

**Self-management Interventions for Psychological Outcomes Following Spinal Cord  
Injury**



*This report is submitted in partial fulfillment of the degree of Master of Psychology (Clinical)*

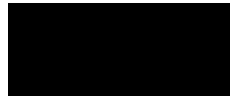
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## **Literature Review**

Self-management Interventions for Spinal Cord Injury: A Literature Review

**Abstract**

A spinal cord injury (SCI) is a significant and lifelong neurological injury with devastating physical and psychological consequences. With no established cure, effective self-management of symptoms is essential for maintaining long-term health and wellbeing. Self-management interventions have demonstrated effectiveness for physical symptoms and sequelae. However, less is known about this approach for mental health outcomes.

Methodological issues, including variation in the specific skills taught in self-management and a reliance on quasi-experimental and uncontrolled study designs, also limit conclusions regarding efficacy. Greater understanding of the psychological benefits of self-management in SCI may be achieved by consolidating the available high-quality evidence in this field.

## **Literature Review**

### **Overview**

Spinal cord injury (SCI) is a chronic condition arising from damage to the spinal cord through trauma, disease or degeneration (Ge et al., 2018; McKinley et al., 2001). SCI is characterised by varying degrees of motor, sensory and autonomic disruption and accompanied by an array of secondary health concerns, resulting in high rates of health care utilisation, decreased community participation and reduced quality of life (Boakye et al., 2012; Post & van Leeuwen, 2012; Sezer et al., 2015). Minimising the occurrence and burden of secondary complications over the lifetime is, therefore, an important goal of SCI rehabilitation, and one that may be achieved by assisting individuals to self-manage their health on a day-to-day basis (Jayasuriya et al., 2001; Marks et al., 2005). To this end, a growing body of SCI research has evaluated the application and effectiveness of interventions to promote self-management. Self-management skills may also have a positive impact on psychological functioning – an important yet often overlooked determinant of overall wellbeing. This review will examine the application and effectiveness of self-management interventions for adults with SCI. To provide context, the nature of SCI – including its aetiologies, subtypes, epidemiology, symptoms and sequelae – will first be described. Particular consideration will be given to the psychological consequences of SCI and the broader implications of disrupted functioning. The application of self-management interventions, including components specific to SCI, will then be discussed and the evidence-base critiqued.

### **Spinal Cord Injury (SCI)**

#### ***Definition, Types and Classifications***

A SCI is a neurological injury resulting from damage to the spinal cord itself or surrounding bones, soft tissues or vessels (Alizadeh et al., 2019). The causes of such damage



are diverse, but can be broadly categorised as either traumatic or non-traumatic. Traumatic aetiologies typically include sudden blows to the spinal region (e.g., as sustained in a motor vehicle or fall), whereas non-traumatic injuries generally result from slower internal damage due to disease, congenital defects or degeneration (e.g., spinal tumours, spina bifida) (Ge et al., 2018; McKinley et al., 2001). To facilitate standardised documentation, an internationally accepted system has been developed to classify and describe SCIs: the ASIA Impairment Scale (American Spinal Injury Association (ASIA), 2019). As per this system, the 31 spinal nerves are numbered and named according to their location: cervical (C1-C8), thoracic (T1–T12), lumbar (L1-L5), and sacral (S1-S5) region. Injuries sustained below the T1 spinal level are described as ‘paraplegic,’ and typically result in loss of function in the trunk, legs and feet (ASIA, 2019; Eckert & Martin, 2017). Injuries sustained above the T1 spinal level are classified as ‘tetraplegic’ (or ‘quadriplegic’) and result in loss of function in both the upper and lower portions of the body – including the arms, hands, trunk and legs (ASIA, 2019; Eckert & Martin, 2017). Injuries may be further classified as ‘complete’ or ‘incomplete.’ A complete SCI results in an absence of all motor and sensory functions below the site of injury, whereas an incomplete injury retains some degree of function below the lesion (ASIA, 2019; Eckert & Martin, 2017).

