

‘Putting a New Perspective on Life’: A Qualitative Grounded Theory of Posttraumatic  
Growth Following Acquired Brain Injury

Ionie Charlotte Corlett Lyon

Date of submission: 28<sup>th</sup> March 2017

Word Count (28,425, excluding appendices)

“This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with the author and that use of any information derived there from must be in accordance with current UK Copyright Law. In addition, any quotation or extract must include full attribution.”

Doctoral Programme in Clinical Psychology

University of East Anglia

**Thesis Abstract: ‘Putting a New Perspective on Life’: A Qualitative Grounded Theory of Posttraumatic Growth Following Acquired Brain Injury**

**Ionie Charlotte Corlett Lyon**

**Year of submission: 2017**

**Background:** Posttraumatic growth is the concept that following a traumatic experience and the resulting struggle with significant adversity some people may start to view their experiences as a springboard for growth (Silva, Ownsworth, Shields, & Fleming, 2011). However, there is currently limited understanding of the process of how posttraumatic growth (PTG) develops following acquired brain injury (ABI).

**Method:** This research explored the process of developing PTG following ABI. Semi-structured interviews with 10 participants about their experience were transcribed and analysed according to a grounded theory method. Participants were recruited from a brain injury charity with the aim of involving them at every step of the research process.

**Results:** The findings suggest a dynamic and fluid process in the development of PTG. Four themes were constructed from the data and comprise the model. These themes are inter-connected and are: “living with a life changing injury”, “trying to ‘beat it’ and acceptance”, “identifying with a new you and others” and “meaningful positive change”.

**Conclusion:** PTG was described by the participants as a process of acceptance, identifying with others and developing new views of themselves and a changed perspective, leading to a belief that there is “life after brain injury”. The theoretical model suggests that identity and relationships are a key process in the development of PTG. Whilst this is consistent with existing literature it also suggests the importance of shared experience which needs to be explored in more detail. Future directions and implications for rehabilitation are discussed.

## **Acknowledgments**

I would like to thank my supervisors, Dr Paul Fisher and Dr Fergus Gracey, for their knowledge, honesty and trust at all stages of the project, and when needed the most.

I will always be grateful to the staff at Headway, and all those who were interested, for their enthusiasm and support, and for ensuring recruitment was possible - I never thought I would be oversubscribed. Last, but not least, I would like to express a heartfelt appreciation to the participants who gave up their time to be interviewed and to share their experiences. Not only would there be no project without you but your openness and enthusiasm were inspiring.

Furthermore, I would like to say 'thank you' to my parents who spent many a weekend and evening looking after my son. Without your support this would not have been possible.

## **Dedication**

This thesis is dedicated to my son, James, who inspires me with his imagination, curiosity, and resilience. Thank you for sharing with me your delight in surprises, and always trying to make me laugh with your jokes.

## Contents

<b>Summary of thesis portfolio</b> .....	<b>7</b>
<b>Systematic Review</b> .....	<b>8</b>
1. Abstract.....	10
2. Introduction.....	11
3. Method.....	16
3.1 Identifying relevant studies.....	17
3.2 Study selection.....	18
3.3 Description of the studies.....	19
3.4 Critical appraisal.....	23
3.5 Method of synthesis.....	24
4. Results.....	25
4.1 Critical appraisal.....	25
4.2 Synthesis of qualitative findings.....	28
5. Discussion.....	36
6. References.....	42
<b>Bridging Chapter</b> .....	<b>49</b>
1. Review of posttraumatic growth literature.....	50
2. Systematic review.....	51
2.1 Spinal cord injury.....	52
3. Research paper.....	52
3.1 Acquired brain injury.....	53
4. Comparison of acquired brain injury and spinal cord injury.....	54
<b>Research Paper</b> .....	<b>57</b>
1. Abstract.....	59
2. Introduction.....	60
3. Methodology.....	63
3.1 Study design.....	63
3.2 Participants.....	64
3.3 Data collection.....	65
3.4 Sensitivity to context.....	66

3.5 Analysis.....	67
5. Results.....	69
5.1 Living with a life changing injury.....	71
5.2 Trying to “beat it” and acceptance.....	72
5.3 Identifying with a new you and others.....	74
5.4 Experiencing meaningful positive change.....	76
6. Discussion.....	79
7. References.....	84
<b>Methodology and Design.....</b>	<b>89</b>
1. Design.....	90
2. Ontology and Epistemology.....	91
3. Methodology.....	93
4. Rigour and Validity.....	95
5. Researcher Position.....	98
6. Reflections on the research process.....	101
6.1 Writing the thesis.....	101
6.2 Dissemination and sculpture.....	102
<b>Discussion and Critical Appraisal.....</b>	<b>104</b>
1. Summary of results.....	105
2. Rigour and Quality markers.....	107
2.1 quality of research paper.....	108
2.2 Quality of Systematic review.....	111
3. Clinical Implications.....	112
3.1 Future work and ideas.....	113
4. Conclusion.....	114
<b>References.....</b>	<b>115</b>
<b>List of Appendices.....</b>	<b>134</b>
<b>Appendix A:</b> Author guidelines for the Journal of Disability and Rehabilitation.....	<b>135</b>
<b>Appendix B:</b> Process of thematic analysis for the systematic review.....	<b>148</b>
<b>Appendix C:</b> UEA Ethical approval for research paper.....	<b>149</b>
<b>Appendix D:</b> Interview Schedule for research paper.....	<b>150</b>
<b>Appendix E:</b> Example of the analysis process for research paper.....	<b>152</b>
<b>Appendix F:</b> Example of an emerging theme of the research paper.....	<b>157</b>

**Appendix G:** Response to the findings from Headway – Sculpture.....160  
**Appendix H:** Headway approval of the research project.....161  
**Appendix I:** Participant Information Sheet for research project.....162  
**Appendix J:** Consent Form for research project.....168

## Summary of Portfolio

**Section A:** Section A is a systematic review of qualitative data using the narrative synthesis method. This synthesis aimed to review the existing literature describing the role social support may play in the development of posttraumatic growth following spinal cord injury. It had two main aims: firstly, to critique the included studies using a structured appraisal tool, in order to be able to make comments about the quality of the existing evidence base. Secondly, following this, a synthesis of the results from the included studies aims to determine similar themes across the studies, focusing on the role of social support in the development of posttraumatic growth.

**Section B:** In order to draw similarities between the synthesis and the research paper (Section C), this bridging chapter explores the similarities between spinal cord injury and acquired brain injury.

**Section C:** This section presents the main research paper. This followed a grounded theory method, exploring the process of posttraumatic growth for adults with acquired brain injury. The results are described in terms of the key themes in the process of posttraumatic growth, and a theoretical model constructed from the data is presented. The findings are integrated with existing theory and research, and clinical and research implications are presented.

**Section D:** This chapter outlines the methodology and design used for both the synthesis and research paper. In addition, quality markers are discussed in relation to carrying out qualitative research with a reflective section to demonstrate the rigour of the study.

**Section E:** This chapter summarises the main findings, with a discussion and critical evaluation of the strengths and limitations of the studies, in addition to the clinical implications and areas of future research.

## **SECTION A**

### Systematic Review

Does the experience of social support promote the development of posttraumatic growth following spinal cord injury? A narrative synthesis of qualitative research

Prepared for submission to the Journal of Disability and Rehabilitation

Word count (7683, excluding references)

**Does the experience of social support promote the development of posttraumatic growth following spinal cord injury? A narrative synthesis of qualitative research**

Ionie Lyon<sup>a\*</sup>, Paul Fisher<sup>b</sup>, and Fergus Gracey<sup>c</sup>

*<sup>a</sup> Trainee Clinical Psychologist, Doctorate in Clinical Psychology, University of East Anglia, Norwich, UK.*

*<sup>b</sup> Clinical Lecturer, Department of Clinical Psychology, School of Medicine, University of East Anglia, Norwich, UK*

*<sup>c</sup> Senior Research Fellow, Department of Clinical Psychology, School of Medicine, University of East Anglia, Norwich, UK*

Address for correspondence\* Ionie Lyon, Trainee Clinical Psychologist, Doctorate Programme in Clinical Psychology, Department of Clinical Psychology, School of Medicine, University of East Anglia, Elizabeth Fry Building, Norwich NR4 7TJ

[I.Lyon@uea.ac.uk](mailto:I.Lyon@uea.ac.uk)

# **Does the experience of social support promote the development of posttraumatic growth following spinal cord injury? A narrative synthesis of qualitative research**

## **Abstract**

Purpose: This narrative synthesis aims to appraise the existing literature and explore subjective experiences of social support in the development of posttraumatic growth (PTG) following spinal cord injury (SCI). *Method – data sources:* Peer-reviewed journals were identified, using PsychInfo, MEDLINE, CINAHL and PubMed search engines. *Study selection:* The search criteria included key words for PTG, SCI and social support. After duplicates were removed 600 abstracts were screened, applying inclusion and exclusion criteria. *Data extraction:* The 10 selected studies were reviewed in detail, critically appraised, with key themes identified. *Results:* Using the Critical Appraisal Skills Programme (CASP) qualitative checklist, the quality of the 10 studies varied, with the studies meeting between five and eight of the ten criteria. In addition, the narrative synthesis identified five interrelated themes: the self in social relationships, re-connecting with the social world, meeting others with SCI, building closer relationships with family, and social support from others. *Conclusions:* The quality of the studies varied, demonstrating the difficulty with using the CASP to evaluate qualitative research. The synthesis suggests that the experience of social support, social identity, and comparison with others can facilitate the development of PTG. Further research into the relationship between social support and PTG is needed.

Keywords: Posttraumatic growth, social support, peer support, identity, spinal cord injury

## **Implications for Rehabilitation**

- Social support from others with SCI may foster the process of PTG. Specialist rehabilitation and community services may be able to facilitate **group membership**, how this can be assessed and incorporated into interventions should be considered.
- Health professionals can enhance a person's opportunity to develop **social relationships** by increasing meaningful activities with others who have experienced SCI.
- Appropriate support from family and friends can facilitate the person incorporating new views of self, of others and of the world following the impact of SCI. The role that educating family and friends has on facilitating successful recovery for the person with SCI needs further consideration.
- Increasing opportunity for upward or downward social comparison via community and/or sporting groups as well as the use of technology such as online forums and/or community groups for survivors of SCI - needs further exploration.

## **Introduction**

Spinal cord injury (SCI) can be considered to be one of the most debilitating injuries which may confront a person [1]. The consequences of such an injury will impact on social relationships and participation, reintegration into the community, and employment [2] as well as mobility [3]. Thus, affecting a person's quality of life and presenting a stressful process for family members, resulting in their own poor physical health [4]. Being confronted with a lifelong process of adapting to a physical disability increases the risk of poor mental health, poor adjustment and poor coping skills such as substance abuse, and risk of suicide [5]. However, research has suggested that people appear to adapt better following SCI when they have sought social support [6] and social participation [7].

### ***Identity and social support***

Learning to live with a disability and the physical changes following an injury such as SCI, may require a person to adapt to how they navigate social circumstances and engage in activities [8]. Being able to adapt and develop new opportunities to participate with social activities has been suggested to increase the feeling of being a part of society [9]. Some authors have explored how coping is linked to social comparison through relating one's own characteristics to those of other people [10-12]. The downward comparison theory [13] suggests that when a person facing serious disease compares themselves to others who they perceive as worse off, this may have an adaptive function [14]. In addition, upward self-identification can foster positive feelings and provide opportunities to learn from others who are coping better [14, 15]. The beneficial effects of various forms of social connectedness within relationships and group membership have been shown to buffer a person's ability to overcome adversity [16, 17].

Furthermore, social support has long been recognized as important in adjusting to the physical and psychosocial challenges following SCI [18]. High levels of social support among people with SCI are associated with higher life satisfaction, higher levels of well-being, and improved employment rates [19] when compared to those receiving less social support. Relationships with others who have shared experiences can be considered the most effective type of support for people experiencing stress [20]. This idea of support via similarities stems from the social comparison theory, which suggests that people prefer to associate with others who have faced a similar crisis so that they can compare and learn effective coping abilities [21]. The impact of SCI, and the challenges this places on a person's self-identity and identity within relationships, may share similarities with the meaning-making process of PTG, whereby, a person understands and makes sense of traumatic experiences. It has been suggested, that following injury people can view themselves as stronger as a result of the active nature of defining self and social

relationships [17]. Therefore, understanding the value of social support following SCI may add to our understanding of the development of PTG.

### *Posttraumatic growth*

Research has started to focus on why some individuals report positive changes following SCI. The phrase posttraumatic growth (PTG) was coined **by Tedeschi and Calhoun** [22] to explain the phenomenon of positive psychological growth following trauma [22-24]. This model of PTG suggests that the struggle with trauma can not only produce psychological distress but can also provide the opportunity for the experience of PTG. The experience of trauma has been assumed to challenge a person's core beliefs that define their assumptions about the world and the self, or their assumptive world [25, 26]. Following trauma these prior assumptions are often shattered and can influence a person's interpretation of the past, and expectations of the future [27], with PTG emerging from the process of coming to terms with the event and rebuilding the assumptive world. This rebuilding of a person's assumptions may result in re-examining many aspects of their life, with PTG often reported in five key areas: relating to others, new possibilities, personal strength, spiritual change, and appreciation of life [24, 25, 28]. This phenomenon is **different from coping or adjusting** to changes following a trauma. This is thought to be because a key element of PTG is that individuals experience and report growth and improvement rather than returning to how they were before [23]. In addition, the organismic valuing process theory [29] suggests that a person moves through a process of assimilation, negative accommodation and positive accommodation of new-trauma information via their motivation to rebuild and re-evaluate their experiences.

Furthermore, theories of PTG do not suggest that PTG is a direct consequence of the traumatic experience, but rather that the focus is on the process whereby a person changes their world view following trauma [28]. PTG is often considered to be both an outcome and

a process, and as such has been suggested that it differs from the concepts of both coping and resilience [30]. Resilience is often understood as a person adapting to distressing life circumstances, with resilience encompassing the ability to cope with trauma and the resulting aftermath [31]. Resilience may be required to cope with the initial distress following trauma but this does not necessarily ensure that PTG will emerge [23]. As such, PTG is viewed to be distinct from the concept of resilience or coping as it requires a person to engage actively in a meaning-making process in which their beliefs about themselves, the world and the future change [32]. This process **of re-evaluation** may be a key influencing factor through which transformation and growth can be developed [22, 25, 33].

Whilst PTG may not be reported by everybody following a traumatic experience, a growing body of literature has indicated that individuals who have sustained an SCI can experience PTG, with “Personal Strength” and “Spiritual Change” being identified as key areas of growth [34]. Further research identified that between 54% and 79% of a sample of people with SCI reported at least some positive change after injury, with the greatest change being people discovering they were stronger than they thought they were [35]. Recent research found that people who experienced PTG following SCI reported more meaningful family relationships, a greater recognition of strengths, and a greater appreciation of life [36]. Family relationships and engagement in and appreciation of life appeared to be predictors of PTG [37].

#### *Posttraumatic growth and social support*

One factor that has been identified as important in the development of PTG is the availability of, and satisfaction with, social support [38]. This suggests that the process of PTG requires the development of a social network which provides opportunity for empathy, and the development of new cognitions around the traumatic event [39]. A changed sense within one’s relationships can involve an experience of deepening relationships, increased

compassion and sympathy for others, and greater ease at expressing emotions. Being visibly disabled is a qualitatively unique experience because of the direct impact that a visible disability has on social relations, body image and identity [40]. Research on the integration necessary for positive adjustment to physical disability shows that people must integrate into society, integrate with the disability community, internally integrate sameness and differentness, and integrate feelings and self-presentation [39].

Considering previous studies on the role that social support and social identity comparison can play in learning to live with SCI, it is important to further explore the notion that social support can facilitate PTG. Understanding the role social support has for facilitating PTG will have clinical implications. Strong social support is suggested as fundamental in facilitating people with SCI being able to reconnect with the community and reconstructing their lives [41], and that close families and friends need to be involved in the rehabilitation process [42]. Yet it is still unclear how these factors may influence the development of PTG. It would be conducive to consider the quality of the current literature and consider what areas of future research may be most applicable.

**Previous reviews** have been applied more broadly to the area of severe physical injury and the concept of PTG [43] or were limited to increased spirituality, following SCI with studies where PTG was a key concept [44]. The aim of this review, therefore is to expand on the current understanding of how social support may play a role in the process of PTG following SCI. Evaluating the findings from previous studies for the role of social support in the process of developing PTG will be important in considering future directions and potential interventions for rehabilitation services.

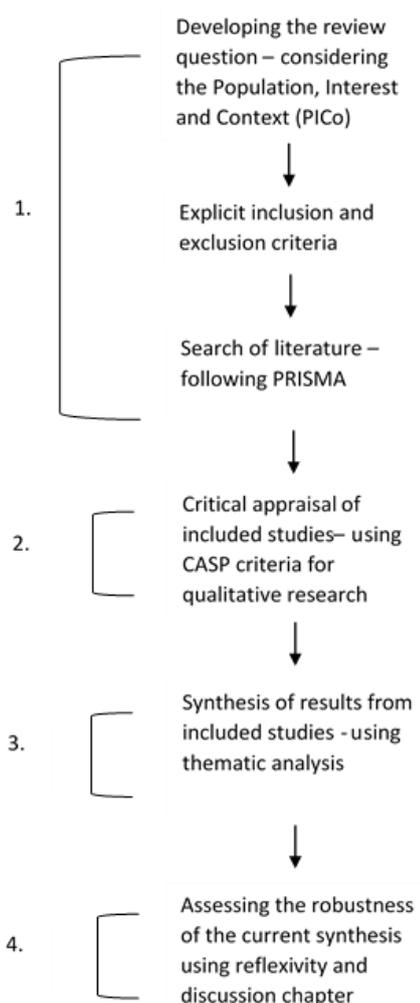
In order to address these aims, the systematic review will use the techniques of a narrative synthesis in order to review and evaluate the descriptive accounts of a person's

experience of social support, and the role that this may play in developing PTG following SCI.

## **Method**

The narrative synthesis was chosen because it is well suited for synthesising findings from multiple studies where the results are qualitative [45]. This review has followed the guidance by Popay [46] for carrying out a narrative synthesis which suggests four elements that reviewers can move along in an iterative manner during the synthesis (Figure 1). These four elements suggested were considered throughout, initially by developing a tightly focused review question in order to identify the study selection criteria in advance, and to limit and focus on the amount of evidence required to address the review question [47]. This was to ensure that a clear, coherent and systematic approach could be followed during the synthesis [48]. The systematic review was undertaken during **December 2016**. Other interpretative qualitative systematic review methods [49] were considered, namely meta-synthesis. The main difference between the narrative synthesis and **meta-synthesis** is that this current review was unable to develop a new theory from the research [45]. However, due to the extent of the available research it was decided that a systematic review may provide further understanding for future research. Furthermore, a pragmatic decision to utilise a narrative synthesis method was taken due to the clear and systematic guidelines that could be followed, and which has been recommended for novice researchers and those working without a team of researchers due to the complexity of carrying out a qualitative meta-synthesis [50].

Figure 1. Method of narrative synthesis carried out in this review



### ***Identifying relevant studies***

A number of search terms were used to identify studies on the topic of PTG and the role social support may have in the development in the field of SCI. These search terms were drawn from previous reviews in this area [43, 44]. The search terms “posttraumatic growth”, “post traumatic growth”, “post-traumatic growth”, “positive growth”, “stress-related growth”, “benefit finding”, “perceived benefits”, “positive changes”, “psychological growth”, “growth from adversity”, and “thriving” were used to identify studies on the topic of PTG. These were then combined with “spinal cord injury” or “spinal cord injuries” and were entered into the following databases: PsychInfo, Medline, CINAHLPlus, and PubMed. To address the question of the role social support plays in the development of PTG the

search terms “family”, “marital interactions”, “relationships”, “friends”, “social support”, “support system”, “peer support”, “families”, “relatives”, “parents” or “siblings” were added to narrow the initial results.

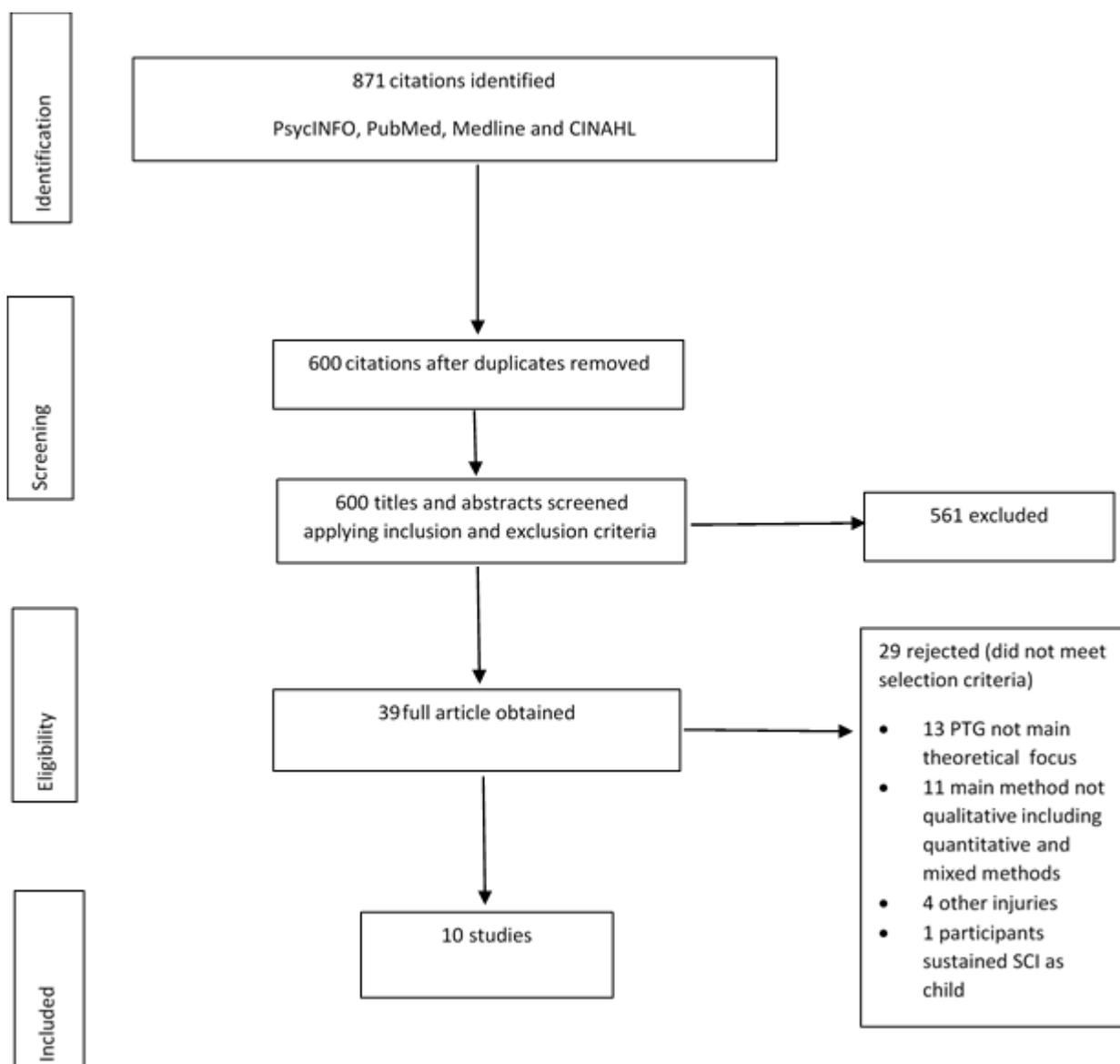
Papers were restricted to studies reporting qualitative data, and as the concept of PTG was first described in 1995 by Tedeschi and Calhoun [25], to those published between 1995 and 2016. Studies were written in English, and editorials and commentaries were excluded.

### *Study selection*

The study limited the search to SCI injury only and excluded studies if they focused on other diagnoses (e.g. head injury), or if they were interested in one specific aspect following SCI (e.g. pain management, sexuality, goal outcomes). This is similar to a recent scoping review [44] and meta-synthesis [43]. To ensure that sufficient descriptive detail was provided, mixed methods and quantitative studies were excluded.

This review included studies where the main focus was PTG and excluded studies that focused on other theoretical ideas or consequence of SCI, e.g. coping or pain. This was to ensure that the studies included in the review would contain the unique features of PTG [51]. The extensive search items for PTG were to ensure that even articles that did not have PTG in the title would be included, in order to ensure that key articles are found [52]. After duplicates were removed, 600 search results required further screening (Figure 2). This initial screening focused on removing obvious studies that did not meet criteria e.g. theses, book chapters, or non-human studies.

Figure 2. PRISMA flow chart



The titles and abstracts were then screened to identify articles that met the eligibility criteria, yielding 39 articles fitting the initial search strategy. The articles were read in full to ensure their quality. All studies were interviews with adults, and studies were excluded where participants had sustained their injury as a child. This was because the degree to which the growth process in children corresponds to the process observed among adults is as yet unclear [53].

### *Description of the studies*

The articles were all published between 2005 and 2015 and were reporting from a variety of countries, all of which were in the **developed world**. All studies reported a range of contextual information, with two studies reporting relationship status (Table 1). The studies used mixed-gender samples, with the exception of two which used male-only participants [54, 55] and one study that did not state the number of males or females within their sample [56].

The age at which participants sustained their injury varied, with the range being between 18 and 77 years. Time since injury also varied from less than one year to 18 years. The cause and severity of SCI also varied across studies, as well as the level of description reported within the studies. The majority of the studies recruited participants through purposeful sampling for PTG [36, 54, 55, 57, 58, 59, 06], or did not state how participants were recruited [56, 61, 62]. For the studies that used purposeful sampling the criteria were specific for each study but included reported good life satisfaction and evidence of achievements, and demonstrated positive psychological outcomes [36, 57, 58], low level distress, growth and resilience [60, 58], participation in a sport [55, 59] and having prior employment [54]. Inclusion criteria varied across the studies, although all participants had experienced SCI and were being interviewed as an adult. Exclusion criteria included having a head injury [62], or not being physically unwell [61].

Table 1. Summary of included studies

First author, year, country, reference	Phenomenon of interest	Key search term	Sample	Injury Characteristics	Relationship status	Community setting and ethnicity	Methods of data gathering	Methods of data analysis	Main results
Lohne, 2005, Norway [56]	Experiences of hope and meaning	Benefit finding	10, 6 men and 4 women, 23 and 77 years of age, one year post injury	2 inner vascular damage, 8 external injuries, 4 complete spinal cord damage, 6 incompletely injured.	Did not state	Recruited from rehabilitation centre. 9 interviewed in own home, 1 in author's office.	Semi-structured interviews	hermeneutic-phenomenological method	Experiences of hope were necessary for further progress and personal development. With 'hoping, struggling, and growing' as a sub-theme, with an important aspect of struggling is becoming personally enriched
Chun, 2008, Canada [36]	Characteristic of PTG	PTG	15 participants with SCI, 10 male and 5 female, ranged in age 27-58, average length of time since injury and work 10.7 years	5 Quadriplegic and 10 paraplegic, caused by car accidents, gunshot, falls, and work accidents.	9 living alone, 6 married with children	Community, 8 held jobs (6 full time and 2 part time), 3 community volunteers, 2 negative cases did not work.	In-depth interviewing	Thematic analysis based on grounded theory methodology	The three most salient themes of PTG were identified: experience of meaningful family relationships, experiences of meaningful engagement and appreciation of life
Chun, 2010, Canada [57]	The role of leisure in experience of PTG	PTG	15 participants with SCI, 10 male and 5 female, ranged in age 27-58, average length of time since injury 10.7 years.	5 Quadriplegic and 10 paraplegic	Did not state	Community. 13 white American and 2 African American.	In-depth interviews	Thematic analysis based on grounded theory methodology	This study found a vital role of meaningful engagement in activities for experiencing PTG
Van de Velde, 2010, Belgium [54]	Perceived participation	Stress-related growth and thriving	11 male patients. Range in age 25-58 years.	Low level SCI (paraplegia)	Living with partner at time of discharge, 6 married, 5 co-habiting	Transition from hospital to home, employed prior to injury.	Semi-structured interviews	Grounded theory	Participant's experienced three different types of participation: occupational, social and socio-occupational participation. Participation were viewed as a set of values with the ability to perform activities enhancing personal growth
Kaiser, 2011, UK [61]	Ability to cope	Thriving and psychological growth	10 patients, 8 men and 2 women aged between 18 and 65. Recruited between 28 – 367 days since injury.	5 cervical, 4 thoracic, 1 lumbar. With 7 complete and 3 incomplete.	Did not state	Inpatient (10-92 days since commenced rehabilitation.	Cross-sectional interview study	Interpretive phenomenological analysis	Appraisals following SCI are complex and relate not only to the individual but also to their context, life stage, roles and relationships. Changes in perceptions of self and the world were also a theme that emerged thus enabling experience to be integrated into an individual's life with this acceptance allowing PTG to occur

Table 1. (Continued)

First author, year, country, reference	Phenomenon of interest	Key search term	Sample	Injury Characteristics	Relationship status	Community setting and ethnicity	Methods of data gathering	Methods of data analysis	Main results
Griffiths, 2012, UK [60]	Positive psychological outcomes	PTG and psychological growth	6 participants, 2 female, 4 male. Between 2 and 11 years post injury age ranges 20-60 years	Incomplete paraplegia to complete tetraplegia.	Did not state	Community	Semi-structured interviews	Interpretive phenomenological analysis	Participants identified social support and meaningful activities as being important to a positive psychological outcome
Chun, 2013, USA [58]	Gratitude in everyday life	Positive changes	15 participants with SCI, ranged in age 28-58, 10 male and 5 female, average time since injury was 10.7	5 Quadriplegic and 10 paraplegic	Did not state	Community	In-depth interview	Thematic analysis based on grounded theory methodology	The findings demonstrated that participants benefited from their efforts to appraise challenging life experiences as positive
Kennedy, 2013, UK [62]	Positive psychological outcomes	PTG and benefit finding	232 participants at 6 weeks, at 12 weeks, 184; at 2 year point, 90, 71 male, 19 female, age range 18 to 74 years. Time since injury was 6 weeks to 2 years.	SCI	Did not state	Recruited from specialist units. Unclear over the course of the study if participants returned to community	Open ended written questions 4 time points: 6 weeks, 12 weeks, 1 year, & 2 years	Thematic analysis - qualitative longitudinal multivariate panel design	A broad range of positive psychological outcomes are possible following SCI including finding positive benefits in relationships
Machida, 2013, Japan [55]	Experiences of sport participation	Benefit finding	12 male wheelchair rugby players, aged 21-41 years	Quadriplegia complete and incomplete injuries	Did not state	Community	In-depth semi-structured interviews	Analytic induction	Gains from the resilience process in terms of positive changes in their social relations after the injury
Crawford, 2014, Canada [59]	Experiences of sport participation and PTG	PTG	12 participants with SCI, ranged in age from 24-55, mean time since injury 18.83.	5 motor accident, 4 sporting events, 1 fall, 1 boat accident, 1 combat exposure.	Did not state	Community	Survey and semi-structured phone interviews	Content analysis using an interpretational analysis	Participation in physical activity can influence perceptions of PTG. Specifically, participants experienced social gains from participation in ParaSport after acquiring SCI

## *Critical Appraisal*

After identifying and selecting the relevant articles, the included studies were appraised using the Critical Appraisal Skills Programme (CASP) for qualitative studies [63]. This appraisal tool was chosen as it has been used widely and recommended [64]. The CASP is an appraisal tool that requires consideration of three broad issues which aim to address the principals and assumptions underpinning qualitative research, these are:

1. Are the results of the study valid
2. What are the results
3. Will the results help locally

Appraising the articles was carried out in three steps; firstly, by familiarisation to the CASP questions (outlined below); secondly, by reading the studies with these CASP questions in mind, and jotting down any initial thoughts; thirdly, by re-reading the studies in detail and scoring the studies on each individual quality question of the CASP and considering whether the study had achieved each criterion. CASP was used to critique the selected qualitative studies by asking 10 questions. The first two questions are used to screen the studies and consider whether it is worth proceeding, these were “was there a clear statement of the aims of the research?” and “is a qualitative methodology appropriate?”. The following eight questions appraise the studies following the three issues above, such as “was the research design appropriate to address the aims of the research?”, “has the relationship between researcher and participants been adequately considered?” and “was the data analysis sufficiently rigorous?”.

