you have to concentrate on the 0.1% that you can still do.” (Mark).

Support as a salvation. Participants talked about how important the support of family, friends and peers was to them in overcoming the barriers of their injury and experiencing new positive growth in their lives. This was especially important to them as many had experienced the loss of significant relationships in the immediate aftermath of the injury. The language used by participants, such as “*dumped*” (Julie) and “*people who I thought were friends*” (Mark), conveys a sense of betrayal, as if they were discarded; “*friends sort of rally round, well some did, some some just dumped you because you couldn’t do.*” (Julie).

“I remember sat with me dad and a group of lads who I were on holiday with were out in a pub. And I were in with me family and they’d walk out of the fire exit door, so they didn’t need to walk past me.” (James)

James’s account gives powerful insight into the heart-breaking loss people experienced as they felt rejected by friends. When support was subsequently offered, it was therefore not only accepted but appreciated more than before the injury; “*I’d valued friends a lot more. I think I’d taken them for granted a fair bit beforehand, erm. But because now I needed them more.*” (Julie)

Some participants described the importance of having peers as role models from whom they could learn how to navigate their world, resulting in them experiencing a new sense of hope and possibility for the future, and new growth along the way:

*“I did that, and watched ** (name removed) treat people and watched how much more he got out of life by respecting people. And also what, you know, basically how to start living your life in a chair.”* (James)

Julie's account describes how her role models became friends and changed the trajectory of her life; *"I'd made a really good friend, a couple of friends erm, while I was in hospital, the chaps who used to come in with the sport. And they, one of them (laughs) phoned me up"* (Julie). This phone call resulted in Julie competing in sport and making a decision to pursue this passion further and compete in the Paralympics; *"that's when I realised, yeah, I'm going to go down this path."* (Julie)

Participants were therefore experiencing loss and rejection as they recovered from their injury, but then found a new hope in people who arrived to offer support. Many participants described having a greater appreciation for others because of the support they offered.

Master theme three: Roses (PTG) and thorns (injury and struggle)

"There are times I wish it had never happened. But [...] what I also got is an incredible journey, and an experience, and a growth and depth that I don't think I would have had otherwise." (Sarah). The third master theme illustrates how participants made sense of their PTG in the long-term phase of their injury. Their narratives suggest that, looking back on their lives, they have experienced some wonderful and positive life changes because of their injury. However, alongside these positive changes has been a continuous struggle with the consequences of their injury. Participants' positive experiences were like the beauty of a rose; the injury and struggle the thorns it bears.

This theme includes three subthemes: 1) Injury as a catalyst for growth; 2) Self-actualisation; 3) The struggle with the injury is continuous.

Injury as a catalyst for growth. In reflecting on how they have experienced PTG, participants described the injury as the reason for the different trajectory their life had followed, and therefore responsible for the growth they have subsequently experienced. *“Everything that’s happened up here has happened as a result of the spinal injury, so I guess it was the catalyst for a whole new life.”* (Thomas). Julie reflected on her injury and viewed it as an opportunity for her to reassess her life: *“it’s perhaps an opportunity for people to, you know, reassess where they are, and you know think well, yeah I didn’t really enjoy the job I was doing so, you know, it’s a good opportunity.”* (Julie). Sarah talked about how her injury and the adversity from it propelled her in life and gave her a new strength and tenacity to pursue her new life goals:

“the courage and the motivation to succeed and to do, and to get out of this hole, this isn’t where you’re meant to be, [...] - it’s this drive from the accident point, this drive - I’m meant to be doing something else. Get up and do it. And that didn’t exist in my life prior to that, you know, I was just on the track, not making things happen but I think there had never been any crisis in my life before that. There had never been anything unpleasant happen in my life, nothing hard had ever happened [...]” (Sarah)

A surprising benefit of their injuries for some participants was being forced to slow down, which was experienced by most as a facilitator of PTG. One participant described how being forced to slow down had positively deepened his relationships with others, especially his children:

“it’s given me time to invest in me children. And then, hopefully they grow up and, you know, I’ve done a good job. And I think that’s what my disability has allowed me, me accident, because I have got the time, and a lot of people don’t have the time.”

(James)

James’s account demonstrates his gratitude for having more time with his children; he views himself in a fortunate position compared to people without an SCI. Another participant described how being forced to slow down enabled her to appreciate nature for the first time and see the world anew; *“you’re able to, perhaps view things differently and take time to appreciate nature, erm, what’s out there, the animals, the trees, I- I used to race up these mountains, I never saw a flippin’ thing [...]”* (Julie). This emphasises that Julie has been able to appreciate life from a different perspective over the long-term period of her injury.

Overall, participants found meaning in their injury and saw it as the catalyst for the life they live now, and all the positive aspects that fill their lives.

Self-actualisation. How participants made sense of their experiences suggested that they had been on a journey not only to survive, but also to prove to themselves and others that they still had worth in the areas of life that were important to them. The journey began as they were forced to regress from adult autonomy to a childlike dependence, becoming utterly dependent on others for their survival; *“you are there for a long time, completely dependent on other people for everything.”* (Mark). Once they were able to leave hospital, participants talked about how others wrapped them up in cotton wool, which then led to a struggle for independence; *“I wanted to become independent again, go out and lead my own life [...] not be erm, babied in a way by my parents, which is what happened when I went home.”* (Julie). Many participants wanted to prove themselves to themselves and others so that they felt worthy and accepted. Julie explained: *“I wanted to, to prove I could do everything I used to*

do and better. Erm, like I said, I was, I felt I had to compete with the people who I worked with just to be accepted.” (Julie). Through this long journey of struggling with the psychological and physical aspects of the injury, and striving to prove themselves, their psychosocial needs were met, and they flourished. Many participants appeared to have experienced significant growth in their relationships, their sense of self, their purpose in life, and developed a new wisdom with which they saw life:

“I broke me neck and a lot of people die. And I’ve been fortunate not to die and you realise how precious life is and, once you’re not here, life still goes on [...] and it just makes you appreciate waking up in the morning and being alive no matter what you’re doing.” (James)

Participants also developed a new and strong desire to give back and help others. This was described in many different contexts, such as contributing to research, educating people about caring for the environment, helping others with a spinal injury by donating equipment or educating them on how to look after themselves. Many wanted to pass on their new wisdom to others:

“It’s a burning desire to help other people, that’s what’s changed. Whereas before it was all about me.” (Sarah)

The continuous struggle with the injury. Being in the long-term phase of their injury, participants were able to reflect on how PTG was experienced and the timeframe in which they experienced PTG. Many participants suggested that PTG is a continual process and that they continue to experience growth even in the long term: *“I became much more*

mentally aware of the benefits of the journey I'd been. And it still goes on, I still- it's ongoing." (Sarah); Thomas reflects about the positive growth in his life as an ongoing process; *"So, things are still happening, which is good. So, growth can happen and is ongoing."* (Thomas).