### ***Epidemiology***

Although estimates of SCI prevalence are inconsistently reported across geographic regions, SCI is considered to be a low incidence condition. Data from developed countries estimates the global incidence to range from 40 to 80 cases per million population (Ackery et al., 2004; M. Wyndaele & J-J. Wyndaele, 2006). The majority of injuries are due to preventable causes such as road traffic accidents, falls or violence (Alizadeh et al., 2019). There is a higher prevalence of traumatic SCIs among males and young people (Ackery et al., 2004; Kang et al., 2017). However, the frequency of injury has also increased significantly

among elderly people since the 1980s, linked to growth in the ageing population and a tendency for older persons to frequently acquire SCIs from falls (Jabbour et al., 2008). Importantly, advances in medical care and technology over the last several decades have seen a marked improvement in survival rates associated with SCI (Middleton et al., 2012).

### *Symptoms and Sequelae*

SCI presents with variable patterns of motor, sensory and autonomic impairment depending on the severity (i.e., lesion completeness) and location of damage to the spinal cord (e.g., above or below T1). Arising from these primary impairments are a broad range of secondary physical and psychological complications with potentially even more debilitating effects.

Sensorimotor disturbances (e.g., muscle spasms, spasticity), changes in bone density (e.g., osteoporosis), respiratory and cardiovascular complications (e.g., hypotension, autonomic dysreflexia), urinary, bowel and sexual dysfunction are all common to SCI (Hagen et al., 2012; Jiang et al., 2006; Park et al., 2017; Rekand et al., 2012). Chronic pain, or pain persisting beyond three months' duration, is also prevalent with an estimated 80% of persons with traumatic SCI reporting this concern (Dijkers et al., 2009). As a disabling condition, SCI can also impede mobility and reduce participation in physical activity (Fernhall et al., 2008). Relatedly, excessive weight gain poses significant health risks to this population, with prevalence estimates indicating that between 40-66% of people with SCI are either overweight or obese (Rajan et al., 2008). Diseases of the skin present further challenges, with pressure ulcers representing an expensive cycle of hospitalisation, surgery and outpatient management (Kruger et al., 2013). As with obesity, the development of pressure ulcers is often linked to immobility and additional SCI-related complications (e.g., poor sensation and circulation; Kruger et al., 2013). Notably, many of the secondary physical concerns experienced by people with SCI are closely interlinked.

Beyond managing physical health, people with SCI must adjust to considerable lifestyle changes and the psychosocial consequences of an acquired, lifelong disability. Challenges commonly faced include a reduced ability to engage in meaningful life roles and activities such as paid employment, changes in family dynamics as spouses become caregivers, stressors related to financial hardship, and problems with community access (Brown et al., 2002; Lidal et al., 2007; North, 1999; Whiteneck et al., 2004). It is perhaps unsurprising, then, to note that SCI can negatively impact on quality of life, including life satisfaction across psychological, social, environmental and physical domains (van Diemen et al., 2017; van Leeuwen et al., 2012). Indeed, persons with SCI have consistently reported lower quality of life in comparison to age-matched healthy peers (Barker et al., 2009; Boakye et al., 2012). Of particular concern, up to 25% of this population experience clinical depressive disorders while up to 60% report depressed or negative mood (Craig et al., 2009). These rates are alarmingly high when compared to estimates of depressive disorder within the general population (4.4%; World Health Organisation, 2017), or even depressive symptoms among other chronic disease groups such as type 1 diabetes (21%) and osteoarthritis (28.3%) (de Groot et al., 2010; Mella et al., 2010).

Poor psychological functioning has important implications for the broader wellbeing of this group, with studies consistently demonstrating links between psychological distress or mood disruption, and reduced physical and social functioning. For example, Bouchard and Hook (2014) observed that chronic psychological stress undermines functional recovery post-injury by compromising glucocorticoid receptor sensitivity and function, contributing to ongoing inflammation and neuronal cell death. Raichle et al. (2007) also noted an association between negative cognitions (e.g., catastrophising) and increased pain interference among their sample of outpatients. Reduced levels of physical and social

independence have additionally been reported by those diagnosed with SCI-related probable depression (Bombardier et al., 2004; Tate et al., 1994).