Whilst, previous reviews looking at mixed-methods have excluded studies based on relevant CASP appraisal tools deeming that good quality papers need to score over 60% [65]. This review included all papers that met the two screening questions, following

previous reviews that have decided on a minimum criteria studies need to achieve [66], and included a low threshold for excluding studies in order to include a wide contribution of studies [67,68].

#### *Method of synthesis*

In addition to the CASP scores a thematic analysis was used to explore relationships across the studies. This approach is well suited to comparing themes from multiple studies and when results are presented textually, is in keeping with the third element suggested by Popay [46]. This **synthesis** and analysing process was completed with all the studies in order to search for reoccurring and broad themes to be identified as well as novel findings. Initial detailed reading of the papers was carried out to help organise and note thoughts throughout, with the results from the previous studies being examined for the description of PTG and social support. An example of this is outlined in Table 2. Following on from this, initial codes were identified by comparing and contrasting the key relationships between the studies. This encouraged identifying recurring themes that could explain the phenomena being described within the studies, and which could answer the review question. The process of defining and reviewing the codes into sub-themes led to the identification of five main overarching themes (for this process please see appendix B) occurring across the results from the included studies.

#### *Reflexivity*

Throughout the synthesis process, thought was given to the robustness of this review via textual descriptions, thematic analysis and evidence tables, in the form of frequencies. Thus, consideration of the fourth element suggested by Popay [46], for conducting a more systematic and transparent narrative synthesis, was followed.

Table 2. Example of the process used to carry out the qualitative synthesis in this review, depicting the included studies authorial interpretation (1 to 3) and current understanding of the textual data to answer this review question (4 to 5)

First author, year, country, reference	1. Actual quote used in original study	2. How did the original author understand this quote	3. What were the original authors theme	4. How is this understood in terms of PTG and social support (this review)	5. Overarching theme for this review	6. How does this link to current ideas and/or theories
Lohne, 2005, Norway [56]	'Ambassador in Improvements'	Experiences of struggling and growth following accident were important and felt that others gradually looked at him as a symbol or possibilities (hope)	Hoping, struggling and growing	Others view of them and their role in relationships.	The self in social relationships	Social identity

## Results

The descriptive characteristics of the studies included are presented in Table 1. Table 3 shows the overall CASP scores for each study, whether the criteria was met for each question and the percentage for each criterion across the studies. This was to ensure that each study was appraised on its own merit but also so the quality of all the studies included in this review could be considered. Table 4 presents the themes generated from this narrative synthesis and the studies overall CASP score. This was to compare the quality of the study with the themes generated from each study.

### *Critical appraisal*

The CASP tool was used to consider the quality of each study with scores varying considerably, achieving between five and eight of the 10 criterion markers (Table 3). However, some criteria on the CASP were met by all the studies. For example, of the 10 included studies, all had a clear statement of aims, outlining the relevance of the research and the goal of the study, with a qualitative methodology being viewed as appropriate for all

Table 3. CASP scores for the included studies

First author, year, country, reference	1. Clear statement	2. Qualitative method	3. Research design	4. Recruitment	5. Data collection	6. Consideration of relationship between researcher and participants	7. Consideration of ethical issues	8. Rigorous data analysis	9. Clear statement of findings	10. How valuable is research	Overall CASP score /10
Lohne, 2005, Norway [56]	Yes	Yes	Yes	No, limited discussion insufficient to follow recruitment procedure	Yes	Yes	Yes	Yes	Yes	No, future questions and impact of research not considered.	8
Chun, 2008, Canada [36]	Yes	Yes	No, insufficient information on rationale for design used.	No, did not explain recruitment process of participants clearly.	Yes	No, did not describe.	No, did not mention ethical approval.	Yes	Yes	Yes	6
Chun, 2010, Canada [57]	Yes	Yes	No, insufficient information on rationale for design used.	No, did not explain recruitment process of participants clearly.	Yes	No, no description of considering this.	No, did not mention ethical approval.	No, unclear how arrived at themes	Yes	Yes	5
Van de Velde, 2010, Belgium [54]	Yes	Yes	Yes	Yes	Yes	No, did not consider own role.	Yes	No, did not consider own role.	Yes	No, no new areas to be considered or what findings contribute.	7
Kaiser, 2011, UK [61]	Yes	Yes	No, insufficient information on rationale for design used.	No, not explain recruitment sufficiently.	No, not enough detail of the data collected	Yes	No, did not mention ethical approval.	Yes	Yes	Yes	6
Griffiths, 2012, UK [60]	Yes	Yes	No, limited justification of design	Yes	Yes	No, did not consider own role.	No, did not mention ethical approval.	No, did not consider own role.	Yes	Yes	6
Chun, 2013, USA [58]	Yes	Yes	No, unclear the rationale for design used.	Yes	Yes	Yes	Yes	No, unclear how arrived at findings.	Yes	Yes	8
Kennedy, 2013, UK [62]	Yes	Yes	No, unclear why method chosen.	No, unclear if question was appropriate.	No, methods unclear and no discussion on missing data	No, did not consider own role.	Yes	No, not enough detail to know how arrived at themes.	Yes	Yes	5

Table 3. (Continued)

First author, year, country	1. Clear statement	2. Qualitative method	3. Research design	4. Recruitment	5. Data collection	6. Consideration of relationship between researcher and participants	7. Consideration of ethical issues	8. Rigorous data analysis	9. Clear statement of findings	10. How valuable is research	Overall CASP score /10
Machida, 2013, Japan [55]	Yes	Yes	Yes	Yes	Yes	No, did not consider own role.	Yes	No, did not consider own role.	Yes	Yes	8
Crawford, 2014, Canada [59]	Yes	Yes	No, no description of why method was chosen.	Yes	Yes	Yes	No, limited information on confidentiality and consent,	Yes	Yes	Yes	8
Percentage of studies that achieved each question on the CASP	100%	100%	30%	50%	80%	40%	50%	40%	100%	80%	-

included studies. These are the first two questions on the CASP, and not meeting these suggests that further **quality assessment** of the studies should not be carried out [63]. All studies met these criteria and as such no studies were excluded from the review on the basis of the CASP score. In addition, all 10 included studies achieved the criterion for having a clear statement of findings (question nine). Despite this, there was variable quality for the other criteria on the CASP, with limited or inconsistent information provided across studies.

When considering the three broad areas outlined by the CASP, what the results are (issue 2), and whether they will help locally (issue 3), appeared to be the most consistently reported on and the criteria achieved most frequently across the studies. However, whether the results are valued (issue 1) appeared to be more open to interpretation, with considerable variation in how this criterion was reported on. The quality that varied between the studies was recruitment (question four). Here there was often limited description or information on the process or description of participants, demonstrating, that a context for generalisability was difficult to deduce.

In addition, consideration of the relationship between participants and researcher (question six) was often not considered or written about sufficiently. This question was also considered in assessing the process of data analysis (question eight) and was a quality marker that only four of the studies achieved. It was therefore, difficult to understand the audit trail or transparency of the research process for these studies. Finally, consideration of ethics was another criterion that was only achieved by half of the studies (question seven), with the studies not presenting details of ethical approval or providing limited consideration of ethical issues. Despite the varying reporting, eight out of 10 studies scored six or above, thus achieving 60% or over which has previously been suggested to be an indicator of good quality research [65].

*Synthesis of qualitative findings*

This narrative synthesis identified five interrelated themes that appeared to support PTG within the context of a person’s experience of social support (Table 4). Taken together, the studies included in this synthesis reported that individuals developed strengthened relationships, re-connecting with others through shared experiences and meaningful participation, alongside a changed sense of self [36, 55, 57, 61 62].

Table 4. Frequency of themes and overall CASP score

Theme	Self in social relationships	Re-connecting with the social world	Meeting others with SCI	Building closer relationships with family	Social support from others	Overall number of themes	Overall CASP score
Frequency	11 of 11	8 of 11	8 of 11	9 of 11	8 of 11	/5	/10
Primary studies:							
Lohne, 2005, Norway [56]	Yes	No	No	No	No	1	8
Chun, 2008, Canada [36]	Yes	Yes	Yes	Yes	Yes	5	6
Chun, 2010, Canada [57]	Yes	Yes	Yes	Yes	No	4	5
Van de Velde, 2010, Belgium [54]	Yes	Yes	No	Yes	No	3	7
Kaiser, 2011, UK [61]	Yes	No	Yes	Yes	Yes	4	6
Griffiths, 2012, UK [60]	Yes	No	Yes	Yes	Yes	4	6
Chun, 2013, USA [58]	Yes	Yes	Yes	Yes	Yes	5	8
Kennedy, 2013, UK [62]	Yes	Yes	No	Yes	Yes	4	5
Machida, 2013, Japan [55]	Yes	Yes	Yes	Yes	Yes	5	8
Crawford, 2014, Canada [59]	Yes	Yes	Yes	Yes	Yes	5	8

### *The self in social relationships*

The theme of ‘self in social relationships’ highlighted that participants often emphasised how they could understand themselves following SCI, for example in terms of developing independence following injury, supporting others and viewing themselves as a better person as a result of their injury. The self in social relationships was a strong theme across all the studies, with participants placing emphasis on how they were viewed by others and their own role within social relationships. One individual described themselves as an “Ambassador in Improvements” [56, p.320], and a common theme across the studies was a desire for other people to view them as being able to add something to society [54, 55, 58].

One aspect of PTG that seemed to be common across the included studies was the belief that they had become better people in terms of their social relationships, following their SCI, by being more caring, open minded and compassionate [36, 57, 58, 59]. This purposeful rumination, and assimilating their trauma into who they are now while considering what is the same and what is different, is key for meaning making and developing PTG:

In a lot of aspects, I think I'm the same—not too much different in a lot of aspects. It's just directed in different ways, directed in different endeavours. I did calm down, I'm nicer. I'm not quite as sarcastic. I am thankful that I learned sensitivity. That's what it was. Not that I was mean, but I wasn't sensitive at all and now I've gotten a little bit more. I watch what I say more often, I try not to hurt people's feelings as much. In that aspect people say that I've become a better person in that aspect. I am very thankful for the change [58, p.16].

Being able to help and provide knowledge to other people in a similar situation, by contributing their own experiences of common difficulties, helped establish an equal identity with others post SCI [54, 58, 59, 62]. For the participants in the studies, being a positive influence and social support for others with SCI provided new opportunities that they felt would not have been available to them prior to their injuries and promoted changes to their view of themselves, a key aspect of PTG:

Able to help others, permanent fundraiser [62, p. 206].

Letting them know that there is life after SCI [58, p.15].

It was important for the participants in the studies to view themselves as being a social support to others with SCI. This was important in order to recognise positive qualities and to share their own story of positive changes, in order to find new meaning in their life following SCI [36, 54, 58, 59, 62]. It was crucial that they felt they could gain recognition

from their peers and impress them with their abilities, e.g. through sport or awards for social services [36, 54, 58, 62], which in turned increased their confidence, social enjoyment and sense of finding purpose leading to the development of PTG.

### *Re-connecting with the social world*

The theme of ‘re-connecting with the social world’ was understood to be different to the self in social relationships. Re-connecting with others resonated with participants’ descriptions of having relationships with others following their SCI and getting involved with different activities and community groups. In addition, across the studies there was a common theme of having experienced strong emotions as a result of sustaining SCI, yet over time this was a necessary phase to move through in order to develop PTG. Feelings of loneliness and fear of rejection from others, and not knowing initially how to interact with friends, subsided over time [36, 55, 57, 62], with the loss of identity and place in the previous ‘world’ and the ensuing struggle emerging from this:

I felt out of place. I didn't feel like I should be there. I felt like everybody was staring at me. I didn't know how to act. I didn't know how to interact with people. I didn't even know how to interact with my friends that have been my friends my whole life. They didn't know what to say to me, and I kind of didn't know what to say to them. So it's kind of very uneasy for a while. [55, p. 1059].

This feeling of being different to their previous peers made the process of developing PTG more difficult. However, being able to connect to a community e.g. via sport [55, 59] or feeling validated, secure and safe in their relationships with family and friends were helpful at this time:

I wanted to know if my wife would take care of me, I wanted to know if the next-door neighbours could come over once in a while and see if I am alright, otherwise I would not feel safe [54, p.352].

Being able to achieve things such as getting a driving licence, promoted the experience of connecting with the social world [36, 58]. Time spent participating in social activities allowed the person to have a sense of success and achievement [36, 54, 58] and facilitated appreciation of relationships with others and the wider society [36, 54, 62]:

Law School is something that I was always going to do. But prior to my injury, it was going to be like corporate law — let's see how far I can take this, and I would pull the 80-hour weeks and see how long it would take me to get to 500,000 dollars. My priorities have drastically changed. My family and my friends and the relationships that I have with my community and giving back things like that. I used to be quite anxious. Stressed all the time about nothing. I always laugh and say then I broke my back and have real things to worry about [59, p.402].

Some participants spoke of losing friends following SCI [36, 57, 58] , but also of re-building social relationships with friends without SCI and developing meaningful relationships whilst discovering who their real and true friends were [57, 62]. The importance of expanding their social networks and of making new friends and sharing similar activities with friends, or helping their friends, led to feelings of happiness and being respected [36, 54, 62].

I got to know new and nice people. I have a strong company and alliance that I didn't know before. [62, p. 206].

I got involved with rugby, being with other people with similar disabilities and becoming friends, a new base of friends. ... I built a larger base of friends now. You know, as a person with disability, I have got so many friends. It's

unbelievable, you know. So it's like I've added a new family in my life. [55, p. 1061].

Two studies mentioned the role that God played for individuals who were Christian. The individuals felt that God had blessed them to receive strong social support from their families and friends. Being part of a Christian community and actively attending church was also another way for people to re-connect and participate in social activities and social relationships [36, 58]. While the non-Christian participants expressed their appreciative feelings to luck [58].

These developing relationships and changed priorities in terms of their social relationships are an important aspect of developing PTG.

#### *Meeting others with SCI*

Following on from the theme of 're-connecting with the social world', participants spoke of the value of 'meeting others with SCI'. Across the studies there was a common theme that highlighted the benefits of meeting people with similar injuries and who enjoyed similar activities [36, 54, 55, 58, 62]. These experiences provided a platform for making new and strengthened relationships through a shared understand of living with SCI and through using each other's shared knowledge as a resource to cope better with their disability [36, 59, 60]:

It's nice to get out and hang around with the guys, you know, in chairs, and talk about different stuff. You know, problems and how to get over things. So it has been a real out and open opportunity. I think, you know, besides the physical aspect of getting in better shape, and just mentally, you know, talking with all other guys and their problems and how they deal with stuff helped me to adapt to disability. [55, p. 1061].

Experiencing being with others who have suffered SCI, and participating in group activities as part of SCI support groups, allowed some of the participants to feel part of a wider community and fostered a sense of belonging and acceptance from their friends [36, 54, 55, 58, 62]. The importance of shared experiences and being able to share stories, knowledge, thoughts and feelings with people who have similar injuries [36, 55, 57, 58, 59, 60] was also a common theme:

I'm meeting and re-meeting people who have similar injuries. I've met a lot of good people with whom I could share my thoughts and feelings. [36, p.883].

Being with others with SCI also allowed individuals to make social comparisons between themselves and others, feeling grateful for what they could do or finding inspiration in how things could be different in the future. Meeting people who were functioning well allowed them to look towards the future and how things could change for the better [36, 55, 57, 61]:

Meeting people who had been injured. It was a nice way to see that life goes on. [60, p. 247].

Some participants across the studies also spoke of comparing themselves to others which may have encouraged a focus on, and appreciation of what they could still do [36, 55, 57-59]:

Oh, you don't have it so bad. You're only a para. Look at those quads - aren't you glad you can do [something by yourself]? At the tennis clinic they have to strap the tennis racquet to their hand, wrap it up with tape so that they could move their arm a little bit, but wow, I can hold on to that thing. That's what just really gets you. I feel a lot luckier. I'm very blessed in so many ways. [36, p. 885].

Developing social relationships and networks with others who had sustained SCI allowed the participants in these studies to find enjoyment in things and discover what is achievable

in the future. These positive changes in terms of how they viewed themselves, others and the world resonated with the idea that trauma challenges a person's belief about the world and that an active meaning-making process is a key process for developing PTG.

#### *Building closer relationships with family*

The theme of 'building closer relationships with family' highlighted that participants' valued and found meaning from building closer relationships with family following their SCI. Another strong theme across the included studies was of the participants strengthening relationships with their families [36, 57, 58, 59, 62] and appreciating [36, 57, 58, 62] and prioritising their families more [36, 57, 58, 59, 62]. Participants across the studies described the experience of building more loving and intimate relationships with their family, and being more open about issues and difficulties with one another:

My dad never once told me he loved me until I broke my neck. We never showed any affection. He came from Germany, and he was just a toughened person. However, after the injury he told me he loved me and shared his life story as a man with one eye. [36, p. 881].

Participants also spoke of changing their attitudes towards their family following SCI, and re-evaluating the importance family had within their lives [36, 58, 59]. They spoke of relying on support from their family but also being able to help their family too, and appreciating and becoming more family orientated than before:

I have more appreciation for my everyday life with my husband. [58, p. 14].

These strengthened relationships appeared to be a critical part of the PTG experience as they allowed participants to experience a sense of trust [36, 54], and a belief that their family would provide unconditional support [54] and relying on them more, as well as a reason to live well and to have a more positive outlook on life [55, 58].

### *Social support from others*

The last theme, 'social support from others', highlighted the importance of social support in participants increasing understanding of their own injuries, and accepting and promoting coping, which may all be factors in the process of PTG. Across the studies there was a theme of being able to use others around them as a source of motivation [36, 55, 61, 62]. There was a sense that the people around them were able to provide support in a way that influenced positive outcomes and encouraged belief in themselves [55, 61, 60]. This came through others considering their feelings, privacy and independence while providing social support:

My husband doesn't overdo it. He doesn't try like my dad "oh you cannot open the refrigerator, here let me get it for you". My husband just lets me do it. He's a good husband [58, p. 15].

The role of professional staff to normalise the participants' experiences was viewed as important, and promoted independence [55, 61, 62].

### **Discussion**

This narrative synthesis aimed to critique and summarise the existing qualitative literature looking at PTG following SCI, with particular focus on looking for commonalities within the context of social support. The synthesis of the 10 included studies highlighted the possibility for people to engage in meaning-making and a process of re-evaluation of themselves, of others and of their place within a wider community. Social support seemed able to facilitate this process via developing shared identities, learning from others' knowledge and providing opportunities for comparisons with others in relation to their self. Belonging to a group identity and the support from family and friends allowed a person to

build upon their autonomy and abilities to do things, and to find purpose in how they are now, thus leading to the development of PTG.

### ***Social Support and Posttraumatic Growth***

The synthesis supports the idea that a person's experience of their social environment and social support can facilitate PTG. The benefit of sharing stories and knowledge with others who have experienced the same life changing event and may have some of the same difficulties resonated across the studies within this synthesis. The challenges to a person's identity following SCI, and their place in society post injury, suggest that the process of PTG emerges from struggling with the consequences of SCI, with the emotional distress likely to occur concurrently with growth. Thus, through a process of accepting their difficulties, discovering what they can still do, and what can be viewed differently, a person can develop PTG within the context of positive social support from peers, family and friends. These ideas resonate with existing models of PTG, namely Tedeschi and Calhoun's model of PTG [32, 69].

### ***Shared experiences***

In addition, this synthesis highlights the possible benefit of being part of a community, either where participants lived, through faith, or by connecting with others with SCI. These experiences allowed people to develop confidence, discover abilities and find purpose in helping others. This supports the important role that peer support workers or mentors may play in assisting people to be able to visualise a positive future [70, 71]. Following SCI, individuals may be struggling with its consequences, and being able to learn about themselves, their abilities and new possibilities through social activities, or meeting others with SCI, may provide the individual with opportunities to see themselves differently, leading to PTG. This idea of learning and having to rebuild [26] their perceptions of themselves, the world and others remains one of the key aspects in the process of PTG [32].

Calhoun and Tedeschi [33] have discussed three aspects of a person's immediate social environment that may influence the experience of PTG following a traumatic event, including the response from significant others, ruminations about their experience with significant others, and PTG behaviour modelled in others with similar experiences. In this way, group membership and peer-support programmes can play a significant role in a person's socio-cultural environment, normalizing their experience and providing role models not replicated by other relationships [69]. People's sense of self can be established through the stories they tell themselves and that relevant others tell them [72]. Importantly, if this self-narrative is challenged by a traumatic event then there is a process of revision, repair and alternative assumptions via validation of one's experience; with warm relationships with others playing a role in this process [32].

#### *Sociocultural considerations*

Furthermore, the ability to offer tips and knowledge of their experience to others, and to learn from others via upward or downward social comparison, demonstrates the important role that community context can have, via meeting practical needs in adjusting to physical changes as well as providing credible hope for the future [13, 15]. Sociocultural considerations are important for understanding the development of PTG, with the disruption to one's **beliefs initiating the process** of growth and a variety of cultural influences possibly playing a significant role in shaping the ways in which a traumatic event is perceived [69].

The role that social comparison can play in the process of PTG can be thought of within the context of rumination, which may involve cognitive processes that revise or re-establish beliefs [26]. This synthesis suggests that meeting people who have experienced similar situations may support the **participants' ability to be discuss and make sense of their experiences**, possibly facilitating the development of PTG. In addition, this includes being able to try things on their own and not be to 'protected', being able to do things well and

connect with others, be it within the wider community or with family and friends. The organismic valuing theory of growth suggests that the social environment is needed to support the positive accommodation process following trauma, with autonomy, competence and relatedness being key [29].

### *Robustness of the Critical Appraisal*

This narrative synthesis followed published guidelines [46], in addition to utilising a recommended and widely used appraisal tool, to determine the quality of the articles [63], thus ensuring a systematic and transparent approach. The potential value of using the CASP type approach is that these guidelines encourage transparency in reporting qualitative research included in systematic reviews [73].

Perhaps an unexpected outcome of this review was the consideration of how best to use the CASP when reviewing qualitative research, especially when considering how to decide what studies to include or exclude. Despite some studies using the CASP as a measure to exclude studies, there is as yet no consensus on how to appraise qualitative papers for inclusion, using such tools [68, 74]. This review suggest that the varied reporting of information may make evaluating qualitative research, using a yes or no criterion, more difficult to interpret when authors be able to describe in detail due to other constraints e.g. word length of articles. As such, excluding qualitatively methodologically ‘weak’ papers may not be possible as researchers’ judgments as to what is flawed vary according to their own disciplines, methodological training and preferences [74]. Therefore, using the CASP as a way of excluding studies rather than as a reflective tool to comment on the quality of studies included may risk discounting important studies [65, 75]. Indeed, the perceived quality of studies by the CASP did not appear to influence the number of themes the studies contributed to, and the richness of data may be an important criteria rather than methodology used.

Therefore, it has been suggested that a yes, no or partial presence may be used for the criteria in future research [76], and in considering how the quality of the studies as measured on the CASP also relate to the relevance of the studies to the question in the synthesis [77].

#### *Robustness of the Synthesis*

The issue of generalisability is also a potential limitation of qualitative research. However, there were several themes that were common across the studies, suggesting the robustness of the studies for describing the experience of PTG following SCI in ways that might be more broadly applicable. Similarly, considering and reporting the context of the findings across the studies, the validity of the studies can be enhanced and allow the original studies to be more transparent in the synthesis [68]. Thus, a strength of this narrative synthesis was that commonality of themes was found across all the studies, with the themes emerging resonating with current literature on the process of PTG. In addition, the studies came from varying countries/cultures and consideration needs to be given to the different views of relationships and disability within these societies, although it has been suggested that the concept of PTG appears cross-culturally [78].

#### *Clinical implications and future research*

Social support and identifying with others can allow the person to share their experience, facilitating meaning making and finding purpose through their shared narratives, knowledge and learning. Following SCI, the impact for the individuals can often affect their mobility and participation in recreation or interpersonal relationships [7]. The implications of this narrative synthesis may share commonality with other research in this area which suggests that when people with SCI participate fully in society they are able to develop more positive psychological outcomes [10].

This synthesis supports previous research that suggests people with SCI may benefit from interventions that are focused on peer involvement and support groups for people with similar injuries. However, from the existing research, it is not clear when or how best to introduce peer support and some people may not feel comfortable doing this straightway. A part of rehabilitation may be to approach this topic first and consider the range of issues - giving consideration to this during the assessment and intervention process may promote the incorporation of a person's goals and their social needs. Research has highlighted the preference of people with a new SCI to have mentors who are matched in terms of gender, personality, interest and injury severity [79]. Future research, focusing on how people can access the relevant social support and exploring people's experience of social connectedness, will develop our understanding of how PTG develops following SCI and where best to focus social support following injury.

## **Conclusion**

In this synthesis two main conclusions can be drawn. Firstly, from a methodological perspective, when appraising articles further consideration needs to be given to how researchers consider ambiguous or insufficient detail of information even though aspects of quality may have been considered by the researchers. Thus, making the distinction between what is not reported and what information is reported but of "weak" quality. Excluding qualitative studies from reviews on the basis of a quality assessment may limit our understanding of the human experience by discounting research that is rich in detail but does not achieve prescriptive criterion. This is a contentious issue and more consensus is needed about how this can be addressed within reporting and appraising qualitative research. Secondly, in terms of the topic area social support plays a role in facilitating a person's sense of self through personal accomplishments and comparisons with others. Relating to others with shared experiences provides opportunities for re-evaluation of traumatic

experiences. As such, social support is a key facilitating factor in the development of PTG following SCI and further research is needed in this area.

### **Acknowledgments**

I would like to acknowledge Hanna Kampman, Lecturer in Positive Psychology and a PhD. Candidate at the Post Traumatic Growth Research Unit (PTGU) at the University of East London, for her advice and thoughtful discussions in relation to posttraumatic growth.

### **Declaration of interest statement**

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

### **References**

1. van Leeuwen CM, Kraaijeveld S, Lindeman E, et al. Associations between psychological factors and quality of life ratings in persons with spinal cord injury: A systematic review. *Spinal Cord*. 2012;50:174-87.
2. Anderson D, Dumont S, Azzaria L, et al. Determinants of return to work among spinal cord injury patients: A literature review. *J of Vocat Rehabil*. 2007;27:57-68.
3. Geyh S, Ballert C, Sinnott A, et al. *Quality of life after spinal cord injury: a comparison across six countries*. *Spinal Cord*. 2013;51:322-326.
4. Kester BL, Rothblum ED, Lobato D, et al. Spouse adjustment to spinal cord injury: Long-term medical and psychosocial factors. *Rehabil Couns Bull*. 1988;32:4-21.
5. Craig A, Tran Y, Middleton J. Psychological morbidity and spinal cord injury: A systematic review. *Spinal Cord*. 2009;47:108-114.
6. Livneh H. Psychosocial adaptation to spinal cord injury: The role of coping strategies. *J of Appl Rehabil Couns*. 2000;31:3-10.
7. Sweet SN, Noreau L, Leblond J, et al. Peer support need fulfilment among adults with spinal cord injury: Relationships with participation, life satisfaction and individual characteristics. *Disabil & Rehabil*. 2016;38:558-565.
8. Berger RJ. Agency, structure, and the transition to disability: A case study with implications for life history research. *The Sociol Q*. 2008;49:309-333.

