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# Post-traumatic growth following spinal cord injury: a systematic review and meta-ethnography

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## ABSTRACT

**Purpose:** Research shows the potential for post-traumatic growth (PTG) following spinal cord injury (SCI). Growing evidence demonstrates the role of social processes in PTG development. However, the mechanisms through which social processes might influence PTG are not well established. The review aimed to synthesise current research to provide insights into social processes involved in PTG development following SCI.

**Methods:** Searches were conducted using the following databases: PsycINFO, MEDLINE, Scopus, Citation Index of Nursing and Allied Health Literature, Web of Science, and EMBASE. Nine studies were included. Studies were quality assessed using the Critical Appraisal Skills Programme checklist. Data synthesis utilised a meta-ethnographic approach.

**Results:** Four themes were generated: Sense of Self and Identity; Close Relationships as Enablers of Growth; Connecting with the Peer Community; and Reintegrating into Society. Identity reconstruction was found to be a central pathway in PTG. Close relationships and peers played a multi-faceted role in enabling identity reconstruction and promoting PTG processes.

**Conclusions:** The review examines PTG development following SCI with a focus on social processes. Identity reconstruction, within the context of the individual's social environment, appeared to be central to PTG. Social participation and integration opportunities are recommended as important considerations for rehabilitation discharge planning.

## ARTICLE HISTORY

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## KEYWORDS

Spinal cord injury; post-traumatic growth; adjustment; systematic review; meta-synthesis

## > IMPLICATIONS FOR REHABILITATION

- The review highlights the importance of rehabilitation professionals actively exploring how the individual is reconstructing their identity post-SCI.
- Reconstructing identity in positive ways can be supported by connecting goal planning and rehabilitation exercises with valued aspects of identity and facilitating access to psychological interventions.
- Assessment of the individual's social environment, including family support and social participation opportunities, is important in supporting discharge from rehabilitation.
- Rehabilitation settings should continue to facilitate and strengthen opportunities to engage with and learn from peers.

## Introduction

Spinal cord injury (SCI) can be life changing [1]; often bringing about substantial physical, social, and psychological consequences [2]. Not only are individuals required to adapt to considerable physical changes and complications [2], they also face psycho-social losses and challenges, including loss of independence, sense of personal control, social roles and status, and identity [3]. Despite this, research shows that through the process of adapting there is potential to experience positive psychological changes [4–6]; attracting interest in the application of post-traumatic growth (PTG) models.

Calhoun and Tedeschi's [7] model of PTG has been applied to SCI. Within this model, PTG is defined as positive psychological change resulting from the struggle with traumatic or highly stressful life circumstances. Trauma is seen as presenting significant disruption to life goals and core beliefs about self, world, and

others, which requires considerable coping efforts and rebuilding of the cognitive infrastructure [8,9]. This is thought to initiate cognitive rumination processes as the individual attempts to make sense of their experiences [9]. Through this process, the individual is thought to develop a revised core belief system, which integrates their new experiences and can lead to PTG [8].

PTG is proposed as occurring in five main domains: (1) appreciation of life; (2) sense of priorities; (3) relationships; (4) sense of personal strength; and (5) recognition of new possibilities and spiritual development [10]. PTG can also occur in personal narrative, whereby life narrative is redefined based on learning from struggling with trauma [9].

Research has confirmed the potential for PTG following SCI in all five PTG domains [4,6]. Further, in line with Tedeschi and Calhoun's [10] model, extant research highlights the role that cognitive processing and coping plays in the development of PTG following SCI [5,11–13].

The current research base appears to focus on individual factors with little attention having been paid to social factors. Yet, the social environment is thought to play an important role in how individuals process, make sense of, and cope with traumatic events or chronic stressors [14]. Thus, social factors and processes are likely to be important in PTG processes following SCI.

Calhoun et al. [8] recognise socio-cultural factors, including the individual social environment (friends, families, neighbours, and communities) and broader societal narratives, in the experience of PTG. Social support is seen as a major facilitator of PTG [10,15] and their model places emphasis on it in facilitating self-disclosure, alleviating emotional distress, and enabling cognitive processing. It is also proposed as directly promoting growth in relationships due to increasing intimacy and closeness [9].

Several studies support the role of social support in the development of PTG following numerous physical health experiences [16–18]. Ghannad et al.'s [16] study found family support to be the most important predictor of PTG and friend support as the most important for life satisfaction in those with SCI. The study did not offer substantial insights as to how support might influence the experience of PTG; however, further insights can be generated from qualitative studies. Khanjani et al. [19] found instrumental support to be important in helping individuals overcome primary problems and experience success, thus enabling growth. Additionally, Griffiths et al. [20] found support and encouragement from others supported coping and beliefs about self.

Engagement and support from role models, individuals who have overcome similar life experiences, are also elements of the PTG model [8]. Role models are felt to be able to provide additional opportunities for self-disclosure, and constructive support and advice, which can promote coping and enable the development of new schemas. Peer support has been found to be a facilitator of PTG following SCI in qualitative research by providing advice and support for coping and changing attitudes towards living with injury through social comparison [19,21].

Finally, societal narratives are proposed to be relevant to PTG [9]. Social stereotypes about disability, and the impact these have on an individual's inter- and intra-personal experiences are argued to be especially important in the context of adjustment to physical disability [3,22]. However, how these factors might influence PTG following SCI remains largely undefined.

### **Aims of the systematic review**

Growing research evidence demonstrates the role of social processes in PTG development. Despite this, the mechanisms through which social processes might influence the development of PTG following SCI are not currently well established. Further understanding of the social processes involved in growth would provide insights regarding how those in the individual's immediate and distal social environment might support or hinder positive adjustment, from which clinical recommendations for SCI rehabilitation could be derived. Systematically reviewing qualitative studies would potentially address current gaps in the literature. Thus, the review aims were:

1. To synthesis and critically appraise qualitative research exploring the experience of PTG following SCI;
2. To derive insights into the social processes which enable or undermine PTG.

