

# A Narrative Review of Research on Adjustment to Spinal Cord Injury and Mental Health: Gaps, Future Directions, and Practice Recommendations

Danielle Sandalic <sup>1,2</sup>, Mohit Arora <sup>1,2</sup>, Ilaria Pozzato <sup>1,2</sup>, Grahame Simpson <sup>1,2</sup>, James Middleton <sup>1,2</sup>, Ashley Craig <sup>1,2</sup>

<sup>1</sup>Faculty of Medicine and Health, The University of Sydney, Sydney, New South Wales, Australia; <sup>2</sup>John Walsh Centre for Rehabilitation Research, Royal North Shore Hospital, Sydney, New South Wales, Australia

Correspondence: Ashley Craig, Faculty of Medicine and Health, The University of Sydney, Sydney, New South Wales, Australia, Email a.craig@sydney.edu.au

**Abstract:** Spinal cord injury (SCI) results in autonomic, motor, and sensory impairments that can compromise mental health. Guidelines directing the management of mental health following SCI presently address clinical anxiety, depression, post-traumatic stress, substance use disorders, and suicide. However, evidence suggests that perhaps as many as 70% of individuals with SCI do not develop a clinically diagnosable mental health disorder. Therefore, the authors contend that understanding non-clinical cognitive and psychological aspects of adjustment post-SCI is paramount and that the application of this knowledge to the formulation of adjustment-enhancing interventions is crucial. To assist with this endeavour, we examine existing mental health guidelines targeting SCI, and present a narrative review of research on the under-represented topics of adjustment, coping, grief, and resilience. We include mild cognitive impairment, which reflects a common factor that can compromise adjustment. Loss and stress trigger processes of adjustment, coping, grief, and resilience. SCI involves loss and stress triggering these processes, arguably without exception. Our study applied a narrative review methodology searching Google Scholar and PsychInfo databases for terms adjustment, coping, grief, resilience, and cognitive impairment. Qualitative studies and quantitative studies were selected to capture bottom-up and top-down perspectives. Reference lists of retrieved papers were searched as appropriate. Reviewed literature suggested that existing guidelines concerning mental health following SCI neglect positive processes of adjustment and suggest this neglect contributes to a deficits-based view of mental health following SCI. Research into “positive” or adjustment-enhancing processes is mostly cross-sectional, heterogenous, and poorly positioned to inform future guideline-development. Researchers should achieve consensus over the operationalisation of essential processes and overcome a fixation with “outcomes” to better inform management of mental health after SCI.

**Keywords:** spinal cord injury, adjustment, coping, grief, resilience, cognitive impairment

## Introduction

Spinal cord injury (SCI) is a neurological injury resulting in loss of autonomic, motor, and sensory functions with related impairments of the upper and/or lower body depending on the level and extent of spinal cord damage. Prior to the 1940s, genitourinary disorders, influenza, pneumonia, and sepsis were major causes of death with many people with SCI dying within months of their injuries.<sup>1</sup> Rehabilitation and management of SCI and secondary conditions has improved over the past decades, contributing to greater life expectancies.<sup>2</sup>

Management of cognitive and psychological conditions still lags relative to improvements to medical care. Research shows adults with SCI have higher rates of alcohol dependence compared to adults without SCI (2.4% versus 1.0%), anxiety (19.3% versus 14.1%), depression (29.3% versus 9.3%), dementia (6.5% versus 0.8%), and psychological multi-morbidity (37.4% versus 23.9%).<sup>3</sup> The Paralyzed Veterans of America (PVA) published guidelines in 1998 that

recognized the need to manage cognitive and psychological conditions in SCI, but these early guidelines addressed the management of depression only.<sup>4</sup>

Guidelines published by the PVA recently focus on a broader range of areas including clinical anxiety, depression, post-traumatic stress, substance use disorders, and suicidal ideation.<sup>5</sup> The inclusion of a greater range of diagnostic conditions is crucial and welcome; however, the Guidelines fail to address “non-diagnosable” psychological consequences of SCI. They also assume diagnostic conditions relevant to the general population can be transposed to the unique and complex experience of SCI. Qualitative studies reporting the subjective experiences of individuals with SCI suggest areas like adjustment, coping, grief, and resilience are pertinent yet under-examined aspects of adjustment to SCI.<sup>6,7</sup>

Just under a third of individuals with SCI develop a diagnosable mental health condition post-injury.<sup>8</sup> This means that extant diagnostic and treatment guidelines that focus entirely on “pathological” conditions, such as clinical anxiety and depression, neglect many people living with SCI. There is an urgent need to shift the focus from deficit models of adjustment and associated reactive management and treatment approaches. The subjective experience of SCI is described as one of grief, learning to cope with disability, and restructuring beliefs relating to self and the world to accommodate a new way of life. We acknowledge this in the present study.