9. Winance M. Being normally different? Changes to normalization processes: From alignment to work on the norm. *Disabil & Soc.* 2007;22:625-638.
10. Kennedy P, Lude P, Taylor N. Quality of life, social participation, appraisals and coping post spinal cord injury: A review of four community samples. *Spinal Cord.* 2006;44:95-105.
11. Tennen H, Mckee TE, Affleck A. Social comparison processes in health and illness. In J Suls, E Wheeler (Eds). *Handbook of social comparison theory and research.* New York: Springer;2000:443-483.
12. Affleck G, Tennen H. Social comparison as a coping process: A critical review and application to chronic pain disorders. *Health, coping, and well-being:* In BP Buunk, FX Gibbons (Eds). *Perspectives from social comparison theory.* New Jersey: Lawrence Erlbaum Associates:1997:263-298.
13. Wills TA. Downward comparison principles in social psychology. *Psychol Bull.* 1981;47:245-271.
14. Buunk AP, Zurriaga R, González P. Social comparison, coping and depression in people with spinal cord injury. *Psychol & Health.* 2006;21:791-807.
15. Stanton AL, Danoff-Burg S, Cameron CL, et al. Social comparison and adjustment to breast cancer: An experimental examination of upward affiliation and downward evaluation. *Health Psychol.* 1999;18:151.
16. Haslam SA, Jetten J, Postmes T. Social identity, health and well-being: An emerging agenda for applied psychology. *Appl Psychol.* 2009;58:1-23.
17. Jones JA, Haslam SA, Jetten J, et al. That which doesn't kill us can make us stronger (and more satisfied with life): The contribution of personal and social changes to well-being after acquired brain injury. *Psychol & Health.* 2011;26:353-369.
18. Trieschmann RB. *Spinal cord injuries: Psychological, social, and vocational rehabilitation.* New York: Demos Publications:1988.
19. Chapin MH, Kewman DG. Factors affecting employment following spinal cord injury: A qualitative study. *Rehabil Psychol.* 2001;46:400-416.
20. Thoits PA. Stress, coping and social support processes: Where are we? What next? *J of Health & Soc Behav.* 1995;53-79.
21. Thoits PA, Hohmann AA, Harvey MR, et al. Similar-other support for men undergoing coronary artery bypass surgery. *Health Psychol.* 2000;19:264-273.

22. Tedeschi RG, Park CL, Calhoun, LG. Posttraumatic growth: Positive changes in the aftermath of crisis. London: Routledge;1998.
23. Tedeschi RG, Calhoun LG, Cann A. Evaluating resource gain: Understanding and misunderstanding posttraumatic growth. *Appl Psychol*. 2007;56:396-406.
24. Lindstrom CM, Cann A, Calhoun LG, et al. The relationship of core belief challenge, rumination, disclosure, and sociocultural elements to posttraumatic growth. *Psychol Trauma: Theory Res Practice & Policy*. 2013;5:50-55.
25. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *J of Trauma Stress*. 1996;9:455-471.
26. Janoff-Bulman R. Rebuilding shattered assumptions after traumatic life events. In CR Snyder (Eds). *Coping: The Psychology of what works*. New York: Oxford University Press;1999:305-323.
27. Triplett KN, Tedeschi RG, Cann A, et al. Posttraumatic Growth, meaning in life, and life satisfaction in response to trauma. *Psychol Trauma: Theory, Res, Practice, and Policy*. 2011;4:400-410.
28. Shakespeare-Finch J, Armstrong D. Trauma type and posttrauma outcomes: Differences between survivors of motor vehicle accidents, sexual assault, and bereavement. *J of Loss & Trauma*. 2010;15:69-82.
29. Joseph S, Linley PA. Positive adjustment to threatening events: An organismic valuing theory of growth through adversity. *Rev of Gen Psychol*. 2005;9:262-280.
30. Westphal M, Bonanno GA. Posttraumatic growth and resilience to trauma: Different sides of the same coins? *Appl Psychol: An Int Rev*. 2007;56:417-427.
31. Zoellner T, Maercker A. Posttraumatic growth in clinical psychology: A critical review and introduction of a two component model. *Clin Psychol Rev*. 2006;26:626-653.
32. Tedeschi RG, Calhoun LG. "Posttraumatic growth: Conceptual foundations and empirical evidence". *Psychol Inq*. 2004;15:1-18.
33. Calhoun LG, Tedeschi RG. Beyond recovery from trauma: Implications for clinical practice. *J of Soc Issues*. 1998;54:357-371.
34. Pollard C, Kennedy P. A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: A 10-year review. *Br J of Health Psychol*. 2007;12:347-362.
35. Kalpakjian CZ, McCullumsmith CB, Fann JR, et al. Post-traumatic growth following spinal cord injury. *J of Spinal Cord Med*. 2014;37:218-25.

36. Chun S, Lee Y. The experience of posttraumatic growth for people with spinal cord injury. *Qual Health Res.* 2008;18:877-890.
37. McMillen JC, Cook CL. The positive by-products of spinal cord injury and their correlates. *Rehabil Psychol.* 2003;48:77-85.
38. Paul MS, Berger R, Berlow N, et al. Posttraumatic growth and social support in individuals with infertility. *Hum Reprod.* 2010;25:133-141.
39. Gill CJ. Four types of integration in disability identity development. *Journal of Vocat Rehabil.* 1997;9:39-46.
40. Charmaz K. *Good days, bad days: The self in chronic illness and time.* New Jersey: Rutgers University Press:1991.
41. Barclay L, McDonald R, Lentin P, et al. Facilitators and barriers to social and community participation following spinal cord injury. *Aust Occup Therapy J.* 2016;63:19-28.
42. Hammell KRW. Spinal cord injury rehabilitation research: Patient priorities, current deficiencies and potential directions. *Disabil & Rehabil.* 2010;32:1209-1218.
43. Kampman H, Hefferon K, Wilson M, et al. "I can do things now that people thought were impossible, actually, things that I thought were impossible": A meta-synthesis of the qualitative findings on posttraumatic growth and severe physical injury. *Can Psychol.* 2015;56:283-294.
44. Jones K, Kenneth G, Briggs L, et al. Does spirituality facilitate adjustment and resilience among individuals and families after SCI? *Disabil & Rehabil.* 2016;38:921-935.
45. Barnett-Page E, Thomas J. *Methods for the synthesis of qualitative research: A critical review.* ESRC National Centre for Research Methods Working Paper Series. 2009.
46. Popay J, Roberts H, Sowden A, et al. *Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme* Version. 2006;1:b92.
47. Alderson P, Green S, Higgins J. *Cochrane Reviewers' Handbook 4.2.2.* The Cochrane Library. 2004;1.
48. Docherty SL, Sandelowski M, Preisser JS. Three months in the symptom life of a teenage girl undergoing treatment for cancer. *Res in Nursing & Health.* 2006;29:294-310.

49. Noblit GW, Hare, RD. *Meta-ethnography: Synthesizing qualitative studies*. Newbury Park, Calif:Sage Univ Press:1998.
50. Thorne S. Meta-synthetic madness: What kind of monster have we created? *Quali Health Res*. 2017;27:3-12.
51. Jayawickreme E, Blackie LE. Post-traumatic growth as positive personality change: Evidence, controversies and future directions. *Eur J of Personal*. 2014;28:312-331.
52. Dixon-Woods M, Cavers D, Agarwal S, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol*. 2006;6:35-48.
53. Cryder CH, Kilmer RP, Tedeschi RG, et al. An exploratory study of posttraumatic growth in children following a natural disaster. *Am J of Orthopsychiatr*. 2006;76:65-69.
54. Van de Veldea D, Bracke P, Van Hove G, et al. Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home. *Int J of Rehabil Res*. 2010;33:346-55.
55. Machida M, Irwin B, Feltz D. Resilience in competitive athletes with spinal cord injury: The role of sport participation. *Qual Health Res*. 2013;23:1054-1065.
56. Lohne V, Severinsson, E. The power of hope: Patients' experiences of hope a year after acute spinal cord injury. *J of Clin Nurs*. 2006;15:315-323.
57. Chun H, Lee Y. The role of leisure in the experience of posttraumatic growth for people with spinal cord injury. *J of Leis Res*. 2010;42:393-415.
58. Chun S, Lee Y. 'I am just thankful': The experience of gratitude following traumatic spinal cord injury. *Disabil & Rehabil*. 2013;35:11-19.
59. Crawford JJ, Gayman AM, Tracey J. An examination of post-traumatic growth in Canadian and American ParaSport athletes with acquired spinal cord injury. *Psychol of Sport and Exerc*. 2014;15:399-406.
60. Griffiths H, Kennedy P. Continuing with life as normal: Positive psychological outcomes following spinal cord injury. *Top in Spinal Cord Inj Rehabil*. 2012;18:241-252.
61. Kaiser S, Kennedy P. An exploration of cognitive appraisals following spinal cord injury. *Psychol Health & Med*. 2011;16:708-718.
62. Kennedy P, Lude P, Elfstrom M, et al. Perceptions of gain following spinal cord injury: A qualitative analysis. *Top in Spinal Cord Inj Rehabil*. 2013;19:202-210.

63. Critical Appraisal Skills Programme, 2017. CASP Qualitative Checklist. Available at: <http://www.casp-uk.net/checklists>, Accessed: 22/12/2016.
64. Hannes K, Lockwood C, Pearson A. A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research. *Qual Health Res.* 2010;21:1736-1743.
65. Day E, Jones L, Langner R, et al. Current understanding of decision-making in adolescents with cancer: A narrative systematic review. *Palliat Med.* 2016;30:920-934.
66. McEwan MJ, Espire CA, Metcalfe J. A systematic review of the contribution of qualitative research to the study of quality of life in children and adolescents with epilepsy. *Seizure.* 2004;13:3-14.
67. Thorne S, Jensen L, Kearney MH, et al. Qualitative metasynthesis: Reflections on methodological orientation and ideological agenda. *Qual Health Res.* 2004;14:1342-1365.
68. Dixon-Woods, M, Bonas S, Booth A, et al. How can systematic reviews incorporate qualitative research? A critical perspective. *Qual Res.* 2006;6:27-44.
69. Calhoun LG, Arnie C, Tedeschi RG. The posttraumatic growth model: Sociocultural considerations. In T Weiss, R Berger. *Posttraumatic growth and culturally competent practice: Lessons learned from around the globe.* New Jersey: John Wiley & Sons;2010:1-14.
70. Boschen KA, Tonack M, Gargaro J. Long-term adjustment and community reintegration following spinal cord injury. *Int J of Rehabil Res.* 2003;26:157-164.
71. Price P, Stephenson S, Krantz L, et al. Beyond my front door: The occupational and social participation of adults with spinal cord injury. *OTJR: Occup, Particip & Health.* 2011;31:81-88.
72. Neimeyer RA. Fostering posttraumatic growth: A narrative elaboration. *Psychol Inq.* 2004;15:53-59.
73. Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol.* 2012;12:181-189.
74. Dixon-Woods M, Shaw RL, Agarwal S, et al. The problem of appraising qualitative research. *Qual and Saf in Health Care.* 2004;13:223-225.

75. Paterson B, Dubouloz CJ, Chevrier J, et al. Conducting qualitative metasynthesis research: Insights from a metasynthesis project. *Int J of Qual Methods*. 2009;8:22-33.
76. Malpass A, Shaw A, Sharp D, et al. "Medication career" or "moral career"? The two sides of managing antidepressants: A meta-ethnography of patients' experience of antidepressants. *Soc Science and Med*. 2009;68:154-168.
77. Aguineldo, JP. Rethinking validity in qualitative research from a social constructionist perspective: From "is this valid research?" to "what is this research valid for?". *The Quali Rep*. 2004;9:127-136.
78. Splevins K, Cohen K, Bowley J, et al. Theories of posttraumatic growth: Cross-cultural perspectives. *J of Loss and Trauma*. 2010;15:259-277.
79. Veith EM, Sherman JE, Pellino TA, et al. Qualitative analysis of the peer-mentoring relationship among individuals with spinal cord injury. *Rehabil Psychol*. 2006;51:289-298.

## **SECTION B**

Bridging Chapter

Word count (1828)

## **Bridging Chapter**

This bridging chapter sets out to link the systematic review and the research paper. Firstly, an overview of posttraumatic growth (PTG) will be presented, followed by a description of spinal cord injury (SCI) and acquired brain injury (ABI). Lastly, there is a discussion on the similarities for these two types of injuries that a person can sustain.

### **Review of Posttraumatic Growth Literature**

The idea of growth following trauma or adversity is not a new concept and has roots in many religions, philosophy and literature, with Nietzsche (1889) stating “that which does not kill us, makes us stronger”. In fact, trauma can be defined as an experience which creates a discrepancy between threatening factors in a situation and individual coping abilities’ (Sar & Ozturk, 2006). Traumatic events threaten a persons’ belief that the world is a comprehensible place (Taylor, 1983), and what separates traumatic experiences from stressful ones is the unpredictability and uncontrollability in the nature of trauma (Allen, Huntoon, Fultz, Stein, Fonagy, & Evans, 2001).

However, it was not until the late 1980s and early 1990s that scientific interest in positive change following trauma appeared (Kalpakjian, McCullumsmith, Fann, Richards, Stoelb, Heinemann, & Bombardier, 2014), with the term of PTG being coined in 1996 (Tedeschi & Calhoun, 1996). PTG has been researched in hugely diverse areas of traumatic events - for example, rape survivors, medical problems (male cardiac patients, SCI, ABI, HIV/AIDS, cancer), natural disasters, combat veterans, and other life experiences (relationship breakdown, bereavement; see Joseph & Butler, 2010 for a review). Overall, 30-70% of survivors will say they have experienced positive changes in some form following trauma (Linley & Joseph, 2004). The literature on PTG shows that even though the causes of trauma may be different, the growth reported often falls into three common categories:

1) Feeling stronger and finding hidden abilities, with people changing how they view themselves and the concept that they are stronger as a result to face new challenges (Calhoun, Cann, Tedeschi, & McMillan, 2000).

2) Relationships are strengthened, with people changing how they appreciate and view others, often describing finding out who their 'true' friends are (Tedeschi & Calhoun, 2004).

3) Priorities and philosophies are altered, with people having a sense of living for the moment or being able to put things into perspective (Joseph & Linley, 2005; Joseph, Murphy, & Regel, 2012).

Furthermore, this growth occurs through a person's struggle with the new reality in the aftermath of trauma, with two main theories in this area being the functional descriptive model of PTG (Tedeschi & Calhoun, 1995, 2004) and the organismic valuing process theory of growth (Joseph & Linley, 2005). Both theories suggest that trauma challenges a person's assumptive world, thus creating incongruity between pre-and post-trauma worldviews, causing significant psychological distress (Splevins, Cohen, Bowley & Joseph, 2010). Therefore, it is through the attempt to adjust to changes, people are able to re-construct their view of themselves and that a new assumptive world view begins to emerge (Joseph, & Linley, 2008), in a meaningful way, enabling a person to experience growth (Tedeschi & Calhoun, 2004).

### **Systematic Review**

This synthesis highlighted that following a SCI a person's assumptive world was shattered such that their view of themselves and others changed. The main finding from this synthesis was the importance of shared identity and reconstruction of a person's view through learning from others and personal accomplishments. Being able to re-connect with

the wider community and having supportive family and friends also facilitated the development of PTG.

### **Spinal Cord Injury**

There are an estimated 50,000 people in the UK and Ireland who are paralysed due to SCI (Spinal-Research, 2017). Compared with many other traumatic injuries, SCI affects a relatively small number of people. Yet research has focused on it due to the profound and overwhelming consequences sustaining a SCI has in virtually all physical and functional abilities (Crewe & Krause, 2009), and in areas such as social relationships and employment (Anderson, Dumont, Azzaria, Bourdais, & Noreau, 2007).

It has been hypothesised that people with SCI change their expectations and values following injury (Duggan & Dijkers, 2001). Being able to make meaningful connections through maintaining close relationships (Dunn & Brody, 2008) and participation in activities outside the home is now recognised as an important outcome for people with an SCI (Carpenter, Forwell, Jongbloed, & Backman, 2007). Research has typically focused on quality of life following SCI, and despite growing literature, the process of PTG following SCI is still not fully understood (Hill, Noonan, Sakakibara, & Miller, 2010).

### **Research Paper**

The research paper focused on exploring people's experiences of the process of PTG following ABI: this was for a number of both theoretical (PTG following trauma) and pragmatic reasons. The research paper focused on ABI as this is a research area of interest for the researcher and supervisors with established links to Headway, the brain injury charity where the study was carried out. An overview of ABI will be described here followed by the rationale for linking ABI and SCI.

## **Acquired Brain Injury**

The lowest estimate of people living in the UK with an ABI is over one million (Fryer, Thomas, & Barnes, 2017), with the consequences of ABI leading to changes in aspects of cognitive, physical, emotional and independent functioning (Langlois, Rutland-Brown, & Wald, 2006).

Sustaining an ABI is one of the most common causes of disability, with the effects often resulting in poor employment, social isolation, and relationship breakdown (Hofgren, Esbjornsson & Sunnerhagen, 2010; Hart, Seignourel, & Sherer, 2009), with the emotional impact being a threat to a person's very existence (Ben-Yishay, & Daniels-Zide, 2000). Research has found that people who, following an ABI, describe negative themes of loss are less able to adapt successfully to a new way of life (Wolters, Stapert, Brands & van Heugten, 2010).

Research into PTG following ABI is relatively recent, as a previously held belief was that the cognitive changes people experienced, particularly if severe, would preclude or limit the amount of PTG a person could experience (Collicutt McGrath & Linley, 2006). This scepticism about the capacity for people with ABI to develop PTG, was due to the cognitive aspects involved in PTG, such as rumination and meaning making (Calhoun et al., 2000).

Despite this, over the past 10 years researchers have begun to report that PTG can develop following an ABI, even when the ABI is severe (McGrath, 2011; Collicutt & Linley 2006; Powell, Ekin-Wood & Collin, 2006; Silva, Ownsworth, Shields & Fleming, 2011; Turner & Cox, 2004), and is a relatively stable phenomenon once established (Powell, Gilson, & Collin, 2012; see research paper for further discussion).

## Comparison of ABI and SCI Populations

The most common causes of SCI in the UK are falls (41.7%), road traffic accidents (36.8%), and sporting and recreational activities (11.6%). Males are most at risk in their young adulthood (20-29 years) and are twice as likely to be injured as females (Spinal-Research, 2017). This is similar to findings from the USA where men account for approximately 80% of new SCI cases (National SCI Statistical Centre, 2016). Similarly, the common causes for ABI in the UK are road traffic accidents (50%; UKABIF, 2017), and in the USA falls were the commonest cause of ABI (35.2%) followed by road traffic accidents (17.3%) and assault (10%; Faul, Xu, Wald, Coronado, & Dellinger, 2010). The highest rate of injury occurred between the ages of 15-24 years (UKABIF, 2017), with men almost twice as likely as women to sustain an ABI (Peeters, van de Brande, Polinder, Brazinove, Steyerberg, Lingsma, & Maas, 2015).

There are also similarities in the nature of the consequences following SCI and ABI. Both SCI and ABI result in changes to a person's previous way of life (e.g., Crewe & Krause, 2009; Hofgren et al., 2010) and the consequences have an impact for social relationships, roles and employment opportunities (e.g., Anderson et al., 2007; Hart et al., 2009). A person's mood is also often impacted on, and following SCI, 27% of individuals will experience significant levels of depression (North, 1999). The rate of suicide following SCI is between two and six times higher than that for the able-bodied population (Beedie & Kennedy, 2002). There are similar findings in samples of people with ABI, with the prevalence of depression estimated to being 40% (Seel, Kreutzer, Rosenthal, Hammond, Corrigan, & Black, 2003) and suicide risk estimated to be three to four times greater than in healthy individuals (Teasdale & Engberg, 2001).

As can be seen there are some similarities between SCI and ABI in the context of injury and the emotional consequences following these injuries. In addition, the nature of

the injury for both SCI and ABI is traumatic due to the suddenness of the person's injury (Lennon, Bramham, Carroll, McElligott, Carton, Waldron, . . . Benson, 2014). This unpredictability of sustaining both SCI and ABI leads to the person questioning the assumptive nature of their world view and therefore the potential to develop PTG. Whilst a person can sustain both an SCI and ABI following injury, the focus of the systematic review and empirical paper is on SCI and ABI individually. Although the nature of the injuries is different, there are often mobility difficulties associated with ABI and SCI, with both requiring adapting to a new way of doing things, with pre-and-post injury comparisons being made (e.g., Gracey, Evans, & Malley, 2009; Yoshida, 1993). PTG may be particularly pertinent as it indicates a persons' ability to develop in a way that is not simply returning to baseline. This may be an important concept in ABI and SCI where due to the consequences of injury it may not be possible to return to a previous baseline of functioning (Levine, Laufer, Stein, Hamama-Raz & Solomon, 2009).

### **Rationale for Considering ABI and SCI**

The research paper focused on ABI due to research interest in this area and potential participants to recruit from. Consideration was given to carrying out a systematic review within ABI literature, however due to the limited amount of research in this area another, yet similar, population was used. This was due to the amount of published data needed for a meaningful review and also due to interest in the similarities and differences between PTG for two traumatic injures (ABI and SCI) that share many features, as described above.

In fact, due to the shared experiences of suffering a sudden onset injury with life changing consequences, a recent study compared people with ABI and SCI and found that, when looking at identity reconstruction, the trauma of an injury impacts more than the type of injury sustained (Lennon et al., 2014). Furthermore, Silva et al., (2011) suggested that there is a current lack of research on the subjective experience of ABI in the process and

development of PTG. Given that the areas of PTG are often similar across types of trauma, and that there is limited research on ABI and PTG, it was decided that SCI would be the focus of the systematic review.

## **SECTION C**

Research Paper

‘Putting a new perspective on life’: A qualitative grounded theory of posttraumatic growth  
following acquired brain injury

Prepared for submission to the Journal of Disability and Rehabilitation

Word count: (6971 excluding references)

**‘Putting a new perspective on life’: A qualitative grounded theory of posttraumatic growth following acquired brain injury**

Ionie Lyon<sup>a\*</sup>, Paul Fisher<sup>b</sup> and Fergus Gracey<sup>c</sup>

*<sup>a</sup> Trainee Clinical Psychologist, Doctorate in Clinical Psychology, University of East Anglia, Norwich, UK.*

*<sup>b</sup> Clinical Lecturer, Department of Clinical Psychology, School of Medicine, University of East Anglia, Norwich, UK*

*<sup>c</sup> Senior Research Fellow, Department of Clinical Psychology, School of Medicine, University of East Anglia, Norwich, UK*

Address for correspondence\* Ionie Lyon, Trainee Clinical Psychologist, Doctorate Programme in Clinical Psychology, Department of Clinical Psychology, School of Medicine, University of East Anglia, Elizabeth Fry Building, Norwich NR4 7TJ

[I.Lyon@uea.ac.uk](mailto:I.Lyon@uea.ac.uk)

# **‘Putting a new perspective on life’: A qualitative grounded theory of posttraumatic growth following acquired brain injury**

## **Abstract**

Purpose: This research sought to interpret the development of positive psychological growth amid acquired brain injury (ABI). Exploring how participants perceive their ABI allowed for emergent ideas of the influencing factors in the process of developing posttraumatic growth (PTG) to be constructed. *Method:* A qualitative study was carried out using the grounded theory method. Semi-structured interviews were carried out with 10 adults with ABI who self-reported having PTG. Interviews were analysed using the constant comparative method. *Results:* An understanding of how people with ABI develop PTG suggested four themes people move through in an iterative process: ‘living with a life changing injury’, ‘trying to beat it and acceptance’, ‘identifying with a new you and others’, and ‘meaningful positive change’. *Conclusions:* Experiencing an ABI is a life changing and often catastrophic event in a person’s life, yet people are able to experience PTG and realise a new purpose and appreciation for life. This study adds to the understanding of the process of PTG following ABI, and highlights a need to explore the role that shared experiences and community engagement play as influencing factors in developing PTG.

Keywords: posttraumatic growth, acquired brain injury, shared experiences, rehabilitation.

## **Implications for rehabilitation**

- The findings suggest that participants go through a fluid process of loss, acceptance and shared experiences in the development of posttraumatic growth. This ongoing process means that rehabilitation services may need to consider the timeliness of intervention.

- Health professionals can enable a person to process and manage feelings of loss by providing a safe, supportive space and by demonstrating warmth, understanding and patience.
- Facilitating opportunities for connection with others promotes posttraumatic growth, and social relationships need to be considered during assessment and intervention.
- Posttraumatic growth was associated with developing new purpose and meaning in life through social relationships and group membership. Holistic and social approaches to rehabilitation need to be considered further.

## **Introduction**

Many previous studies have focused on the losses experienced following acquired brain injury (ABI), with long term implications for cognitive, emotional and physical abilities and relationships with family and friends [1]. Having a life changing event such as an ABI can be viewed as an interruption to a person's way of life that can lead to a period of life transition [2]. Adjustment to a loss of prior identity [3], and a person's ability to accept changes following their ABI, have implications for recovery, with people who describe more negative experiences and loss being less able to adapt successfully to a new way of life [4]. Individuals who have experienced ABI will go through changes in personal identity and social relationships [5]. Following ABI the process of re-evaluating priorities and values in life may be associated with emotional distress during the early stages of community reintegration [6]. How a person manages this may depend in part on the support the person has. A person will need to adapt to their new way of life, with changed cognitive abilities, possible increased dependency on others, loss of roles, and a need for accessing external support becoming factors that will need considering [7]. These changes are associated with the emotional experiences of grief and depression following injury and can foster a perceived change in self-identity [3]. One of the challenges of adjustment following ABI is

that the person is faced with a threat to their sense of self and of belonging to society [8]. Over the last 10 years a small number of studies have started to focus on the idea that a person's struggle with the new reality following ABI can result in developing positive psychological change [e.g., 1, 9]. This idea suggests that, following trauma, people are capable not only of learning how to cope with and adjust to their negative experiences but also that they can start to view their experiences as a springboard for growth [6].

The term 'posttraumatic growth' (PTG) describes the phenomenon of positive psychological growth following a traumatic life event [10], with the suggestion that people can achieve a higher level of functioning than existed prior to the event. The construct of PTG provides an appealing notion of hope following trauma and incorporates a growing trend in positive psychology [11]. Despite this, critics of PTG have questioned whether this can represent genuine positive change, or if it explains a coping process [12]. Furthermore, it has been questioned whether self-reported PTG reflects life changes, or retrospective understanding of the trauma experienced as a way to self-protect themselves by unrealistic and optimistic beliefs from the trauma they have experienced [13]. Additionally, it is important to bear in mind that not everyone who experiences a traumatic event will report PTG. Despite this, the notion of PTG does not discount a person's struggle with the emotional aftermath of a traumatic event rather, it is through the struggle and re-evaluation of who they are and the world around them following a traumatic experience that PTG emerges [14]. Although these concerns with PTG may appear intuitive, studies have consistently demonstrated that people report similar aspects of positive change such as a greater appreciation of life, strengthened relationships, a belief that they are stronger because of their experience, changed priorities and deepening spiritual belief [15]. Furthermore, the idea that a person has the ability to learn from surviving a serious trauma, which can shape their identity and lead to growth [16], appears to be an important concept for ABI where people's sense of identity and cognitive abilities are often shattered.

It has been found that people with ABI reported substantial PTG such as improved life quality, enhanced personal satisfaction and increased spirituality [17]. A further study, interviewing 103 people via telephone, suggest that positive psychological growth was found in half of the sample. It has been suggested that PTG takes time to develop and is often reported five or more years post injury [18], mirroring the long recovery process following ABI [19]. Despite this, one study which sampled people six months post discharge reported modest levels of PTG ranging between no change, a very small degree of change (spirituality), and a small to moderate degree of change (a greater appreciation of life) [6], suggesting that PTG can develop relatively soon following ABI. Given this, it may therefore not be the length of time since injury that needs to be further understood, but the process of development.

Previous research has described how clinicians can focus their effort into supporting development of PTG [1], highlighting the benefits and context of social support, activity and new relationships as key factors in the development of PTG following ABI [1, 16, 20]. A person's social identity is constructed through social relationships, and is influenced by identification with social groups which are often disrupted or threatened following ABI [21]. Research has highlighted the significance of shared experiences as a protective factor in maintaining positive social identity following a stroke [22], and positive meaning can be derived through the reconstruction of sense of self following ABI [7]. The consequences of ABI can fundamentally change a person's way of life and their sense of who they are, and this influences how they see themselves in the future [23, 24]. Despite these changes to the sense of self following ABI, rehabilitation often focuses on how to support people with functional outcomes and psychological distress, rather than on how trauma has changed their self-understanding [25]. Therefore, understanding the role that social support may have in the development of PTG is important when considering the impact ABI has on a person's self-concept and changes to social roles and loss of friends.

This positive psychological perspective highlights the need to explore both loss and potential for growth following ABI [26]. As such, the concept of PTG may be understood as **different to resilience and coping**, as these may exist without a person experiencing trauma [20]. Furthermore, resilience can be defined as the positive adaptation in the face of a traumatic event [27], with perhaps the important distinction with PTG being that growth represents a change for the better following adversity [15]. As yet, it is unclear how the process of PTG develops following ABI and there is currently a lack of research on the subjective experience for understanding the process and development of PTG [6]. Therefore, this current study aims to take initial steps towards the development of a theoretical model, and to understand the process whereby PTG emerges following ABI. Furthermore, understanding how PTG develops will provide insight into how rehabilitation services can support the development of PTG following ABI.

## **Methodology**

### ***Study design***

This study was approached from a social constructionist perspective, i.e. that understandings of the world are actively constructed in co-ordination with other people [28]. Grounded Theory (GT) was used as a way of analysing multiple socially constructed realities whilst enabling the development of a model from the data [29]. This study adhered to the guidelines set out by Charmaz's social constructionist approach to GT that is concerned with the psychological processes within a social setting, and the influencing factors that construct a particular phenomenon [30]. This study used GT-lite [31] which completes the earlier stages of GT (initial coding and concept development), thus providing an indication of the relationships between concepts being studied, but it might not lead to generation of a full theory. It has been suggested that very few studies carry out full GT as it is only achievable in a large research project [32].