### **Method**

The review is registered on PROSPERO database (reference CRD42021253502).

#### **Search strategy**

The databases PsycINFO, MEDLINE, Scopus, Citation Index of Nursing and Allied Health Literature (CINAHL), Web of Science, and EMBASE were searched individually for relevant studies. The initial searches were completed in August 2021 and updated in January 2023. The databases were searched using synonyms of SCI (spinal cord injuries, spinal cord injur\*, hemiplegia, paraplegia, quadriplegia, paraplegi\*, quadriplegi\*, hemiplegi\*, tetraplegi\*, spinal trauma, spinal injur\*) and PTG (posttraumatic growth, post traumatic growth, personal growth, personal gain\*, meaning making, self-growth, benefit finding, gratitude, positive psychological change, positive change, positive outcome\*, positive experience\*, post traumatic depreciation or posttraumatic depreciation). Date limits were not applied to allow comprehensive search of this relatively specialist research area.

#### **Inclusion and exclusion criteria**

Studies that fulfilled the following criteria were included:

1. published in a peer-reviewed journal;
2. published in English;
3. sample consisted predominately of individuals who had acquired SCI in adulthood (16 years or over in line with clinical practice in SCI rehabilitation settings);
4. employed a substantive qualitative methodology (such as interviews, surveys, or focus groups) and analysis (such as grounded theory, narrative, phenomenology, or thematic analysis) of textual rather than numerical data;
5. investigated PTG or provided conceptual data relevant to PTG (evidence of core belief change and/or change in PTG domains as defined in Tedeschi et al.'s [9] model);
6. provided knowledge of relevant social processes in the development of PTG. Social processes were defined, but were not solely limited to, social comparison, social support, peer support, social participation, and social narratives.

Studies were excluded if the majority of participants:

1. had been interviewed less than one year post injury (since reports of PTG in early stages may represent an illusory effect related to avoidance coping strategies [13]);
2. had sustained SCI in childhood (it is unclear whether growth processes in children accord to growth processes in adults due to developmental differences in trauma responses [23,24]);
3. if the study concerned the experience of SCI in childhood (to provide insights grounded in the experience of SCI in adulthood and derive clinical practice recommendations for adult rehabilitation settings).

#### **Study selection**

Identified studies were transferred into Endnote, where duplicates were removed. Titles and abstracts were screened for eligibility.

Full texts were then comprehensively assessed for eligibility based on inclusion and exclusion criteria. Where there was ambiguity regarding inclusion, articles were reviewed by the senior researcher before agreement was reached on the final list of studies by all authors. Finally, reference lists of included studies were reviewed for additional references.

### Quality appraisal process

Studies were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist [25]. Studies were not excluded based on quality scores, as methodological quality does not necessarily reflect potential contribution of the study to review aims [26,27]. Excluding articles based on quality can come with a risk of missing meaningful findings that could provide new insights or strengthen themes [26,27]. Therefore, quality appraisal was used to consider strengths and weaknesses of studies, rather than for inclusion decisions.

To establish inter-rater reliability, the senior researcher independently quality assessed a subset of five articles. Inter-rater agreement was 74% with a kappa score of 0.42, representing moderate level of agreement between reviewers [28]. Consideration was given to pursuing inter-rater reliability for all studies, but as good agreement was achieved by independently appraising five studies, the approach was deemed sufficiently confirmatory of appropriate application of the CASP tool by the first author.

### Data synthesis

A meta-ethnographic approach [29] was chosen to combine and analyse the data derived from the search outcomes. Meta-ethnography is considered an interpretive synthesis methodology [30,31]. The aim for this approach is to compare findings across studies to understand how they “translate” into one another and provide an interpretation of these translations [31]. This allows for synthesis of common findings and highlights gaps in understanding [32]. Furthermore, meta-ethnography is an inductive methodology, allowing the findings to emerge from the raw data

rather than restraining the findings by imposing specific psychological models [30,31].

The approach enables the researcher to re-interpret conceptual data created by the original authors to produce new conceptual theories that help to capture the data [33]. Thus, findings are revealed that go beyond the original meaning identified in one study [34]. This aligned with the aims of the review to develop analytical findings about the processes involved in PTG rather than to provide descriptive findings of previous studies.

The meta-ethnography was conducted following the steps outlined by Noblit and Hare [29] with guidance from Sattar et al. [35]. Table 1 demonstrates the application of the meta-ethnographic procedure to this study as well as the tools used to construct the dataset. Points 1–7 specify the required procedural steps in meta-ethnography and column 2 outlines specific procedural processes undertaken in this review. Steps 3–7 were undertaken by the first author and verified by the research team.

### Results

Database searches yielded 1136 records. Removal of duplicates resulted in 504 records for screening. Initial abstract screening resulted in 450 being removed and 54 remaining records for full text screening. Application of inclusion and exclusion criteria resulted in removal of 44 studies and inclusion of nine studies in the review. Reference lists of included studies revealed no further studies for inclusion (Figure 1).

### Study characteristics

Nine studies, published between 2008 and 2017, met inclusion criteria. Studies explored 278 participants’ experiences of SCI within seven countries: USA (4); Canada (1); UK (2); Germany (1); Netherlands (1); Iran (1); and China (1). Chun and Lee’s [21,38,39] articles used the same participant pool and thus participants from these studies were included in the total calculation only once. The age range was 18–79 years. Seven studies provided information about gender, showing 39 participants were male and 26 were female. Eight studies provided information regarding time