The primary aim of this study is to conduct a narrative review of research conducted into coping, grief, resilience, and cognitive impairment with a view to guide clinical management of these common processes until formal guidelines are developed. Secondary aims are as follows: (i) to examine definitions of psychosocial constructs to stimulate the development of consensus; (ii) to discuss relevant theoretical developments in relation to positive psychology, strengths-based approaches, and wellness, and (iii) to provide a review of the contribution of cognitive impairment post-SCI given studies have accumulated, and continuing to accumulate, to suggest cognitive changes following SCI might compromise adjustment.<sup>9</sup>

To provide context for this review, we begin with a brief examination of the existing PVA Clinical Practice Psychological Morbidity Guideline for health care professionals.<sup>5</sup>

## **PVA Guideline for the Management of Mental Health Disorders, Substance Use Disorders, and Suicide**

The PVA recently published the Clinical Practice Guideline on Management of Mental Health Disorders, Substance Use Disorders, and Suicide in Adults with Spinal Cord Injury (The Guidelines).<sup>5</sup> This followed the efforts of Dr Lester Butt and his working group, who in 2003 presented a proposal to the Consortium for Spinal Cord Medicine to develop a comprehensive set of psychosocial guidelines to define and elevate standards of care for individuals with SCI.<sup>5</sup>

Initial bids to fund research into areas that individuals with SCI consider pertinent to adjustment, such as aging, coping, family, pain, and traumatic brain injury were not successful, resulting in a decision to restrict attention to disorders listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM), including clinical anxiety, depression, post-traumatic stress, and substance use.<sup>5</sup> Suicidality was included because of its prevalence in SCI, being at least three times higher than rates found among those who are able-bodied.<sup>5</sup>

The Guidelines are accessible in electronic form <https://pva.org>, and we refer readers here for the latest evidence-based direction concerning management of DSM-listed disorders. These Guidelines are briefly summarized for readers' convenience, but more importantly, they are referenced to show that current conceptualisations of mental health following SCI are limited to diagnostic categories borrowed from the general population. We aim to fill a gap by capturing a spectrum of cognitive and psychological conditions individuals with SCI most commonly report.

## **The PVA Guidelines Summary**

The Guidelines recommendations draw on existing guidelines, expert opinion, and relevant research involving SCI and non-SCI populations. Ratings of scientific evidence comprise five levels: (i) randomized clinical trial (RCT) of adequate size to ensure low risk of false negative and false-positive results; (ii) small RCTs that may or may not show trends and may include false negative and false-positive results; (iii) non-randomized trials, cohort studies, cross-sectional data, case

series; (iv) expert opinion, and (v) peer opinion. Strength of evidence ranges from A, supported by at least one Level I evidence; B, supported by at least one Level II evidence; to C, supported by Level III to V evidence.<sup>5</sup>

Every Guideline recommendation received a rating of level IV, strength C, agreement “strong” but for one exception, illustrating a lack of reliable scientific evidence guiding the management of mental health following SCI. The single recommendation with a rating of level I, strength A, agreement “strong”, pertains to treatment of depression aligning with general population recommendations to incorporate pharmacological and/or nonpharmacological approaches based on clinical presentation (eg comorbid conditions), treatment efficacy, and patient preferences.<sup>5</sup> Thus, even for DSM-listed disorders that receive most SCI research attention, few if any RCTs exist to guide research and clinical practice.

## The PVA Guidelines Recommendations

A very brief summary of the full clinical guideline recommendations<sup>5</sup> is presented next as three sections: i) screening, ii) referral, and iii) support and treatment.

### Screening

Screen individuals for anxiety, depression, post-traumatic stress, substance use disorders, and suicide risk during inpatient rehabilitation, at the first-discharge follow-up point and at least annually or more frequently depending on risk-stratification factors. Risk stratification factors include previous history of anxiety, chronic pain, depression, trauma-exposure, and problematic drug-use. Use only validated screens. Warning signs of suicide include suicidal communication, preparation for suicide, and seeking access to lethal means.

### Referral

Refer individuals who screen positively for anxiety, depression, post-traumatic stress, substance use disorders, or risk of suicide for comprehensive diagnostic assessment by trained mental health professionals who are able to rule out differential diagnoses such as medication side-effects or other medical conditions.

### Support and Treatment

All healthcare professionals involved in rehabilitation (eg nurses, psychiatrists, psychologists, and social workers) should support management of anxiety, depression, post-traumatic stress, substance use disorders, and risk of suicide with non-specific and disorder-specific therapeutic strategies. Suggested supports include the facilitation of hope through the establishment of easily achievable goals, promotion of self-efficacy, provision of meaningful and purposeful activities, and supportive relationships. Pharmacological treatments should be offered and referrals made to specialized programs for patients with severe substance use disorders who are able and willing to participate. Patients with post-traumatic stress require evidence-based treatments (eg cognitive processing therapy, exposure therapy, eye movement desensitization and reprocessing). Suicide management and prevention require safety planning for the appropriate response to potential suicidal crises.