## Participants

Participants were adults (six men and four females) who had acquired their ABI after the age of 18, and who self-identified with developing PTG since injury (Table1). The average age of participants was 49.9 years, with the range of ages being between 32 and 77 years. The average time since injury was 15.6 years, ranging from two to 58 years. All participants were currently living in the community and none of them had returned to paid employment.

Table 1. Participant characteristics

Participant * pseudo name and number indicating which Headway centre	Age	Type of injury	Years since injury	Marital status and living environment	Children
John (2)	48	TBI	16	Married, living at home	Yes
Pete (2)	38	TBI	14	Married, living at home	No
Mary (2)	41	Infection causing abscess	6	Married, living at home	No
Helen (1)	32	TBI	6	Married, living at home	Yes
Kathy (1)	51	Hematoma	2	Separated, living at home with support	Yes
Harriet (1)	46	TBI	14	Divorced prior to ABI, living at home	Yes
Nate (1)	38	TBI	16	Single, living at home with parents	No

Colin (3)	77	TBI	58	Married, living on own	No
Elliot (3)	59	Haemorrhage	5	Living with partner	No
Wayne (3)	39	Haemorrhage	19	Single, living at home with support	No

---

Participants were recruited from one of three Headway centres. Headway is a UK-wide registered charity, which works to improve life after brain injury. The charity works to raise awareness of brain injury and the effects it can have. It also helps survivors of brain injury and their families and carers regain some quality of life through a wide range of services, including rehabilitation programmes, carer support, social re-integration, community outreach and respite care.

Participants had to have sufficient language and communication abilities to participate in interviews. Informal information sessions were held at the three Headway centres and participants who expressed an interest made contact with a member of Headway staff who contacted the researcher. Written informed consent was gained from all participants, with an opportunity to discuss any concerns with staff, family and the researcher prior to the study. Particular consideration was given to ensuring the anonymity of participants and managing any distressing emotions during the interview. Ethical approval was sought and gained from the Research Ethics Committee of the Faculty of Medicine and Health Sciences at the University of East Anglia (Appendix C).

### *Data Collection*

Face-to-face semi-structured interviews (SSIs) were carried out with participants at the three Headway centres. Audiotaped interviews ranged from 45 minutes to 70 minutes. An interview schedule (Appendix D) was developed by considering open and curious questions

which addressed the process of PTG and followed GT guidelines [30]. This schedule was broadly followed, as this allowed the interview to remain an active process, using the participant's language, in a way that resembled a conversation and promoted a co-construction of the interview between participant and researcher [33].

Initially, questions asked people to describe their experiences following their ABI, with the aim of allowing the participant to reflect on the development of PTG. In keeping with GT, the questions in subsequent interviews became more focused, based on provisional analysis. The iterative process of data collection, analysis, **theoretical sampling** and focused coding was continued until 'theoretical sufficiency' [34] was judged to be achieved. Achieving 'theoretical sufficiency' is the point at which the categories have good explanatory power, and does not necessarily mean exhaustion of data sources [35]. Ten participants were interviewed in total, with 6-10 participants being viewed as sufficient for GT-lite [31]. In discussion with the project supervisors it was decided that theoretical sufficiency was reached following the 10 participants. This was due to the depth of analyses reached so far, and that later interviews were providing no new information in relation to the research question, such that the analysis was not indicating any new themes or ways of understanding the process of PTG.

#### *Sensitivity to context*

The researcher (I.L.) aimed to experience the social setting as the participants did— from the inside - and this meant spending considerable time mixing with members of Headway at their local Headway centre. It was acknowledged that the researcher was not able to replicate participants' views or to reproduce their experiences, but it was still necessary to enter their settings in order to avoid being separate from their experiences. Being present in the participants' everyday surroundings gave the researcher otherwise unobtainable views,

and allowed for discovery of what was significant from the viewpoints and actions of the participants within their social milieu [34].

### *Reflexivity and Rigour*

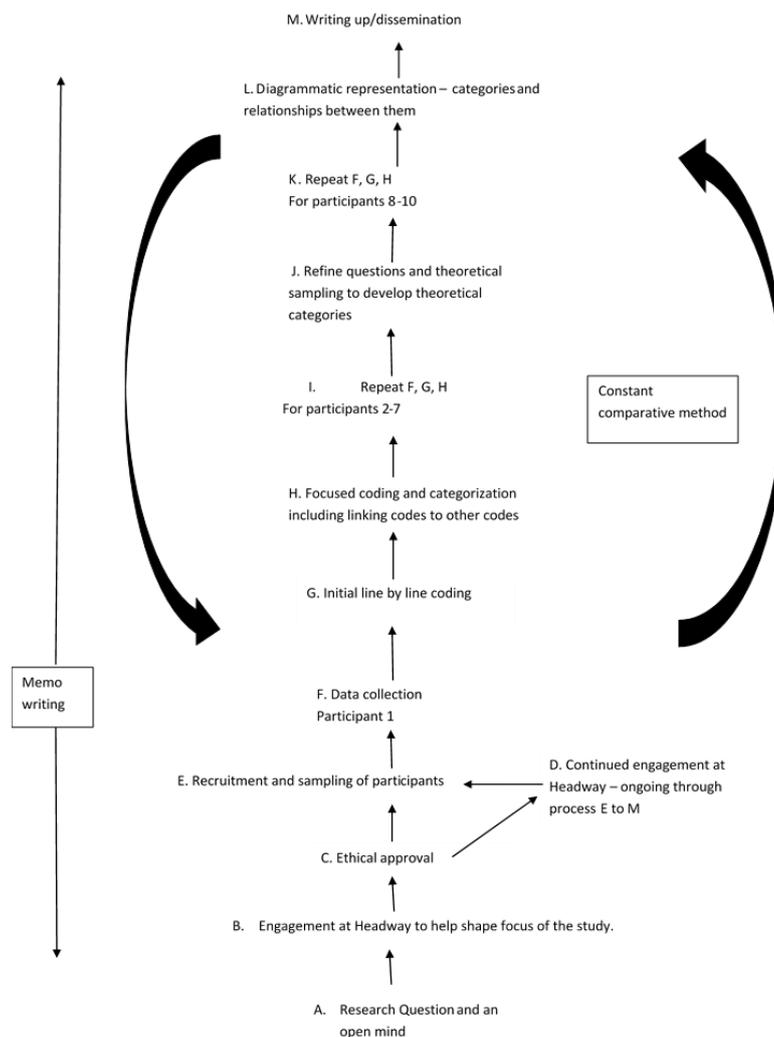
By entering the participants' social setting, the experiences and views of the researcher (I.L.) might influence the direction of the study and interpretation of the data. Therefore, during the course of the study, numerous steps were taken to ensure reflectivity and transparency. A reflective journal was completed throughout the study. This is recognised as good practice [36] in order to think through emerging ideas and make any influences explicit.

Reflection was also given to pre-existing conceptualisations that might influence 'theoretical sensitivity'. By not confusing an 'open mind with an empty head' [34, p. 176] the research could be approached with the pragmatic view that prior knowledge can be used to inform analysis but not direct it. As well as taking part in discussion with supervisors, the researcher attended an ABI research supervision and qualitative forum with other trainee clinical psychologists. This was utilised to ensure trustworthiness of the data and analysis.

### *Analysis*

Data collection and analysis followed GT guidelines [30], ensuring that a constant comparative method was used by adopting simultaneous collection of data and analysis (Figure 1).

Figure 1. Flow chart of the recruitment, interviewing and analysis process following grounded theory method



The interviews were analysed, firstly using line-by-line coding to allow the researcher (I.L.) to study the data closely and to begin conceptualising ideas. Following this, focused coding was used as a way to start to separate, sort and synthesize the data into codes that had analytical significance for this study. These initial codes were sorted and reduced to establish theoretical categories, with the emerging categories being formed in an iterative process. Initially, purposive sampling was used to select the sample based on self-reported PTG. Following the process of analysis and developing categories from the data, the participants who self-reported PTG were then chosen by theoretical sampling, thus ensuring that subsequent data was collected by selecting participants, in order to develop a theory as it emerged so as to further refine and clarify concepts. Theoretical sampling was introduced after interviewing the first seven participants, and focused on time since injury. In keeping

with a grounded theory approach, later interviews were influenced by the analysis to date, with more specific questions being asked in the later interviews. This process ensured that the theory being developed fitted with the data, and that ‘theoretical sufficiency’ was achieved.

Throughout this process, a journal was kept and memos were written in order to reflect on and keep track of developing ideas and how categories had been arrived at, to ensure rigour of the study. Member checking was not used in this study, as social constructionist grounded theory arises from the interaction between the researcher and participant, with the researcher’s perspective being part of the process. Rather, demonstrating the process by which the researcher arrived at the themes was used in order to ensure trustworthiness.

Where necessary, participant quotations have been slightly edited to enhance understanding and ensure anonymity.

## **Results**

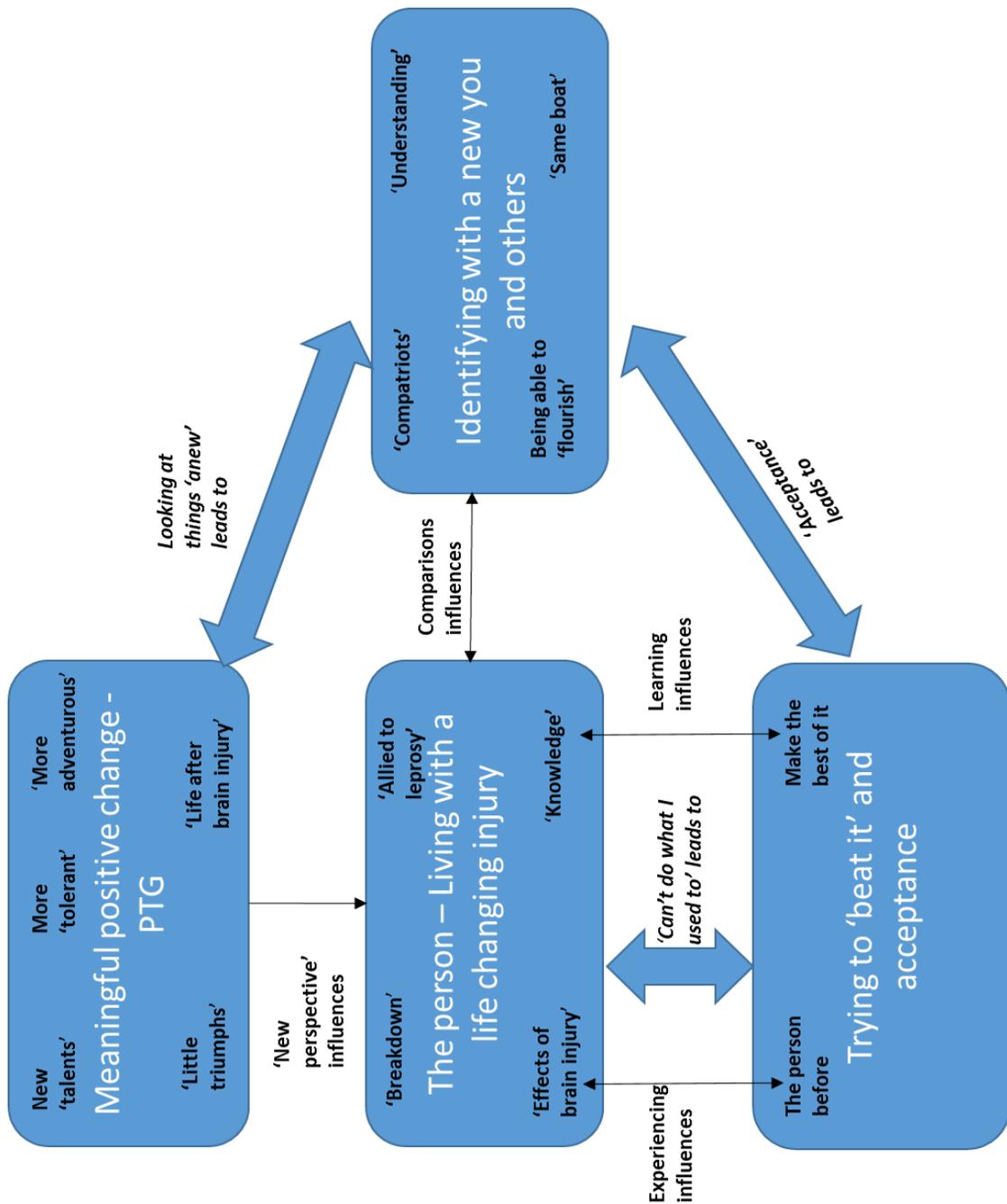
Data from this study suggested that the process of developing PTG moves through four phases, but that these are fluid and a person may move back and forth between these different phases in such a way that PTG is an ongoing process. The four key themes that were constructed from the data in the process and development of PTG were:

- Living with a life changing injury
- Trying to “beat it” and acceptance
- Identifying with a new you and others
- Meaningful positive change

Figure 2 displays, in diagrammatic form, the conceptualised connections between the themes. Each box represents one theme, with the large arrows representing how one theme

leads to the next and the smaller arrows showing how the themes influence one another. Participants described active engagement with the process rather than something that happens to them. Therefore, the model that emerged from the data placed the person at the centre of the process, with their experience being key in the process of developing PTG.

Figure 2. Model of posttraumatic growth following acquired brain injury



### *Living with a life changing injury*

The participants needed to go through a process of loss and managing their emotional difficulties following their injury. The theme of 'living with a life changing injury' shows that the person experiences loss in relation to what they used to be able to do, here described by Harriet.

I had a bit of a breakdown, 'cos I was the one in control of me and my life but when I got home I felt like I couldn't cope. I used to cry a lot and I was angry, agitated and upset and frustrated because I couldn't do what I used to be able to. So I didn't want to get out of bed. (Harriet)

The participants described not understanding what they were experiencing leading to feelings of isolation, as described by Elliot.

I felt bewildered [before specialist rehabilitation]. I'd got some leaflets about the effects of brain injury but I was still struggling to come to terms with all the different feelings, which were going on in my head without the knowledge of how to control those emotions. I just felt pretty lonely pretty desperate. (Elliot)

Changes following their injury were not only felt in relation to themselves but also, as John describes here, in terms of relationships.

It messed my life up completely, from that point those roles [between his wife and him] have had to change. I suppose our social life has been destroyed to some extent because having a brain injury is allied to leprosy. (John)

The change to social relationships was often due to cognitive changes associated with the ABI and not being able to do what they could previously, as described by Mary

I used to have one very close friend and she used to come round regularly when I first had the brain injury, she was hugely supportive, but over time I hardly ever see her and that is a shame. It is because I used to be the instigator, I used to do all the arranging and since [the ABI] I've not been able to do all that, I hardly ever see her now and I feel that is because I'm not able to do all those things any more. (Mary)

Participants needed to experience feelings of loss, and as the model shows, the process of acceptance emerges from gaining knowledge and adjusting to losses.

#### *Trying to "beat it" and acceptance*

As this model shows, the process of loss and not being able to deal with things that they used to leads to participants trying to "beat" their ABI and the subsequent acceptance that it is not something that can be beaten. At first it was difficult for participants to live with the consequences of their ABI and to understand how it had changed their way of life, as described by Elliot.

I tried to go back to work because I thought I was ready, but I was nowhere near and after a couple of months I was made redundant. (Elliot)

The process of adjusting to and accepting the changes following their ABI was influenced by others' understanding, as described by Helen, who is talking about the community support she received from a health professional.

A lot of people don't see that your brain process has changed, but when they do realise that, your life changes because you feel finally someone believes me. They know that something is wrong with me and they're going to help me find out how to get rid of it, you can't but they did teach you how to deal

with it. I think it was their kindness, the fact that they went out of their way to help in areas where I really needed help. (Helen)

Participants also spoke about comparing themselves to their old selves, and the importance of doing things in the process of acceptance. This comparison to the old self can be connected to the effects of their ABI, as described in the first theme; as described by Mary.

In the early years, I used to compare but over the years I kind of don't make that comparison. I just live my life now and I'm lucky because I'm active throughout the week and occupied and I'm not sitting at home, thinking and pondering. Maybe that makes quite a difference, being active and not on your own, that has helped with my acceptance as well. (Mary)

The process of acceptance was influenced, as described by John, by a realisation that it was not possible to go back to how he was and that he would have to start viewing things differently.

For years, I thought I could beat it, and then you start to learn it isn't something you can beat, it's always there. You are always remembering, trying to hope that you were the person before the accident. It helps when people are accepting more, and more importantly, me accepting it more. It's like you are locked inside this room, you become a prisoner and in the beginning you are banging on the door asking someone to let you out. You finally discover you can't get out of there. So you start to think I've got to live in here, so you start to move the furniture around so in a more acceptable position, you get those bits and make a little cooker, you start to use the wall as a calendar the whole thing starts to change. I have to make the best of this, let's work on this from here. (John)

A process of acceptance leads to being able to identify with a new you and others through understanding and shared experiences, leading to the next theme.

*Identifying with a new you and others*

Participants in this theme described being able to still enjoy the things they had prior to their injury but also that comparing themselves to others influenced how they viewed themselves following their ABI. Being able to do things that they had enjoyed before was important for developing a coherent understanding, as described by Colin.

I think mainly just being interested in things. I was still fascinated by reading and to try and cope with what I'd been left with. (Colin)

Mary describes how being in a safe environment where she was able to share her experiences with people who had similar experiences helped her re-connect with others.

When I first came to Headway I was very embarrassed that I might answer a question with a silly answer, and you know, that never ever happened - not one person ever giggled or laughed. For me, being amongst other people that also have had a brain injury and have a little bit of understanding of what struggles you have, for me it's a huge comfort - I feel relaxed in the environment. (Mary)

Being with others who have shared experiences encouraged rumination and reflection, as Wayne explains.

Headway has helped me a lot with my having a bit of a chip on my shoulder and helping in my life. I've always wanted to do things and I've never at the time realised that I couldn't actually do it, and Headway has been a good anchor to try and explain it. The activities I do and even socialising with the

people at Headway help because everyone else is in the same boat and it's like a family situation - you've got more understanding. (Wayne)

Being with others allowed the participants to try new things and develop a changed role in social relationships. Being with others and doing things in a different way influenced how participants viewed themselves following their ABI, connecting the themes of identifying with a new you and meaningful positive change; as described by Pete.

One thing that has changed in me - because I do try and make people smile, I try and make them laugh - and that's one thing I like about myself since my accident. Now don't get me wrong, for quite a long time I was very reserved, if I was in a new situation it was very difficult, but one of the things that's happened here at Headway is that its allowed me to flourish in a way that I hadn't done before and its allowed me to do things that I couldn't do. (Pete)

Participants also compared themselves to other people around them who they felt they had a shared identity with, as described by John.

I look round and I feel that I am lucky and I see there are people worse off than I am and that's another thing Headway has shown me. I mean, I am very lucky I still have the same wife, I mean lots of compatriots here, their marriages have been destroyed by the brain injury. (John)

Below, Nate describes the process of PTG- connecting how comparing himself to other people who have an ABI influenced his knowledge of living with a life changing injury. It also shows that acceptance of the person he is now leads to identifying with others who he may not have identified with before, thus leading to meaningful positive change.

More caring about other people in my situation.... I just think caring for other people, whereas some people, I mean, not being funny, the people I grew up with, they've just turned out right ruffians and they haven't got a care in the world - like people who come here, they probably come here and take the mick out of them for how they are but I'm not like that because I know I've been through it. That's why I care about people more, if you know what I mean. (Nate)

Being able to practise cognitive strategies was facilitated by being with others, as explained by Helen.

[Before Headway] my ability to stop, look and listen wasn't there. I didn't know how to do any of that. It's a very important day for me because I'm here with people who are just like me. When you go outside you feel like the minority 'cos it is a very big world. When you come here you feel at home because people praise you they don't degrade you - people outside do that a lot. (Helen)

As the model shows, this process of identifying with a new you and others provides a process whereby participants can accept their ABI and the consequences of this. By making comparisons to others and developing a new identity, participants were able to look at things in a new way, which led to the next theme in the process of PTG.

#### *Experiencing meaningful positive change*

After a process of acceptance, identifying with others and developing a change of identity, participants were able to achieve meaningful positive change. John spoke about being able to strengthen relationships with his family through shared experiences following his ABI.

I've become a lot closer to my sister than I ever was before- things became more bonded from speaking once a year to everyday, not straight from brain injury, it's something that has sort of grown. My sister's husband has been unwell and my experience is not too dissimilar to that I think it helped her in a way. (John)

Pete describes the dynamic process of acceptance, finding the positive experiences and opportunities because of his ABI, whilst acknowledging the negative aspects too.

Life is too short, there's never enough chocolate and never enough sex and there's so little time. What I mean is if you've got a brain injury for heaven's sake look at it as an opportunity. There is negativity about brain injury not just for the person but for the people around them, and a lot of things wrong. There are a lot of things you don't recover from, there are a lot of things you can't do anymore but at the same time I've found in my experience there are an awful lot of things you can do. A lot of things that you can look at anew and you can actually turn some aspects of the brain injury into a positive thing, you know, which I have done successfully and I think everybody has these little triumphs. (Pete)

Participants spoke about the process of viewing themselves in a much more positive way following their ABI, as described by Colin.

I've learnt to tolerate a lot of things that I wouldn't have tolerated before, other people. I used to - just before the accident I think I was flying high and I was very full of it I think. Tolerance has increased because of the head injury. I recognise my own failings more than I use to. (Colin)

The importance of appreciating being alive, whilst acknowledging the traumatic experiences, allowed the process of viewing things more positively, as described by Harriet,

Don't be a grouchy person 'cos things have happened to you that weren't very pleasant, you're alive you've got another day, you breath the fresh air in your lungs and you sort yourself out and say 'oh I've got so and so today', 'I'm going to do this', meet new people and get the memory stimulating. I think more positive now and I have to keep trying to be more adventurous and progress every day. (Harriet)

Helen speaks about discovering new talents and being able to listen more over time.

It's amazing, I found different talents that I didn't think I had and things that I thought I wasn't good at before. As time was progressing and I was calmer - you see when you're not angry and you're calm you can listen a little more. (Helen)

The process of growth and being able to develop a life for themselves and their family, as well as being able to feel more fortunate is described by Mary.

You don't have a choice, there is no magic cure to bring your old self back. I'm not saying it's easy and I'm not saying I 100% accept it but I feel that I am better. I just feel fortunate to be able to do what I can do now I'm making the best of what I can do. I used to bump into things and be clumsy and my husband had to learn because everything has got to stay in the same place, so it's been a learning curve for my husband. I feel I'm lucky because we've got a different life now but we still do have a lifestyle. (Mary)

As described by Mary above, the process of PTG conceptualised in this model involves gaining knowledge of how to manage the things they can't do now which leads to acceptance. This process of acceptance leads to identifying with a new you and a new lifestyle appreciating the things that can still be done and leading to meaningful positive change.

Participants spoke of enjoying the same things but in a different way. Kathy describes the process of PTG and being able to re-evaluate her life through her experiences

I would have enjoyed the sun but not in the same way [before injury]. I was sitting the other morning and thinking, isn't this wonderful isn't this good to be sitting here and watching the sun rise, realising there's a purpose to it. I think prior to the head injury you kind of think life just ticks away and you lose the concept of what really life is about. The simple things like the sun coming up, stupid simple things, being able to do things now, being able to move on and read again and enjoying a book, seeing things come on and move on and not stand still. There is a life after brain injury you have to put a new perspective on life. (Kathy)

As the model shows, the themes of living with a life changing injury lead to trying to beat it, and acceptance which leads to identifying with a new you and others. After the process of acceptance participants were able to look at things in new ways which led to PTG and meaningful positive change. This meaningful positive change and a new perspective on life influence the person living with a life changing injury and how they accept it and how they view themselves and others, thus identifying with and experiencing PTG. Therefore, the themes are linked in a dynamic and fluid process.

## **Discussion**

In this study, the development of PTG was conceptualised as a dynamic process whereby people moved iteratively through phases of loss, acceptance and re-connecting with others. **The process** of PTG was conceptualised in this study to emerge from the changes the participants experienced and struggled with following their ABI. Through a process of acceptance and meeting others in a similar situation the participants reported developing

PTG. This enabled the participants to change not only how they viewed themselves and relationships but also their priorities in life. Following their ABI, the initial process was of engaging with and managing the emotional consequences, experiencing changes to roles, loss of friendship and the ability to do things, as described in the first theme 'living with a life changing injury'. The findings from this study echo previous conceptualizations of PTG as the result of a struggle with highly challenging events which represent a significant challenge to the person and their ways of understanding the world and their place within it [37]. Thus, the current findings may support previous research that also suggest that PTG can emerge following ABI.

Attempting to return to previous roles and to maintain previous friendships was described in this study as an initial response, before the participants learnt to accept, and gain understanding as described in the second theme 'trying to "beat it" and acceptance'. As described in the third theme 'identifying with a new you and others' the process of understanding their experiences and meeting others in a similar situation, led to the emergence of a changed view of themselves and their priorities, as described in the final theme 'experiencing meaningful positive change'. These findings support previous research that suggests the initial negative emotions following a traumatic event signal to the person that a significant part of the self has been lost or damaged, and that this negative emotion must first be acknowledged and examined in order to create the potential for new aspects of the self to emerge [38].

As described by the participants in the final theme being able to focus on what they can do and feeling fortunate for this may have supported the process of PTG. This may resonate with previous studies that have found, following ABI, learning to accept oneself and developing pride in one's achievements were important steps in viewing oneself in a positive way [10]. Further consideration may be needed to be given to previous research

that effortful cognitive processes (e.g. reinterpretation of the event and its meaning) are important for people to redefine their beliefs about themselves and the world [37]. In time these processes restore one's sense of meaning in life and lead to fundamental changes in values and directions in life, self-identity and relationships [39].

This **study conceptualized** the development of PTG as a dynamic process within which the participants spoke of the benefits of being with others who shared similar injuries, difficulties, strengths and experiences. This resonates with recent research which describes the value of relating to others with a similar experience [40]. The participants in this study described learning and broadening their opportunities and developing as people who were less 'set in their ways' and more willing to try new and different things than they would have been previously. As previous research has suggested people may positively redefine themselves in a dynamic and multi-faceted process by forming new priorities and interests (e.g. joining support groups) which can restore self-esteem and enhance satisfaction with life [41]. The participants in this study spoke of the benefits of understanding their own ABI and the consequences in relation to themselves and other people with an ABI. This idea of comparison to others may resonate with previous research that suggests that it is through the social context that people can gain meaning in life and a sense of identity [42]. People often come to know who they are, partly by knowing who they are as group members [43].

The participants in this study described the benefits of being able to talk with others who understood them and the importance of not feeling embarrassed or judged by others. However, previous research have suggested that cognitive ability, communication and other sequels of the injury can lead to disruption to social opportunities, facing negative judgments and resulting in exclusion from groups [41]. These negative instances post-injury are experienced as a threat to self and may lead to attempts to cope via avoidance and, withdrawal from social and activity contexts [7]. This finding resonates with the ideas of

the ‘Y-shaped model’ [44] which proposed that coming to awareness, and understanding, and resolving discrepancies with the self before and self now, involves the process of adaptation and leads to reintegration into society. In particular, this relates to the conceptualisation of the process of change and the reduction of self-discrepancy for the psychological (meaning, identity, understanding, expectations) and the social (roles, activities, contexts, relationships), which can occur through **engagement in activities** [7]. Being able to engage with others has been suggested to support the re-creation of a narrative, which is essential in giving a person’s life a sense of meaning and purpose [21]. It has been suggested that PTG should not be viewed as ‘one piece of the complex puzzle, but rather as the fundamental frame that holds the entire puzzle together’ [45, p. 65]. Therefore, the importance of opportunities for people to narrate their experiences and story of recovery after ABI could be part of the process for PTG to emerge.

### *Clinical implications and recommendations*

This study may be of **clinical relevance** for those working with ABI as it may suggest that PTG can be experienced by people following ABI, and that the process may be a fluid and iterative process that people progress through. Therefore, clinicians may need to consider the timeliness of interventions which may support a person along this process. Previous research suggests that identification with others can provide a positive means to redefine the self after ABI [46]. This study may in some way suggest that feedback from others who have shared experiences may provide a positive environment where people are able to attempt new things. The benefits of being with others who have shared experiences following ABI may need to be considered when working within this setting and how best this can be facilitated within a safe trusting and cooperative environment, as suggested by the holistic rehabilitation approach [47].

Furthermore, the idea of ‘social neuropsychology’ [22], which can promote personal identities and increased social participation as a desired outcome, may be an important factor when considering a person’s progress following ABI. Thus, the clinical implications may be to consider and **evaluate how** rehabilitation is currently promoting social participation and psychological adaptation, whilst considering the social context and resources within the community [7], as well as the influence this may have on the process and development of PTG.

#### *Limitations of the study and future directions*

Due to the social constructionist position of the researcher, the results were co-constructed between participants from Headway and the researcher, and this study makes no attempt to claim that the findings are objective or are generalizable, in the statistical sense, to other populations. In particular, all the participants were members of Headway and other settings may have different processes and result in different experiences. Despite this, the three centres were very different in terms of space, geographical location and staffing. When considering the findings of this study, it is also important to consider the **social milieu of Headway**. The participants were all passionate advocates of Headway and this may have emphasised the role and importance of social support. Despite this, the participants all spoke about the emotional struggle following ABI and this was conceptualised to be an important aspect in the process of PTG. As detailed in the methodology (for a more detailed account please see methodology chapter), numerous steps were taken to make the role of the researcher as transparent as possible.