**Table 1.** Process of meta-ethnography.

Phase	Process
(1) Getting started	The topic of interest was chosen based on identified gaps in knowledge in the existing literature, and value for clinical practice.
(2) Deciding what is relevant	The search strategy was developed and conducted. Decisions about inclusion were made. Quality assessment was completed.
(3) Reading the studies	The main researcher became familiar with the data by thoroughly reading the studies and making sense of the findings. The raw data from the studies was extracted into a data extraction form, adapted from Sattar et al. [35]. Raw data included first-order (participants quotations) and second-order constructs (primary authors interpretations such as themes or concepts). The data were extracted verbatim to reduce the risk of losing important data [30]. A separate form was used to extract information about study characteristics.
(4) Determining how the studies are related	To understand the relationship between the key concepts in different papers a list of themes was created from the studies. These were compared against each other to identify common and recurring concepts and recognise difference across the studies. The themes were clustered into categories of similar concepts and ideas.
(5) Translating the studies into one another	This phase involved comparing the metaphors and concepts in one account to those of another. The studies were arranged chronologically. The themes and concepts from paper 1 were summarised, followed by paper 2. Similarities, contributions, and differences between the two papers were noted [30]. The papers were then looked at in turn with the same process. A translation table was created to support this process by providing a visual display of the analysis; adapted from Sattar et al. [35]. The translation table included a descriptor of similar concepts across studies, and corresponding first-order data (raw quotes) and second-order themes from the original studies. The researcher also kept a journal to remain aware of their theoretical position. Key concepts and their meanings were discussed with the research team.
(6) Synthesising translations	Reciprocal translation synthesis was conducted as the studies were deemed sufficiently similar in their accounts [35]. Third-order constructs were generated by reading the primary data synthesis alongside the translations table and drawing out the main points to form the reciprocal translations [35]. Line of argument synthesis was then conducted by looking across the third-order constructs to explore the relationship between themes and creating a diagrammatic model [35,36].
(7) Expressing the synthesis	A written narrative of the proposed synthesis was developed; themes were refined during this process.

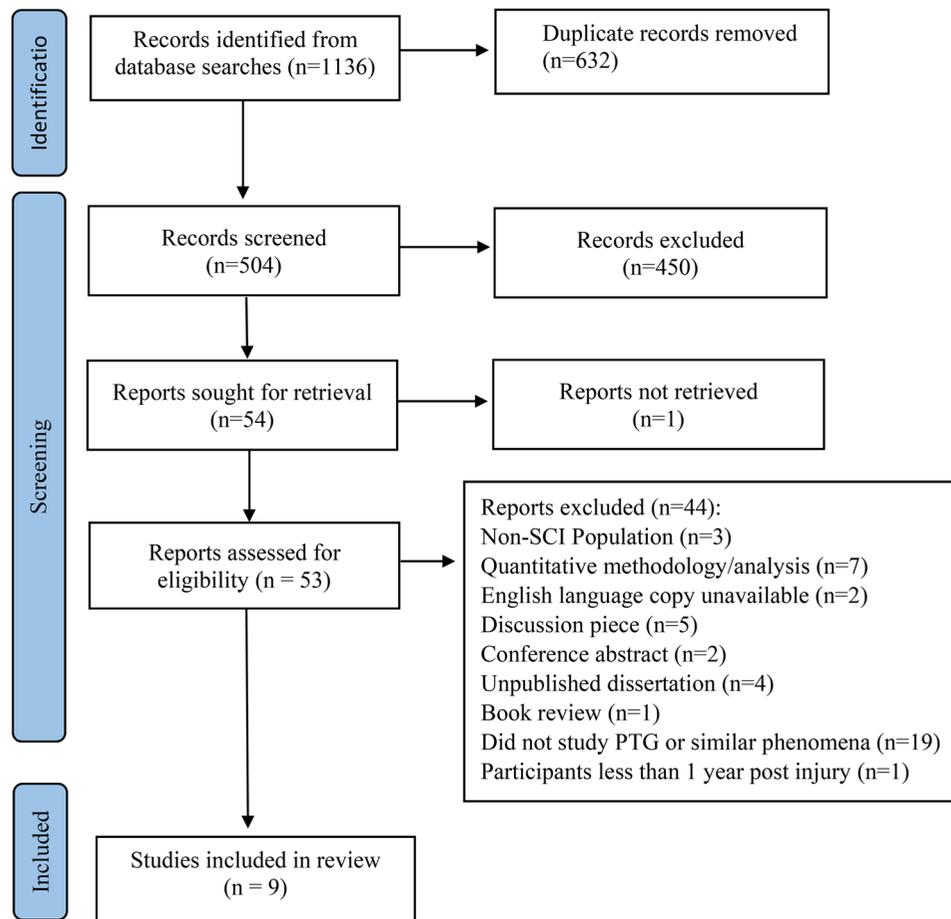


Figure 1. PRISMA flow diagram demonstrating study selection process [37].

since injury. Six studies interviewed participants at least one year post-injury. Kennedy et al. [40] interviewed participants at four time points (6 weeks, 12 weeks, 1 year, and 2 years). Littooij et al. [41] interviewed participants between 9- and 24-months post-SCI. Crawford et al. [42] did not provide this information. Overall, interviews ranged from 6 weeks to 34 years post-SCI.

The vast majority of participants (98.5%) were over 16 years when they sustained SCI. Three studies [20,40,41] excluded participants under 16 years at injury. Chun and Lee's [21,38,39] studies included two participants injured in childhood and Khanjani et al. [19] and Wang et al. [43] each included one such participant. Crawford et al. [42] did not provide this information. Thus, age of injury ranged from 7 to 78 years.

Most studies (6/9) recruited from rehabilitation centres, but Crawford et al. [42] recruited from para-sports programmes and Griffiths et al. [20] from community samples. Khanjani et al. [19] did not provide this information. Interviews were utilised by eight studies for data collection. Crawford et al. [42] used interviews and surveys, and Kennedy et al. [40] used questionnaires and written disclosures. Data analysis methods included thematic analysis (4); IPA (2); content analysis (2); and grounded theory (1).

All studies examined participants' perceptions of positive outcomes experienced through having a SCI. All produced findings and derived themes which provided insights not just about the individual but also the social processes which promoted growth and positive psychological outcomes. Where authors specified the growth models they used these included PTG (5), gain (2), gratitude (1), and global meaning (1) (Table 2).