## Narrative Review of Research on Adjustment to Spinal Cord Injury and Mental Health: Gaps, Future Directions, and Practice Recommendations

As argued above, the existing PVA Guidelines for the management of mental health following SCI address “pathological” conditions sufficiently severe to warrant a diagnosis. Guidance on the management of factors that influence adjustment, such as coping, grief, and resilience, the middle-ground between pathology and wellness, have not been addressed by any formal guidelines and have thus by-passed attention. Lack of expert consensus explains this neglect in part, and it is our intention to highlight the need to develop consensus on these topics to inform future guideline development. Reaching consensus in these areas may not be possible with the state of the literature being as it is.<sup>10</sup> We review selected research, highlight areas for further study, and propose recommendations to guide the management of common reactions to SCI, at least until consensus is achieved and formal guidelines are developed.

## Methodology

Articles reporting qualitative and quantitative research were sourced via Google Scholar and PsycInfo. Keywords “adjustment”, “cognitive impairment”, “coping”, “grief”, “resilience”, and “spinal cord injury” were entered into these databases without limits set to year of publication to capture developments across areas; however, recent articles were prioritized when feasible. Preference was given to sourcing material from meta-analyses and systematic reviews in the case of quantitative studies. Selected articles were written and published in English.

## Results of Review of Research Related to the Process of Adjustment

A systematic evaluation of competing theories of adjustment is not the focus of this review. However, existing reviews have shown convincingly that the process of adjustment is dynamic, individualized, and multidimensional, and for this reason cannot be generalized.<sup>11–15</sup> For the sake of brevity and to maintain a clinical and practical focus on the management of mental health in individuals with SCI, we have chosen to operationalize adjustment as a process, or set of interacting processes, that sustain a sufficient match between individual appraisals and reality, where this matching promotes coping behaviors that respond suitably to stressors and yield outcomes that a person values. This is in line with the theory of adjustment proposed by Craig et al<sup>16</sup> and the reality-matching hypothesis suggested by Christensen et al<sup>17</sup> and Park et al.<sup>18</sup> Shifting the focus from theoretical models to processes permits the formulation and guiding of individualized conceptualizations of adjustment and personalized interventions. The clinician’s task involves identifying and tailoring interventions to address processes that interfere with adjustment, whether these be internal processes such as perceptions of personal control in uncontrollable situations reflecting poor reality matches, and/or external processes where situational barriers obstruct verified agentic abilities, and/or the interaction of internal and external processes that are context- and time-bound.

Existing definitions of adjustment to SCI refer to a process that is life-long and non-linear, with shifts between grief, loss, and acceptance, the integration of existing and developing self-, other-, and world-views, and the establishment or re-establishment of connections with communities and groups.<sup>12,14–16,19–24</sup> It is noted that individuals with SCI age prematurely, meaning they are exposed to earlier-than-expected declines of already compromised health and physical capacities,<sup>25</sup> and this complicates adjustment processes. Larsen argues there is a need to separate process from outcome when considering what comprises adjustment,<sup>26</sup> given an outcome such as return-to-work may reflect adjustment at one timepoint but will likely be less important or redundant as years go by. Processes accounts of adjustment need to account for the time-sensitive demands individuals confront. Outcome-focused conceptualizations arguably do little to illuminate the path to adjustment, much like viewing a finished house fails to reveal the methods required to build. Research into adjustment to SCI has been criticized for being mostly cross-sectional and for neglecting the study of essential mechanisms of change.<sup>13</sup> To inspire process-oriented research and practice into the facilitation of adjustment to SCI, we propose that the following processes may be among those most central to adjustment and encourage longitudinal research to investigate these.

## Acquiring an Understanding of SCI and Associated Functional Limitations

If adjustment reflects a match between appraisals and reality, then individuals may not adjust to SCI successfully until they process information sufficiently to understand the nature and implications of their injuries. Knowledge is a non-negotiable determinant of the capacity to adjust and live independently with SCI.<sup>27</sup> Requisite learning is onerous, encompassing many topics, including bladder and bowel management, management of autonomic dysreflexia, pressure ulcer prevention, sexuality, and ways to access and navigate various support systems, including those that provide financial and other supports. There is a need to acknowledge the heavy learning burden and potential for information overload and to make accommodations to ensure that information is comprehended and retained rather than merely delivered.<sup>28,29</sup> The most basic level of understanding required for the process of adjustment to begin is an understanding of the level and completeness of the injury and the likely impact of the injury on current and potential functioning. Topics such as bladder, bowel, and skin care are very important from the patient perspective.<sup>30,31</sup> Use of a validated scale, such

as the freely available Needs Assessment Checklist developed by Kennedy and Hamilton,<sup>32</sup> is recommended to assess individuals' understanding of SCI-specific self-care.