Participants made sense of PTG as an ongoing process that evolved through the struggles and journeys they were pursuing. An interesting theme that arose from the narratives was that even in the long-term phase of their injury, the struggle with the injury remained and had evolved as they aged with the injury. Many now feared losing the independence they had strived so hard to achieve in their early years of recovery; *"As I get older I get more frightened about not being in charge, not being able to cope, erm, having to have somebody do basic care for me."* (Julie); Frank also explains how his strength is reducing as he ages. *"I used to be able to transfer and stuff, because I was still quite upper body strong, erm, but since then, now, with me age and stuff obviously I can't transfer as good as I used to."* (Frank). So even though the struggle remains and presents itself in new ways, growth also continues. The participants' narratives gave a sense that even in the long-term phase of their injury, you cannot have one without the other.

Discussion

This study explored the experiences and understanding of PTG in individuals during the long-term phase of their SCI. IPA was employed for interpretative meaning-making, developing three overarching master themes: (1) 'The earthshattering consequences of injury', (2) 'Determination to reclaim one's life', and (3) 'Roses (PTG) and thorns (injury and struggle)'.

Participants described their experiences of PTG and illustrated how their traumatic injury was a catalyst for a new life trajectory. From their narratives, the first master theme ‘The earthshattering consequences of injury’ was developed, capturing how, pre- injury, participants’ lives appeared carefree and revolved around themselves. Their lives appeared to be full of hopes and dreams; participants either had successful lives already, or successful futures mapped out. Their injuries were sudden and traumatic, shattering their lives and dreams in an instant. Some participants described not knowing about their injury until they woke to the tragic news, unable to move their body like a cruel joke. Their families’ lives were also shattered as they saw their loved ones in hospital. Families were suddenly forced to become carers, adapting their own homes, and in some cases, participants experienced a return to a childlike state of dependence. This theme demonstrates how both participants and their families were forced into a new reality and a struggle to reclaim their lives. This theme wove throughout participants’ narratives as an integral part of how they made sense of their PTG through rebuilding their lives. It maps closely onto Tedeschi and Calhoun’s ‘shattering hypothesis’ that suggests that it is not necessarily the trauma that leads to PTG, but the extent to which the individual’s reality is altered and their struggle with their new reality (Tedeschi & Calhoun, 2004).

The second master theme that arose from participants’ narratives was ‘determination to reclaim one’s life’. This theme captures how participants experienced PTG. Participants described a crucial turning point in their rehabilitation where they actively decided to hold onto their lives and take control. They explained how they made a conscious choice to no longer dwell on the tragedy of their injury, but to reclaim their lives. Over time, this facilitated an acceptance of their injury. However, for many, even in the long-term phase of their injury, the loss of their previous life still haunted them, and they still mourned. This

appears to be a novel finding in the qualitative literature for PTG in spinal injuries, as other studies have identified either the early struggle (Wang et al., 2017), or focused on what PTG was experienced (Chun & Lee, 2008; Kennedy et al., 2013) and its facilitators (Chun & Lee, 2010; Crawford, Gayman, & Tracey, 2014; Griffiths & Kennedy, 2012; Khanjani, Younesi, Khankeh, & Azkhosh, 2017). However, this study identified that although PTG was experienced and participants had accepted their injury, even in the long-term phase of their injury there was a sense of an enduring grief that remained quietly hidden as they engaged in the positive aspects of their lives.

Participants also described how focusing on the positive aspects of their lives protected them in the early stages from not only dwelling, but also from losing the support of loved ones. This positive mindset appeared to be put in place as a coping strategy due to an increased sense of vulnerability. In turn, this positivity seemed to facilitate PTG through enhancing relationships and increasing support from loved ones. For some, this positivity appeared to be learnt from role models or by observing the consequences of a negative outlook in other patients with spinal injuries. Positive reinterpretation coping, along with acceptance coping, is considered to be an important part of the growth process (Park, Cohen, & Murch, 1996). A meta-analytic review demonstrated that positive reappraisal coping was highly correlated with benefit finding (Helgeson, Reynolds, & Tomich, 2006). The finding of this study also provides further support for Chun and Lee's (2013) grounded theory finding which identified that participants who engaged in positive reappraisal coping were more likely to successfully adapt to their injury and experience PTG. As the present study focused on *how* individuals experienced PTG, it was able to shed light on the reasons underlying their positive reappraisal and interpret how this led to experiencing growth.

Another important theme was that support was a salvation as it arrived at a time when some participants felt discarded by friends. Chun and Lee (2008) also identified that participants were abandoned by others when they needed support the most. However, participants' accounts implied that support was their salvation, and then came peers and role models, community, and family and friends, instilling a sense of hope in many of the participants. One strength of the present study is that participants were able to reflect over the long-term phase of their injury and make sense of how this support steered some of them onto a new life course, facilitating further growth over the years.

Other qualitative studies have identified social support as a facilitator for overcoming barriers, and pursuing new life goals and activities (Crawford et al., 2014; Weitzner et al., 2011). Similar to the findings in this study, they have found that social support led to a new and greater appreciation and gratitude for others (Chun & Lee, 2008; Chun & Lee, 2013; Kennedy et al., 2013).

The final theme 'Roses (PTG) and thorns (injury and struggle)' was interpreted from the powerful sense that participants experienced many areas of positive growth in their lives, alongside an ongoing struggle with their injury. Participants identified that their injury was the catalyst for experiencing positive growth in their lives. They noted that one of the 'benefits' of their injury was that it forced them to slow down. In the long-term phase of their injury, this opened their eyes to see the world anew and spend more quality time with the people that mattered most in their lives, leading to a deeper connectedness both with nature and in their relationships. Other qualitative studies also identified that SCIs have facilitated growth by forcing participants to slow down (Crawford, 2014; DeRoon-Cassini et al., 2013; Wang et al., 2017; Weitzner et al., 2011).

As participants' narratives were generated from reflections on the long-term phase of their injury, they were able to reveal a process to experiencing growth. They had been stripped of their humanity in an instant and became dependent on others for their basic survival needs. They decided to focus on the positive in life and pursued a journey of self-discovery to redefine and prove themselves, experiencing positive growth along the way. Once their needs were met and their sense of self restored, many participants were close to reaching the pinnacle of their aspirations. They developed a strong motivation and strived to make a difference in the world. They also developed new wisdom and insight into how fragile and precious life is. Their journey appeared to somewhat mirror Maslow's (1943) hierarchy of needs as well as Calhoun and Tedeschi's (2004) model of PTG. Maslow's hierarchy of needs suggests that each human need must be fulfilled before they can move to the next stage. Once each need is met, another higher need slowly materialises which is pursued until the individual is satisfied (Maslow, 1943). Maslow suggests that (in order) the hierarchy moves from 1) physiological needs, 2) safety needs, 3) love needs, 4) self-esteem needs and 5) self-actualisation (Maslow, 1943). Maslow states that even when all needs are met, individuals continue to strive to be all they can be (Maslow, 1943). Participants in the long-term phase of their injury appeared to have moved along this trajectory, not necessarily in a linear fashion, but journeying from being dependent on others for their basic needs, to the peak of all they wanted to become, and still pursued more. This was displayed in giving back to others and contributing to making the world a better place, and existentially seeing the world anew.