### Quality appraisal

The CASP tool showed studies were moderate to high quality, with most studies (6/9) scoring 17 or above. All studies provided clear aims and rationale for methodology choices. The studies scored lowest for research design, reflexivity, and ethical considerations. Chun and Lee's studies [21,38,39] appeared to use the same data with transparency lacking in their 2010 paper. This was captured in the scoring. All studies were assessed as providing valuable contributions to research and clinical practice, against CASP criteria (Table 3).

### Meta-ethnography findings

Four interrelated themes were identified which provide knowledge about the social processes that might aid or undermine the experience of PTG following SCI. The identified themes were: (1) Sense of Self and Identity; (2) Close Relationships as Enablers of Growth; (3) Connecting with the Peer Community; and (4) Reintegrating into Society. A written narrative of themes is provided below. Table 4 shows the frequency of themes across studies.

### Sense of Self and Identity

The first theme reflects the impact of SCI on Sense of Self and Identity. This was influenced by perceptions of societal narratives and stigma regarding disability. Individuals engaged with cognitive and behavioural processes as part of reconstructing their identity.

Table 2. Study characteristics.

Study	Title	Country	Aim	Recruitment setting	Participant characteristics	Data collection and analysis methods	Key findings, themes
Chun and Lee [38]	The experience of posttraumatic growth for people with spinal cord injury.	USA	To explore the characteristics of PTG for people with spinal cord injury.	Former and current clients of rehabilitation hospitals.	15 (including 2 negative cases). 10 male and 5 female, 27–58 years, 1–34 years post injury, age of injury 14–57 years.	Individual interviews. Thematic analysis based on grounded theory methodology [44,45]	The experience of meaningful family relationships. The experience of meaningful engagement. An appreciation of life.
Chun and Lee [39]	The role of leisure in the experience of posttraumatic growth for people with spinal cord injury.	USA	To explore the role of leisure in the experience of PTG for people with SCI.	Former and current clients of rehabilitation hospitals.	15 (including 2 negative cases). 10 male and 5 female, 27–58 years, 1–34 years post injury, age of injury 14–57 years.	Individual interviews. Thematic analysis based on grounded theory methodology [44,45]	Providing opportunities to discover unique abilities and hidden potential. Building companionship and meaningful relationships. Making sense of traumatic experience and finding meaning in everyday life. Generating positive emotions.
Griffiths et al. [20]	Continuing with life as normal: positive psychological outcomes following spinal cord injury.	UK	How do individuals describe their positive outcomes? What processes do people go through in order to achieve these positive outcomes?	Individuals with SCI in the community.	6 participants including 4 male and 2 female. Aged between mid-20s and mid-60s, between 2 and 11 years post injury.	Semi-structured interviews. IPA [46]	Living a normal life, just doing things differently. Overcoming challenges: determination to succeed. Using the resources available to me.
Kennedy et al. [40]	Perceptions of gain following spinal cord injury: a qualitative analysis.	Europe – UK and Germany	To explore the ways in which people perceive that they have benefitted positively from the experience of SCI.	Specialist units in British and German SCI centres.	201 participants between the age of 18 and 74 years, sustained injury between 16 and 73.	Open ended question asked at 4 time points post injury (6 weeks, 12 weeks, 1 year, and 2 years). Thematic analysis.	Relationships. Appreciation of relationships. Perspective and appreciation of life. New goals or priorities. Understanding of SCI or disability. Appreciation of health or health care. Changed personality. Opportunity or challenge. Knowledge of SCI or body. Newly acquired skills. Spirituality. Acceptance. Nothing.
Chun and Lee [21]	I am just thankful: the experience of gratitude following traumatic spinal cord injury.	USA	To explore the experience of gratitude in everyday life following traumatic SCI.	Former and current clients of rehabilitation hospitals.	15 (including 2 negative cases). 10 male and 5 female. Aged between 28 and 58. Average onset injury 30 (range 14–57). Average length of time since injury 10.7 years (range 1–34 years).	Individual interviews. Thematic analysis based on grounded theory methodology [44,45]	Gratitude for everyday life. Gratitude for family support. Gratitude for new opportunities. Gratitude for a positive sense of self. Gratitude to God.

(Continued)

Table 2. Continued.

Study	Title	Country	Aim	Recruitment setting	Participant characteristics	Data collection and analysis methods	Key findings, themes
Crawford, Gayman and Tracey [42]	An examination of post-traumatic growth in Canadian and American ParaSport athletes with acquired spinal cord injury.	Canada and USA	Does participation in ParaSport following acquired SCI influence people's perceptions of PTG? What specific dimensions of PTG, if any, do ParaSport athletes report experiencing?	Parasports in Canada or USA.	12 participants aged between 24 and 55. Mean age at which participant acquired SCI was 23 and mean time since SCI was 18.83 years.	Survey and semi-structured phone interview. Content analysis using an interpretational analysis guided by Tesch [47]	Injury relevant processing. Appreciation for life. Reactive behaviour as a result of attempted integration into ParaSport. Relating to others. Health and well-being.
Littooij et al. [41]	Global meaning in people with spinal cord injury: Content and changes.	Netherlands	To explore the content of global meaning of people with SCI, and to explore whether or not global meaning changes after SCI.	Outpatients of rehabilitation centre.	16 participants including 9 male and 7 female, aged between 26 and 79, between 9 months and 2 years post injury.	Semi-structured interviews. Grounded theory [44]	Core values. Relationships. Worldview. Identity. Inner posture.
Khanjani et al. [19]	Exploring facilitators of post-traumatic growth in patients with spinal cord injury: a qualitative study.	Iran	To explain the facilitators of PTG based on the experiences of patients with a SCI.	Not provided	16 participants including 9 male, 7 female, aged 26–63 years, average age was 46.6, age of injury 7–54 years, 5–32 years post injury.	Semi-structured interviews. Qualitative content analysis.	Existence of support resources. Contact with SCI associations. Spiritual beliefs. Positive attitude towards injury. Access to proper facilities. Enhancement of knowledge and awareness. Active presence in society.
Wang et al. [43]	The process of posttraumatic growth in individuals with traumatic spinal cord injury in Mainland China: an interpretative phenomenological analysis.	China	To explore the process of adjustment and growth of people with SCI in mainland China and identify the factors that contribute to a positive attitude towards the SCI.	Halfway house for SCI program at Rehabilitation centre.	12 participants including 7 male, 5 female, aged 25–46, age of injury between 11 and 34, time since injury between 3 and 20 years.	Semi-structured interviews. IPA [48]	Struggling in hopelessness. Disentangling from disability. Facing challenge and achieving positive growth.