## Appraising SCI as Manageable

Appraisal theory maintains that individuals adjust or cope with stressors when they appraise them as being manageable and believe they have the resources required to manage these stressors.<sup>33</sup> SCI is a biogenic and psychosocial stressor as the injury itself and appraisals of the injury prompt physiological and psychological stress reactions. Primary and secondary appraisals are relevant to adjustment to SCI in the context of it being a psychosocial stressor, as these appraisals have been shown to be cognitive preconditions to the selection and activation of behavioral and mental coping strategies.<sup>34,35</sup> Perceiving SCI as an uncontrollable threat is believed to evoke avoidant coping, whereas appraising it as a controllable challenge is thought to promote approach coping.<sup>36</sup> Several models, including the SCI Adjustment Model (SCIAM),<sup>16,37</sup> propose appraisal-re-appraisal feedback mechanisms where the failure or success of a coping strategy is continually appraised to inform the continuation, discontinuation, and/or adoption of new coping strategies. The bulk of literature associates avoidant coping with poor adjustment and approach coping with positive adjustment,<sup>38</sup> and there is support for interventions that teach specific coping strategies.<sup>39,40</sup> Recent research has shown that appraisals and psychological resources have direct effects on adaptation outcomes as opposed to simply having indirect effects that are mediated by the choice of coping strategies.<sup>20</sup> Therefore, targeting specific coping strategies may not be essential. There may be value in interventions that target appraisals independently of coping strategies and in the promotion of behavioral and cognitive flexibility.

Accommodating existing beliefs about self, others, and the world, and assimilating information about the injury into existing beliefs to retain connection to premorbid identities.

Accommodation is a term used here to refer to a cognitive process of adjusting or reorganizing existing beliefs about self, others, and the world, primarily to acknowledge and integrate changes to objective reality that may conflict with these beliefs. Jean Piaget distinguished accommodation from assimilation, where individuals preserve rather than adapt old schemas to interpret new information in his theory of cognitive development.<sup>41</sup> Processes of assimilation and accommodation seem relevant to adjustment to SCI as the injury casts individuals into states of cognitive dissonance where two or more attitudes, beliefs, or values may conflict and contribute to distress or discomfort prior to resolution. People who believe they are independent and that their worth is largely contingent on independence will need to accommodate these beliefs if they are to navigate successfully, the reality of having to depend on others for some or all aspects of their self-care. These same people may need to maintain continuity with former lives by working to accept aspects of their disabilities in addition to adjusting beliefs to preserve the integrity of former identities such as those concerning family roles (eg accepting changes as to how one cares for children). Some processes can reflect identity reconstruction. Several theorists recognize that personal and social identities are reconstructed in response to disability,<sup>42-44</sup> suggesting that adjustment to SCI involves multifaceted cognitive reflections and responses to self in-context (ie "who am I?"; "what is my role?"; "where do I belong?"). Yoshida describes a pendulum-type process of self-reconstruction after SCI involving oscillations between the nondisabled and disabled aspects of the self, which is initiated by processes of loss, sustainment, integration, continuity, and self-development.<sup>45</sup>

## Proposed Areas for Further Research on Adjustment

- (a) Outcome-focused operationalizations of adjustment should make way for process-focused conceptualizations because adjustment to SCI is time-sensitive across the course of injury with outcomes relevant in the acute stage potentially being less relevant at later stages.
- (b) Processes meriting further attention might include the role of knowledge in adjusting to SCI, the role of appraisals across time, and the reconfiguring of beliefs relating to self, others, and the world via cognitive processes including accommodation and assimilation.
- (c) There is a need for longitudinal research into processes that facilitate and/or hinder adjustment to SCI to balance overreliance on cross-sectional research methodologies.

## Practice Recommendations Concerning Adjustment

- (a) Assess and support individuals' understanding of SCI, including an understanding of the functional implications of the injury at critical timepoints such as at the acute stage of injury, during significant life transitions, and when changes to care are required.
- (b) Evaluate how individuals appraise SCI and the impact of SCI on lifestyle to identify positive appraisals related to challenge and negative appraisals relating to threat. Refer individuals to suitably qualified psychologists when negative appraisals are thought to interfere with adjustment and functioning.
- (c) Understand that there are many paths to adjustment and that the time required to adjust varies from person to person. The adjustment process is non-linear and may reflect trajectories of improvement, followed by decompensation, particularly at times of life transitions, much like people with grief oscillate between "stages."