A strength of this study was that all participants were in the long-term phase of their injury and their accounts reflected the trajectory of growth and *how* they experienced it. It was apparent that most participants continued to struggle with their injury either physically

and/or psychologically. One area reported by most of the participants was a struggle with ageing. As participants were ageing with their injury, some described it as a threat to their sense of self and independence (so hard-won after the injury), as their strength was declining. This was presenting participants with new challenges to face. However, alongside this, participants conveyed a sense that growth was still continuing as they aged and struggled with their injury. This appeared to be a novel finding in the qualitative literature on PTG following an SCI, possibly due to the homogeneity of the sample being in the long-term phase, and the added perspective of IPA. IPA offers another qualitative perspective as it not only explores *what* PTG is experienced, but also focuses on *how* it is experienced and *how* participants make sense of their experience.

Strengths and Limitations

This study has a number of limitations. Firstly, as it employed IPA methodology with a recommended small sample size (Smith et al., 2009), the findings of this study are based on an interpretation of the experiences of only six participants. This does, however, give a rich understanding that readers can place into the context of their own knowledge (Smith et al., 2009). Injury levels varied in completeness, and duration since injury also varied between participants. Durations ranged from 10 years to 36 years. However, no significant differences were found in the analysis of participant accounts, suggesting homogeneity was retained. It is important to highlight that all the individuals in this study appeared to have been quite driven, determined and positive people prior to their SCI. This may therefore present a possible bias in how PTG was experienced, and should be taken into account by the reader and considered when recruiting for future studies in this area.

This study focused solely on individuals in the long-term phase of their injury, relying on only one interview for each participant. This involved participants having to remember

and reflect over many years to recount their experiences, which may have impacted the accurate retelling of events. Finally, this study utilised purposive sampling which may have led to an unintentional bias. The experiences of participants in this study may have led to an overrepresentation of people who wanted to give back, leading to this becoming part of a subtheme. Given the high reported prevalence of PTG in individuals following an SCI, it is likely that there remain many untold stories of PTG.

Research Implications

This is the first qualitative study using IPA, exploring PTG in individuals in the long-term phase of their SCI. It has captured rich experiences of PTG and has provided insight into how individuals experience PTG over time. Future qualitative research is recommended and should consider longitudinal designs using multiple interviews in order to better capture change over time. Particular attention should be given to encompassing a more culturally diverse population in order to gain a more representative experience of PTG following an SCI. This study highlighted the importance of positive reappraisal coping and this could be better understood through future qualitative research.

Clinical Implications

This study demonstrates that PTG can be experienced by individuals following an SCI. It also illustrates that this is not a process that begins once the struggle ends. Rather, the struggle does not end, and growth is something that continues alongside it, even as new challenges emerge as individuals age. This is important to stress when informing individuals on the possibility of PTG, otherwise they may assume that one day their struggle will significantly reduce and then they will experience growth. Where in reality, struggle and growth appear to be an entwined process.

This study has also identified the importance of social support, especially as some individuals reported being rejected by friends. Clinicians should reinforce the importance of this to individuals and their families during the rehabilitation phase of their recovery. Where possible, Clinicians should aim to facilitate social support by enabling flexible visiting times, so that families can maximise the time they spend time with their loved ones during their recovery, especially, given that some individuals may be far from home during their rehabilitation. In addition, role models were also identified by some as important in the process of experiencing positive growth. Therefore, it may be beneficial for individuals who have experienced an SCI and positive growth to facilitate support groups, as this may instil hope in individuals who are living with an SCI and their families.

Finally, this study has highlighted the importance of positive reappraisal coping as a form of self-preservation and a facilitator of PTG in this sample. This should be considered within the wider context of spinal rehabilitation.

Conclusion

This study utilised IPA to explore the experiences of PTG in individuals in the long-term phase of their SCI. The findings identified that PTG is an ongoing process that is intertwined with the continual struggle faced by individuals in the long-term phase of their SCI. This study highlights how the traumatic nature of an SCI stripped individuals of all their hopes, dreams and aspirations and shows the tenacity they demonstrated to rebuild and reclaim their lives. The results also demonstrate how the challenges of an SCI continue alongside the experience of positive life changes through the long-term phase of an SCI. Finally, there is a need for longitudinal qualitative designs to truly capture the experiences of PTG over time.

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RE: Experiences of post-traumatic growth following a spinal cord injury: An interpretative phenomenological analysis

Trainee: Lloyd Gemson
Supervisors: Dr Gundi Kiemle, Dr Jen Unwin

Dear Lloyd,

Thank you for your response to the reviewers' comments of your research proposal submitted to the D.Clin.Psychol. Research Review Committee (letter not dated, submitted 13/07/16 and electronically 18/07/16).

I can now confirm that your amended proposal (version 2, date 18/07/16) and budget (no version number, dated 18/07/16) meet the requirements of the committee and have been approved by the Committee Vice-Chair.

Please take this Chairs Action decision as final approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

A handwritten signature in black ink, appearing to be 'Catrin Eames', written over a horizontal line.

Dr Catrin Eames
Vice-Chair D.Clin.Psychol. Research Review Committee. A member of the

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18 November 2016

Sponsor Ref: UoL001256

Re: Sponsorship Approval

"Experiences of post-traumatic growth following a spinal cord injury: An interpretative phenomenological analysis"

Dear Dr Kiemle

After consideration at the JRO Non Interventional Sponsorship Sub Committee on 19th October 2016 I am pleased to confirm that the University of Liverpool is prepared to act as Sponsor under the Department of Health's Research Governance Framework for Health and Social Care 2nd Edition (2005) for the above study.

The following documents have been received by the Joint Research Office

Document title	Version	Date
Protocol	2	November 2016
Recruitment and research flowchart	2	November 2016

Please note this letter does NOT allow you to commence recruitment to your study.

A notification of Sponsor Permission to Proceed will be issued when governance and regulatory requirements have been met. Please see Appendix 1 to this letter for a list of the documents required.

If you have not already applied for regulatory approvals through IRAS you may now do so at <https://www.myresearchproject.org.uk/Home.aspx>.