SCI has also been linked to cognitive behavioural difficulties, particularly low self-efficacy or perceived capability to successfully perform particular behaviours (Bandura, 1977; Geyh et al., 2012). Importantly, self-efficacy (SE) – a key concept within Bandura's (1977) social cognitive theory – is considered to be a robust predictor of engagement in various health behaviours (Williams & Rhodes, 2016). According to Bandura (1977), SE impacts on health behaviour in two important ways. First, SE beliefs influence decision making and goal setting: people with low expectations of success are less likely to commit to, and engage in, new or challenging activities (e.g., demanding exercise routines or self-care regimes). Second, SE influences coping efforts if or when health behaviours are initiated: individuals with low SE are said to expend less effort in their endeavours, and demonstrate poor persistence in the face of stress, challenges or adversity (e.g., environmental barriers at fitness centres; Arbour-Nicitopoulos et al., 2009) (Bandura, 1977).

Given its significant influence over health behaviours, low self-efficacy has been consistently linked to poor overall management of chronic conditions and is considered to be an important contributor to the experience of disability following SCI (Amtmann et al., 2012; Martos-Méndez, 2015). Indeed, significant inverse relationships between low SE and increased somatic complications post-injury (e.g., chronic pain) have been demonstrated, although the magnitude of these relationships has varied across the spectrum of secondary SCI symptoms and sequelae (Pearson  $r$  range: -.13 to -.59; van Diemen et al., 2017). Moreover, low self-confidence and perceived capability can harm mental health: elevated levels of depressive mood and diminished quality of life have been reported amongst persons with SCI who also report low SE (Craig et al., 2013; Middleton et al., 2007; Shnek et al., 1997; van Diemen et al., 2017).

In sum, SCI is a complex and lifelong condition associated with a myriad of interlinked health complications. In turn, these complications result in high health care utilisation, decreased community participation, and reduced quality of life. Whilst there is a clear impetus to prevent or manage serious secondary medical conditions (e.g., pressure ulcers), psychological issues, such as depressed mood and low self-efficacy, also represent important treatment targets. Equipping patients with effective skills to manage their health and wellbeing over the long-term is, therefore, essential in order to minimise the occurrence and burden of secondary issues across the lifespan.

## **Self-management**

### ***Definition***

At its broadest level, self-management can be considered an individual's day-to-day management of a chronic condition. More specifically, this encompasses an individual's ability to manage the various symptoms, consequences (e.g., physical limitations, social restrictions, emotional issues), and lifestyle changes associated with their illness or disability (Barlow et al., 2002). However, self-management remains a term that is inconsistently conceptualised in both research and practise. Indeed, various definitions and interchangeable terms have been used (e.g., self-care, self-monitoring), contributing to a lack of clarity around what self-management actually entails (Grady & Gough, 2014; Walker et al., 2003).

Similarly, there is a lack of consensus regarding what constitutes a 'self-management intervention.' Several authors have suggested that such interventions should be defined according to pre-determined numbers (e.g.,  $\geq 3$ ) or types of intervention components and targets (for example definitions, see: Jonkman et al., 2016 and Pearce et al., 2016). However, this prescriptive approach potentially overlooks the unique treatment priorities and corresponding self-management targets required for a complex and chronic condition such as SCI. Nonetheless, there is broad agreement that self-management interventions should, at a

minimum, provide some level of patient education or knowledge acquisition (e.g., about a condition and management), whilst also actively involving and supporting patients in taking personal responsibility for their care (Jonkman et al., 2016; Vernooj et al., 2016). These goals are often achieved by teaching, modelling, and encouraging patients to practise skills required to deal with the various medical (e.g., medication, diet), role-related (e.g., social changes, behaviours) and emotional (e.g., anger, fear) aspects of their chronic condition (Jonkman et al., 2016; Lorig & Holman, 2003). Examples of such skills include problem-solving, goal setting, communication, coping, lifestyle and behavioural change, self-monitoring, and decision-making (Jonkman et al., 2016; Lorig, 2003; Meade et al., 2016; Pearce et al., 2016). Depending on the needs of the patient group, self-management approaches may be facilitated by a trained health care professional or peer mentor, delivered individually or within a group setting, and involve a combination of modalities and resources (e.g., face-to-face, online communication, written materials, telephone contact) (Fryer et al., 2016). Regardless of the delivery format and structure, the common goal of a self-management program is to support people in actively managing their health to maintain, and optimise, quality of life.