## Results of Review of Research Related to Coping

Coping strategies are categorized broadly as approach-oriented, avoidant, emotion-focused, and problem-focused.<sup>46–48</sup> The distinctions between avoidant and emotion-focused and approach and problem-focused may be moot in practice to the extent that emotion-focused coping involves regulating emotional responses to stressors, thereby influencing stressors indirectly, as opposed to problem-focused coping which focuses on approaching stressors to manage them directly. Some contend emotion-focused coping is a category of avoidant coping comprising emotion pacification strategies that can become mostly maladaptive in the case of prolonged avoidance.<sup>49</sup> When avoidant- and emotion-focused coping are applied to manageable stressors over a long period of time, they can reflect escape behaviors that contribute to protracted distress and these should be replaced by problem-focused coping actions and behaviours directed at addressing stressors.

Individuals with SCI are thought to utilize many coping strategies, and research has found these are mostly constructive. For example, Anderson et al found only 28% of their sample of adults with adult-onset and paediatric-onset SCI used behavioral disengagement and 15% misused substances.<sup>50</sup> Ninety per cent of the sample used active coping and positive reframing, and acceptance of reality, seeking emotional support, and using religion or spirituality was positively associated with life satisfaction. Using qualitative research methods, Shamshiri et al found six themes represent coping in the context of SCI, including accepting the incurability of SCI, developing desire to be independent, forming relationships, praying for divine help, patience and persuasion, and the passage of time.<sup>51</sup> Notwithstanding obvious maladaptive coping strategies such as drug taking, contextual factors seem to determine the adaptiveness of most coping strategies.

Evidence suggests that Coping Effectiveness Training (CET) is the most widely implemented and well-researched coping-specific intervention adapted to SCI. It has been found to reduce anxiety, depression, and reactivated trauma,<sup>39</sup> and to promote independence and positive coping strategies in individual and group formats.<sup>19,52</sup> More research is required to determine whether CET works by promoting coping strategies. The single existing randomized control trial comparing CET to an active alternative psychological intervention found no differences in adaptation outcomes between intervention groups.<sup>40</sup> There were no differences between individuals with SCI receiving CET and those receiving Supportive Group Therapy (SGT) on adjustment to disability at 3-months follow-up, suggesting CET was no more effective at promoting adjustment than were interventions that purely supported individuals. These results echoed the researchers' prior research showing that CET influenced anxiety and depression by facilitating positive appraisals and positive changes to individuals' self-perceptions without necessarily changing coping skills.<sup>53</sup>

Contextual factors are most likely to determine the effectiveness of any coping strategy, and this reiterates the importance of focusing interventions on the promotion of behavioral and cognitive flexibility above the adoption or use of one strategy over another.<sup>54,55</sup> In the early stages of SCI when emotions are intense, putatively negative strategies such as denial may be adaptive to the extent they help to prevent being overwhelmed. Weisman suggested that coping strategies are nuanced when he differentiated first-order denial, where facts of an illness or injury are denied, from second-order denial, where the illness or injury is accepted, but the worst implications of the illness or injury are denied. When first-order denial occurs in the case of a terminally ill patient, Weisman proposes that the denial naturally remits because disease progression renders first-order

denial untenable.<sup>56</sup> Whether nuances are inherent to the coping strategies employed by individuals with SCI and if and how these affect adaptation processes are questions worthy of future investigation.

## Proposed Areas for Further Research on Coping

- (a) CET is the only coping-specific intervention investigated for use in SCI populations, so adapting and investigating the effects of a wider range of interventions appears necessary.
- (b) Research examining behavioral and psychological flexibility of responses across time and factors that impair or support flexibility could help to inform future coping interventions.
- (c) Shifting the focus of coping research from content (specific strategies) to processes, particularly those constituting behavioral and psychological flexibility, seems meritorious.

## Practice Recommendations Concerning Coping

- (a) Interventions that teach specific coping skills, such as CET, promote coping. However, these may be no more effective than usual supportive care. Therefore, interventions should not be prescriptive but rather adapted responsively to the needs of individuals.
- (b) Promote behavioral and psychological flexibility. Third-wave cognitive behavioral therapies that target behavioral and cognitive processes such as Acceptance and Commitment Therapy might help to guide the development of suitable interventions.