Table 3. Quality appraisals.

Study	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship and reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research	Total score
Chun and Lee [38]	✓	✓	?	✓	✓	?	X	✓	✓	✓	16
Chun and Lee [39]	✓	✓	?	✓	?	?	X	✓	✓	✓	15
Chun and Lee [21]	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	19
Crawford et al. [42]	✓	✓	✓	✓	✓	X	✓	?	✓	✓	17
Griffiths et al. [20]	✓	✓	✓	✓	✓	X	?	✓	✓	✓	17
Kennedy et al. [40]	✓	✓	?	✓	?	X	✓	?	?	✓	14
Khanjani et al. [19]	✓	✓	✓	?	✓	?	✓	✓	?	✓	17
Littooij et al. [41]	✓	✓	?	✓	✓	X	✓	✓	✓	✓	17
Wang et al. [43]	✓	✓	?	✓	?	?	✓	✓	✓	✓	17

(✓) Yes, (X) No, (?) Can't tell.

Studies are given a score out of 20 (Yes = 2, Can't tell = 1, No = 0) for quality; higher scores represent higher methodological quality.

Findings showed the potential for individuals to experience growth in self-view and relating to others through the process of reconstructing a new identity. Identity reconstruction happens as the individual interacts with their social world; thus, this theme runs throughout the other themes of the review.

### *SCI as a Threat to Identity*

Three out of nine studies highlighted how SCI had the potential to break down the individual's sense of previous identity. This appeared to be due to significant global changes experienced to the physical, psychological, and social self:

Table 4. Identified themes.

Identified themes		Total	Chun and Lee [38]	Chun and Lee [39]	Griffiths et al. [20]	Chun and Lee [21]	Kennedy et al. [40]	Crawford et al. [42]	Littooij et al. [41]	Khanjani et al. [19]	Wang et al. [43]
Sense of Self and Identity	SCI as a Threat to Identity	3			✓			✓			✓
	SCI and the Disabled Identity	4						✓		✓	✓
	Reconstructing Identity	4			✓			✓	✓		✓
	Personal Growth	6	✓			✓	✓	✓	✓		✓
Close Relationships as Enablers of Growth	Sense of Belonging	5	✓		✓	✓		✓	✓		
	Providing Meaning and Motivation	5	✓		✓	✓		✓	✓		✓
	Support in Living with SCI	5	✓		✓	✓		✓		✓	✓
Connecting with the Peer Community	Encouraging Exploration	6	✓	✓	✓	✓				✓	✓
	Strengthened Relationships	6	✓			✓		✓			✓
	Fostering a Sense of Belonging and Acceptance	5	✓	✓			✓	✓			✓
	Support from a Lived Experience Perspective	5	✓	✓				✓		✓	✓
Reintegrating into Society	Knowing There is Life After SCI	4			✓	✓				✓	✓
	Appreciation Through Social Comparison	4	✓	✓		✓		✓			
	Giving Back to the Peer Community	6		✓	✓	✓	✓	✓			✓
	Navigating the Social World with Disability	3	✓						✓		✓
	Exploring Abilities and Finding Hidden Strengths	5	✓	✓	✓		✓	✓			
	Re-establishing a Valued Social Identity	7		✓	✓	✓	✓	✓		✓	✓

Dealing with the physical aspect, the physical changes to your being. Dealing with psychological and psychosocial difficulties, so how do the physical changes impact on you as a person, and your environment, how does that all fit together. [20,p.245]

I also did not realize the more nuance things. Such as, you know, your identity being completely shattered more or less. [42,p.401]

### *SCI and the Disabled Identity*

SCI seemed to come with a “forced new identity” [42] as a disabled person. This impacted on the individual’s sense of self and self-esteem due to the influence of stigma, discrimination, and societal narratives about disability. Across four studies, there were ideas about what it might mean for individuals to be given a label or identity of “disabled”. Individuals used words such as “burden” [43,p.641], “failure” [42,p.404], “bother” [41,p.200], “ineffective” [19,p.3548], and “inferior” [43,p.642] to describe societal or self-perceptions due to visible impairment. Based on these ideas, there were concerns about how people in their social world might perceive and interact with them, including fears of rejection:

I didn’t like that they look at me as an ineffective disabled person, especially my family, because when you are disabled, no matter how kind your family members are, they still look at you as a disabled person who can’t work. [19,p.3548]

### *Reconstructing Identity*

Findings from four studies showed individuals re-constructed their identities through cognitive processes based on their experiences in their social world. The extent varied to which individuals either re-aligned with previous identities or built a new identity based on their new physical, psychological, and social self:

I lost my sexuality, the image that I was, everything was totally gone. I had to totally rebuild myself as a new person. [42,p.401]

In my situation, the way I know myself ... (own name) is still (own name). Nothing different about that. Yes, I have a SCI... I am (own name) with a little extra. [41,p.201]

Moving beyond a disabled identity appeared to be an important part of being able to rebuild a more positive sense of self, described by Wang et al. [43] as “disentangling from disability”:

Don’t consider yourself disabled, you just do things in a different way. We’re social men using wheelchairs as legs.... [43,p.643]

### *Personal Growth*

Six studies found individuals with SCI reported on how being in an unexpected social position prompted reflection on changes in personality including associated changes in how they related to others:

...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. [21,p.16]

### *Close Relationships as Enablers of Growth*

The second theme reflects the role of close relationships in enabling positive adjustment through providing a “Sense of Belonging”, “Meaning and Motivation” to continue living and improving, “Support in Living with SCI”, and “Encouraging Exploration” of abilities and identity.