In order to meet the requirements of the Research Governance Framework 2nd Ed 2005, the University requires you to agree to the following Chief Investigator responsibilities:

1. Comply with the Research Governance Framework 2nd Ed 2005 and all relevant legislation, including but not limited to the Data Protection Act 1998, the Mental Capacity Act 2005 and the Human Tissue Act 2004;
2. Inform the Research Support Office as soon as possible of any adverse events especially SUSARs and SAE's, Serious Breaches to protocol or relevant legislation or any concerns regarding research conduct;
3. Approval must be gained from the Research Support Office for any amendments to, or changes of status in the study prior to submission to REC and any other regulatory authorities;
4. It is a requirement that Annual Progress Reports are sent to the NHS Research Ethics Committee (REC) annually following the date of Favourable Ethical Approval. You must provide copies of any reports submitted to REC and other regulatory authorities to the Research Support Office;
5. Maintain the study master file;
6. Make available for review any study documentation when requested by the sponsors and regulatory authorities;
7. Upon the completion of the study it is a requirement to submit an End of Study Declaration (within 90 days of the end of the study) and End of Study Report to REC (within 12 months of the end of the study). You must provide copies of this to the Research Support Office;
8. Ensure you and your study team are up to date with the current RSO SOPs throughout the duration of the study.

The University also requires you to comply with the following:

1. University professional indemnity and clinical trials insurances will apply to the study as appropriate. This is on the assumption that no part of the clinical trial will take place outside of the UK. If you wish to conduct any part of the study in a site outside the UK or you wish to sub-contract any part of the study to a third party specific approvals and consideration of appropriate indemnity would be required;

If you have any queries regarding the sponsorship of the study or the above conditions, please do not hesitate to contact the Joint Research Office governance team on 0151 794 8373 (email sponsor@liv.ac.uk).

TEM012 JRO UoL Sponsor Approval template
Version 6.00 Date 21/07/2016

Page 2 of 5

Yours sincerely

A handwritten signature in black ink, appearing to read 'A. Astor'.

Mr Alex Astor
Head of Liverpool Joint Research Office

I, the Chief Investigator, agree to the terms and conditions of the University of Liverpool Sponsorship **approval for Experiences of post-traumatic growth following a spinal cord injury: An interpretative phenomenological analysis, UoL001256** and I am aware of my responsibilities under the Research Governance Framework. I also agree to provide the Research Support Office with the documents listed overleaf when available.

By signing this agreement you also declare you have read and understood all applicable SOPs on the Research Support Office webpage and you have made these available to all members of the research team, including students.

CI Name:

CI Signed:

Dated:

Please return a signed copy of this letter to the Research Support Office within 30 days of the date of this letter. Scanned copies are accepted, and the original version should be retained for inclusion in the Study Master File. Failure to do so may result in Sponsorship being withdrawn.

Appendix 1

In order for the Joint Research Office to review the clinical research governance elements of the study please provide the following documentation when available;

All Studies - Pre HRA Approval submission

- a) IRAS combined form completed - please see attached IRAS guidance
- b) Draft Schedule of Events and Statement of Activities for different research site types - please contact us if you require any advice
 - a. All site activities
- c) Confirmation all documentation has IRAS number inserted

Other documents

- a) Signed CI Sponsor Agreement - please return within 30 days
- b) Signed and dated Chief Investigator CV
- c) Signed and dated research Team CVs (as per part C of Sponsorship form);
 - a. Lloyd Gemson
 - b. Jen Unwin
- d) REC Favourable Ethical Opinion
- e) REC Approved study documentation
- f) REC Conditions complied with and REC informed
- g) HRA Approval
- h) Agreed Statement of Activities from Lead Trust

North West - Greater Manchester East Research Ethics Committee

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8019

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

24 August 2017

Dr Gundi Kiemle
Doctorate in Clinical Psychology Training Programme
University of Liverpool, School of Psychology, Whelan Building,
Liverpool
L69 3GB

Dear Dr Kiemle

Study title: Experiences of post-traumatic growth following a spinal cord injury: An interpretative phenomenological analysis
REC reference: 17/NW/0375
Protocol number: UoL001256
IRAS project ID: 221140

I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 04 July 2017

Documents received

The documents received were as follows:

Document	Version	Date
Participant consent form	2	02 August 2017
Participant information sheet (PIS)	2	02 August 2017

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Recruitment Advert]	Version 1	15 May 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsorship Insurance or Indemnity]		02 August 2016

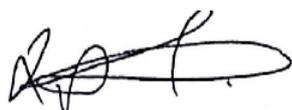
Interview schedules or topic guides for participants [Interview Questions]	Version 1	15 May 2017
Interview schedules or topic guides for participants [Demographics Form]	Version 1	15 May 2017
IRAS Application Form [IRAS_Form_26052017]		26 May 2017
IRAS Application Form XML file [IRAS_Form_26052017]		26 May 2017
IRAS Checklist XML [Checklist_26052017]		26 May 2017
Letter from funder [Research Review Committee Approval Letter]		27 July 2016
Letter from sponsor [Liverpool Joint Research Office (Liverpool Health Partners) Sponsorship Approval]		18 November 2016
Other [Participant Debrief Sheet]	Version 1	15 May 2017
Other [Chief Investigator Signed Sponsorship Form]		21 November 2016
Participant consent form [Participant Consent Form]	Version 1	15 May 2017
Participant consent form	2	02 August 2017
Participant information sheet (PIS) [Participant Information Sheet]	Version 1	15 May 2017
Participant information sheet (PIS)	2	02 August 2017
Research protocol or project proposal [Comprehensive Research Proposal]	Version 1	15 May 2017
Summary CV for Chief Investigator (CI) [CV - Gundi Kiemle - Chief Investigator - Supervisor]	Version 1	09 May 2017
Summary CV for student [CV - Lloyd Gemson Principal Investigator - Student]	Version 1	14 May 2017
Summary CV for supervisor (student research) [CV - Jen Unwin - Supervisor]	Version 1	15 May 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Recruitment and Research Flowchart]	Version 1	15 May 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

17/NW/0375

Please quote this number on all correspondence

Yours sincerely



Zainab Tauqeer

REC Assistant

E-mail: nrescommittee.northwest-gmeast@nhs.net

Copy to: Mr Alex Astor
Paula Scott, St Helens and Knowsley Teaching Hospitals NHS Trust

Dr Gundi Kiemle
Doctorate in Clinical Psychology Training Programme
University of Liverpool
School of Psychology
Whelan Building
Liverpool
L69 3GB
g.kiemle@liverpool.ac.uk

Email: hra.approval@nhs.net

05 September 2017

Dear Dr Kiemle,

Letter of HRA Approval

Study title:	Experiences of post-traumatic growth following a spinal cord injury: An interpretative phenomenological analysis
IRAS project ID:	221140
Protocol number:	UoL001256
REC reference:	17/NW/0375
Sponsor	University of Liverpool

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **221140**. Please quote this on all correspondence.