## Results of Review of Research Related to Grief

Grieving is understudied in SCI. For example, a PsycInfo search using keywords “grief” and “spinal cord injury” conducted at the time of writing this review yielded less than 25 articles of which less than 5 were related to grief. Klyce et al maintain that grief following SCI should be studied as grief demonstrates incremental validity, serving as an independent predictor of functional impairment, health behaviors, and suicidal ideation.<sup>57</sup> This incremental validity stems from grief possessing features that are discrete from depression, specifically reflecting loss-related and trauma-related factors.<sup>58,59</sup> Unlike clinical depression that reflects themes of worthlessness, which are never normal and always warrant intervention, grief is believed to require intervention only when it has been present for more than six months and reflects “pathological” or protracted grief producing significant impairment.<sup>60</sup> Relevant meta-analyses of treatments for grief in non-SCI samples indicate that (1) interventions aimed at “preventing” grief are not effective and may be harmful; and that (2) targeting symptoms of grief early provides minimal and transient positive effects.<sup>61–64</sup> “Watchful waiting” is recommended when grief is present within the first six months of SCI in place of interventions that involve confrontation or the “working through” of loss to avoid potential iatrogenic effects.<sup>60</sup> When grief-specific treatment is indicated, treatment that combines loss-oriented cognitive behavioural therapy and restoration-oriented interpersonal therapy might be suitable; however, this has not been tested in the context of SCI.<sup>65–67</sup>

Adopting autoethnography to report his own experience with grief, Clifton<sup>6</sup> argues that SCI-related grief is analogous to the death of a loved one in the sense that loss of the body and its functions, perceptions, and sensations is akin to body-mind separation. “Broken” and “dead” are adjectives he applies to his body, referring to his lived experience of having a discontinuous sense of self where the body resembles “a second person” in place of an embodied self. He reports transitions through anger and denial before questioning whether it is possible ultimately to achieve “acceptance” given SCI involves lifelong disability and recurrent physical and psychological challenges.<sup>6</sup> In his view, grief over SCI-associated losses creates a series of “existential crises” that might be resolved through re-examination and reconstruction of personal narratives towards newfound stories. To support restoration or reintegration of personal identities, he recommends interventions that provide for “open narrative environments” where therapists “hear what others cannot” which validate pain as real without resorting to simple reassurances. Therapists, in his view, require “storied understandings of grief” understanding that the loss of a story’s central character disrupts the life story, and this must be reorganized and rewritten to bridge past and present intelligibly.<sup>6</sup>

## Proposed Areas for Further Research on Grief

- (a) Differentiating clinical depression from grief is crucial as correct diagnosis underpins effective treatment. Identifying factors other than loss and worthlessness to differentiate grief and clinical depression, respectively, seems relevant to making differential diagnoses.
- (b) There are no trials into the effectiveness of loss-oriented cognitive behavioral therapy or restoration-oriented interpersonal therapy for protracted grief following SCI. These therapies likely require adaptation to fit losses that are specific to SCI.

## Practice Recommendations Concerning Grief

- (a) Employ ‘watchful waiting’ and supportive therapy when grief is present within the first six months of SCI in place of interventions that aim to promote confrontation or the “working through” of loss to avoid potential iatrogenic effects.
- (b) When grief reflects protracted or preoccupied grief, loss-oriented cognitive-behavioral therapy plus restoration-oriented interpersonal therapy may be effective; however, neither treatment has been adapted to nor studied for SCI-associated grief.

## Results of Review of Research Related to Resilience

Resilience in SCI is a poorly understood phenomenon. Only one scoping review of quantitative studies and one systematic review of qualitative studies on resilience following SCI exists.<sup>7,10</sup> The quantitative review, published as recently as 2020, concluded aptly that resilience in SCI has considerable definitional and conceptual heterogeneity across studies.<sup>10</sup> This heterogeneity has reportedly precluded translation of research findings to clinical practice and is compounded by other problems noted to include lack of studies on processes central to resilience, in addition to neglect of assessments and descriptions of adversity and hardship specific to SCI.<sup>10</sup> The problem of inadequately conceptualizing adversity following SCI seems critical given that understanding the context of adversity is necessary for understanding resilience.<sup>68,69</sup> SCI researchers appear to have conducted cross-sectional assessments of resilience at inappropriate times and these dominate the literature.<sup>70</sup> That is, and problematically, many cross-sectional assessments have been conducted years after the onset of injury, and this may not reflect resilience to SCI entirely if adjustment has intervened or taken place, or if resilience was pre-existing. The shift away from thinking of resilience as the mere absence of adversity to acknowledge that it includes positive outcomes such as optimism and post-traumatic growth<sup>71–74</sup> is missing from research that aims to elucidate processes and inform the development of a mechanistic understanding of resilience.