### *Sense of Belonging*

Findings from five studies showed close relationships were important in enabling individuals to experience a sense of belonging and attachment. Despite experiencing a significant injury individuals could see their families still loved, cared, and were “always there” for them [21,p.15]:

...as close as you can come to complete and utter failure. Not being able to feed yourself and put clothes on. Seeing people that still love you. It sounds really you know silly to say that as most people would say of course we still love you. But until you actually see it. It was hard to actually understand why someone would still care about me. [42,p.404]

Continued acceptance and belonging in the family appeared to be an important aspect of positive adjustment as this provided continuity of aspects of social roles and identity within the family.

Daddy is still dad. [20,p.245]

I used to do everything for myself, [then] I couldn't do anything. It affected my life even when it came to my kids because my mum went and got guardianship of them. That's been really hard, and I'm still in court fighting for my kids. [38,p.882]

For the participant in Griffiths et al.'s [20] study, the response from his family enabled him to hold on to his identity as a father. Whereas, the quote from an individual who had not experienced PTG in Chun and Lee's [38] study demonstrates how close relationships can undermine growth when valued parts of social identity, such as being a mother, are not supported.

### *Providing Meaning and Motivation*

Five studies referred to the importance of close family relationships in "Providing Meaning and Motivation" to continue living and to improve:

I realized that if I stayed at home, it would become hard for me, and I would get bed sores and other problems. I realized that, in that way, I would harm both myself and my family; therefore, I decided to begin an activity and started to work. [19,p.3548]

### *Support in Living with SCI*

Five studies referred to the role of family in providing practical support and opportunities for self-disclosure needed to come to terms with the injury and learn to live well:

I wouldn't have achieved anything without the help of my family. I would've been, probably, cooped up in the house, just the same as I was in the first year after the injury. My families were sympathetic to me...and stood by my side as much as they could. [19,p.3547]

### *Encouraging Exploration*

The importance of being encouraged and enabled to explore and understand their new physical and social self, through leisure, social activities, and activities of daily living, was referred to in six studies:

My friends had me up on my mule. Though I couldn't walk or take a step, they had me riding. If I couldn't have ridden I would have given up. I knew God was not punishing me because I could still ride.... [39,p.408]

In contrast, overprotection from family could be a barrier to positive adjustment:

For six years, I never had a chance to go out except to see the doctor. My parents considered it unnecessary for me to go out. I do not want to be enclosed in the house. I hope to go out of the house and visit all places of society. [43,p.642]

Being enabled and encouraged to explore their new physical and social self was an important part of the development of growth as it enabled participants to challenge previous assumptions and understand what they were capable of and what life could be like with a SCI. This appeared to be important for reconstructing identity.

### *Strengthened Relationships*

Six studies found participants experienced strengthened relationships with family following SCI due to appreciation of support

and through re-appraising life priorities due to experiencing significant vulnerability:

Sometimes I feel that I have died, now every day is a reward for me. I want to cherish every moment and dedicate it to the people around me. [43,p.645]

Close people move even closer together. [40,p.206]

### *Connecting with the Peer Community*

This theme reflects the importance of connecting with peers with SCI in the experience of positive adjustment. Peers appeared to be important in "Fostering a Sense of Belonging and Acceptance", providing "Support from a Lived Experience Perspective", "Knowing There is Life after SCI" and providing opportunities to re-appraise and appreciate their own situation through "Social Comparison". From positive experiences within the peer community could come a desire for "Giving Back to the SCI Community".

### *Fostering a Sense of Belonging and Acceptance*

Five studies referred to the usefulness of joining SCI or disability groups in providing opportunities to rebuild and expand social networks. Building friendships and connections through shared understanding fostered a sense of belonging and acceptance in a social group outside of their immediate network:

The sense of belonging in this group changed my mood. I could share my thoughts and feelings with them. My heart opened and I wasn't so melancholic. [43,p.644]

You know connecting you to a community of similar abilities or experiences that was more positive. It was like a new family. [42,p.404]

### *Support from a Lived Experience Perspective*

Five studies referred to the role of peers in providing emotional and informational support. Findings show participants felt able to self-disclose about emotions, thoughts, and personal issues due to a shared understanding of difficulties:

it was good to see other people who could talk about my personal issues such as a 'bowel program' because nobody else really understood and did not talk about those issues if he/she was not in a chair. [39,p.406]

Participants valued the information and empathy provided by peers, and felt enabled to learn to live better with SCI:

There were some personal problems that every patient with a spinal cord injury experiences. With the help of the experiences of other patients in the association, I learned how to deal with my problems in a better way. [19,p.3547]

### *Knowing There is Life after SCI*

Four studies found engaging with peers enabled individuals to see life could continue and they could live well with a SCI:

There are other people like me; it's not the end of the world. They can continue their lives, and it is up to them. It is all dependent on our mindset and beliefs. If we have correct beliefs, nothing is a limitation. [19,p.3547]

This seemed to be important as part reconstructing beliefs about disability and future possibilities.

### ***Appreciation Through Social Comparison***

Meeting others with SCI was found in four studies to provide individuals with opportunities for downwards social comparisons, comparing to those who they perceived as functionally worse in terms of injury, physical ability, or social circumstances, which helped in re-appraising their injuries and circumstance more positively:

Oh, you don't have it so bad. You're only a para. Look at these quads. Aren't you glad you can do [something by yourself]...I feel a lot luckier. I'm very blessed in so many ways. [38,p.885]

### ***Desire to give back to the peer community***

Six studies referred to this subtheme. Due to receiving support and encouragement from the peer community, many individuals reported a desire to give back, including through involvement with charities or sharing stories online:

I'll try to publicize my positive energy. I have uploaded some videos, when other people with SCI see me they can learn from me. Many peers say I'm their idol and spiritual pillar. I want to tell people that life with a SCI can be so exciting. [43,p.646]

### ***Reintegrating into Society***

The final theme refers to the influence of reintegration into society through work, education, leisure, sports, or travel on the development of growth. Though not a linear process, reintegrating into wider society seemed to be conclusive for participants in regaining their identity and sense of belonging and acceptance in the social world.