Yours sincerely

Gemma Oakes
Assessor

Email: hra.approval@nhs.net

Copy to: *Mr Alex Astor, University of Liverpool [Sponsor Contact]*
sponsor@liv.ac.uk
Paula Scott, St Helens and Knowsley Teaching Hospitals NHS Trust [Lead NHS R&D Contact]
paula.scott@sthk.nhs.uk
Mr Lloyd Gemson, University of Liverpool [Student]
Lloyd.Gemson@Liverpool.ac.uk

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment Advert]	Version 1	15 May 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsorship Insurance or Indemnity]		02 August 2016
HRA Schedule of Events	1	24 August 2017
HRA Statement of Activities	1	24 August 2017
Interview schedules or topic guides for participants [Interview Questions]	Version 1	15 May 2017
Interview schedules or topic guides for participants [Demographics Form]	Version 1	15 May 2017
IRAS Application Form [IRAS_Form_26052017]		26 May 2017
IRAS Application Form XML file [IRAS_Form_26052017]		26 May 2017
IRAS Checklist XML [Checklist_26052017]		26 May 2017
Letter from funder [Research Review Committee Approval Letter]		27 July 2016
Letter from sponsor [Liverpool Joint Research Office (Liverpool Health Partners) Sponsorship Approval]		18 November 2016
Letter from sponsor [Sponsor confirmation that changes are non-substantial]		18 August 2017
Other [Participant Debrief Sheet]	Version 1	15 May 2017
Participant consent form [Participant Consent Form]	Version 1	15 May 2017
Participant consent form [clean copy]	2	02 August 2017
Participant consent form [tracked copy]	2	02 August 2017
Participant information sheet (PIS) [Participant Information Sheet]	Version 1	15 May 2017
Participant information sheet (PIS)	2	02 August 2017
Research protocol or project proposal [Comprehensive Research Proposal]	Version 1	15 May 2017
Summary CV for Chief Investigator (CI) [CV - Gundi Kiemle - Chief Investigator - Supervisor]	Version 1	09 May 2017
Summary CV for student [CV - Lloyd Gemson Principal Investigator - Student]	Version 1	14 May 2017
Summary CV for supervisor (student research) [CV - Jen Unwin - Supervisor]	Version 1	15 May 2017
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Recruitment and Research Flowchart]	Version 1	15 May 2017

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Mr Alex Astor

Tel: 0151 794 8739

Email: sponsor@liv.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments.
2.1	Participant information/consent documents and consent process	Yes	Following REC review, the applicant provided an updated consent form to bring it line with HRA Standards. This change was deemed as non-substantial by the sponsor and does not require submission to REC. The applicant has confirmed that a copy of the signed Consent Form will not be filed on the participants' medical records.
3.1	Protocol assessment	Yes	No comments.
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has provided statement of activities and schedule of events. No other form of agreement is required, or

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			will be used.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study.
4.3	Financial arrangements assessed	Yes	The study is not externally funded.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments.
5.3	Compliance with any applicable laws or regulations	Yes	No comments.
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion (with additional conditions) was issued on 04 July 2017. The applicant provided updated documentation and the REC acknowledged conditions had been met on 24 August 2017.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments.
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments.
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments.

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type participating in this study. All research activity is the same at participating NHS sites as detailed in the study protocol and supporting documentation.

Please note that the remit of HRA Approval is limited to the NHS involvement in the study. Research activity undertaken at non-NHS sites is therefore not covered and the research team should make appropriate alternative arrangements with relevant management at these organisations to conduct the research there.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The sponsor has confirmed that a Local Collaborator is required at participating NHS Site who has already been identified.

The sponsor has confirmed that no training is required.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Local members of staff undertaking research activities do not require access arrangements.

Where arrangements are not already in place, network staff (or similar) undertaking any research activities that may impact on the quality of care of the participant (such as informed consent procedures), would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.
- Please note the final list of documentation does not match with the final list of REC approved documentation. This is due to the submission of a non-substantial amendment (that does not require submission to REC) in order to bring the study in line with HRA Standards.
- Local sites will be expected to facilitate access to a meeting room for the interviews to be conducted.

RECRUITING PARTICIPANTS FOR RESEARCH

Post-traumatic growth following spinal injury

Post-traumatic growth means that some positive life changes can be experienced as a result of the struggle with a major traumatic event. We are conducting research with people who have had a sudden spinal cord injury in the past, to explore **HOW** they have been able to experience some positive personal change and growth over time, and **WHAT** this means to them personally.

To take part you must:

1. be under the care of the North West Regional Spinal Injuries Centre
2. be fluent in English
3. have experienced a sudden and unexpected spinal cord injury as an adult (18 years or older) at least 10 years ago
4. feel that you have experienced some positive personal change and growth in your life since your spinal cord injury, and be willing to talk about this for an hour with a researcher

If you have experience of this and would like to share your story or would like more information, please email lloyd.gemson@liverpool.ac.uk or complete a reply slip (behind reception at the Spinal Injuries Centre). Alternatively, you can phone **Emily Joseph (Research Administrator – Tel: 0151 7945102)** and leave a contact telephone number and a message saying that you are interested.

Thank you
Lloyd Gemson



Appendix F

Advert Reply Slip



D.Clin.Psychology Programme, School of Psychology, Whelan Building, Quadrangle, Brownlow Hill, LIVERPOOL, L69 3GB
Tel: 0151 794 5530/5534/5877/ Fax: 0151 794 5537
www.liv.ac.uk/dclinpsychol

Reply Slip

Post-traumatic growth following spinal injury

Researcher: Lloyd Gemson (Trainee Clinical Psychologist, University of Liverpool)

Primary Supervisor: Dr. Gundi Kiemle
(Doctorate in Clinical Psychology Training
Programme, University of Liverpool)

Secondary Supervisor: Dr. Jen Unwin
(Dept. Clinical Health Psychology, Southport
and Ormskirk Hospital NHS Trust)

Please only provide contact details below that you are happy for Lloyd Gemson to contact you on.

I am interested in your study and would like you to contact me and provide more information regarding taking part in your research.

Name: _____

Age: _____

Address: _____

Home phone number: _____

Mobile phone number: _____

Email address: _____

I _____ consent to Lloyd Gemson (Trainee Clinical Psychologist) contacting me via the details that I have provided above.

Please post this reply slip to Lloyd Gemson in a provided stamped addressed envelope.

Appendix G

Participant Information Sheet and Opt-in Form



D.Clin.Psychology Programme, School of Psychology, Whelan Building, Quadrangle, Brownlow Hill, LIVERPOOL, L69 3GB
Tel: 0151 794 5530/5534/5877/ Fax: 0151 794 5537
www.liv.ac.uk/dclinpsychol

Participant Information Sheet

Title of research:

Post-traumatic growth following spinal injury

Invitation

I would like to invite you to take part in a research study. This leaflet contains information about why the research is being carried out and what will be involved. It is important that you take your time to read this leaflet carefully before deciding whether to take part. Please do not hesitate to ask me any questions that you may have about the research.