Researchers outside of SCI conceptualize resilience as comprising at least three processes: an intrapersonal process, an interpersonal process, and a social process.<sup>75</sup> One intrapersonal account looks beyond typical trait models to consider information processing, suggesting that information processing influences affect, cognition, and motivations presumed to underpin self-regulation. Threats are thought to direct attention and motivation toward goal-relevant information, as goal-irrelevant information is inhibited by direct attention and action in adverse situations.<sup>76</sup> This selective attention and effort allows individuals to attend to and sustain focus on goal-directed behaviour for whatever duration is required to resolve a threat. The inability to shift towards an “open” mode of information processing when goal-achievement is thwarted, rendering an adverse situation uncontrollable, is thought to account for rumination and unhelpful perseveration or persistence.<sup>77–79</sup> Therefore, being able to modulate attention by shifting attention to match the controllability or uncontrollability of an adverse situation is considered an essential path to resilience. Where situations are uncontrollable, ongoing goal-pursuit aimed at changing a situation is considered unproductive, and the preferred information processing mode is one that enables consideration of information that was initially inhibited as goal-irrelevant to assist identification of potentially alternative actions.<sup>75</sup> When SCI is accompanied by cognitive impairment, information processing to build resilience may be hard to initiate and sustain.<sup>73</sup>

Simpson and his team have adopted a systemic approach to studying capacity-building resilience in the context of SCI and traumatic brain injuries (TBI). This initiative responds to observed treatment silos where allied health teams such as social work and psychology seem to operate independently in place of working collaboratively. The demands of psychosocially supporting individuals with SCI are reported to outweigh the capacities of existing formal support

systems such as government and insurance-based schemes, and it is argued that this necessitates interventions that strive to enhance the capacities of the informal supports families provide.<sup>80</sup>

Resilience-based interventions are emerging in the field of neurorehabilitation. Resilience and Adjustment Intervention (RAI) among individuals with TBI associates with clinically significant improvements in resilience.<sup>81</sup> Strength to Strength (S2S) is a single-existing evidence-based treatment available to support carers of relatives with neuro-disability, including SCI. S2S is a manualized intervention incorporating grief and loss theory, learning theory, cognitive behaviour therapy, narrative and solution-focused therapy, and group work theory. Randomized controlled trials incorporating S2S are testing whether specialized interventions promote increased use of management strategies, resilience, and self-efficacy compared to usual care among relatives who support individuals with TBI.<sup>80</sup>

## Proposed Areas for Further Research On Resilience

- (a) Definitional and conceptual clarity and consistency are required so that resilience following SCI is operationalized in a way that leads to translational research and effective practice.
- (b) Qualitative research to better understand the nature of adversity across the life-course of SCI may help to adapt resilience-focused interventions that satisfy the unique needs of individuals with SCI through major life transitions.
- (c) Process models of resilience that incorporate strength-based perspectives over deficit-based perspectives are required to bring SCI conceptualizations of SCI in line with those found to apply in the general population and other illness communities.
- (d) Studies of resilience conducted months or years after SCI may not measure resilience to SCI if adjustment has occurred or if resilience is pre-existing, yet these pervade the literature. We need longitudinal studies beginning soon after the injury.
- (e) Systemic resilience is understudied but warrants attention because SCI impacts families who provide for over half of the care needs individuals with SCI receive. The cost-effectiveness of strengthening families versus formal supports merits evaluation.

## Practice Recommendations Concerning Resilience

- (a) Individuals with compromised information processing may struggle to shift attention from irrelevant information or continue to persevere on information that was once relevant but not viable when stressors are uncontrollable. It is important to rule out the potential contribution of cognitive deficits in individuals who struggle to make reasonable adjustments to accommodate the stressors of SCI.
- (b) Fostering resilience involves supporting individuals' capacities to manage stress in addition to supporting interpersonal relationships, including those support systems outside the immediate family. S2S, should it be shown to be effective, could be offered to build the resources of families who serve as informal caregivers providing a bulk of the psychosocial care individuals with SCI receive.

## Results of Review of Research Related to Mild Cognitive Impairment

As stated in the aims, cognitive impairment is an important area to discuss as evidence suggests it can negatively impact adjustment potentially as a common factor. An increasing body of knowledge supports the routine assessment and management of cognitive impairment in individuals with SCI.<sup>9,82,83</sup> Early studies investigating the potential problem of cognitive impairment in the 1980s raised concerns as they showed individuals with SCI display deficits in areas of attention, executive functioning, memory, and processing speed relative to able-bodied individuals.<sup>84–86</sup> Recent studies have theorised about such deficits, postulating that individuals with SCI are prone to premature cognitive aging,<sup>83,87–89</sup> but the studies are heterogenous and hence inconclusive. The hypothesis of advanced cognitive aging is in keeping with evidence of accelerated aging of other bodily systems, such as the cardiovascular, endocrine, genitourinary, immunological, musculoskeletal, nervous and respiratory systems.<sup>25,90,91</sup>