### ***Navigating the Social World with Disability***

In three studies, participants referred to how people in the wider social world, such as neighbours or strangers, interacted differently with them due to visible impairment. Individuals who experienced positive adjustment were able to find ways to manage and be able to reintegrate into society and re-construct their identity in the social world:

At first, when other people gazed me, I always thought "what do they take me for, a gorilla in the zoo or others"? Generally, my mentality changed. I find their smiles show not only curiosity but include care for me. [43,p.643]

### ***Exploring Abilities and Finding Hidden Strengths***

Leisure and sports activities were referred to in five studies as ways in which individuals were able to take risks and explore their physical and psychological selves. Through these processes individuals could find hidden strengths, helping them to re-appraise their abilities:

It was like basically learning a new sport, figuring out how to use a wheelchair. I have to figure out how to lift my body to get from the bed to the wheelchair. So the determination and the athletes' mindset of, let's just get on with it...in terms of pushing my physical limits I was able to...take risks. [42,p.403]

### ***Re-establishing a Valued Social Identity***

Seven studies referenced how re-integrating into the social world provided opportunities to align with valued characteristics or roles within society, and therefore move away from a disabled identity:

they still look at you as a disabled person who can't work; this really annoyed me, and I didn't want to be this viewpoint toward me. So, I

went looking for a job, and after I started working, I felt better about myself, and I didn't feel as a burden anymore. [19,p.3548]

...I found out about rugby and realized it was full contact...that was pretty cool for me knowing that aspect was still there. In high school, I was always the "athlete" that is just who I was. Knowing that part of my life was still there was huge for me. [42,p.402]

Re-establishing an identity as a working person, student, or athlete helped individuals to feel they could be valued members of society. Many gained social recognition and acceptance in this way:

The organization that I worked...told me that I had to enter my workplace again, and they said that they needed me; therefore, I really felt that, despite my condition, they needed me and wanted me. [19,p.3547]

## **Discussion**

The review aimed to examine social processes involved in the development of PTG as part of adjustment to SCI. Systematic review of the literature identified nine relevant studies across seven different countries, including both Eastern and Western cultures. Studies were critically appraised using the CASP tool [25], finding moderate to high quality. Utilising a meta-ethnographic approach [29] provided a rigorous approach which enabled the synthesis of studies exploring positive psychological change and interpretation of the findings to derive insights regarding PTG following SCI. This process generated four inter-related themes: (1) Sense of Self and Identity; (2) Close Relationships as Enablers of Growth; (3) Connecting with the Peer Community; and (4) Reintegrating into Society.

The meta-ethnography suggests identity reconstruction processes may be central to the experience of PTG following SCI. Experiencing SCI seemed to have the potential to shatter an individual's personal narrative and sense of self, as they described confronting a new identity. This is in line with Tedeschi and Calhoun's [10] idea of trauma disrupting an individual's core beliefs about self, world, and others. The findings also support research suggesting SCI may result in "biographic disruption" to personal narratives [3,49]. The findings indicated negotiation of a disabled identity was influenced by social stereotypes in line with Tedeschi et al.'s [9] proposal and previous research [3].

The meta-ethnography revealed that disrupted identity led to cognitive and behavioural processes as the individual explored ideas about disability, acceptance and belonging within the context of their social world. Tedeschi and Calhoun [10] focus heavily on the role of cognitive processes, through self-analysis and self-disclosure, in rebuilding core beliefs. The findings supported the role of self-disclosure; however, the findings also show that within the context of acquired disability, behavioural processes of exploring a new body (through leisure and everyday activities) and understanding one's capabilities are also important for PTG. This is supported by previous research [5], and suggests a potential addition to Tedeschi et al.'s [9] model.

Individuals who experienced PTG appeared to have dis-entangled from a disabled identity in ways that enabled them to re-construct their personal narrative and experience more positive outcomes. This supports previous studies showing that identity integration following acquired disability influences psychological wellbeing and maturation [50]. The process of identity re-negotiation following acquired disability is not currently included within Tedeschi et al.'s [9] model; however, models in the SCI field may be applied. Yoshida's [51] pendulum model of identity reconstruction proposes the individual oscillates between

nondisabled and disabled aspects of self as they reconstruct their identity following SCI. The meta-ethnography findings are consistent with this model, which highlights that moving beyond a predominant identity of the disabled self is important for well-being. Moreover, the meta-ethnography shows individuals reconstruct their beliefs about the self, world, and others within a relational context; in line with Tedeschi et al. [9] and Yoshida [51] models.

In agreement with previous research and theory, close relationships were shown to play an important and multifaceted role in enabling PTG [9,16,17]. First, close relationships were found to provide meaning for the individual to live well and strive to improve; and second to provide support, and opportunities for self-disclosure, which enabled the individual to reflect, adjust, and learn to live well. This is in line with Tedeschi et al.'s [9] model which sees social support as important in enabling coping and cognitive processing. In extension of Tedeschi's model, close relationships, encouraging and facilitating exploration of self, were also shown to be important as they enabled the individual to understand their capabilities, exert independence and explore their social world.

Furthermore, close relationships were shown to provide a relational space for the individual to make sense of the impact of SCI on identity and participation in the social world. Relationships that protect the individual's sense of belonging, acceptance and role within the family appear to enable challenging and reconstruction of beliefs about disability and development of positive sense of self. Additionally, support of exploration appeared to be important not only for exploring the physical self, but for how this might reinforce or challenge personal narratives about disability, and therefore interacted with identity reconstruction processes.