What is the purpose of the research?

My name is Lloyd Gemson and I am a Trainee Clinical Psychologist on the University of Liverpool's Doctorate in Clinical Psychology Programme. I am undertaking this research as part of my professional training.

There is research to show that it is possible for individuals who have experienced traumatic events and injuries, to experience some positive personal change over time. This is understood to result from the struggle of coming to terms with the traumatic event, and is referred to as post-traumatic growth. Our research aims to improve understanding of HOW some individuals with a spinal cord injury experience post-traumatic growth, and WHAT personal meaning they can find in this. The findings of this research could be used to inform and instil hope in individuals who are living with a spinal cord injury, as well as their families, and the healthcare professionals involved in their treatment and care.

Why have I been invited?

You have been invited to take part in this research, as you (1) are currently under the care of the North West Regional Spinal Injuries Centre, (2) are fluent in English, (3) experienced an acute (sudden and unexpected) spinal cord injury as an adult (18 years or older), (4) at least 10

years ago, (5) and feel you have experienced some post-traumatic growth and positive personal change in your life since your spinal cord injury, and are willing to talk about this with me.

Do I have to take part?

No, it is entirely up to you to decide. If you decide to take part in the research, you or someone else on your behalf can let me know by email (lloyd.gemson@liverpool.ac.uk), or by completing the attached opt-in form. Alternatively, you could phone Emily Joseph (Research Administrator – Tel: 0151 7945102) and leave a contact telephone number and a message explaining that you would like to take part in the research. Once you have opted-in, if you decide it is not for you, then you are free to withdraw from the research (up to two weeks after the interview). Whether you do or do not decide to take part in this research, your standard of care will not be affected.

What will happen if I do take part?

First, I will contact you to further discuss the details of the research and answer any questions that you may have. If you are happy to continue, I will check that you meet the inclusion criteria for the study, and if so, then you will be invited to take part in an hour long interview with myself at a date, time and location (home or at the Spinal Centre) that is best for you. The interview will be audio recorded on a digital voice recorder. The interview recording will be anonymous, and will be transcribed (typed) into written format by a University approved transcriber. After the transcription is completed, the recording will be erased. Your personal details, and any other identifiable details, will be deleted or anonymised when your interview has been transcribed.

What are the benefits of taking part and what are the risks?

There are no direct benefits of taking part in this research. However, taking part in the interview will allow you the space to reflect on the changes and any positive experiences you have had since your spinal cord injury. Although there are no anticipated risks, it is important to acknowledge that talking about your experiences may be very distressing. You do not have to answer anything that you are uncomfortable with, and you can take a break or stop the interview at any time. If you do find that the process raises any distressing feelings that you may want help with, you will be able to make an appointment to speak to Dr. Suzanne Clarke (Clinical Psychologist – details at the end of this form).

What if something goes wrong?

If you are unhappy with any aspect of the research process, I will be more than happy to discuss it with you (Lloyd Gemson – contact details at the end), or you could contact my primary supervisor (Dr. Gundi Kiemle – contact details at the end), who will do their best to answer any of your concerns. However, if you feel that you would like to make a formal complaint, please contact: Mr Alex Astor, **The Head of Health and Life Sciences Research Support Office**; Email: sponsor@liv.ac.uk ; Address: 2nd Floor Block D Waterhouse Building, 3 Brownlow Street, Liverpool, L69 3GL; Tel: 0151 794 8739.

Will my taking part in this research be kept confidential?

Yes, all information that I collect from you during the research will be kept strictly confidential. Your data will be handled in line with the Data Protection Act (1998), and the University of Liverpool's policy on research data management.

- The interview will be listened to and transcribed into a Microsoft Word file by a University approved transcriber. All identifying information will have been removed.
- The recorded file will be password protected and stored on a secure electronic drive at the University of Liverpool. All audio recordings will be destroyed as soon as the analysis process is complete.
- Your anonymised interview or interview transcript may be listened to or read by my research supervisors, in order to ensure that I am carrying out the interviews appropriately.
- Once the research is completed (September 2018), all hard copies of data will be destroyed via the University Records Management Services. All electronic (but not audio) data will be securely stored for a minimum of ten years. My Supervisor, Dr Gundi Kiemle, will be the data custodian, and will ensure that all copies of data files related to the project are securely destroyed at the end of the data retention period (10 years).
- I will only break confidentiality if you discuss anything that would cause me to have a serious concern about the safety or wellbeing of you or others, as I have a duty of care to share this information. This would involve speaking to my supervisors, Dr Gundi Kiemle and Dr Jen Unwin, and may involve talking to your GP or other professionals. Where possible, I would discuss this with you first. Confidentiality will be discussed again with you at the start of the interview, which will give you another opportunity to ask any questions regarding the boundaries of confidentiality.

What will happen to the results of the study?

The results of this research will be written up and submitted in part-fulfilment of the Doctorate in Clinical Psychology Programme. It is intended that the findings of this research, along with relevant participant quotes, will be published in a scientific journal and may also be presented at relevant conferences. All participants will remain anonymous and individual quotes will not be personally identifiable. If you would like to receive a summary report on the findings of this research, please contact me (Lloyd Gemson – contact details at the end).

Who is funding this research?

This research is funded by the University of Liverpool.

Who has authorised this study?

This study has been approved by the Research Review Committee for the University of Liverpool's Doctorate in Clinical Psychology Programme, and has been sponsored by Liverpool Health Partnership. It has also been given full approval by an NHS Research Ethics Committee and by Southport and Ormskirk Hospital NHS Trust's Research and Development Team.

For Further information, please contact:

Lloyd Gemson

Doctorate in Clinical
Psychology Programme
University of Liverpool
School of Psychology
Whelan Building
Liverpool, L69 3GB
Tel: 0151 794 5877 (office hours)
Email: lloyd.gemson@liverpool.ac.uk

This research is supervised by:

Dr. Gundi Kiemle

HCPC registered Clinical
Psychologist & Academic Director
Doctorate in Clinical
Psychology Training Programme
University of Liverpool
Whelan Building
Liverpool, L69 3GB

Email: g.kiemle@liverpool.ac.uk

Tel: 0151 794 5877/ 5534/ 5530 (office hours)

Dr Jen Unwin

Consultant Clinical Psychologist
Clinical Health Psychology Department
5 Curzon Road
Southport, PR8 6PL

Email: j.unwin@nhs.net

Tel: 01704 387020 (office hours)

Clinical Psychologist at North West Regional

Spinal Injuries Centre:

Dr. Suzanne Clarke

North West Regional Spinal Injuries Centre
Southport District General Hospital
Town Lane
Southport
Merseyside, PR8 6PN

Email: suzanne.clarke8@nhs.net

Tel: 01704 704345 (office hours)



D.Clin.Psychology Programme, School of Psychology, Whelan Building, Quadrangle, Brownlow Hill, LIVERPOOL, L69 3GB
Tel: 0151 794 5530/5534/5877/ Fax: 0151 794 5537
www.liv.ac.uk/dclinpsychol

Research Opt-in Form

Post-traumatic growth following spinal injury

If you would like to take part in the research, you or someone else on your behalf can email Lloyd Gemson (lloyd.gemson@Liverpool.ac.uk) to arrange an interview, or complete this opt-in form. Alternatively, you can phone Emily Joseph (Research Administrator – Tel: 0151 7945102) and leave a contact telephone number and a message explaining that you would like to take part in the research.