Two studies have examined the idea that individuals with SCI cognitively age prematurely. Chiaravalloti et al assessed attention, executive control, information processing, new learning, memory, and working memory in adults

with SCI, and compared results with those obtained from age-matched healthy controls (AMHC) and older healthy controls (OHC). Differences found in information processing speed, new learning, and verbal fluency between AMHC and SCI, which were not present between SCI and OHC, were interpreted as evidence of premature cognitive aging.<sup>87</sup> This conclusion could be challenged as the study involved two groups in place of repeated measures and individual differences between the SCI and OHC groups were large, indicating potential confounding factors. Statistically significant between-group differences obtained from cross-sectional studies do not reflect individual-level changes. This weakness applies equally to a study by Molina et al that is frequently cited as support for the accelerated cognitive aging hypothesis. Significant deficits were found in memory and learning between a group of individuals with SCI who were at least 12 months post-injury compared to a group of individuals with acute SCI.<sup>89</sup>

Clinically speaking, the possibility of advanced cognitive aging in SCI seems possible. Deficits found in individuals with SCI to date have mostly involved fluid thinking,<sup>9,92-94</sup> and these areas of cognition are known to deteriorate with age because of general slowing, frontal decline, and unidentified factors.<sup>95-98</sup> In the general population, declines in fluid thinking have been found to correlate positively and strongly with declines in the ability to function and live independently, compromising the ability to perform everyday tasks such as following medication instructions, adapting to life changes, and paying bills.<sup>99</sup> Limited independence is a known risk factor for indicators of poor psychosocial adjustment to SCI, including anxiety, depression,<sup>100-102</sup> lowered self-esteem<sup>103</sup> and quality of life,<sup>104-106</sup> as well as SCI-specific physical complications such as bladder and bowel infections and skin pressure wounds. The association between cognitive decline and functional independence requires attention.

## Proposed Areas for Further Research on Cognitive Impairment

- (a) Longitudinal studies beginning in the acute stage of injury and incorporating repeated measures are needed to explore the hypothesis of accelerated cognitive aging in SCI.
- (b) Researchers should work towards an internationally agreed set of cognitive measures to investigate mild cognitive impairment and its impact following SCI so that results can be compared to reach consensus about its impact on adjustment.

## Practice Recommendations Concerning Cognitive Impairment

- (a) Assess cognition using validated screens at the initial stage of injury, at discharge, and at least annually to monitor for decline in cognitive functioning that may compromise adjustment, independence and self-care.
- (b) Compare obtained cognitive assessment results to baseline measures if available. If baseline measures of cognitive functioning are not available employ proxies such as validated tests of premorbid functioning (eg Test of Premorbid Functioning).

## Conclusions

The development of the recent PVA mental health guidelines (The Guidelines) is a positive step towards improving clinical management of mental health in the context of adjustment following SCI, and we congratulate Bombardier et al. That said, we believe much work remains to be done to improve our understanding of common “non-pathological” responses to SCI, which we argue may be impacted by comorbid cognitive impairment. Once our understanding of adjustment to SCI advances, improvements to the psychosocial management of SCI should follow. We hope this paper stimulates further investigation into areas not covered by existing mental health guidelines (ie “positive” processes) to inform guideline development more comprehensively and to better match existing literature which shows adjustment to SCI is dynamic and not-necessarily “pathological”.

Our review identified several gaps in the extant literature in the areas of adjustment, coping, grief, and resilience. These topics were selected as the foci of this review to address an apparent over-emphasis on deficit- or pathology-based conceptualizations of mental health following SCI and to acknowledge that individuals with SCI consider adjustment, coping, grief, and resilience to be concepts common to the SCI experience. The apparent over-emphasis on “outcomes” at the neglect of “processes” is a major gap, as is the cross-sectional nature of research conducted to date, often many years after SCI-onset by which point it becomes very difficult if not impossible to properly capture the processes underpinning

adjustment. These gaps are compounded by diverse or inconsistent conceptualizations of concepts that preclude comparison of studies and the triangulation of data necessary to enhance confidence in the validity of conclusions drawn and future hypotheses we may make.

## Abbreviations

SCI, spinal cord injury; TBI, traumatic brain injury; PTSD, post-traumatic stress disorder; PVA, Paralyzed Veterans of America; RCT, randomized clinical trial.

## Ethics Statement

Human ethical approval was not applicable to this study given it involved a narrative review of the literature.

## Author Contributions

DS led all aspects of this paper as part of her doctoral research. DS, MA, IP, JM, AC and GS all contributed significantly to the conception, execution, acquisition, analysis and interpretation of the literature for the paper. All authors agreed to submit the article to this journal, all critically reviewed the article, during revision and any significant changes introduced at the proofing stage. All agreed to take responsibility and be accountable for the contents of the paper.

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