Another significant finding of the meta-ethnography was the pivotal role of engaging with those with lived experience. Peers were found to provide opportunities for self-disclosure, support and advice, promoting coping and thus enabling PTG, providing support for Tedeschi et al. [9]. However, the role of peers was found to be more multi-faceted than captured in the model. Engaging with a peer community was found to foster belonging and acceptance, enabling the individual to build new friendships and experience social acceptance outside their immediate social network. Social comparison processes were also found to be important in re-constructing ideas about disability and possible futures, and in facilitating feelings of gratitude in comparison. Furthermore, the findings showed individuals felt it was important to give back to peers. It is possible this was both an outcome of PTG (i.e., changes in personal characteristics), as well as part of the process of experiencing PTG. Giving back may have produced feelings of worth and value, and reciprocity of relationships, supporting the rebuilding of beliefs about self in relation to others.

Finally, the meta-ethnography showed the importance of social participation, including work, education, leisure, sports, or travel. This was found to enable individuals to explore and understand strengths and limitations of new physical and psychological selves. It was also significant in enabling individuals to re-discover or re-build valued social identities, and experience social acceptance and recognition. These ideas were important in terms of reconstructing beliefs about self and participation in the social world as part of PTG processes. The findings align with an interview study by Hammer et al. [52] showing the role of para-sports participation in promoting PTG through fostering feelings of competence, autonomy, and social connection, and in facilitating identity processes.

## Limitations

The review is limited by the current research base. A relatively small number of studies were found which met inclusion criteria. Additionally, the Chun and Lee [21,38,39] studies appeared to use the same data; further limiting the review scope. Despite the small number of studies, the review was able to provide meaningful insights and clinical implications.

The review investigated experiences of individuals living across seven different countries and cultures. There was evidence to suggest themes were consistent across countries and cultures, indicating themes can be considered universal rather than culturally specific. However, the review likely did not fully capture how the experience of SCI and PTG varies cross-culturally as most studies were conducted in Western countries.

Furthermore, the use of terms for growth varied across studies due to a lack of unified theory in SCI. Four studies explored "positive psychological outcomes", "changes in global meaning", "gain", or "gratitude". Thus, it was only possible to establish that participants included in the review reported experiencing some form of positive psychological change following SCI, though this might not be equivalent to PTG. On balance it was agreed that studies examined concepts that were theoretically similar enough to PTG, in terms of the outcomes and processes under study, to provide knowledge for the review aims.

Finally, the concept of PTG has been criticised and so nesting our findings with this framework needs to also be acknowledged as both a limitation and strength. For example, there are potential methodological difficulties with quantifying how growth can be measured, and differential findings regarding whether PTG equates to wellbeing and mental health outcomes, which has led to criticisms of PTG as being "illusory" [53]. This was investigated in a longitudinal study by Kunz et al. [13], who examined whether reports of PTG independently predicted psychological adjustment in those recently diagnosed with SCI. The results showed a weak association with actual changes in self-efficacy and purpose in life. However, PTG was shown to be associated with better psychological adjustment (depressive symptoms, anxiety, and life satisfaction) at rehabilitation discharge. The research was taken as potentially supporting the Janus face model of Zoellner and Maercker [54], which proposes PTG reported in the early stages may be related to avoidance coping and thus lesser adjustment; suggesting an illusory effect of PTG. However, with time and use of approach coping (cognitive processing and reappraisal) PTG may be related to better adjustment. This study attests to the veracity of the experience of PTG and its links to adjustment post-SCI. However, further prospective longitudinal studies are needed to investigate the validity of the personal reports of growth by many following traumatic events [53,55,56].

Despite ongoing debate within the field, the study of PTG remains of clinical relevance as it provides insights into how individuals process and make sense of life-changing events in ways that can enable them to rebuild their beliefs and lives in meaningful ways. The qualitative insights about these adjustment processes are thought to be important in providing knowledge applicable to clinical practice in supporting individuals.

## Clinical implications

The findings suggest it would be important that healthcare professionals working in adult rehabilitation settings actively ascertain how the individual is re-constructing their personal narrative as part of clinical assessment, formulation, and intervention process.

Interdisciplinary teams might also consider specific ways they can support this process, for example, through connecting goal planning and rehabilitation exercises with valued aspects of identity or social roles. Moreover, the findings support the use of psychological interventions that promote the development of a positive sense of self. Acceptance and commitment therapy is a promising intervention due to its focus on creating flexibility in how the individual describes and relates to their self-identity, exploring individual values, and promoting living in line with one's values.

The findings also support the importance of understanding the individual's social environment as part of a comprehensive bio-psychosocial assessment. Rehabilitation services should consider ways current practice works with families to support the transition home and strengthens the family's ability to provide support that enables independence, exploration, and role continuation. Furthermore, the findings show that social participation and integration opportunities are an important consideration as part of discharge planning to support individuals to consider ways in which they might connect with valued social roles and explore capabilities and strengths in meaningful ways.

Finally, rehabilitation services should consider how current provision enables engagement and learning opportunities with peers and consider strengthening opportunities in collaboration with the third sector.

### Future research

Systematic search of the research field revealed a relatively small number of qualitative studies, demonstrating a need for further qualitative studies of adaptation and growth to understand the lived experience of SCI. The review highlighted specific research areas that could be the target of qualitative studies, including identity reconstruction processes post-SCI, and the role of relationships and social support in the development of PTG. Additionally, the findings highlighted some PTG processes not currently defined within Tedeschi et al.'s [9] model, suggesting the need for further model testing in the context of acquired disability. Quantitative studies to test and understand how social factors and processes interact with PTG processes and outcomes would be beneficial to theoretical understanding of PTG following SCI and clinical practice.

### Conclusions

The meta-ethnography provided unique insights into the social processes involved in development of PTG following SCI. Identity reconstruction processes were found to be a central pathway, as the individual explores ideas of acceptance, belonging and value within their close networks, peer community, and wider society. This can promote the reconstruction of a positive self-identity when the individual is able to challenge previously held narratives about disability, which have developed due to societal narratives, and generate ideas about how disability can be integrated into identity. Close relationships and peers were also shown to be important in providing social support and promoting PTG processes.

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