Future areas of interest would be the role that social relationships and belonging to a group have in the idea and development of PTG, as well as exploring the concept of a recovery narrative following ABI. The role of comparisons to others is an interesting idea in PTG - whilst the literature suggests that social relationships and re-connecting with

community and people, following trauma, are important, this idea of comparing oneself to others has not been widely addressed. Further research is needed to explore the role that both upward and downward social comparison has for people, following ABI, and the part this may play in the process of PTG.

## **Conclusions**

The ongoing development of PTG evolved through a dynamic process of managing loss, acceptance and establishing a changed perspective on life. The social and interpersonal context for the participants within this study could be viewed as the foundation for an active process of viewing things differently and experiencing PTG. The re-engagement with meaningful social groups, roles and activities leads to looking at things in a new way and a realisation of meaningful positive change as a result of participants' ABI. These meaningful positive changes grew as a result of a person's experiences throughout this process, leading to a new perspective on life and a view that, although changed, there is life after ABI.

## **Acknowledgments**

I would like to acknowledge and thank everyone at Headway for their support and enthusiasm with this research.

## **Declaration of interest statement**

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

## **References**

1. Powell T, Gilson R, Collin C. TBI 13 years on: Factors associated with post-traumatic growth. *Disabil and Rehabil.* 2012;34:1461-1467.
2. Doering, BK, Conrad N, Rief W, et al. Life goals after brain injury in the light of the dual process approach: Empirical evidence and implications for neuropsychological rehabilitation. *Neuropsychol Rehabil.* 2011;21:515-538.

3. Carroll E, Coetzer R. Identity, grief and self-awareness after traumatic brain injury. *Neuropsychol Rehabil.* 2011;21:289-305.
4. Wolters G, Stapert, S, Brands I, et al. Coping styles in relation to cognitive rehabilitation and quality of life after brain injury. *Neuropsychol Rehabil.* 2010;20:587-600.
5. Haslam SA, Jetten J, Postmes T, et al. Social identity, health and well-being: An emerging agenda for applied psychology. *Appl Psychol.* 2009;58:1-23.
6. Silva J, Ownsworth T, Shields C, et al. Enhanced appreciation of life following acquired brain injury: Posttraumatic growth at 6 months post discharge. *Brain Impair.* 2011;12:93-104.
7. Gracey F, Ownsworth T. The experience of self in the world: The personal and social contexts of identity change after brain injury. In J Jetten, C Haslam, SA Haslam. *The social cure: Identity, health and well-being.* US: Psychol Press;2012:273-295.
8. Conneeley AL, Quality of life and traumatic brain injury: A one-year longitudinal qualitative study. *Br J of Occup Ther.* 2003;66:440-446.
9. Collicutt McGrath J, Linley PA. Post-traumatic growth in acquired brain injury: A preliminary small scale study. *Brain Inj.* 2006;20:767-773.
10. Calhoun LG, Tedeschi RG. Early posttraumatic interventions: Facilitating possibilities for growth. In JM Violanti, P Douglas, C Dunning (Eds). *Posttraumatic stress intervention: Challenges, issues, and perspectives.* Springfield, IL, US: Charles C Thomas Publisher;2000:135-152.
11. Westphal M, Bonanno GA. Posttraumatic growth and resilience to trauma: Different sides of the same coin or different coins? *Appl Psychol.* 2007;56:417-427.
12. McMillen JC, Cook CL. The positive by-products of spinal cord injury and their correlates. *Rehabil Psychol.* 2003;48:77-85.
13. McFarland C, Alvaro C. The impact of motivation on temporal comparisons: Coping with traumatic events by perceiving personal growth. *J of Personal & Soc Psychol.* 2000;79:327-343.
14. Triplett KN, Tedeschi RG, Cann A, et al. Posttraumatic growth, meaning in life, and life satisfaction in response to trauma. *Psychol Trauma: Theory, Res, Pract & Policy.* 2011;4:400-410.
15. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *J of Trauma Stress.* 1996;9:455-471.

16. Linley PA, Joseph S. Positive change following trauma and adversity: A review. *J of Trauma Stress*. 2004;17:11-21.
17. McGrath JC. Posttraumatic growth and spirituality after brain injury. *Brain Impair*. 2011;12:82-92.
18. Powell T, Ekin-Wood A, Collin C. Post-traumatic growth after head injury: A long-term follow-up. *Brain Injury*. 2007;21:31-38.
19. McGrath J. Beyond restoration to transformation: Positive outcomes in the rehabilitation of acquired brain injury. *Clin Rehabil*. 2004;18:767-775.
20. Levine SZ, Laufer A, Stein E, et al. Examining the relationship between resilience and posttraumatic growth. *J of Trauma Stress*. 2009;22:282-286.
21. Nochi M. Reconstructing self-narratives in coping with traumatic brain injury. *Soc Sci & Med*. 2000;51:1795-1804.
22. Haslam C, Holme A, Haslam SA, et al. Maintaining group memberships: Social identity continuity predicts well-being after stroke. *Neuropsychol Rehabil*. 2008;18:671-691.
23. Evans JJ. Positive psychology and brain injury rehabilitation. *Brain Impair*. 2011;12:117-127.
24. Ownsworth T. *Self-identity after brain injury*. London: Psychol Press;2014.
25. Ownsworth T, Haslam C. Impact of rehabilitation on self-concept following traumatic brain injury: An exploratory systematic review of intervention methodology and efficacy. *Neuropsychol Rehabil*. 2016;26:1-35.
26. Tedeschi RG, Calhoun LG, Groleau JM. Clinical applications of posttraumatic growth. In Joseph S (Eds) *Positive Psychology in Practice: Promoting Human Flourishing in Work, Health, Education, and Everyday Life*. New Jersey: John Wiley & Sons. 2015;503-518.
27. Newman L, Dale A. Network structure, diversity, and proactive resilience building: A response to Tompkins and Adger. *Ecol & Soc*. 2005;10.
28. Burr V. *Social constructionism*. London: Routledge Oxford;2003.
29. Fassinger RE. Paradigms, praxis, problems, and promise: Grounded theory in counseling psychology research. *J of Couns Psychol*. 2005;52:156-166.
30. Charmaz K. *Constructing grounded theory: Introducing qualitative methods*. London: SAGE;2014.
31. Braun V, Clarke V. *Successful qualitative research: A practical guide for beginners*. London: Sage;2013.

32. Pidgeon N, Henwood K. Using grounded theory in psychological research. In N Hayes (Eds). *Doing qualitative analysis in psychology*. UK: Taylor & Francis;1997:245-273.
33. Kvale S, Brinkmann S. *Interviews: Learning the craft of qualitative research*. California, US: SAGE;2009.
34. Dey I. Grounding categories. In A Bryant, K Charmaz (Eds). *The SAGE handbook of grounded theory*. London: Sage Publications Ltd;2010:167-190.
35. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006;18:59-82.
36. Yardley L. Dilemmas in qualitative health research. *Psychol & Health*. 2000;15:215-228.
37. Tedeschi RG, Calhoun LG. Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychol Inq*. 2004;15:1-18.
38. Magai C, Nusbaum B. Personality change in adulthood. In C Magai, SH McFadden (Eds). *Handbook of emotion, adult development, and aging*. London: Academic Press;1996:403-420.
39. Park CL. Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychol Bulletin*. 2010;136:257.
40. Salas CE, Casassus M, Rowlands L, et al. "Relating through sameness": A qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychol Rehabil*. 2016;1-18.
41. Douglas JM. Conceptualizing self and maintaining social connection following severe traumatic brain injury. *Brain Injury*. 2013;27:60-74.
42. Swann Jr WB, Jetten J, Gómez A, et al. When group membership gets personal: A theory of identity fusion. *Psychol Rev*. 2012;119:441-456.
43. Turner JC, Oakes PJ. The significance of the social identity concept for social psychology with reference to individualism, interactionism and social influence. *Br J of Soc Psychol*. 1986;25:237-252.
44. Gracey F, Evans JJ, Malley D. Capturing process and outcome in complex rehabilitation interventions: A "Y-shaped" model. *Neuropsychol Rehabil*. 2009;19:867-890.
45. Pals JL, McAdams DP. The transformed self: A narrative understanding of posttraumatic growth. *Psychol Inq*. 2004;15:65-69.

46. Jones JM, Williams WH, Jetten J, et al. The role of psychological symptoms and social group memberships in the development of post-traumatic stress after traumatic injury. *Br J of Health Psychol.* 2012;17:798-811.
47. Ben-Yishay Y. Postacute neuropsychological rehabilitation. In AL Christensen, BP Uzzell (Eds). *International handbook of neuropsychological rehabilitation.* New York: Kluwer Academic/Plenum Publishers;2000:127-135.

## **SECTION D**

Methodology and Design Chapter

Word Count (4,081 excluding references)

## **Methodology and Design**

This methodology section will briefly outline the rationale for both the systematic review and the research paper. Furthermore, in order to ensure that the criteria were met for quality qualitative research (e.g. Tracy, 2010) additional headings will include ‘Ontology and Epistemology’, ‘Researcher Position’ and ‘Rigour’.

### **Design**

The systematic review and the research paper both use qualitative research methods, focusing on the rich data that can be understood through participants’ subjective accounts of their own experiences (Yardley, 2000). Qualitative research is often concerned with understanding the experiences of people as they ‘encounter, engage and live through situations’ (Elliot, Fischer, & Rennie, 1999 p., 216).

It was decided to focus on qualitative research for the narrative synthesis because, in order to fully understand the role of social support in posttraumatic growth (PTG), it was necessary to understand the participants’ perspectives. The aim of this synthesis was the critical appraisal and the aggregation of qualitative findings, using systematic methods (please see Section A for more detail). It is common for thematic analysis to be used (Popay, Roberts, Sowden, Petticrew, Arai, Rodgers, . . . & Duffy, 2006) to identify the main, recurrent and most important themes in the literature, allowing the findings from the selected articles to be summarised and grouped.

It is convention to conduct quantitative systematic reviews focusing on the study quality being in terms of methodological quality, e.g. minimizing bias and systematic error (Gates, 2002). However, there has been considerable debate about the quality assessment in qualitative research: whether or not there is a plausible rationale for undertaking such

assessments, if such a rationale exists, and what criteria should be used to inform judgments about quality (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998; Schwandt, Lincoln, & Guba, 2007). The two main arguments are appraising the methodology (Dixon-Woods, Shaw, Agarwal & Smith, 2004) or focusing on the rigour of interpreting the results (Lincoln, Lynham & Guba, 2011). Despite this, it has been argued that the same criteria can be used to assess qualitative and quantitative research (Cook & Campbell, 1979; Kirk & Miller, 1986), or the adaptation of the methods used for assessing (Hammersley, 1992). Considering these debates, the Critical Appraisal Skills Programme (2017) was used because this quality checklist has been developed and tested over time, and is widely recommended for use within health care research (e.g., McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004).

### **Ontology and Epistemology**

For most qualitative researchers, there is an assumption that the researcher cannot be objective. As such, the researchers ontological, epistemological and methodological beliefs are vital in ensuring a robust and appropriate research design (Denzin & Lincoln, 2005), and the paradigm must be congruent with their own beliefs in relation to the phenomenon being studied (Mills, Bonner & Francis, 2006).

Epistemologically, this thesis was approached from a social constructionism view of knowledge which emphasis the subjective interrelationship between the researcher and the participant, and the co-construction of meaning (Hayes & Oppenheim, 1997). The ontological position is relativist (Mills et al., 2006), suggesting that relations between concepts exists in relation to culture, society or historical context, denying the existence of an objective reality. Instead, realities are socially constructed from an individual's meaning and understanding of experiences (Guba & Lincoln, 1989).

### **Research Context**

It is acknowledged that the researcher's own theoretical and socio-cultural perspectives will become part of the study, with a co-construction of meaning between the researcher and participants (Hayes & Oppenheim, 1997). As Yardley (2008; p.237) suggests, attempting to minimize the influence of the researcher 'would make it very difficult to retain the benefits of qualitative research' for example, researchers' active engagement with the participants (McLeod & Balamoutsou, 2006). Therefore, the context within which the research is carried out is important.

The project was undertaken during the second and third years of the researcher's doctorate in Clinical Psychology. The research was carried out at Headway, a brain injury charity. As such, the social milieu and context of the participant's engagement and involvement in Headway was an important consideration. A person's knowledge of the world around them comes from their experiences which are produced in particular contexts. Therefore, in contrast to the positivist and quantitative ideal of being able to obtain objective knowledge qualitative research acknowledges that biases exist for both the participants within the specific context and the researcher entering this context during the research process, and incorporates them into the analysis (Braun & Clarke, 2014).

Furthermore, it is considered good practice to involve service users<sup>1</sup> throughout the research process (Department of Health, 2005). Consideration was given to the rationale for involving service users of Headway: how they would be involved and to what extent. Discussion took place with supervisors and the gatekeeper for the project at Headway as to how best involvement could be facilitated and be inclusive for all service users even those who did not participate in the study. Attention was given to ensuring that the involvement of those at Headway was not a 'tokenism' approach (Wright, Foster, Amir, Elliott, & Wilson 2010) which may inadvertently undermine the real value of including service user

---

<sup>1</sup> The term service user is used here to include members of Headway

involvement in research. This involved, the committee members of Headway, including staff and service users, reading, discussing and approving the study proposal, commenting on participant information sheets and led to a discussion around key ethical issues such as confidentiality, and potential risks to participants.

Following on from this idea are the reported benefits of involving communities throughout the research process as a way of creating connections through the use of shared knowledge and valuable experiences (Butterfoss, Goodman & Wandersman, 1993). In this case, the research explored participants' experiences of PTG and required participants to self-identify and express an interest in the study. Emerging from this collaboration is a deeper understanding of a community's unique circumstances (Hall, 1992), and also keeping close to the context of Headway and the process of PTG.

In order to fit closely to the methodology and epistemological approach taken, the researcher aimed, throughout the process of research, to embed themselves within the context of Headway. The researcher dedicated considerable time to experiencing the environment from which participants would be recruited by participating in groups run at the centres, conversing at break times, making tea and coffee, eating lunch with Headway members and keeping close links with staff through updates during the research. The aim was to allow this process to be meaningful and the researcher was invited to present at a Headway event prior to the recruitment stage. The aim of being embedded within the research context not only ties into the methodology followed but can also establish a mutual trust that enhances both the quality and quantity of data collected (Israel, Schulz, Parker, & Becker, 2001).

### **Methodology**

This research used grounded theory (GT) methodology, developed in the 1960s to analyse and explain social and psychological processes (Glaser & Strauss, 1967). The

different approaches to grounded theory reflect that it was one of the first methods to attempt to develop a systematic method for analysing qualitative data (Glaser & Strauss, 1965, 1967). Grounded theory is also a methodology, not just a method, and as such each particular version of grounded theory has an inbuilt theoretical framework (e.g. Charmaz, 2014). Consideration was given to other qualitative methods, such as thematic analysis which was discounted because, although it aims to produce conceptually informed interpretations of the data, it does not attempt to develop a theory of a phenomenon or explicitly seek to understand a process (Braun & Clarke, p50. 2014). In contrast, GT techniques can be used for the development of categories and an understanding of the relationships between the various themes (Pidgeon & Henwood, 1997). Over the past four decades, GT has evolved in a complex fashion resulting in a wide variation of methods and perspectives (Tan, 2010).

Grounded theory is based on the theoretical framework of symbolic interactionism (Heath & Cowley, 2004), which views the self, situation and society as products of social constructions that people create through their actions and interactions. This supports the idea that behaviour or actions are best understood on the basis of meanings derived from social interactions with others (Wertz, Charmaz, McMullen, Josselson, Anderson, & McSpadden, 2011). Grounded theory interrogates the meaning created in these social relationships, attempting to discover how groups of people define their realities on the basis of their understandings of interpersonal interactions (Cutcliffe, 2000). The aim of the GT approach is to produce innovative theory that is “grounded” in data collected from participants, on the basis of the complexities of their lived experiences in a social context (Fassinger, 2005).

Grounded theory methodology views the researcher’s own perspectives as integral to the study process (Charmaz, 2008). This is partly due to the assumption that researchers

construct categories of the data via an interpretative understanding of the studied phenomenon within that context (Cho and Lee, 2014). As this research was concerned with the process of development of PTG within a specific social context, a social constructionist perspective was followed (Burr, 2003).

### **Rigour and Validity**

Commitment to the researcher's ontological, epistemological and methodological beliefs is important in ensuring a robust and appropriate research design (Denzin & Lincoln, 2005). Within the literature there have been various suggestions for how to demonstrate the rigour of qualitative research, with the guidelines for carrying out qualitative research continually evolving.

Guba and Lincoln (1989) highlighted the criteria of credibility, transferability and dependability in ensuring trustworthiness of research and resonating with readers are important quality markers. It is important to reveal the researcher's orientation and personal involvement in the research (Stiles, 1993). By providing descriptions of values and assumptions, descriptions of the participants and their life circumstances allows for the data to demonstrate credibility and coherence (Elliot et al, 1999).

Furthermore, describing the original context adequately allows for a judgment of transferability to be made by readers, to ensure findings can 'fit' into contexts outside the original study situation (Sandelowski, 1986). Other researchers suggest that sufficient contextual information should be provided to make similar judgments by others (Reinharz, 1983). Dependability is the ability for the process to be audited, and in order to show the way in which interpretations have been arrived at to ensure credibility and transferability (Koch, 2006).

Overlapping principles have been drawn together with sensitivity to contexts, commitment and rigour, transparency and coherence and impact being important principles

(Yardley, 2000). More recently, eight criteria have been suggested which are: worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence (Tracy, 2010). These are suggested criteria and are not rigid rules to adhere to. Instead they are open to flexible interpretation, and the way in which a particular investigation will fulfil these criteria will vary depending on the methodological approach (Secker, Wimbush, Watson, & Milburn, 1995). Consideration was given to these quality criteria throughout the research process by providing context of the participants and consideration of the researcher and participants' co-construction of the data. In addition, to following a consistent and systematic approach to ensure transparency and trustworthiness of the data (please see the discussion Chapter for a review of rigour and validity). Considering the methodological approach is also important and this research, in addition to those quality criterion described above, approached the study guided by specific principles for social constructionist GT (Charmaz, 2008). These are:

- 1) Treat the research process as a social construction
- 2) Reflect on research decisions and directions
- 3) Be analytical in your approach
- 4) Collect sufficient data

The first principle refers to the researcher responding to emergent questions and new insights while simultaneously carrying out the analysis, and the importance of the researcher embedding themselves within the process. Charmaz, (2004) describes entering the phenomenon that is being studied in order to discover what is significant from the viewpoints and actions of the people who experienced it, without assuming what is significant. The researcher's engagement with Headway and the process of embedding themselves within the context (described above) ensured that this principle was achieved, and provided credibility and transferability for the emergent results. In addition, the

researcher ensured that they were fully present during the interview and immersing the self in the data afterwards. This active involvement with the data shapes the analysis (Goffman, 1989) and involved the researcher carrying out initial line-by-line coding by hand, on paper, to feel less removed from the data.

The second principle relates to the researchers own reflectivity on this process and the importance of a transparent audit trail of the thoughts and thinking throughout the research about the decisions they are taking and how these are operationalized, often through the use of a reflective journal, memos and supervision. As with transparency, there needs to be a clear process from transcription, to line-by-line initial coding. This was done on paper and then the initial themes, with reference to line, quote, and theme, were put in a spreadsheet to ensure that the theme was staying close to the data and that transparency and a clear process were being followed (for an example please see Appendix E and F).

This is related to the third principle, in that researchers need to be enquiring throughout this process, and analytical in their approach. Supervision was used as a time to discuss this process and how the researcher was able to account for what they did. The reflective diary was also used as a way to keep an audit trail as a way to record how critical moments throughout the study were made, observed and reflected on. Therefore, during the course of the study a reflective journal was kept to document ideas and understanding of PTG. Keeping a reflective journal is recognised as good practice for making explicit any influences (Yardley, 2000), and this is a part of GT. It is not viewed as being possible for the researcher to maintain a neutral stance rather the role of the researcher is to take an active stance (Charmaz, 2014), and the data is co-constructed with the participant and researcher. Given this, the reflectivity of the researcher is a critical component when carrying out GT. The use of memo writing and a reflective journal makes explicit any experiences or pre-existing knowledge that will shape the research process. In order to learn

about participants' meanings, the researcher needs to be reflective about their own views of reality (please see excerpt of reflective journal figure 1), and through the process of research to learn the reality of the participant being studied and not impose their own reality on it (Charmaz 2004). Hence, the importance of the researcher position which is described in more detail in the next section.

The fourth principle highlights the importance of obtaining rich data in order to facilitate understanding meanings and actions to construct useful GT, whereby immersing the self in the research context, as described above. Rigour also refers to the resulting completeness of the data collection and analysis. This depends partly on the adequacy of the sample and its ability to supply all the information needed for a comprehensive analysis – in GT this is known as 'saturated data'. The researcher ensures this was reached by following an iterative process and reviewing previous interviews and emerging codes and themes continually through the analysis and interviewing stage. This back and forth process allows for the completeness of data and to ensure that links between the themes can be revised and developed from what the participants are saying. This process was stopped following discussion with the supervisor, it was felt that no new data would provide any more depth of detail to the constructed themes. In addition, to the time restraints placed on the study.

## **Researcher Position**

### **Researcher Experience and Interest**

The idea that we are all influenced by our history and cultural context, which shapes how we view the world, and make sense of the world, suggests that the researcher's own experiences and perspectives will influence their interaction with the data, and thus the analysis (Mills et al., 2006).

I<sup>2</sup> am a 34 year old white British trainee clinical psychologist with experience of working as an assistant psychologist with adults with an acquired brain injury, both in the community and in inpatient rehabilitation settings, for two and half years. This experience of working in both these settings shaped my views about the importance of community rehabilitation for providing opportunities for people to do all that they can, and for developing and sustaining relationships. When working within brain injury services the focus was often on a person's journey from the moment they sustained an ABI, and I often observed how some people spoke of their experience as providing new opportunities, direction and meaning. Despite this, the focus in acute inpatient settings was often one of reaching functional goals, often at the expense of the person's preferences, interests or qualities as a person. This focus on what the person has lost often jarred with positive experiences of other people, especially within the community, and I was left wondering about a person's journey following ABI and the process of the positive psychological changes that can occur. This experience also influenced my interest in qualitative research which was able to provide a richer understanding of people's lives rather than a measure of a particular aspect but that may not explain the complexity and often subtle experiences which have meaning for a person. Working in the community, I also had experience of visiting the acute wards in hospital where people were recovering from their acquired brain injury, often still in induced comas and with the medical use of machines, and the constant presence of staff. Experiencing the journey of people with brain injury may have also influenced how I interpreted the process of the development of PTG.

My interest in identity and social constructs stemmed from experiences growing up. Growing up in London but with parents from the North of England highlighted the importance of shared social identity in relation to not only geographically identified values

---

<sup>2</sup> Due to the reflective nature of this section I am writing in first person.

and identities but also social and cultural contexts. Having parents who came from a working class and a middle class background highlighted the juxtaposition of these experiences, and how social identities can influence a person's view of the world and how they interpret and understand their experiences.

Both personally and via my clinical experience, these influences were reflected on during the course of the project, for example in the excerpt below from my reflective journal.

Figure 1 example of reflective diary

I arrived at Headway just as everyone was arriving for the start of the morning session. The members were very welcoming and friendly and were chatting to one another. I was aware of the art work and I wondered how this might influence my interpretation of growth and positive changes. I thought of the common and shared experience of seeing the art work and what it is communicating to people at Headway and those who visit.

During the interview, the participant became tearful and angry when speaking about the loss they had experienced. After the interview, I felt bewildered and reflected on the different feelings I had felt in a very short space of time, going from inspiration to anger. This reminded me of the importance to listen to what the participants are saying and to use their words. Even if the feeling of Headway and the context feels different. I am now thinking that loss and emotions may have a part to play and that I can not only focus on the positive (however much I may want to).

It reminded me of people who I have worked with who felt very angry following their injury and how a loss of role and friendship must feel completely bewildering for the person to as they try and muddle through the best they can and make sense of it.

Following this interview I felt bewildered, but staying close to the methodology I embraced this bewilderment and contradiction, as Charmaz (2004) advocates: 'treat bewilderment as a sign that you are entering the phenomenon' (p., 981). Through this struggle with the bewilderment following the interview, the contradiction between the experiences reported and emotions expressed during the interview, and context of the setting I felt that I was able to gain a deeper understanding of the phenomenon and of the processes involved in PTG.

Using my own understanding of the participants' reports of their inner experiences (thoughts, feelings, beliefs, perceptions, intentions) as data may make inferences about participants' experiences based on interaction and interpretation (Stiles, 1993). Empathic understanding draws on the researcher's own experiences and self-knowledge (Stolorow & Atwood, 1984).

I had no previous experience of using grounded theory and approached the task with both openness and uncertainty. Before commencing the project considerable effort was made to gain an adequate level of competence in the methodology, through supervision, training courses, reading texts, discussion in a qualitative forum and ABI research group with other trainee clinical psychologists, and lectures with an interest in qualitative and ABI research. It has been suggested that novice researchers should conform to the tenets of a specific GT tradition (Creswell, 2013) in order to understand fully the philosophical assumptions and procedural steps (Achora & Matua, 2016), and the researcher followed the steps outlined by Charmaz (Charmaz, 2014).

### **Reflections on the Research Process**

I found carrying out the research a process in itself, where I developed skills and knowledge, and learning from the participants interviewed. The interviews often left me considering the process of PTG and feeling humbled and appreciative of the participants' enthusiasm and openness during the data collection process. I was left reflecting on being more grateful for my own health and friends and was often left considering the fragility of how life can change in an instant.

### **Writing the Thesis**

In writing up the thesis I was mindful of the strategy within social constructionist GT that advocates a writing style that is more literary than scientific in intent, and that is suggestive of the participants' experiences and is analytical in approach (Charmaz, 2004). I

often found a dilemma between developing a conceptual analysis and account of the participants' stories, and creating a presence in the final text. I found this to be a balancing act and wanted to include all the quotes from all the participants, finding it hard to select which quotes to use. I aimed to keep participants' words intact in the process of analysis in order to maintain their presence throughout (Charmaz & Belgrave, 2002), as well as including participants words in the final model (Please see research paper). This process often felt iterative, going back and forth and resonated with the analysis process of GT.

In the process of writing the research paper I reflected on the CASP (2017) and what to include within the restrictions of the journal, and also on the quality markers and whether I had achieved them. Including enough detail within a word count was a fine balancing act between providing enough detail on the methodology (e.g. recruitment strategy, data collection, ethical issues and reflectivity) and providing enough data to ensure the results were transparent and clear in the construction of the themes. Given the word restrictions of the research paper, it felt difficult to elaborate on some of the criteria, such as ethical issues, as although they were considered throughout, these of course would have been considered as a part of the ethical approval process. It may also be that my view of this was influenced by my epistemological perspective, and the reluctance to carry out qualitative research in what I might perceive as a tick box exercise that does not mirror the open and flexible approach of qualitative guidelines.

### **Dissemination and Sculpture**

The co-construction of the research, and the enthusiasm that the participants and Headway more generally had for this research, can be seen in the collaborative idea between Headway and participants to develop and exhibit a sculpture based on the experience and process of PTG. This idea was initially discussed between myself, supervisors and Headway at the proposal stage as a form of dissemination. Following the findings, key themes and ideas were disseminated back to headway, and Headway, as a response to the research, designed a

sculpture (please see Appendix G for the model plan). This development of the sculpture highlights how the function of qualitative research is not to describe but to construct a version of reality (Bruner, 1991; Freeman, 2006).

## **SECTION E**

### **Discussion and Critical Appraisal Chapter**

Word count (3014 excluding references)

## Summary of Results

Both the systematic review and the research paper suggest that the process of posttraumatic growth (PTG) can develop following acquired brain injury (ABI) and spinal cord injury (SCI), with one of the shared foundations for growth being social support. The role that social support plays in the development of PTG can be seen from the synthesis of the systematic review and from the themes of the research paper. Importantly, the shared experiences with others, and opportunities created by being with others to learn and develop a new sense of self.

Social identity was defined by Tajfel (1982) as an individual's knowledge that they belong to certain social groups, and that membership of these group has emotional and meaningful significance for them. Belonging to a group with others who have sustained similar injuries emerged as key themes in this thesis. Thus, supporting the notion that, when understanding social identity, it is important to first consider how the group influences the individual (Reicher, Spears, & Haslam, 2010).

Studies have often focused on the change in self-identity as an important aspect of life after ABI, with loss and reconstruction of self-identity and personhood being recurring themes in the narratives of people talking about their experiences of surviving ABI (Levack, Boland, Taylor, Siegert, Kayes, Fadyl, & McPherson, 2014). Loss of identity is understood to be of major importance following ABI (Nochi, 1998), and it has been suggested that the consequences of injury on prior identities - such as occupation, gender or family identities - are crucial to how individuals see themselves and cope in the aftermath of their injury (Walsh, Fortune, Gallagher & Muldoon, 2014). The importance of social identity has been suggested to buffer against the negative consequences of a person's circumstance (Haslam, Jetten, Postmes, & Haslam, 2009). Thus, identity is an emergent resource that people can adapt too, and identities can be built upon beyond coming to terms with impairment, and

extending even to the notion of growth (Silva, Ownsworth, Shields & Fleming, 2011).

Therefore, social support is an important foundation for growth: it allows the person with SCI or ABI to reconsider their post-injury identity through accepting what has been lost, and seeking what they can still do and what is new, all of which are vital in the process of PTG.