I _____ have read and understand the Participant Information Sheet and would like to take part in your study. Please could Lloyd Gemson phone me on _____ or email me at _____ to arrange an interview.

Only include your address details below if you would prefer Lloyd Gemson to arrange your interview by post, rather than phone or email.

Address: _____

Please post this reply slip to Lloyd Gemson in the provided stamped addressed envelope.

Appendix H

Consent Form



D.Clin.Psychology Programme, School of Psychology, Whelan Building, Quadrangle, Brownlow Hill, LIVERPOOL, L69 3GB
Tel: 0151 794 5530/5534/5877/ Fax: 0151 794 5537
www.liv.ac.uk/dclinpsychol

Participant Consent Form

Post-traumatic growth following spinal injury

Researcher: Lloyd Gemson (Trainee Clinical Psychologist, University of Liverpool)

Primary Supervisor: Dr. Gundi Kiemle
(Doctorate in Clinical Psychology Training Programme, University of Liverpool)

Secondary Supervisor: Dr. Jen Unwin
(Dept. Clinical Health Psychology, Southport and Ormskirk Hospital NHS Trust)

I confirm that:

Please
initial:

- I have read and fully understood the contents of the Participant Information Sheet (version 2, dated: 07/07/2017) for this study.
- I have carefully considered all of the information presented and I have had the opportunity to ask Lloyd Gemson (Trainee Clinical Psychologist) questions regarding my participation in the above study, and I am satisfied with all of the answers given.
- I consent to my interview with Lloyd Gemson being audio recorded, and transcribed by a University of Liverpool approved transcriber who will adhere to a signed confidentiality agreement.
- I understand that Lloyd Gemson has a duty of care to break confidentiality and share information if he has a serious concern about my safety or wellbeing, or the safety or wellbeing of others. I understand that this would involve speaking to his supervisors, Dr Gundi Kiemle and Dr Jen Unwin, and may involve talking to my GP or other professionals. I understand that, where possible, Lloyd Gemson would discuss this with me first.

- As part of monitoring quality, I understand that my data could be reviewed by responsible individuals at the University of Liverpool or from regulatory authorities.

- I permit for the information that I provide (including the recording of my interview) being stored in line with the Data Protection Act (1998), and the University of Liverpool's policy on research data management (Document Number: RDM-PLN-POL_006).

- I consent to the audio recording of my interview being destroyed following transcription (by September 2017).

- I consent for all hard copies of data to be destroyed via the University Records Management Services once the research is completed (September 2018).

- I consent to all electronic (but not audio) data being securely stored for a minimum of ten years, as required by the University of Liverpool's policy on research data management (Document Number: RDM-PLN-POL_006).

- I consent to anonymised direct quotes to be taken from my interview and used in any publication or conference resulting from this study. I understand that it will not be possible for me to be identified in this way.

- I fully understand that my participation in this study is completely voluntary, and I am free to withdraw from this study and request withdrawal of my data for a period of two weeks after the interview, without any justification, and that this will not affect the service that I receive from the North West Regional Spinal Injuries Centre.

- I understand that if I withdraw from this study more than two weeks after my interview date, any information given by me (including my interview) will have been anonymised and transcribed, and will therefore be used in the study, and in any publication or presentation resulting from this study.
- I agree to all the information described in the Participant Information Sheet and this Consent Form, and fully consent to taking part in the above study.
- I would like to receive a summary report on the findings of this research.

Name of Participant (Print)

Signature

Date

Name of Trainee (Print)

Signature

Date

One copy to be given to the participant; one copy to be stored at the University of Liverpool.

Appendix I

Demographics Form

Gender: _____

Age: _____

Ethnicity: _____

Religion: _____

Marital Status: _____

Employment Status: _____

Age at time of injury: _____

Injury Type: Incomplete Paraplegia / Complete Paraplegia
(Please circle injury type) Incomplete Tetraplegia / Complete Tetraplegia

Appendix J

Semi-Structured Interview Schedule

Introduction

- Welcome the participant
- Introduce myself and explain my role
- Reiterate the focus of the research for the participant
- Discuss the boundaries of confidentiality
- Explain to the participant that they do not have to answer anything that they are uncomfortable with, and they can take a break or stop the interview, or withdraw from the research, at any time
- Ask the participant to complete the consent form
- Complete the demographics form with the participant

Before Spinal Cord Injury

1. Please tell me a little bit about yourself and what made you interested in taking part in this research?

2. Please can you tell me a bit about how your SCI happened?

Prompt

- What was the nature of your injuries?
- What was your experience in hospital like?
- What was your experience of the treatment you were having before you were discharged home?
- What were your home circumstances (accessibility) like pre-injury and then when returning home?

3. How would you describe yourself before the SCI?

Prompt

- What was your outlook on life?
- What was your purpose/what got you up in the morning?
- How did you view the world, others and self?
- How might others have described you?

Spinal Cord Injury Changes

4. How did your life change following the SCI?

Prompt

- Examples: Changes in daily functioning, independence, beliefs about the world, others and self, relationships, work, spiritual, hobbies/interests.
- What helped you to cope with these changes?
- How have you changed as a person following the SCI?

5. How did you experience these changes?

Prompt

- Over what period of time did the changes happen?
- How do you see the SCI contributing to the changes you have experienced?
- How did these changes affect your life? Are they still happening?

6. How did you make sense of your SCI?

Prompt

- How did you process what happened?
- Over time, how have your thoughts about your injury and your future changed?
- What helped you to find meaning in your life following your SCI?

Post-traumatic Growth

7. Over time, what positive personal change and growth have you experienced in your life, and how did these changes happen?

Prompt

- Example: Beliefs, opportunities, personal strength, spiritual, relationships, outlook on life.
- How have you changed as a person?

8. How do you make sense of these positive changes?

Prompt

- What helped make these changes happen?
- How did these positive changes affect your thoughts about your injury, yourself, your life and your future?
- What do these changes mean to you?

9. How would you describe yourself now?

Prompt

- What is your outlook on life, opportunities, and relationships now?
- How do you view the world, others and self now?
- How would others describe you now?
- How do you handle difficulties, problems or challenges now?