### ***Applications in SCI Rehabilitation***

Whilst the notion of self-management emerged in the mid-1960s, its importance in chronic illness and disability management has become more evident in recent years amidst growing recognition that acute care models cannot adequately serve longer-term health needs (Barlow et al., 2002; Holman & Lorig, 2004). Self-management shifts the sole responsibility of care away from health professionals and systems, emphasising the role of individuals in maintaining their wellbeing (Barlow et al., 2002). Indeed, many adults with chronic conditions, such as SCI, now perform health care activities at home, with little direct input from health professionals (Auduly, 2013; Jonkman et al., 2016). It is therefore crucial for

these individuals to possess the knowledge, skills and confidence necessary to safely and successfully self-manage their health. To this end, targeted SCI interventions aiming to facilitate and support self-management are increasing in popularity (McIntyre et al., 2020).

**Intervention Components and Targets.** Recent efforts to identify the core components embedded in self-management interventions for SCI have aided in characterising this growing body of work. In their scoping review, McIntyre et al. (2020) evaluated the core features of 112 studies representing 102 unique self-management interventions for SCI. Study characteristics and intervention descriptions were coded according to established self-management intervention taxonomies (Barlow et al., 2002; Lorig & Holman, 2003; Pearce et al., 2016). Among the self-management components identified, the provision of information regarding SCI was most often utilised. Other common components included skill development for injury and symptom management, psychological training (e.g., problem-solving strategies, relaxation, self-monitoring, goal setting) and coping. Given the widespread impact of SCI symptoms on various life domains, it is argued that this multi-component approach to self-management is critical (Newman et al., 2004). Importantly, each of the aforementioned components reflect those often seen, and shown to have efficacy, for a range of other chronic conditions (for a review see Barlow et al., 2002).

However, the degree to which these individual components are implemented in SCI research has varied. For example, Froehlich-Grobe et al. (2014) provided generic information and education on the benefits of exercise to suit the general needs of their mixed cohort of adults with mobility impairments necessitating wheelchair use, including adults with SCI. In contrast, Meade et al. (2016) sought to address the diverse needs of individuals with SCI by tailoring information in their comprehensive *Health Mechanics* program. Participants attended sessions during which facilitators encouraged them to apply each set of skills to their lives, situations, or self-identified concerns (e.g., anxiety, sexual dysfunction,

weight management). Self-management interventions have also tailored self-monitoring, as a key component, in different ways. For example, interventions to improve urinary and bowel function have facilitated self-monitoring by having participants diarise output (e.g., urinary volume), establish reminders to perform routines (e.g., bowel emptying), and keep records of concerning symptoms (e.g., blood or discolouration) (Huang et al., 2019; Kryger et al., 2019). Similarly, interventions targeting skin health have reinforced the need to accurately document skin care behaviours, or maintain photo records to monitor for pressure injuries and skin breakdown (Kim & Cho, 2017; Kryger et al., 2019). Other studies seeking to promote mobility have facilitated self-monitoring with materials such as calendar schedules and heart-rate monitors (Froehlich-Grobe et al., 2014; Latimer et al., 2006).

Notably, the majority of SCI self-management interventions that have been evaluated have targeted key physical concerns that present tangible and imminent threats to health. This includes Rintala et al.'s (2008) preventative pressure ulcer program for veterans and Huang et al.'s (2019) group-based 'Quality Control Circle' intervention to address neurogenic bladder disorders. Encouragingly, both of these randomised controlled trials reported promising results, including reduced rates of pressure ulcer recurrence (Rintala et al., 2008), improved awareness of bladder symptoms, and greater recovery of bladder function (Huang et al., 2019). Additional physical health benefits associated with SCI self-management interventions have included improved pain coping and reduced pain interference, weight loss, and increased leisure-time physical activity (e.g., Burns et al., 2013; Chen et al., 2006; Tomasone et al., 2018). Importantly, early efforts to consolidate the self-management and SCI literature on physical health outcomes have yielded encouraging results. Systematic reviews of behaviour change techniques have found that SCI interventions using core self-management components, such as education and training/rehearsal of psychological strategies, have resulted in significant and positive



changes to physical activity levels alongside small-to-medium improvements in skin care knowledge and behaviours (Hedges'  $g$  range: 0.13 to 0.71) (Baron et al., 2018; Tomasone et al., 2018).