The experience of positive psychological change, experienced as a result of a struggle with highly challenging events, represents a significant challenge to the person and their ways of understanding the world and their place within it (Janoff-Bulman & McPherson Frantz, 1997). This study supported the idea that, following initial challenges and experiencing distressing emotions, participants were able to develop new and different ways of understanding themselves and to begin to view the changes in their life as positive. Furthermore, involvement in meaningful activities such as sport, following SCI, results in psychosocial benefits that can facilitate positive psychological growth (Day, 2013). The narrative synthesise adds to the existing literature on peer support (Sweet, Noreau, Leblond, & Martin Ginis, 2016) and the importance of family and friends following SCI (Beauregard & Noreau, 2009). The findings also support recent research into the importance of relating to other people with similar injuries (Salas, Casassus, Rowlands, Pimm, & Flanagan, 2016).

Aspects of PTG that may be strengthened via social support are strengthening of social relationships, allowing a person to demonstrate personal strengths and experience positive emotions (Chun & Lee, 2008), with identity being enhanced following SCI by joining sporting groups (McDonough, Sabiston, & Ullrich-French, 2011). Re-establishing self-identity via physical activity challenges existing assumptions and fosters a new sense of self (Day, 2013). The strengthening or establishment of supportive relationships following SCI enhanced people's abilities to realise the supportiveness of family and friends, to meet people they would not have met otherwise and to learn from others (Crawford, Gayman, & Tracey, 2014).

The findings from this current study mirror previous findings that people with ABI do not just accept their injuries but that they revise their self-narratives and can shift this self-narrative from 'in spite of ABI' to 'because of ABI' (Nochi, 2000). This study suggested that the process of developing PTG is a fluid and dynamic process, and this has similarities with identity models for both SCI and ABI. Yoshida (1993) has suggested a model of identity-reconstruction following SCI, based on a pendulum swinging back and forth between a person's previous identity and that which is defined by disability. This is a continuously evolving, fluid, and dual-directional process. Similarly, Muenchberger, Kendall, and Neal (2008) propose a non-linear model of self-reconstruction following ABI which is a dynamic process between a person experiencing a diminished sense of self and a broader sense of self.

### **Rigour and Quality Markers**

The primary reason for adopting qualitative methodology is a recognition that our knowledge and experiences of the world cannot consist of an objective appraisal of some external reality, but are profoundly shaped by our subjective and cultural perspective, and by our conversations and activities (Yardley, 1997). If this is the case then there can be no fixed criteria for establishing knowledge from qualitative research since, to be rigid in limiting the criteria for understanding and making meaning would mean restricting the possibilities for knowledge (Yardley, 2000). Consequently, while qualitative researchers recognise the need to establish tentative agreement as to the validity of a piece of research for a certain purpose, in a particular situation and for a specific community of people most reject the idea that there ever could or should be a universal code of practice for the use of qualitative research (Feldman, 1995; Greenhalgh & Taylor, 1997). Furthermore, in qualitative research the commitment to the methodological approach and ontological and

epistemological perspectives is important for the trustworthiness and credibility of the data produced (Koch, 2006).

### **Quality of Research Paper**

In order to evaluate the quality of research the principles of quality and rigour are followed in qualitative research (see method chapter for further description). This section will therefore critique the strengths and limitations of the research paper according to the guiding principles for grounded theory (GT) outlined by Charmaz (Charmaz, 2008).

**Treat the research process as a social construction.** Involving participants in the research process is not a new concept. Lewin (1946) pioneered an approach whereby the researcher acted in the social system with theory generation. A particular strength of this study was the meaningful engagement the researcher made with Headway. This resulted in a sculpture emerging as a response to the research and the findings that were disseminated back. This resonates with the social constructionists' stance taken by the researcher, and the aim to give priority to the participants' experiences, rather than the views of the researcher, as integral to the analysis (Charmaz, 2008). The process of the researcher immersing themselves with the context allowed for credibility and transferability of the findings by ensuring the researcher was able to consider what is significant for the participants and not for the researcher.

Despite the above strengths, a consideration of the limitations also needs to be considered. A limitation of this study may be the generalisability of the findings. The participants in this study had mostly maintained marriages and close family ties, which may be unrepresentative of people with ABI. Despite this, the study drew participants from three geographically different centres. In addition to this is the impact of context that may limit this research. There may also be common narratives that are specific to Headway that influence the development of PTG for these particular participants.

**Reflect on research decisions and directions.** Another particular area of strength in this study was the researcher's attempt to document decisions made, and to demonstrate an audit trail of the analysis to establish transparency of the findings. The researcher attempted to do this by following clear steps throughout the analysis stage, as well as by keeping quotes and themes close together so that data remained close to the participant's words. In addition, the researcher returned to the data throughout the analysis process to pursue these ideas further and ground the theory in the data. Furthermore, the researcher returned to the data throughout the analysis, and by keeping memos it allowed them to continually 'test out' additions and aspects of how the themes linked. The researcher also attempted to demonstrate credibility by detailing the process of how they got to the categories, and being transparent in the iterative process between data and emerging analysis. This was done during discussions in supervision about how the links were made, and demonstrating through discussions, how the emerging themes fitted closely to the data. The final interview questions changed as the iteration between data and emerging analysis progressed and to help demonstrate interaction between the themes.

**Be analytical in your approach.** The importance of revealing the researcher's orientation and personal involvement in the research is a quality marker of qualitative research (Stiles, 1993). The researcher attempted to carry out this research with a commitment to their position, and this may also be considered to be a particular strength and to ensure coherence and trustworthiness. Self-awareness in the researcher is essential, interpreting their experiences and processes of interactions throughout the research process (Guba & Lincoln, 1989). The researcher aimed to ensure reflectivity during supervision and by keeping a journal throughout the process as this enables the researcher to approach the data generated with 'open mindedness' (Starks & Trinidad, 2007), resulting in greater theoretical transparency (Tan, 2010). This could be suggested to be a strength of this research. A further strength of this study was the researcher's attempt at transparency. This

was done by discussion of the transcripts of the interviews in supervision and attempting to look for exceptions during the interview process.

Despite these strengths, a limitation of this study may be that the method of triangulation was not used, whereby multiple sources of information are considered. Despite not utilising member checking of the themes, the results were fed back to Headway and discussion of the process resonated with people who had and hadn't participated in the study. Another key factor that needs to be considered is the limited prior qualitative experience of the researcher: good qualitative research analysis relies on the vision and integrity of the researcher which often comes with experience and training (Pope, Ziebland & Mays, 2000).

**Collect sufficient data.** Rigour refers to the resulting completeness of the data collection and analysis. This depends partly on the adequacy of the sample and its ability to supply all the information needed for a comprehensive analysis – in grounded theory this is referred to as 'saturated data'. This study attempted to collect rich and detailed quotes of the phenomenon being studied. This being a particular strength of the study. It has been suggested that when researchers actively engage communities in their research, as this study has attempted to, it can establish a mutual trust that enhances both the quantity and the quality of data collected (Schulz, Parker, Israel, Becker, Maciak, & Hollis, 1998). It also allows a deeper understanding of a community's unique circumstances and a more accurate picture of its social and psychological processes (Altman, 1995), in terms of PTG. The researcher also attempted to ask open and curious questions during the interviews, and refrained from defining constructs or providing participants with words, in order for the data to be emergent from the participants' experiences.

Despite these strengths, a limitation of this study may be due to the purposeful sampling used. The participants who were recruited for this study identified with

experiencing PTG, and so the generalisations of the findings are specific to people who self-identify as having grown as a result of their ABI. For example, whilst acceptance was important for the participants to develop PTG, it cannot be inferred that acceptance will inevitably lead to PTG. Rather, for those who identify as having experienced PTG, acceptance was a necessary stage. Furthermore, although 10 participants were interviewed there were more potential participants who expressed an interest but it was not possible to interview them. Not being able to interview all potential participants who self-reported PTG may have limited the theoretical sensitivity of the data.

### **Quality of Systematic Review**

Although a systematic and structured approach to quality assessment was taken, as yet there is no consensus in relation to the systematic review, on the criteria that might constitute quality standards (Khan, Ter Riet, Glanville, Sowden, & Kleijnen, 2001), or on how to exclude studies based on the quality standards used (Dixon-Woods, Bonas, Booth, Jones, Miller, Sutton, . . . Young, 2006). Without specific guidance on how to exclude studies based on quality it was appropriate to include all relevant studies in the synthesis (Day, Jones, Langner, & Bluebond-Langner, 2016; Dixon-Woods et al., 2006). A common sense argument could be that papers of ‘poor quality’ do not offer richness of data and so do not contribute to a large component of the themes within this narrative synthesis (Thomas & Harden, 2008). However, in this synthesis the perceived quality of studies as rated using the CASP, did not appear to influence the number of themes the studies contributed to. Thus, there may be a more conceptual discussion needed as to whether it is appropriate to appraise qualitative research with similar methods used for assessing quantitative studies, although accurate and detailed reporting on the methods used in a study can certainly be of assistance to critical appraisal (Attree & Milton, 2006). Consideration needs to be given to whether the current criteria used for quality appraisal can identify the choices and rationale the

researchers have made in contrast to the descriptive and interpretive accounts of the research (Hannes, Lockwood, & Pearson, 2010).

A potential limitation of this narrative synthesis may be that concepts identified in one setting are not applicable to others, impacting on the generalisability of the findings to other settings. Some have suggested that the studies that are synthesised should share a similar methodology, and caution should be taken when identifying similar themes across studies if there are differences in the epistemological underpinnings (Jensen & Allen, 1996).

### **Clinical Implications**

Taking a much more holistic view of ABI and SCI, and incorporating social support into rehabilitation, could have implications for recovery and living a good quality of life that provides meaning and purpose. Rehabilitation, can foster this meaning making process by taking into consideration the social context and relationships that are important in the process of PTG for ABI and SCI. The identities people hold are a product of the groups they belong to, and individual behaviour is a function of their identity (Reicher et al., 2010). A social identity approach suggests that identities are generated in contexts and emerge from social interaction (Levine, 1999). It has been suggested that rehabilitation following ABI is about enabling people to be all that they be can in terms of their psychological, social, leisure, vocational and everyday functioning (Wilson, Gracey, Malley, Bateman, & Evans, 2009).

Additional implications for rehabilitation are that providing a supportive group atmosphere that facilitates emotional expression may inadvertently promote PTG (Calhoun, & Tedeschi, 1999). To date, however, interventions have not explicitly been aimed at increasing perceptions of growth, and it has been suggested that there needs to be more understanding about the explicit conditions under which growth occurs for growth based-

interventions to occur (Park & Helgeson, 2006). McGrath (2004) highlighted the need for placing emphasis on positive change within rehabilitation. Clinicians may be able to play a part in the development of PTG by: considering the worth of each person; focusing on the persons promise and potential; actively celebrating changes to each persons' sense of self; and involving patients in their own care trajectory (Turner & Cox, 2004). Moving the focus away from deficits to one that promotes people finding meaning and growth from the experiences of stress would be an important aspect to develop in clinical interventions, for both SCI and ABI. However, more needs to be known about the process of PTG and what can facilitate its development.

Research into SCI is being increasingly focused on the importance of social support in quality of life following injury. The importance of clinical interventions, focusing on enabling engagement in meaningful activities in the community, has been identified in improving the quality of life for people with SCI who are living in the community (Barclay, McDonald, Lentin, & Bourke-Taylor, 2016).

The implications for rehabilitation for both ABI and SCI are the consideration of interpersonal processes (Zerubavel, & Smith, 2010) throughout the rehabilitation process, and how these can integrate the biological with the social, in an attempt to not only 'fix what's wrong, but also to build what's strong' (Duckworth, Steen, & Seligman, 2005 p., 631)

### **Future Work and Ideas**

Future work may need to consider the use of peer support, but also to explore the appropriateness and timeliness of this support. Furthermore, there needs to be an increasing awareness that ABI is not a one-off event, and could perhaps be reframed as a chronic health condition or as a disease process (Corrigan & Hammond, 2013; Masel & DeWitt,

2010). Neuropsychology must look outwards to relationships and context, and also, at the influences of PTG and social identify for the individual and group memberships.

Future research could explore the importance of timeliness of support and the role that group membership has on PTG, and involving participants may also provide new insights.

### **Conclusion**

This thesis explored the phenomenon of PTG following SCI and ABI. The systematic review and the research paper highlight important related ideas about the role of social identity and group membership following injury, and the process of developing PTG. These findings will be important to consider in future interventions following ABI, including a focus on how making connections with others in similar situations can be incorporated into rehabilitation strategies. Importantly, positive changes and a new perspective of the self and one's place in the world is possible, and it is hoped that, whilst recognising the emotional consequences of these injuries, these findings will go some way to promote the idea that there is "life after brain injury".

## References

- Achora, S., & Matua, G. A. (2016). Essential methodological considerations when using grounded theory. *Nurse Researcher*, 23(6), 31-36. doi: 10.7748/nr.2016.e1409
- Allen, J. G., Huntoon, J., Fultz, J., Stein, H., Fonagy, P., & Evans, R. B. (2001). A model for brief assessment of attachment and its application to women in inpatient treatment for trauma-related psychiatric disorders. *Journal of Personality Assessment*, 76(3), 421-447. doi: 10.1207/S15327752JPA7603\_05
- Altman, D. G. (1995). Sustaining interventions in community systems: On the relationship between researchers and communities. *Health Psychology*, 14(6), 526. Retrieved from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.616.7622&rep=rep1&type=pdf>
- Anderson, D., Dumont, S., Azzaria, L., Bourdais, M. L., & Noreau, L. (2007). Determinants of return to work among spinal cord injury patients: A literature review. *Journal of Vocational Rehabilitation*, 27(1), 57-68. Retrieved from <http://web.a.ebscohost.com.ueaezproxy.uea.ac.uk:2048/ehost/pdfviewer/pdfviewer?sid=ee18e56d-5955-49f4-aba1-ca3eb2224ded%40sessionmgr4006&vid=1&hid=4112>
- Attree, P., & Milton, B. (2006). Critically appraising qualitative research for systematic reviews: Defusing the methodological cluster bombs. *Evidence & Policy: A Journal of Research, Debate and Practice*, 2(1), 109-126. doi: 10.1332/174426406775249688
- Barclay, L., McDonald, R., Lentin, P., & Bourke-Taylor, H. (2016). Facilitators and barriers to social and community participation following spinal cord injury. *Australian occupational therapy journal*, 63(1), 19-28. doi: 10.1111/1440-1630.12241

- Beauregard, L., & Noreau, L. (2009). Spouses of persons with spinal cord injury: Impact and coping. *British Journal of Social Work, 40*(6), 1945-1959. doi: 10.1093/bjsw/bcp140
- Beedie, A., & Kennedy, P. (2002). Quality of social support predicts hopelessness and depression post spinal cord injury. *Journal of Clinical Psychology in Medical Settings, 9*(3), 227-234. doi: 10.1023/A:1016003428370
- Ben-Yishay, Y., & Daniels-Zide, E. (2000). Examined lives: Outcomes after holistic rehabilitation. *Rehabilitation Psychology, 45*(2), 112. doi: 10.1037/0090-5550.45.2.112
- Braun, V. & Clarke, V. (2014). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Bruner, J. (1991). The narrative construction of reality. *Critical Inquiry, 18*(1), 1-21.  
Retrieved from [http://www.jstor.org/stable/1343711?seq=1#page\\_scan\\_tab\\_contents](http://www.jstor.org/stable/1343711?seq=1#page_scan_tab_contents)
- Burr, V. (2015). *Social constructionism*. Hove: Routledge.
- Butterfoss, F. D., Goodman, R. M., & Wandersman, A. (1993). Community coalitions for prevention and health promotion. *Health Education Research, 8*(3), 315-330.  
Retrieved from [https://www.researchgate.net/profile/Frances\\_Butterfoss/publication/13152507\\_Community\\_Coalitions\\_for\\_Prevention\\_and\\_Health\\_Promotion/links/0a85e534c56f790cad000000.pdf](https://www.researchgate.net/profile/Frances_Butterfoss/publication/13152507_Community_Coalitions_for_Prevention_and_Health_Promotion/links/0a85e534c56f790cad000000.pdf)
- Calhoun, L. G., & Tedeschi, R. G. (1999). *Facilitating posttraumatic growth: A clinician's guide*. London: Routledge.

- Calhoun, L. G., Cann, A., Tedeschi, R. G., & McMillan, J. (2000). A correlational test of the relationship between posttraumatic growth, religion, and cognitive processing. *Journal of Traumatic Stress, 13*(3), 521-527. doi: 10.1023/A:1007745627077
- Carpenter, C., Forwell, S. J., Jongbloed, L. E., & Backman, C. L. (2007). Community participation after spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 88*(4), 427-433. doi: 10.1016/j.apmr.2006.12.043
- Charmaz, K. (2004). Premises, principles, and practices in qualitative research: Revisiting the foundations. *Qualitative Health Research, 14*(7), 976-993. doi: 10.1177/1049732304266795
- Charmaz, K. (2008). Constructionism and the grounded theory method. In J.A. Holstein, & J.F. Gubrium (Eds), *Handbook of constructionist research*, (pp. 397-412). New York: Guilford Press.
- Charmaz, K. (2014). *Constructing grounded theory*. London: Sage.
- Charmaz, K., & Belgrave, L. (2002). Qualitative interviewing and grounded theory analysis. In J.F. Gubrium, J.A. Holstein, A.B. Marvasti, & K.D. McKinney (Eds), *The SAGE handbook of interview research: The complexity of the craft* (pp. 675-694). London: Sage.
- Cho, J. Y., & Lee, E. H. (2014). Reducing confusion about grounded theory and qualitative content analysis: Similarities and differences. *The Qualitative Report, 19*(32), 1-20. Retrieved from <http://nsuworks.nova.edu/tqr/vol19/iss32/2>
- Chun, S., & Lee, Y. (2008). The experience of posttraumatic growth for people with spinal cord injury. *Qualitative Health Research, 18*(7), 877-890. doi: 10.1177/1049732308318028

- Collicutt McGrath, J., & Linley, P. A. (2006). Post-traumatic growth in acquired brain injury: A preliminary small scale study. *Brain Injury, 20*(7), 767-773. doi: 10.1080/02699050600664566
- Cook, T. D., & Campbell, D. T. (1979). *Quasi-experimentation: Design and analysis for field settings*. Rand McNally.
- Corrigan, J. D., & Hammond, F. M. (2013). Traumatic brain injury as a chronic health condition. *Archives of Physical Medicine and Rehabilitation, 94*(6), 1199-1201. doi: 10.1016/j.apmr.2013.01.023
- Crawford, J. J., Gayman, A. M., & Tracey, J. (2014). An examination of post-traumatic growth in Canadian and American ParaSport athletes with acquired spinal cord injury. *Psychology of Sport and Exercise, 15*(4), 399-406. doi: 10.1016/j.psychsport.2014.03.008
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. London: Sage.
- Crewe, N. M., & Krause, J. S. (2009). Spinal cord injury. In Brodwin, M.G., Siu, F.W., Howard, J., & Brodwin, E.R (Eds), *Medical, psychosocial and vocational aspects of disability*. Athens: Elliott and Fitzpatrick (pp. 289-304). Retrieved from <http://www.kvccdocs.com/KVCC/2014-Spring/MHT226/Medical%20Aspects.pdf#page=299>
- Critical Appraisal Skills Programme (2017). CASP Qualitative Checklist. Retrieved from <http://www.casp-uk.net/checklists>, Accessed: 22/12/2016.
- Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing, 31*(6), 1476-1484. doi: 10.1046/j.1365-2648.2000.01430.x

- Day, M. C. (2013). The role of initial physical activity experiences in promoting posttraumatic growth in Paralympic athletes with an acquired disability. *Disability and Rehabilitation, 35*(24), 2064-2072. doi: 10.3109/09638288.2013.805822
- Day, E., Jones, L., Langner, R., & Bluebond-Langner, M. (2016). Current understanding of decision-making in adolescents with cancer: A narrative systematic review. *Palliative Medicine, 30*(10), 920-934. doi: 10.1177/0269216316648072
- Denzin, N. K., & Lincoln, Y. S. (2005). *Handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Department of Health. (2005) Research Governance Framework for Health and Social Care. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/139565/dh\\_4122427.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf)
- Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care, 13*(3), 223-225. doi: 10.1136/qshc.2003.008714
- Dixon-Woods, M., Bonas, S., Booth, A., Jones, D. R., Miller, T., Sutton, A. J., ... & Young, B. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research, 6*(1), 27-44. doi: 10.1177/1468794106058867
- Duckworth, A. L., Steen, T. A., & Seligman, M. E. P. (2005). Positive psychology in clinical practice. *Annual Review of Clinical Psychology, 1*, 629-651. doi: 10.1146/annurev.clinpsy.1.102803.144154
- Duggan, C. H., & Dijkers, M. (2001). Quality of life after spinal cord injury: A qualitative study. *Rehabilitation Psychology, 46*(1), 3-27. doi: 10.1037/0090-5550.46.1.3

- Dunn, D. S., & Brody, C. (2008). Defining the good life following acquired physical disability. *Rehabilitation Psychology, 53*(4), 413-425. doi: 10.1037/a0013749
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*(3), 215-229. doi: 10.1348/014466599162782
- Fassinger, R. E. (2005). Paradigms, praxis, problems, and promise: Grounded theory in counseling psychology research. *Journal of Counseling Psychology, 52*(2), 156-166. doi: 10.1037/0022-0167.52.2.156
- Faul, M., Xu, L., Wald, M. M., Coronado, V., & Dellinger, A. M. (2010). Traumatic brain injury in the United States: National estimates of prevalence and incidence, 2002–2006. *Injury Prevention, 16*(1), 1-268. doi: 10.1136/ip.2010.029215.951
- Feldman, M. S. (1995). *Strategies for interpreting qualitative data*. Thousand Oak, CA: Sage.
- Freeman, T. (2006). 'Best practice' in focus group research: Making sense of different views. *Journal of Advanced Nursing, 56*(5), 491-497. doi: 10.1111/j.1365-2648.2006.04043.x
- Fryer, K., Thomas, S., & Barnes, M. (2017). Disease insight report – Acquired brain injury. Retrieved from <http://ukabif.org.uk/wp-content/uploads/2017/03/NHiS-ABI-Report-Web.pdf>
- Gates, S. (2002). Review of methodology of quantitative reviews using meta-analysis in ecology. *Journal of Animal Ecology, 71*(4), 547-557. doi: 10.1046/j.1365-2656.2002.00634.x
- Glaser, B. G., & Strauss, A. L. (1965). Discovery of substantive theory: A basic strategy underlying qualitative research. *American Behavioral Scientist, 8*(6), 5-12.

- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. London: Weidenfield & Nicolson.
- Goffman, E. (1989). On fieldwork. *Journal of Contemporary Ethnography*, 18(2), 123-132. Retrieved from [https://is.muni.cz/el/1423/jaro2016/SOC560/um/61907340/goffman-on\\_fieldwork.pdf](https://is.muni.cz/el/1423/jaro2016/SOC560/um/61907340/goffman-on_fieldwork.pdf)
- Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. *Neuropsychological Rehabilitation*, 19(6), 867-890. doi: 10.1080/09602010903027763
- Greenhalgh, T., & Taylor, R. (1997). Papers that go beyond numbers (qualitative research). *British Medical Journal*, 315(7110), 740- 743. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2127518/pdf/9314762.pdf>
- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. London: Sage.
- Hall, B. L. (1992). From margins to center? The development and purpose of participatory research. *The American Sociologist*, 23(4), 15-28. doi: 10.1007/BF02691928
- Hammersley, M. (1992). Deconstructing the qualitative-quantitative divide. In Brannen, J. (Eds), *Mixing methods: Qualitative and quantitative research* (pp. 39-55). Aldershot: Avebury.
- Hannes, K., Lockwood, C., & Pearson, A. (2010). A comparative analysis of three online appraisal instruments’ ability to assess validity in qualitative research. *Qualitative Health Research*, 20(12), 1736-1743. doi: 10.1177/1049732310378656
- Hart, T., Seignourel, P. J., & Sherer, M. (2009). A longitudinal study of awareness of deficit after moderate to severe traumatic brain injury. *Neuropsychological Rehabilitation*, 19(2), 161-176. doi: 10.1080/09602010802188393

- Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social identity, health and well-being: an emerging agenda for applied psychology. *Applied Psychology, 58*(1), 1-23. doi: 10.1111/j.1464-0597.2008.00379.x
- Hayes, R., & Oppenheim, R. (1997). Constructivism: Reality is what you make it. In T. Sexton & B. Griffin (Eds.), *Constructivist thinking in counseling practice, research and training* (pp. 19-41). New York: Teachers College Press
- Heath, H., & Cowley, S. (2004). Developing a grounded theory approach: A comparison of Glaser and Strauss. *International Journal of Nursing Studies, 41*(2), 141-150. doi: 10.1016/S0020-7489(03)00113-5
- Hill, M. R., Noonan, V. K., Sakakibara, B. M., & Miller, W. C. (2010). Quality of life instruments and definitions in individuals with spinal cord injury: A systematic review. *Spinal Cord, 48*(6), 438-450. doi: 10.1038/sc.2009.164
- Hofgren, C., Esbjörnsson, E., & Sunnerhagen, K. S. (2010). Return to work after acquired brain injury: Facilitators and hindrances observed in a sub-acute rehabilitation setting. *Work, 36*(4), 431-439. doi: 10.3233/WOR-2010-1039
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (2001). Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for Health, 14*(2), 182-197. Retrieved from [http://scholar.google.co.uk/scholar?q=Israel%2C+B.+A.%2C+Schulz%2C+A.+J.%2C+Parker%2C+E.+A.%2C+%26+Becker%2C+A.+B.+%282001%29.+Community-based+participatory+research%3A+policy+recommendations+for+promoting+a+partnership+approach+in+health+research.+Education+for+Health%2C+14%282%29%2C+182-197.&btnG=&hl=en&as\\_sdt=0%2C5](http://scholar.google.co.uk/scholar?q=Israel%2C+B.+A.%2C+Schulz%2C+A.+J.%2C+Parker%2C+E.+A.%2C+%26+Becker%2C+A.+B.+%282001%29.+Community-based+participatory+research%3A+policy+recommendations+for+promoting+a+partnership+approach+in+health+research.+Education+for+Health%2C+14%282%29%2C+182-197.&btnG=&hl=en&as_sdt=0%2C5)

- Janoff-Bulman, R., & McPherson Frantz, C. (1997). The impact of trauma on meaning: From meaningless world to meaningful life. In M.J. Power, C.R. Brewin (Eds), *The transformation of meaning in psychological therapies: Integrating theory and practice*, (pp. 91-106). New Jersey: John Wiley & Sons Inc.
- Jensen, L. A., & Allen, M. N. (1996). Meta-synthesis of qualitative findings. *Qualitative Health Research*, 6(4), 553-560. Retrieved from <http://journals.sagepub.com/doi/pdf/10.1177/104973239600600407>
- Joseph, S., & Butler, L.D. (2010). Positive changes following adversity. *PTSD Research Quarterly*, 21(3), 1–8. Retrieved from <https://pdfs.semanticscholar.org/8664/5bdee79393cae9131c4a7a4c694e3566eb76.pdf>
- Joseph, S., & Linley, P. A. (2005). Positive adjustment to threatening events: An organismic valuing theory of growth through adversity. *Review of General Psychology*, 9(3), 262-280. doi: 10.1037/1089-2680.9.3.262
- Joseph, S., & Linley, P. A. (2008). Positive psychological perspectives on posttraumatic stress: An integrative psychosocial framework. In S. Joseph & P.A. Linley (Eds), *Trauma, recovery, and growth: Positive psychological perspectives on posttraumatic stress*, (pp. 3-20). New Jersey: John Wiley & Sons, Inc.
- Joseph, S., Murphy, D., & Regel, S. (2012). An affective–cognitive processing model of post-traumatic growth. *Clinical Psychology & Psychotherapy*, 19(4), 316-325. doi: 10.1002/cpp.1798
- Kalpakjian, C. Z., McCullumsmith, C. B., Fann, J. R., Richards, J. S., Stoelb, B. L., Heinemann, A. W., & Bombardier, C. H. (2014). Post-traumatic growth following

spinal cord injury. *The Journal of Spinal Cord Medicine*, 37(2), 218-225. doi: 10.1179/2045772313Y.0000000169

Khan, K. S., Ter Riet, G., Glanville, J., Sowden, A. J., & Kleijnen, J. (2001). *Undertaking Systematic Reviews of Research on Effectiveness: CRD's Guidance for those Carrying Out or Commissioning Reviews (CRD Report Number 4)* (2nd edition). York (UK): NHS Centre for Reviews and Dissemination, University of York, 2001.

Kirk, J., & Miller, M. L. (1986). *Reliability and validity in qualitative research*. London: Sage.