Other

10. Is there anything else you would like to tell me about post-traumatic growth/positive change following your SCI?

Debrief

- Is there anything else that you would like to say, add or expand on?
- How did you find taking part in the interview?
- How do you feel at the end of the interview?
- Do you have any questions you would like to ask me about the research?
- Thank you again for taking part in this research (go through the debrief sheet with the participant).

Appendix K
Debrief Sheet



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Debrief Sheet

Post-traumatic growth following spinal injury

Researcher: Lloyd Gemson (Trainee Clinical Psychologist, University of Liverpool)

Primary Supervisor: Dr. Gundi Kiemle
(Doctorate in Clinical Psychology Training
Programme, University of Liverpool)

Secondary Supervisor: Dr. Jen Unwin
(Dept. Clinical Health Psychology, Southport
and Ormskirk Hospital NHS Trust)

Participation

I would like to thank you for taking part in our research. The purpose of this research is to develop an understanding of HOW some individuals with a spinal cord injury experience post-traumatic growth, and to gain insight into their personal meaning-making of this experience. The findings of this research may help improve our understanding of post-traumatic growth and may help to provide hope for individuals who are living with a spinal cord injury, their families, and the healthcare professionals involved in their treatment and care. If you would like to receive a summary report on the findings of this research, please contact me (see below).

Further support

I hope that I was able to answer all of your questions during the interview, but if you have any further questions, please contact me (see below). **Importantly**, if taking part in the interview has left you feeling upset and you feel you would like to talk to a professional, you can make an appointment to speak to Dr Suzanne Clarke (Clinical Psychologist – details at the end of this form). For further support, you may also wish to contact your GP, or ask to be referred to a local psychological therapies service, or you can contact the services listed on the following page for support.

Finally, I would like to take this opportunity to thank you again for taking part in our research.

Lloyd Gemson

Doctorate in Clinical Psychology Programme
University of Liverpool, School of Psychology

Whelan Building, Liverpool, L69 3GB

Tel: 0151 794 5877 (office hours) **Email:** lloyd.gemson@Liverpool.ac.uk

Support Services:

Spinal Injuries Association

Telephone: 01908 604 191

Advice Line: 0800 980 0501

Samaritans

Telephone: 116123 (24 hours)

Email: Jo@samaritans.org

Mind

Telephone: 0300 1233393 (09:00 – 18:00, Mon – Fri)

Email: info@mind.org.uk

NHS: Big White Wall

Online support (24 hours)

<http://www.nhs.uk/Conditions/online-mental-health-services/Pages/big-white-wall.aspx>

Clinical Psychologist at North West Regional Spinal Injuries Centre:

Dr. Suzanne Clarke

North West Regional Spinal Injuries Centre

Southport District General Hospital

Town Lane

Southport

Merseyside

PR8 6PN

Email: suzanne.clarke8@nhs.net

Tel: 01704 704345 (office hours)

This research is supervised by:

Dr. Gundi Kiemle

HCPC registered Clinical Psychologist & Academic Director

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University of Liverpool,

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Liverpool, L69 3GB

Email: g.kiemle@liverpool.ac.uk

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Dr. Jen Unwin

Consultant Clinical Psychologist

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5 Curzon Road,

Southport

PR8 6PL

Email: j.unwin@nhs.net

Tel: 01704 387020 (office hours)

Appendix L

(Sarah) Example of exploratory comments and coding

Emergent Themes	Transcript	Descriptive	Linguistic	Conceptual comments
<p>Courage and determination to pursue new life purpose</p> <p>Survivor not a victim</p> <p>Adversity as the catalyst for growth and resilience</p> <p>Ongoing struggle</p>	<p>1. And the courage and the motivation to succeed and to do, and to get out of this hole, this isn't where you're meant to be, you're meant to be- it's this drive from the accident point, this drive- I'm meant to be doing something else. <u>Get up</u> and do it. <u>And that didn't exist in my life prior to that</u>, you know, I was just <u>on the track, not making things happen</u> but-</p> <p>2. And can you tell me more about that please? How that didn't exist but, since your injury, that kind of drive started?</p> <p>3. I think there <u>had never been any crisis in my life before that</u>. There had never been anything unpleasant happen in my life, nothing hard had ever happened, you know, I'd lost some grandparents, that was as hard as it got. But one of my best friends lost her father, you know, these things open your eyes but there wasn't very much had, there wasn't any adversity, much adversity had crossed my path prior to that. And I think that's what was quite difficult because, yes, a lot of my friends, you know, no adversity passed them and now I <u>was in the middle of it</u>. But since then that adversity, that's what fires me to achieve. It's a real firing of, you know, if I feel like I've got caught in a slump then things aren't well and I'm, you know, sometimes the injuries they play havoc and arthritis has set in, about six years ago now, and I take the right things. And I'm constantly <u>on this mission</u> to be doing the right thing for myself. Because if I don't, I know that if I go about three months without action, without physical</p>	<p>Courage and determination drive you forward</p> <p>They come from the notion that you are meant to be doing something more important with your life</p> <p>On the track not making things happen</p> <p>No adversity in her life before</p> <p>Adversity gives her a need to achieve</p> <p>Gets her out of slumps</p> <p>Constantly on a mission to do the right things</p>	<p><u>Get up</u> – Survivor?</p> <p><u>And that didn't exist in my life prior to that</u> – a new clarity and courage have arisen from the accident</p> <p><u>on the track not making things happen</u> – a new sense of purpose and drive</p> <p><u>had never been any crisis in my life before that</u> – crisis was the catalyst for her growth</p> <p><u>was in the middle</u> – now come out the other side?</p> <p><u>On a mission</u> – New sense of purpose</p>	<p>Tenacity</p> <p>Courage</p> <p>New sense of purpose</p> <p>Sarah appears to put her personal growth down to the injury and the adversity and struggle that followed</p> <p>the struggle is ongoing</p>

Appendix M

Master Themes and Sub-themes for Each Participant

Master Theme	Sub-theme	Mark	Julie	Frank	Sarah	Thomas	James
The earthshattering consequences of injury	Carefree and the world at one's feet	✓	✓	✓	✓	✓	✓
	Plunged into a cruel new world	✓	✓	✓	✓	✓	✓
	Life changing impact for family	✓	✓	✓	✓	✓	✓
Determination to reclaim one's life	Survival is a choice	✓	✓	✓	✓		✓
	Grieving and accepting the permanence of the injury	✓	✓	✓	✓	✓	✓
	Protecting the fragile self	✓	✓	✓	✓	✓	✓
	Support as a salvation	✓	✓		✓	✓	✓
Roses (PTG) and thorns (injury and struggle)	Injury as a catalyst for growth	✓	✓	✓	✓	✓	✓
	Self-actualisation	✓	✓	✓	✓	✓	✓
	The continuous struggle with the injury	✓	✓	✓	✓	✓	✓