Koch, T. (2006). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, 53(1), 91-100. doi: 10.1111/j.1365-2648.2006.03681.x

Langlois, J. A., Rutland-Brown, W., & Wald, M. M. (2006). The epidemiology and impact of traumatic brain injury: A brief overview. *The Journal of Head Trauma Rehabilitation*, 21(5), 375-378. Retrieved from <https://pdfs.semanticscholar.org/7d37/b53a118a7e51c40ee4d9dc5c72cafa0df5a6.pdf>

Lennon, A., Bramham, J., Carroll, A., McElligott, J., Carton, S., Waldron, B., ... & Benson, C. (2014). A qualitative exploration of how individuals reconstruct their sense of self following acquired brain injury in comparison with spinal cord injury. *Brain Injury*, 28(1), 27-37. doi: 10.3109/02699052.2013.848378

Levack, W. M., Boland, P., Taylor, W. J., Siegert, R. J., Kayes, N. M., Fadyl, J. K., & McPherson, K. M. (2014). Establishing a person-centred framework of self-identity after traumatic brain injury: A grounded theory study to inform measure development. *BMJ Open*, 4(5), e004630. doi: 10.1136/bmjopen-2013-004630

- Levine, R. M. (1999). Identity and illness: The effects of identity salience and frame of reference on evaluation of illness and injury. *British Journal of Health Psychology*, 4(1), 63-80. doi: 10.1348/135910799168470
- Levine, S. Z., Laufer, A., Stein, E., Hamama-Raz, Y., & Solomon, Z. (2009). Examining the relationship between resilience and posttraumatic growth. *Journal of Traumatic Stress*, 22(4), 282-286. doi: 10.1002/jts.20409
- Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues*, 2(4), 34-46. doi: 10.1111/j.1540-4560.1946.tb02295.x
- Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N.K. Denzin & Y.S. Lincoln (Eds), *The Sage handbook of qualitative research*, (pp. 97-128). London: Sage.
- Linley, P. A., & Joseph, S. (2004). Positive change following trauma and adversity: A review. *Journal of Traumatic Stress*, 17(1), 11-21. doi: 10.1023/B:JOTS.0000014671.27856.7e
- Masel, B. E., & DeWitt, D. S. (2010). Traumatic brain injury: A disease process, not an event. *Journal of Neurotrauma*, 27(8), 1529-1540. doi: 10.1089/neu.2010.1358
- McDonough, M. H., Sabiston, C. M., & Ullrich-French, S. (2011). The development of social relationships, social support, and posttraumatic growth in a dragon boating team for breast cancer survivors. *Journal of Sport and Exercise Psychology*, 33(5), 627-648. doi: 10.1123/jsep.33.5.627
- McEwan, M. J., Espie, C. A., Metcalfe, J., Brodie, M. J., & Wilson, M. T. (2004). Quality of life and psychosocial development in adolescents with epilepsy: A qualitative investigation using focus group methods. *Seizure*, 13(1), 15-31. doi: 10.1016/S1059-1311(03)00080-3

- McGrath, J. (2004). Beyond restoration to transformation: Positive outcomes in the rehabilitation of acquired brain injury. *Clinical Rehabilitation*, 18(7), 767-775. Retrieved from <http://journals.sagepub.com/doi/pdf/10.1191/0269215504cr802oa>
- McGrath, J. C. (2011). Posttraumatic growth and spirituality after brain injury. *Brain Impairment*, 12(2), 82-92. Retrieved from <http://eds.a.ebscohost.com/eds/pdfviewer/pdfviewer?sid=de60b71c-8bd1-4f2b-8bd6-f8becccc90d2%40sessionmgr4008&vid=0&hid=4202>
- McLeod, J., & Balamoutsou, S. (2006). A method for qualitative narrative analysis of psychotherapy transcripts. In J. Frommer & D. L. Rennie (Eds.), *Qualitative psychotherapy research: Methods and methodology*, (pp. 128–152). Lengerich, Germany: Pabst Science.
- Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods*, 5(1), 25-35. Retrieved from <http://journals.sagepub.com/doi/pdf/10.1177/160940690600500103>
- Muenchberger, H., Kendall, E., & Neal, R. (2008). Identity transition following traumatic brain injury: A dynamic process of contraction, expansion and tentative balance. *Brain Injury*, 22(12), 979-992. doi: 10.1080/02699050802530532
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S., & Watson, P. (1998). Qualitative research methods in health technology assessment: A review of the literature. *Health Technology Assessment*, 2(16), 1-260. Retrieved from <http://www.hta.ac.uk/fullmono/mon216.pdf>
- National SCI Statistical Centre (2016). Spinal cord injury Facts and figures at a glance. Retrieved from <https://www.nscisc.uab.edu/Public/Facts%202016.pdf>

- Nietzsche, F. (1889). *Twilight of the idols and the anti-Christ*. (R. J. Hollingdale, Trans.). p. 52, 2003, New York: Penguin Books.
- Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine*, 46(7), 869-878. doi: 10.1016/S0277-9536(97)00211-6
- Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science & Medicine*, 51(12), 1795-1804. doi: 10.1016/S0277-9536(00)00111-8
- North, N. T. (1999). The psychological effects of spinal cord injury: A review. *Spinal Cord*, 37(10), 671-679. Retrieved from <http://eds.a.ebscohost.com/eds/pdfviewer/pdfviewer?sid=71098218-11e3-43ce-9ac6-d257deb62d0f%40sessionmgr4009&vid=0&hid=4202>
- Park, C. L., & Helgeson, V. S. (2006). Introduction to the special section: Growth following highly stressful life events--current status and future directions. *Journal of Consulting and Clinical Psychology*, 74(5), 791-796. doi: 10.1037/0022-006X.74.5.791
- Peeters, W., van den Brande, R., Polinder, S., Brazinova, A., Steyerberg, E. W., Lingsma, H. F., & Maas, A. I. (2015). Epidemiology of traumatic brain injury in Europe. *Acta Neurochirurgica*, 157(10), 1683-1696. doi: 10.1007/s00701-015-2512-7
- Pidgeon, N., & Henwood, K. (1997). Using grounded theory in psychological research. In N. Hayes (Eds.), *Doing qualitative analysis in psychology*, (pp. 245-273). England: Taylor & Francis.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., ... & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. A

product from the ESRC methods programme Version, 1. Retrieved from [https://www.researchgate.net/profile/Lisa\\_Arai/publication/242311393\\_Guidance\\_on\\_the\\_conduct\\_of\\_narrative\\_synthesis\\_in\\_systematic\\_reviews\\_a\\_comparison\\_of\\_guidance-led\\_narrative\\_synthesis\\_versus\\_meta-analysis/links/5532159f0cf2f2a588ad67fd.pdf](https://www.researchgate.net/profile/Lisa_Arai/publication/242311393_Guidance_on_the_conduct_of_narrative_synthesis_in_systematic_reviews_a_comparison_of_guidance-led_narrative_synthesis_versus_meta-analysis/links/5532159f0cf2f2a588ad67fd.pdf)

Pope, C., Ziebland, S., & Mays, N. (2000). Analysing qualitative data. *British Medical Journal*, 320(7227), 114-116. Retrieved from <http://www.brown.uk.com/teaching/HEST5001/pope.pdf>

Powell, T., Ekin-Wood, A., & Collin, C. (2007). Post-traumatic growth after head injury: A long-term follow-up. *Brain Injury*, 21(1), 31-38. doi: 10.1080/02699050601106245

Powell, T., Gilson, R. and Collin, C. 2012. TBI 13 years on: Factors associated with post-traumatic growth. *Disability & Rehabilitation*, 34(17): 1461–1467. doi: 10.3109/09638288.2011.644384

Reicher, S., Spears, R., & Haslam, S. A. (2010). The social identity approach in social psychology. In M.S. Wetherell & C.T. Mohanty (Eds.), *Sage identities handbook*, (pp. 45-62). London: Sage.

Reinharz, S. (1983). Experiential analysis: A contribution to feminist research. In G. Bowles & R. Duelli-Klein (Eds.), *Theories of women's studies*, (pp. 162-191). Boston: Routledge & Kegan Paul.

Salas, C. E., Casassus, M., Rowlands, L., Pimm, S., & Flanagan, D. A. (2016). “Relating through sameness”: A qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychological Rehabilitation*, 1-18. doi: 10.1080/09602011.2016.1247730

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37. Retrieved from [http://ovidsp.tx.ovid.com/sp-3.24.1b/ovidweb.cgi?WebLinkFrameset=1&S=DNJJFPJFEADDKCJINCHKNGDCBPKIAA00&returnUrl=ovidweb.cgi%3fMain%2bSearch%2bPage%3d1%26S%3dDNJJFPJFEADDKCJINCHKNGDCBPKIAA00&directlink=http%3a%2f%2fovidsp.tx.ovid.com%2fovftpdfs%2fFPDDNCDCNGJIEA00%2ffs047%2fovft%2flive%2fgv038%2f00012272%2f00012272-198604000-00005.pdf&filename=The+problem+of+rigor+in+qualitative+research.&link\\_from=S.sh.24%7c1&pdf\\_key=FPDDNCDCNGJIEA00&pdf\\_index=/fs047/ovft/live/gv038/00012272/00012272-198604000-00005&D=ovft](http://ovidsp.tx.ovid.com/sp-3.24.1b/ovidweb.cgi?WebLinkFrameset=1&S=DNJJFPJFEADDKCJINCHKNGDCBPKIAA00&returnUrl=ovidweb.cgi%3fMain%2bSearch%2bPage%3d1%26S%3dDNJJFPJFEADDKCJINCHKNGDCBPKIAA00&directlink=http%3a%2f%2fovidsp.tx.ovid.com%2fovftpdfs%2fFPDDNCDCNGJIEA00%2ffs047%2fovft%2flive%2fgv038%2f00012272%2f00012272-198604000-00005.pdf&filename=The+problem+of+rigor+in+qualitative+research.&link_from=S.sh.24%7c1&pdf_key=FPDDNCDCNGJIEA00&pdf_index=/fs047/ovft/live/gv038/00012272/00012272-198604000-00005&D=ovft)

Schwandt, T. A., Lincoln, Y. S., & Guba, E. G. (2007). Judging interpretations: But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Evaluation*, 2007(114), 11-25. doi: 10.1002/ev.223

Schulz, A. J., Parker, E. A., Israel, B. A., Becker, A. B., Maciak, B. J., & Hollis, R. (1998). Conducting a participatory community-based survey for a community health intervention on Detroit's east side. *Journal of Public Health Management and Practice*, 4(2), 10-24. Retrieved from [http://s3.amazonaws.com/academia.edu.documents/38384709/CEI-5.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1490400558&Signature=eaKRqxOTktI6IZFUPtn3u%2Bt7jXQ%3D&response-content-disposition=inline%3B%20filename%3DConducting\\_a\\_Participatory\\_Community-Bas.pdf](http://s3.amazonaws.com/academia.edu.documents/38384709/CEI-5.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1490400558&Signature=eaKRqxOTktI6IZFUPtn3u%2Bt7jXQ%3D&response-content-disposition=inline%3B%20filename%3DConducting_a_Participatory_Community-Bas.pdf)

Secker, J., Wimbush, E., Watson, J., & Milburn, K. (1995). Qualitative methods in health promotion research: Some criteria for quality. *Health Education Journal*, 54(1), 74-87. Retrieved from

<http://journals.sagepub.com/doi/abs/10.1177/001789699505400108?journalCode=heja>

Seel, R. T., Kreutzer, J. S., Rosenthal, M., Hammond, F. M., Corrigan, J. D., & Black, K. (2003). Depression after traumatic brain injury: A National Institute on Disability and Rehabilitation Research Model Systems multicenter investigation. *Archives of Physical Medicine and Rehabilitation, 84*(2), 177-184. doi:

10.1053/apmr.2003.50106

Silva, J., Ownsworth, T., Shields, C., & Fleming, J. (2011). Enhanced appreciation of life following acquired brain injury: Posttraumatic growth at 6 months postdischarge.

*Brain Impairment, 12*(02), 93-104. doi: 10.1375/brim.12.2.93

Spinal-Research (2017). The Facts. Retrieved from <https://www.spinal-research.org/>

Spinal-Research (2017). Causes of traumatic spinal cord injury. Retrieved from

<https://www.spinal-research.org/injury/what-spinal-cord-injury>

Splevins, K., Cohen, K., Bowley, J., & Joseph, S. (2010). Theories of posttraumatic growth:

Cross-cultural perspectives. *Journal of Loss and Trauma, 15*(3), 259-277. doi:

10.1080/15325020903382111

Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of

phenomenology, discourse analysis, and grounded theory. *Qualitative Health*

*Research, 17*(10), 1372-1380. doi: 10.1177/1049732307307031

Stiles, W. B. (1993). Quality control in qualitative research. *Clinical Psychology Review,*

*13*(6), 593-618. doi: 10.1016/0272-7358(93)90048-Q

Stolorow, R. D., & Atwood, G. E. (1984). Psychoanalytic phenomenology: Toward a

science of human experience. *Psychoanalytic Inquiry, 4*(1), 87-105. doi:

10.1080/07351698409533532

- Sweet, S. N., Noreau, L., Leblond, J., & Martin Ginis, K. A. (2016). Peer support need fulfillment among adults with spinal cord injury: Relationships with participation, life satisfaction and individual characteristics. *Disability and Rehabilitation*, 38(6), 558-565. doi: 10.3109/09638288.2015.1049376
- Tajfel, H. (1982). Social psychology of intergroup relations. *Annual Review of Psychology*, 33(1), 1-39. Retrieved from <http://www.annualreviews.org/doi/pdf/10.1146/annurev.ps.33.020182.000245>
- Tan, J. (2010). Grounded theory in practice: Issues and discussion for new qualitative researchers. *Journal of Documentation*, 66(1), 93-112. doi: 10.1108/00220411011016380
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, 38(11), 1161-1173. doi: 10.1037/0003-066X.38.11.1161
- Teasdale, T. W., & Engberg, A. W. (2001). Suicide after traumatic brain injury: A population study. *Journal of Neurology, Neurosurgery & Psychiatry*, 71(4), 436-440. Retrieved from <http://jnnp.bmj.com/content/jnnp/71/4/436.full.pdf>
- Tedeschi, R. G., & Calhoun, L. G. (1995). *Trauma and transformation: Growing in the aftermath of suffering*. London: Sage Publications.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9(3), 455-471. doi: 10.1007/BF02103658
- Tedeschi, R. G., & Calhoun, L. G. (2004). "Posttraumatic growth: Conceptual foundations and empirical evidence". *Psychological Inquiry*, 15(1), 1-18. doi: 10.1207/s15327965pli1501\_01

- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45-55. doi: 10.1186/1471-2288-8-45
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837-851. doi: 10.1177/1077800410383121
- Turner, S., & Cox, H. (2004). Facilitating post traumatic growth. *Health and Quality of Life Outcomes*, 2(1), 34-43. doi: 10.1186/1477-7525-2-34
- UKABIF (2017). The United Kingdom Acquired Brain Injury Forum – about brain injury. Retrieved from <http://ukabif.org.uk/data/>
- Vedat Sar MD & Erdinc Ozturk PhD (2006) What Is Trauma and Dissociation? *Journal of Trauma Practice*, 4(1-2), 7-20. doi: 10.1300/J189v04n01\_02
- Walsh, R. S., Fortune, D. G., Gallagher, S., & Muldoon, O. T. (2014). Acquired brain injury: Combining social psychological and neuropsychological perspectives. *Health Psychology Review*, 8(4), 458-472. doi: 10.1080/17437199.2012.733914
- Wertz, F. J., Charmaz, K., McMullen, L. J., Josselson, R., Anderson, R., and McSpadden, E. (2011). *Five Ways of Doing Qualitative Analysis: Phenomenological Psychology, Grounded Theory, Discourse Analysis, Narrative Research, and Intuitive Inquiry*. New York: Guilford.
- Wilson, B.A., Gracey, F., Malley, D., Bateman, A., & Evans, J.J. (2009). The Oliver Zangwill centre approach to neuropsychological rehabilitation, In AB.A. Wilson, F. Gracey, J.J. Evans, & A. Bateman (Eds.), *Neuropsychological rehabilitation: Theory, models, therapy and outcome* (pp. 47-68). Cambridge, UK: Cambridge University Press.

- Wolters, G., Stapert, S., Brands, I., & Van Heugten, C. (2010). Coping styles in relation to cognitive rehabilitation and quality of life after brain injury. *Neuropsychological Rehabilitation, 20*(4), 587-600. doi: 10.1080/09602011003683836
- Wright, D., Foster, C., Amir, Z., Elliott, J., & Wilson, R. (2010). Critical appraisal guidelines for assessing the quality and impact of user involvement in research. *Health Expectations, 13*(4), 359-368. doi: 10.1111/j.1369-7625.2010.00607.x
- Yardley, L. (1997). Introducing discursive methods. In L. Yardley (Eds.), *Material discourses of health and illness* (pp. 25-50). London: Routledge.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215-228. doi: 10.1080/08870440008400302
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J.A. Smith (Eds.), *Qualitative Psychology: A Practical guide to research methods*, (pp. 257-272). London: Sage.
- Yoshida, K. K. (1993). Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health & Illness, 15*(2), 217-245. doi: 10.1111/1467-9566.ep11346888
- Zerubavel, E., & Smith, E. R. (2010). Transcending cognitive individualism. *Social Psychology Quarterly, 73*(4), 321-325. doi: 10.1177/0190272510388998

## **List of Appendices**

**Appendix A:** Authorial guidelines for the Journal of Disability and Rehabilitation – guidelines followed in preparation for submission of the systematic review and research paper

**Appendix B:** Process of thematic analysis for the systematic review – detailing codes, sub themes and overarching themes

**Appendix C:** University of East Anglia ethical approval for the research paper

**Appendix D:** Interview Schedule for the research paper

**Appendix E:** Example of the process for one participant of the Grounded Theory method used for analysis in the research paper

**Appendix F:** Example of the emerging theme ‘trying to “beat it” and acceptance’ from the data in the research project – Grounded Theory method

**Appendix G:** Response to the findings from Headway – model of the planned sculpture

**Appendix H:** Headway approval of the research project

**Appendix I:** Participant Information Sheet for research project

**Appendix J:** Participant consent form for research project

## **Appendix A: Author guidelines for the Journal of Disability and Rehabilitation**

### **Instructions for authors**

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our [Author Services website](#).



### **SCHOLARONE MANUSCRIPTS™**

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

### **Contents list**

[About the journal](#)

[Peer review](#)

[Preparing your paper](#)

- [Structure](#)
- [Word count](#)
- [Style guidelines](#)

## **Appendix A: Author guidelines for the Journal of Disability and Rehabilitation**

- [Formatting and templates](#)
- [References](#)
- [Checklist](#)

[Using third-party material in your paper](#)

[Declaration of interest statement](#)

[Clinical Trials Registry](#)

[Complying with ethics of experimentation](#)

- [Consent](#)
- [Health and safety](#)

[Submitting your paper](#)

[Publication charges](#)

[Copyright options](#)

[Complying with funding agencies](#)

[Open access](#)

[My Authored Works](#)

[Article reprints](#)

### **About the journal**

*Disability and Rehabilitation* is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy. Please note that this journal only publishes manuscripts in

## **Appendix A: Author guidelines for the Journal of Disability and Rehabilitation**

English. *Disability and Rehabilitation* accepts the following types of article: Reviews, Research Papers, Case Studies, Perspectives on Rehabilitation, Reports on Rehabilitation in Practice,

Education and Training, and Correspondence. Systematic Reviews should be submitted as “Review” and Narrative Reviews should be submitted as “Perspectives in Rehabilitation”.

Special Issues and specific sections on contemporary themes of interest to the Journal’s readership are published. Please contact the Editor for more information.

### **Peer review**

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. For submissions to *Disability and Rehabilitation* authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is ‘Anonymous’ or ‘Not Anonymous’ during submission, and should pay particular attention to the below:

- Authors who wish to remain **anonymous** should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the “Main Document” and will be sent to the referees. A separate title page should be included providing the full affiliations of all authors. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.
- Authors who wish to be **identified** should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the “Main Document”.

## **Appendix A: Author guidelines for the Journal of Disability and Rehabilitation**

Once your paper has been assessed for suitability by the editor, it will be peer-reviewed by independent, anonymous expert referees. Find out more about [what to expect during peer review](#) and read our guidance on [publishing ethics](#).

### **Preparing your paper**

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the [Uniform Requirements for Manuscripts Submitted to Biomedical Journals](#), prepared by the International Committee of Medical Journal Editors (ICMJE).

We also refer authors to the community standards explicit in the [American Psychological Association's \(APA\) Ethical Principles of Psychologists and Code of Conduct](#).

We encourage authors to be aware of standardised reporting guidelines below when preparing their manuscripts:

- Case reports - [CARE](#)
- Diagnostic accuracy - [STARD](#)
- Observational studies - [STROBE](#)
- Randomized controlled trial - [CONSORT](#)
- Systematic reviews, meta-analyses - [PRISMA](#)

Whilst the use of such guidelines is supported, due to the multi-disciplinary nature of the Journal, it is not compulsory.

### **Structure**

## **Appendix A: Author guidelines for the Journal of Disability and Rehabilitation**

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

### **Word count**

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

### **Style guidelines**

Please refer to these [style guidelines](#) when preparing your paper, rather than any published articles or a sample copy. Please use any spelling consistently throughout your manuscript.

## **Appendix A: Author guidelines for the Journal of Disability and Rehabilitation**

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

For tables and figures, the usual statistical conventions should be used.

Drugs should be referred to by generic names. Trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

### **Formatting and templates**

Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

[Word templates](#) are available for this journal. Please save the template to your hard drive, ready for use.

A [LaTeX template](#) is available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the templates via the links (or if you have any other template queries) please contact [authortemplate@tandf.co.uk](mailto:authortemplate@tandf.co.uk)

### **References**

Please use this [reference guide](#) when preparing your paper. An [EndNote output style](#) is also available to assist you.

### **Checklist: what to include**

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) [requirements for authorship](#) is included as an

## Appendix A: Author guidelines for the Journal of Disability and Rehabilitation

author of your paper. Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page. Where available, please also include [ORCiDs](#) and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. [Read more on authorship](#).

2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on [writing your abstract](#).
3. You can opt to include a **video abstract** with your article. [Find out how these can help your work reach a wider audience, and what to think about when filming](#).
4. 5-8 **keywords**. Read [making your article more discoverable](#), including information on choosing a title and search engine optimization.
5. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document.

Below are examples:

*Example 1: Leprosy*

## Appendix A: Author guidelines for the Journal of Disability and Rehabilitation

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group
- In a relatively small sample this study shows participation and social functioning improved after surgery.

### *Example 2: Multiple Sclerosis*

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

6. **Acknowledgement.** Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants:* This work was supported by the under Grant . *For multiple agency grants:* This work was supported by the under Grant ; under Grant ; and under Grant .
7. **Declaration of Interest.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. [Further guidance on what is a declaration of interest and how to disclose it.](#)
8. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about [supplemental material and how to submit it with your article.](#)

## Appendix A: Author guidelines for the Journal of Disability and Rehabilitation

9. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.
10. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
11. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about [mathematical symbols and equations](#).
12. **Units.** Please use [SI units](#) (non-italicized).

Referencing style [http://www.tandf.co.uk/journals/authors/style/reference/tf\\_NLM.pdf](http://www.tandf.co.uk/journals/authors/style/reference/tf_NLM.pdf)

AUTHORSERVICES  
Supporting Taylor & Francis authors

### Taylor & Francis Standard Reference Style | NLM

National Library of Medicine (NLM) is a member of the National Information Standards Organization and its various published standards have been adopted for the Library's MEDLINE/PubMed database. See <https://www.nlm.nih.gov/citingmedicine/> for complete guidance, including less frequently used reference types. Please note that Taylor & Francis does not require the inclusion of all optional elements, so you should match the samples below.  
If you are using this reference style the EndNote output style can be found at <http://endnote.com/downloads/style/tf-standard-nlm>

#### Version 2.0

Date of issue: 14 May 2013

Date of version: 10 August 2016

Updates in this version: placement of text citations; updated link for ISO 4 information; guidance on online books; multiple volumes; series; issue number; conference; thesis; online articles not yet placed in an issue; clarity about inclusion of DOI references; more example references provided.

#### Contents

In the text.....	2
Tables and figures .....	3
Reference list.....	3
Journal .....	3
Book.....	5
Conference .....	7
Thesis .....	8
Unpublished work.....	8
Online sources .....	8
Newspaper or magazine .....	9
Report .....	9
Personal communication .....	10
Other reference types.....	10

## Appendix A: Author guidelines for the Journal of Disability and Rehabilitation

<b>In the text</b>	
<b>Placement</b>	<p>References are numbered consecutively in the order in which they are first mentioned in the text. Identify references in text, tables, and captions by bracketed numbers [1], and provide a list of references at the end of the article in numerical order with square brackets around the numbers. Reuse the original number assigned to the reference each time a reference is repeated in the text.</p> <p>Insert the citation numbers at the relevant place in the text, inside any adjacent punctuation mark. Examples:</p> <p>Myopathy typically occurs in fewer than one in 10,000 patients on standard doses [1].</p> <p>This approach was successfully implemented by Benders et al. [30] and Zhao [31] for modular NN.</p> <p>For this purpose, the NNs were widely used in structural inverse problems [24], damage identification [14,25], or parameters estimation [26], among many applications.</p>
<b>Multiple references</b>	<p>When citing multiple references, use commas (without spaces) to separate them. Use an unspaced en dash to join inclusive first and last numbers, e.g. [2,3,4,5,7,10] would be abbreviated to [2–5,7,10]. Examples:</p> <p>Compared to the initial shape, the optimized surface shape can substantially improve the structural characteristics [12,13].</p> <p>Most of the optimization methods proposed in previous studies are parametric methods [3–7].</p> <p>See, for example, [1,3,10–13,15–20,22–25,27,28].</p> <p>For some work along these lines, see [3,13,17,18,27].</p> <p>The crack boundary was discretized using 10 discontinuous quadratic elements, where the crack-tip elements are discontinuous quarter-point [see 17,28].</p>
<b>Reference citing author name(s) in the text</b>	<p>Give a number even if the author is named in the text:</p> <p>Jones [10] has argued that ...</p> <p>Jones and Smith [12] have argued that ...</p> <p>If you want to name more than two authors in the text, use:</p> <p>Jones et al. [3] have argued that ...</p>
<b>Repeat mentions in the same paragraph</b>	<p>Other efforts are including the perturbation method described in [8,11,12,16] and the perturbation method described in [11,15].</p>
<b>Page number</b>	<p>Jones [10,p.23–27] states that ...</p> <p>Note that page numbers in the text are different from those in the reference list, with no space before or after the page number. Do not elide page number ranges. Use an unspaced en dash between page numbers.</p>

## Appendix A: Author guidelines for the Journal of Disability and Rehabilitation

	In the text and in the reference list NLM uses p. rather than pp.
With a quotation	Author maintains that "This is author's quoted text" [1,p.3].
Personal communication	References to personal communications are cited only in the text. ... and most of these proved to be fatal (2003 letter from RS Grant to me; unreferenced, see "Notes") ...

### Tables and figures

Table and figure captions	References cited only in tables or figure captions should be numbered in accordance with the sequence established by the first identification in the text of the particular table or figure.
---------------------------	--

### Reference list

Order	Numerical order based on first appearance in the text.
Form of author name	Surname and initials. Capitalize surnames and enter spaces within surnames as they appear in the document you are citing, e.g. Van Der Horn <i>or</i> van der Horn; De Wolf <i>or</i> de Wolf <i>or</i> DeWolf. Initials follow surname without punctuation, without spaces or full points between initials, e.g. Author AA. Place family designations of rank after the initials, without punctuation, e.g. Author AA Jr. See <a href="http://www.ncbi.nlm.nih.gov/books/NBK7282/">http://www.ncbi.nlm.nih.gov/books/NBK7282/</a> for further guidance.
<b>Journal</b>	
Journal titles	Journal titles are abbreviated according to ISO 4. See <a href="http://www.issn.org/services/online-services/access-to-the-Itwa/">http://www.issn.org/services/online-services/access-to-the-Itwa/</a> Journal title abbreviations should not include full points, except at the end of the title; see examples below. Do not abbreviate journal titles consisting of a single word.
Issue numbers	The month is omitted if the journal is continuously paginated throughout the volume. The issue number can be omitted if the journal is paginated consecutively through the volume, but it is not incorrect to include it.
DOIs	There is no need to include the DOI numbers for published articles; they will be added as links in any online version of the article during the production process.
Basic format (with one author)	Author AA. Title of article. Abbreviated Journal Title. Date;volume(number):pages. MacGregor RJ. A functional view of consciousness and its relations in

Warning: Not controlled when printed

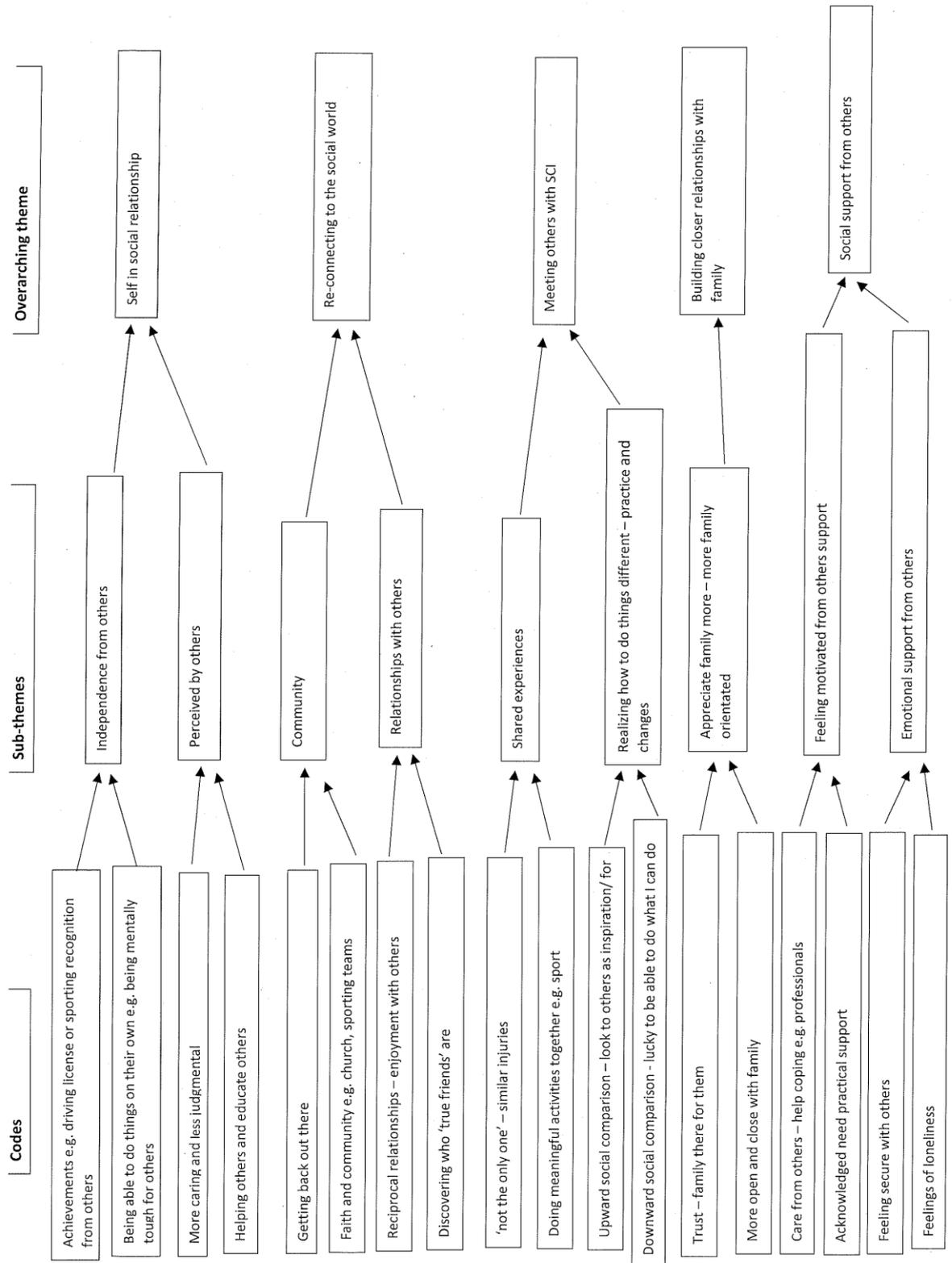
## Appendix A: Author guidelines for the Journal of Disability and Rehabilitation

	brain. <i>J Integr Neurosci</i> . 2004;3(3):253–266.
Two authors	Prokai-Tatrai K, Prokai L. Modifying peptide properties by prodrug design for enhanced transport into the CNS. <i>Prog Drug Res</i> . 2003;61:155–188.
Three authors	Veronesi U, Maisonneuve P, Decensi A. Tamoxifen: an enduring star. <i>J Natl Cancer Inst</i> . 2007;99(4):258–260.
More than three authors	Meneton P, Jeunemaitre X, de Wardener HE, et al. Links between dietary salt intake, renal salt handling, blood pressure, and cardiovascular diseases. <i>Physiol Rev</i> . 2005;85:679–715.
Organization as author	American Diabetes Association. Diabetes update. <i>Nursing</i> . 2003 Nov;Suppl:19–20, 24.
No author	Pelvic floor exercise can reduce stress incontinence. <i>Health News</i> . 2005;11(4):11.
Not in English	Translate non-English titles into English where possible; place the translation in square brackets. Place the original language title or romanized title before the translation. Capitalize only the first word of the title, proper nouns, proper adjectives, acronyms, and initialisms unless the conventions of a particular language require other capitalization. Indicate the language after the pagination:  Berrino F, Gatta G, Crosignani P. [Case-control evaluation of screening efficacy]. <i>Epidemiol Prev</i> . 2004;28:354–359. Italian.  Wilkniess SM, Hunter RH, Silverstein SM. Traitement multimodal de l'agressivité et de la violence chez des personnes souffrant de psychose [Multimodal treatment of aggression and violence in individuals with psychosis]. <i>Santé Ment Que</i> . 2004 Autumn;29(2):143–174. French.
Article published online only or online ahead of placement in an issue	Include any date of update or revision and a date of citation in square brackets following the date of publication. Use the dates for the individual journal article being cited.  If the location (pagination) of the article is not provided, provide the DOI or URL of the article. Do not include a full point at the end of DOI or URL addresses.  Author B. Title of article. Abbreviated Journal Title. Year [cited date]; [page length]. DOI:00.0000
Not the Version of Record (including Author Manuscript Online, Advanced Author Version, etc.)	Author AA. Article title. Abbreviated Journal Title. Forthcoming. [cited Date]:[pages]. [Format] available at [URL or DOI]  Zheng H, Ng F, Liu Y, et al. Spatial and circadian regulation of <i>cry</i> in <i>Drosophila</i> . <i>J Biol Rhythms</i> . Forthcoming. [cited 2008 Aug 11]:[18 p.]. Author's manuscript available at <a href="http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&amp;pubmedid=18663236">http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&amp;pubmedid=18663236</a> PubMed Central; PMID: PMC2504742.
Supplementary	If a journal article has supplemental material accompanying it in the form of

## Appendix A: Author guidelines for the Journal of Disability and Rehabilitation

material	a CD-ROM, DVD, or other medium, begin by citing the article. Add the phrase "Accompanied by:" followed by a description of the medium. Author AH. Article title. Abbreviated Journal Title. Date;volume(number):pages. Accompanied by: Video on CD-ROM.
Article type	An article type alerts the user that the reference is to something other than a full article. Place, e.g., [abstract], [book review] or [letter] after the article title: Author K. Article title [book review]. Abbreviated Journal Title. Date;volume(number):pages.
<b>Book</b>	
Place of publication	Always list the town or city, and always include the two-letter state abbreviation for US and Canadian cities. Include the country name for other countries only to avoid ambiguity: Cambridge (MA) Cambridge (UK) If more than one place of publication is found, use the first listed place of publication. If no place of publication can be found but can be reasonably inferred, enclose it in square brackets, e.g. [Chicago (IL)]. If no place of publication can be found or inferred, use [place unknown].
Publisher	Abbreviate well-known publisher names, e.g. John Wiley & Sons, Ltd. may become simply Wiley. If no publisher can be determined, use the words "publisher unknown" enclosed in square brackets.
Page numbers	Note that page numbers in the reference list are different from those in the text, with a space before the page number. Do not elide page number ranges. Use an unspaced en dash between page numbers. In the text and in the reference list NLM uses p. rather than pp.
Basic format (with one author)	Author AA. Book title: and subtitle. Place: Publisher; Year. Jenkins PF. Making sense of the chest x-ray: a hands-on guide. New York (NY): Oxford University Press; 2005.
Two authors	Van de Velde R, Degoulet P. Clinical information systems: a component-based approach. New York (NY): Springer; 2003.
Three authors	Hamric AB, Spross JA, Hanson CM. Advanced practice nursing: an integrative approach. 3rd ed. St. Louis (MO): Elsevier Saunders; 2005.
More than three authors	Wenger NK, Sivarajan Froelicher E, Smith LK, et al. Cardiac rehabilitation. Rockville (MD): Agency for Health Care Policy and Research (US); 1995.
Organization as author	Advanced Life Support Group. Acute medical emergencies: the practical approach. London: BMJ Books; 2001.

**Appendix B: Process of thematic analysis for the systematic review – detailing codes, sub themes and overarching themes**



## Appendix C: University of East Anglia ethical approval for the research paper

Faculty of Medicine and Health Sciences Research Ethics Committee



Ionie Lyon  
MED

Research & Enterprise Services  
West Office (Science Building)  
University of East Anglia  
Norwich Research Park  
Norwich, NR4 7TJ

Telephone: +44 (0) 1603 591720

Email: [fmh.ethics@uea.ac.uk](mailto:fmh.ethics@uea.ac.uk)

Web: [www.uea.ac.uk/researchandenterprise](http://www.uea.ac.uk/researchandenterprise)

1.4.16

Dear Ionie,

**The Development of Post-Traumatic Growth Following Acquired Brain Injury: A Grounded Theory: 20152016 - 62**

Thank you for your e-mail dated (23.4.16) notifying us of the amendments you would like to make to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely,

pp 

Mark Wilkinson  
Chair FMH Research Ethics Committee

Cc Paul Fisher

## Appendix D: Interview Schedule for the research paper

Version 2 24/11/2015

### Interview guide



*Please note: This is an interview guide only.*

Participant identifier:

Date:

1. Can you tell me about your brain injury
  - a. When did it happen?
  - b. How did it happen?
2. What was life like for you after your brain injury?
  - a. How did it impact on your identity/sense of self?
  - b. Your relationships with friends/family/work colleagues?
3. How do you describe the person you are now? The person you were before?
4. Can you tell me if you feel that the experiences you had before your brain injury affected how you handled changes following your brain injury?
5. What positive changes have happened in your life since your brain injury? And/or how has your view of positive changes developed since your brain injury?
  - a. Can you tell me about any strengths discovered following brain injury?
  - b. Can you tell me about the values you hold about yourself now?
  - c. Can you tell me what you think others most value about you now?
6. From your point of view, what has contributed to these positive changes you have spoken about?
  - a. Can you tell me who has been most helpful to you during this time? How have they been helpful/unhelpful?

#### **Appendix D: Interview Schedule for the research paper**

- b. Can you tell me if any organisation has been helpful to you during this time?  
What has been helpful/unhelpful?
  - c. Can you tell me if you feel that the experiences you had before your brain injury affected how you handled changes following brain injury?
7. If I asked you, what one important lesson you feel that you have learnt through experiencing a brain injury, what would it be?

**Appendix E: Example of the process for one participant of the Grounded Theory method used for analysis in the research paper**

Participant	Page line and number	Reference to transcript – line by line coding	Focused coding	Themes (theoretical codes)	Possible quotes
Helen	12-13 p 1	ummm well I only really discovered my brain injury two years after the incident	Not realise brain injury something that had to be discovered over time.	Lack of understanding at first – needs to be discovered	
	16-19 p1	I knew when I'd had the accident that I had a brain injury I knew there was something wrong with me I didn't know it was my brain I just knew is it my nerves	Not understand the brain injury. At first notice the nerves -or emotions – were more noticeable – following ABI.	Emotions - nerves	I knew when I'd had the accident that I had a brain injury I knew there was something wrong with me I didn't know it was my brain I just knew is it my nerves
	20-22 p.1	Known that I'd had been in a very severe accident but I didn't understand and that's the difference	Being in a severe accident – life changing- not understanding at first and that is different.	Not understanding – the severity/impact	
	26-27 p1	I discharge myself and then went back to my parents' house	Discharged self-left hospital – insight.	Not accepting – limited insight - discharge	
	29-34 p.1	I stayed at my parents' house for a couple of weeks I wasn't happy you know and I was very quick tempered... so I got in my wheelchair and trotted home, it was snowing and cold	Expressing disbelief at how behaved after the injury. The emotion – quick tempered-, emotion and impact of injury.	Trying to run away from it – the emotion – quick tempered	
	35- 43 p1-2	It wasn't until I'd come out of that house and moved somewhere else that I was actually getting more services	Transition from living with parents to living on own. Needing to get	Others understanding –	

**Appendix E: Example of the process for one participant of the Grounded Theory method used for analysis in the research paper**

		involved... it was services that changed my life .... What I did the two years after was terrible	services involved – with the help of services – changed her life. The first two years ‘terrible’.	services – changed my life.	
	50-51 p2	I don’t know.... I can’t always do it quickly	Explaining how she does things now and how things are different.		
	68-71 p.2	These are simple tasks I’m going to give you.... Simple tasks.. Go back to	Being able to start with simple tasks.	The simple tasks	
	75-77 p. 2	Infant school you know and I could just about do it not completely but just about and then we’d try something else... and realised not working and she discovered.. How brain processes changed	Going back to infant school – being a child again. Just good enough and then learn more. Discovering together how to do things and how things have – brain processes- changed.	Trying and discovering – learning with others	
	83-88 p.2	For other people to understand they don’t see that your brain process has changed but when they do realise that.. Your life changes because you feel someone believes me	How others understanding – don’t see brain process has changed – hidden. When others realise the changes you change too – are believed.	Hidden changes. Other people understanding.	
	88-91 p.2	Know that something is wrong with me and they’re going to help me find out how to get rid of it you know and you can’t but they did teach me how to deal with it	The need to understand and know what is wrong and others are going to help – to get rid- but realising you can’t, but can learn to deal with it.	Can’t get rid of it – ‘beat it’ acceptance and learning	Know that something is wrong with me and they’re going to help me find out how to get rid of it you know and you can’t but they

**Appendix E: Example of the process for one participant of the Grounded Theory method used for analysis in the research paper**

					did teach me how to deal with it
92-93 102 p.2	their kindness the fact they went out of their way to help in areas where I needed help... she took longer sometimes	Others being kind and making the time – treat you like a person.	Others kindness and time		
121-123 p.2	talking to me about things that were blocking my development my brain development...she take that time to let me explain	Talking with someone about how things could develop – and what blocking. The importance of time	Talking and learning together - time		
129-141 p. 2	She came regularly... a relationship began and trust began because I didn't trust anybody.... She taught me to be positive... her patience, diligence, kindness but her understanding	Explaining how she learnt to trust again and how learnt to be positive through support from others and their understanding.	Others support – relationship		She came regularly... a relationship began and trust began because I didn't trust anybody.... She taught me to be positive... her patience, diligence, kindness but her understanding
158 p.5	started to understand my speech problems	The process of understand had to start	Understanding others and self		
162-164 p.5	I had problems with seeing things I didn't tell anybody I kept it to myself for such a long period but I'd got to know her...	Feeling embarrassed about saying things – what have difficulty with. Getting to know SLT made it easier	Feeling embarrassed – not wanting to tell others.		

**Appendix E: Example of the process for one participant of the Grounded Theory method used for analysis in the research paper**

				to express what struggling with.		
169, 181-182 p.5	never let me down... when you lose your memory you're unsure		Importance of consistency and regular support – know what to expect.			
202 p. 6	I will do things I never would have done before		Doing things that she would not have done before	Trying new things – gaining more than before		
203-205 p.6	I can take my child out .. He is responsible because he had to learn to go through brain injury		Being more independent – others learning to go through – brain injury too.	Others learning		
210-211 p.6	[going on holiday] a dream that I never thought I'd ever fulfil again especially when I had the accident		Explaining how she has gone beyond expectations – a dream- fulfilling despite of her accident.	Fulfilling - growing		
228 p.6	started cooking again		Starting to do things again.			
230-232 p.6	It's amazing... I found different talents that I didn't think I had and things that I thought I wasn't good at before		Explaining finding talents – amazing – discovering new and old talents. Changed expectations of what good at.	New talents – changed expectations	It's amazing... I found different talents that I didn't think I had and things that I wasn't good at before	
235-238 p. 7	As time was progressing and I was calmer you see when you're not angry and you're calm and you can listen a little more		Over time and being able to note the changes – progressing – it's possible to be calmer and able to listen more.	Changes in how feel – calmer and able to notice the progression over time		

**Appendix E: Example of the process for one participant of the Grounded Theory method used for analysis in the research paper**

	267-270 p.7	when I first came to headway I must have been a handful but there were some lovely members of staff	Reflecting back on how things changed – how she was – handful and how others being –lovely		
	278-280 p.7	Different [activities] at headway which means I'm more accepting because I can now for the first time give an activity a try	Being able to try new things helps but so does acceptance in order to try new things.	Trying new things and acceptance	Different [activities] at headway which means I'm more accepting because I can now for the first time give an activity a try
	288-295 p. 8	I look back and now much nicer I wanted to be like these people (SLT) ... I had a wonderful psychologist and they really helped me to believe in myself and it took a lot of crying	Through this process she is able to look back – Others support and wanting to be like others. This was important in learning to believe in herself and the importance of – crying.	Move beyond (PTG)– change in self (nicer) – through others support and – crying.	I look back and now much nicer I wanted to be like these people (SLT) ... I had a wonderful psychologist and they really helped me to believe in myself and it took a lot of crying

## **Appendix F: Example of the emerging theme ‘trying to “beat it” and acceptance’ from the data in the research project – Grounded Theory method**

### **Example of theme Summary - Trying to “beat it” and acceptance**

#### **Main idea/theme**

The idea of having to let go or give up fighting against the changes – of trying to overcome and go back to how they were before their brain injury. Being okay and accepting the changes needs the person to adapt to and understand. It is also for other people to understand and adapt, not try and do things the same way – or go back to how things were before.

#### **Example of related material: First 7 interviews (in italics are the main themes/codes from transcript)**

‘For years I thought I could beat it and then you start to learn that it isn’t something you can beat it's always there’ (John 166; 16 years post injury). – *Beat it*

‘There is a lot of negativity, there is a lot of things wrong, there are a lot of things you don't recover from, but at the same time. I’ve found in my experience there are an awful lot of things you can do, that you can look at anew’ (Peter 874; 14 years post injury). – *Do things anew*

‘To come to terms with it, I’ve struggled. I used to bump into things and my husband had to learn how things had to go in the home. I can’t pin point acceptance as such, a long time, and I think time itself and adjusting to the new you’ (Mary 355; 6 years post injury). – *Others learning too and time*

‘I knew that something is wrong with me and they’re [services] going to help me find out how to get rid [brain injury] of it, and you can’t, but they did teach me how to deal with it’ (Helen 88; 7 years post injury). – *How to deal with it*

‘You can’t do what you used to be able to do but you’ve changed in a different way, I’ve learnt to so different things’ (Harriet 559; 14 years post injury) – *Re-learn/different*

‘I just think coming to terms with it, I never came to terms with it. I never got over it and that was always biting me but then that was always sort of niggling away at me and I got depressed about it, and I see doctors and talked to them just help to come to terms if you

## **Appendix F: Example of the emerging theme ‘trying to “beat it” and acceptance’ from the data in the research project – Grounded Theory method**

don't it just niggles away at you' (Nate 435; 16 years post injury). - *Niggles away/biting me/talking to others*

'I get told my son will get a new mother back, he won't get his old mother back which I'm coming to terms with. It's been difficult, the rationalised side of me knows that going back is not going to happen but the un-rationalised side of me wants to be back at work. I have learnt to try and accept and focus on the positive aspects – the simple things' (Kathy 307; 18 months post injury). - *Dilemma of acceptance*

'Because I am stubborn and very determined, basically I won't give in and that's always been me like this it is not going to beat me' (Kathy 105; 18 months post injury). – *I'll beat it*

### **Connections between idea/themes**

Beat it? – the suddenness no time to prepare and theme of living with a life changing injury.

The emotion – not going to be the same – biting- linked to the theme of living with a life changing injury.

Others accepting and adapting too – theme of identifying with a new you and others.

Focus on the positives – what have rather than what lost –importance of trying new things. Linked to the theme identifying with a new you and experiencing meaningful positive change.

Changed in a different way – walk a new path – can't beat it but do things in a new way – perceived growth beyond baseline – PTG and theme of experiencing meaningful change.

### **Other ways of thinking about idea/theme**

- The dilemma – does a person have to surrender to the changes if they cannot beat it.
- Expectations people hold about themselves and what others hold about them. The importance of experiences and opportunities in 'discovering' their brain injury. Is this linked to emotions – and judgment the expectations others hold about the person.

**Appendix F: Example of the emerging theme ‘trying to “beat it” and acceptance’ from the data in the research project – Grounded Theory method**

**Example abstract from memo**

The person initially does not surrender to the idea of change, trying to ‘beat it’ and not lose who they were but retain that sense of self. The emotion as well and the need to talk to others to express feelings and make sense of it. Through understanding and not being able to return to who they were before, the person does things different finds new ways so that they can accept the different ways of doing things. Others support and adapting too can help show different ways are possible and that a person can re-define the self and develop as a person in positive ways.

**Appendix G: Response to the findings from Headway – model of the planned sculpture**



**Appendix H: Headway approval of the research project**



# Headway

[Redacted]  
[Redacted]  
[Redacted]  
[Redacted]

[Redacted]

29<sup>th</sup> July 2015

Research Project

Post Traumatic Growth (PTG) following Acquired Brain Injury (ABI)

To whom it may concern.

The Board of Trustees of [Redacted] Headway is pleased to inform you that it unanimously approved collaboration with the above project at the Board Meeting, held on 12<sup>th</sup> May 2015. This followed discussion and information gathering in both this and the preceding meeting (14<sup>th</sup> April 2015). Discussion had been held with the University of East Anglia researcher and [Redacted], staff and members of [Redacted] Headway to ensure the project could be carried out to the benefit of all.

We are happy to provide the necessary support from our organisation and pleased to be involved in a research project which may significantly improve the involvement of, and outcomes for, those who live with Acquired Brain Injury.

With kindest regards,

[Redacted]

Chair of Trustees

[Redacted]

[Redacted] Website: [www.headway-nw.org.uk](http://www.headway-nw.org.uk)

[Redacted]

## Appendix I: Participant Information Sheet for research project



# Headway

Participant Information Sheet

### **“Post-traumatic growth following acquired brain injury: A grounded theory”.**

We would like you to take part in our research study, before you decide, we would like you to understand why the research is being done, and what it would involve.

Please ask if there is anything that you do not understand or if you have any questions. You can contact us by email, or write to us using the contact details below.

#### **Who are the researchers?**

If you would like to discuss anything in this information sheet, or wish to discuss taking part in the research, please contact **Ionie Lyon** (Principal Investigator) at [i.lyon@uea.ac.uk](mailto:i.lyon@uea.ac.uk), or on [insert study mobile phone number here] or the Research Supervisor, **Paul Fisher**, via [p.fisher@uea.ac.uk](mailto:p.fisher@uea.ac.uk)

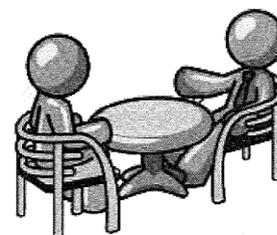
#### **What's involved?**

Brain injury can be a traumatic event which may result in changes and adjustment to new ways of doing things. People often report loss and difficulties with returning to previous ways of doing things. However, there is increasing information showing that people can experience positive changes following brain injury. This may be with their relationships, how they view the world and themselves, or their spiritual beliefs. Post-traumatic growth is used to describe positive changes that people may report following a brain injury.

The aim of this study will be to explore, through interviews, how people describe positive changes since their brain injury, and the processes they believe are involved in the development of this.

## Appendix I: Participant Information Sheet for research project

We are interested in talking to you to find out how your brain injury has resulted in positive changes, and what has helped or hindered this process. It will involve being interviewed individually. The interview will be audio recorded and a word-for-word transcript of what was said in the interview prepared. The total time for the interview will be no longer than 60 minutes, and it could be shorter.



There is limited research on how post traumatic growth develops following a brain injury, and we feel that this is an important gap in the research.

### **Do I have to take part?**

You do not have to take part in this study. It is up to you to decide if you want to join the study or not. If you agree to take part, we will ask you to sign the consent form which is attached to this information sheet.

### **Will my taking part in the study be kept confidential?**

We take your confidentiality very seriously. However, it is important that you understand that in this type of research it is not possible to promise complete anonymity. This means that there is a small chance that you may be identifiable from the information you provide. This is because sometimes quotes from your interviews are used to support the findings from the study.

At the start of the interview, you will be offered the chance to choose a different name for the study to protect your real identity, and this pseudonym will be used for all transcribing of data and when reporting the findings or quotes. The information within the interview will also be anonymised by either removing identifiable information or changing it, for example playing football could be changed to rugby or more generically sport.

We may need to speak with a member of staff at Headway to confirm any demographic information you provide. This is to ensure that we have the correct address if we visit you at home and when we send you a copy of the consent form to your address. We will also discuss if there are any reasons why participation in the study would be inappropriate for you at this time.

The member of staff at Headway is supporting this research project will know that you have been approached to take part in the study, and if you

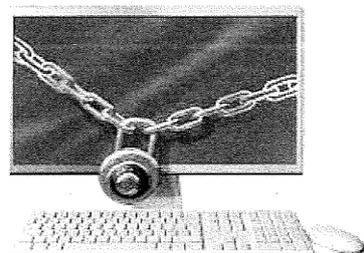
## Appendix I: Participant Information Sheet for research project

choose to participate, who you can speak with about taking part in this research project. You can speak with other people if you wish.

If, during the research interview, you tell the researcher something which makes them concerned that you or someone else may be at risk of harm, this information may have to be shared with the manager at Headway, staff responsible for your care, or with your GP. You would be told before this happened, and whenever possible the situation would be discussed openly with you so that you understand why it was necessary to break confidentiality. However, if telling you first would jeopardise your safety or the safety of someone else it may be necessary to break confidentiality without letting a participant know first.

### What will you do with the information from my interview?

After a participant has been interviewed, the audio recording will be written into a transcript of the conversation. This will be done soon after the interview, as a result you will have **48 hours after the interview** to change your mind and withdraw from the study without giving a reason why. If you choose to do this, your data will not be used and will be destroyed.



The tape recording will be immediately transferred from the recording device to a secure, encrypted laptop or desktop computer, and the original recording deleted. If this cannot be done immediately it will be transferred onto a secure, encrypted memory stick and then transferred as soon as possible to the encrypted computer hard drive.

Any audio files emailed to a professional transcriber will be sent password protected. The professional transcriber will sign a confidentiality waiver before they are able to transcribe any of the information.

A hard copy of the interview transcript will be stored in a locked filing cabinet at a secure location. All data will be stored according to current data protection legislation and will be destroyed after 10 years.

## Appendix I: Participant Information Sheet for research project

### Are there any possible disadvantages of taking part?



It can be tiring talking to someone new, and it is possible that talking may bring up feelings – some good or some bad, although care will be taken and your privacy will be respected. If you do feel upset or just need a break, please tell the researcher who will be able to provide reassurance and offer a break. If you want more support I will put you in touch with your key worker.

The interviews will take up to 60 minutes and you will not be paid for your time. The interviews will be held on Headway premises and will be held during your normal hours of attendance. If there is a reason why this is not possible an interview may be arranged to take place at your home address.

### Are there any possible benefits of taking part?

Some people find that having the chance to talk to someone in detail about an experience very helpful, and it can feel good to put into words something which you may not have spoken about before. It may also benefit other people who have also had a brain injury to hear the stories of other people stories who have experience positive changes since their injury.



You will also be taking part in research that is asking a question that has not been explored before. You will be contributing to improving our general understanding of how positive changes occur following a brain injury. This new information may be helpful for rehabilitation services to understand and may benefit people in the future who have a head injury.

### What happens if I start the study and then decide I don't want to carry on?

You can change your mind and you do not have to explain why. You have the right to withdraw your participation at any time up to and including the end of **48 hours after** your interview. There is a time limit on this because it is very difficult to take out data from this type of analysis. You will need to let Ionie Lyon (principal investigator) know that you have changed your mind using the contact details above.

### What will happen with the research findings?

## **Appendix I: Participant Information Sheet for research project**

The findings of the research will be shared with the participants and there will be dedicated time for you to discuss the findings and to reflect on what it was like for you to be involved (this is usually called the “debrief”).

It is important to share the findings of the research so that other people who are interested in this area can learn what the research has found. This could be verbally or in writing and will involve using quotes and presented to Headway or to external organisations. Some of the quotes may also be used as part of an art project taking place at Headway, and with the aim of displaying this at Headway and external organisations.

The findings will also be written up and it is possible that the write-up could be published in an academic journal. It is also likely that a summary of the research will be put into a poster for display at a research conference, where lots of different research projects will be discussed, or that the researcher will present a summary of the main findings by doing a presentation.

### **Who has reviewed the study and how is it funded?**

The study has been checked at several stages during planning by service users, and has been approved by the board of trustees at Headway. It has also been reviewed by UEA internal review panels, and has full UEA FMH ethical approval.

This research study is being carried out as part of a training course that the researcher is doing. There is no research grant or funding associated with this study, apart from a small budget to cover costs such as photocopying, postage stamps and professional transcriber services.

### **What if there is a problem?**

If you have any concerns about any aspect of this study, you could speak to the researchers who will do their best to answer your questions. If you would like to discuss anything in this information sheet, please contact Ionie Lyon (Principal Investigator) at [i.lyon@uea.ac.uk](mailto:i.lyon@uea.ac.uk) and research mobile number [to be added], or the Primary Research Supervisor, Paul Fisher, via [Paul.Fisher@uea.ac.uk](mailto:Paul.Fisher@uea.ac.uk). Or, write to Ionie and/or Paul at:

Department of Clinical Psychology  
The Elizabeth Fry Building  
Norwich Research Park  
University of East Anglia

## Appendix I: Participant Information Sheet for research project

Norwich  
Norfolk  
NR4 7TJ

Alternatively, you can also contact Professor Ken Laidlaw (Director of the UEA clinical Psychology Course; 01603 593076)

### Further questions?

- 1. Who is organising and funding this study?** The research study is being carried out as part of a doctorate in clinical psychology and has been approved by Headway.
- 2. How have patients and the public been involved in this study?** The researchers have involved Headway in the design of the study and the information sheets have been discussed with them too. The information will also be fed back to the participants', Headway and wider audiences.
- 3. What to expect during the consent process?** If you would like to be involved in the study the research team will run groups at Headway. This is an opportunity to ask more questions and to hear more details about the study.
- 4. Will everyone who is interested be able to take part?** Unfortunately, it may not be possible to interview everyone who is interested. This is due to time constraints of the research study. It is also not possible to interview people who had their brain injury before they turned 18 years old, or who have a progressive illness.

If you think you would be interested in taking part, please let Ionie or [REDACTED] (Senior Occupational Therapist) know. [REDACTED] has agreed to be the communication link for this study between Headway and the study researchers.

Thank you for reading!

## Appendix J: Participant Consent form for research project



# Headway

### Appendix G: Participant Consent form

**Participant ID:**

**CONSENT FORM**

Title of Project: **Post-traumatic growth following acquired brain injury: A grounded theory.**

Name of Researcher: **Ionie Lyon [email: [i.lyon@uea.ac.uk](mailto:i.lyon@uea.ac.uk); Tel: insert study mobile phone here].**

Please initial box

1. I confirm that I have read and understood the information sheet, and I have had the opportunity to ask questions, and these have been answered to my satisfaction.
2. I confirm that I am signing this consent form at least 48 hours after having first had the study explained to me.
3. I understand that my participation is completely voluntary and that I am free to withdraw without giving any reason, without my medical or legal rights being affected. This will not affect my participation at Headway Norfolk and Waveney.
4. I can change my mind and withdraw my interview data from the study up to 48 hours after the interview. It will be my responsibility to contact the researcher or gatekeeper [insert name] to let them know.
5. I understand that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers.
6. I understand that the interview will be audio-recorded and the file securely stored.
7. I understand that data used for publication or dissemination will be anonymised and all possible identifiable information will be changed and or removed
8. I understand that the information will be disseminated back to Headway Norfolk and Waveney and wider audiences.
9. I agree to take part in the above study.

## Appendix J: Participant consent form for research project

9. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.