The degree to which self-management interventions successfully promote skills to enhance psychological functioning following a SCI is less clear, with mixed findings in this space. For example, Kooijmans et al. (2017) evaluated their *HABITS* program to facilitate physical activity among inactive adults with chronic SCI (> 10 years post-injury). *HABITS* incorporated various self-management elements ranging from peer support and professional guidance to problem solving, information and self-help resources. However, when compared to an information-only group, *HABITS* participants reported similar levels of physical activity, as well as comparable ratings on secondary measures of self-efficacy and proactive coping. In contrast, Burns et al.'s (2013) interdisciplinary self-management program, which used a combination of strategies (e.g., education, relaxation, exercise) to target SCI-related chronic pain, significantly ( $p = .005$ ) improved participants' sense of control over their lives.

Other studies have taken a 'holistic' approach by giving equal weight to physical and psychosocial goals with the aim of mitigating secondary complications generally. This includes Houlihan et al.'s (2013) randomised pilot trial of a self-management intervention, *CareCall*, for participants with SCI and Multiple Sclerosis. Automated phone calls were provided to the intervention group on a tapered schedule, with educational content on depression, skin care, wellness and health care utilisation delivered by peers and clinicians. Relative to peers receiving standard medical care, *CareCall* had a positive effect on depression symptom severity. Similarly, Phillips et al. (2001) examined the effectiveness of tele-educational sessions, involving a structured review of health concerns and routines, psychosocial issues and equipment needs delivered over nine weeks. Post-intervention, participants reported significantly higher quality of life scores compared to controls who

received standard care. Between-group differences in depression ratings were, however, not significant: both groups reported reduced symptoms. Although further efforts are needed to clarify the consistency and strength of these noted treatment effects, the aforementioned findings indicate that holistic self-management programs have promising effects on psychological functioning,

**Methodological Limitations.** The noted mixed findings may, in part, be explained by sample and methodological confounds. This includes the use of heterogeneous disability groups. For example, Hughes et al. (2006) examined the efficacy of a stress self-management program for women with a range of physical disabilities including arthritis, post-polio, traumatic brain injury and SCI. Their six, 2.5-hour weekly group sessions included information on stress and stress reduction techniques. Relative to waitlist controls, large and significant improvements in perceived stress (Cohen's  $d = -1.23$ ,  $p = .02$ ) and general mental health (i.e., anxiety, depression, psychological wellbeing) were reported by participants who completed the self-management program ( $d = -1.09$ ,  $p = .01$ ). However, whether those with SCI responded differently to the intervention is unknown, as these data were not reported separately. It is quite possible that the generic skills-building program examined by Hughes et al. (2006) was not equally effective across disability groups, particularly given the functional limitations and heightened risk for secondary psychological concerns among those with SCI (McIntyre et al., 2020; Mercier et al., 2015).

The single-group design, which typically aims to evaluate the feasibility of a novel intervention, has also characterised much of the self-management and SCI literature. Whilst a valuable precursor to larger, randomised controlled trials, these studies often include small sample sizes and may therefore be underpowered to detect significant pre-post differences (Button et al., 2013). This was demonstrated in Allin et al.'s (2018) web-based *SCI & U* program, which produced small to moderate but non-significant improvements in both

depressive symptoms and self-efficacy among a small convenience sample of 10 participants. Even with larger samples, the validity of noted treatment effects in single-group studies may be compromised due to the lack of a comparison condition (Knapp, 2016). Moreover, where pilot studies focus on developing or evaluating interventions in their early stages, analyses are often limited to issues around the feasibility and subjective evaluation of programs, rather than quantitative outcomes (e.g., Meade et al., 2016).

Non-randomised study designs, such as Block et al.'s (2010) evaluation of *Project Shake-It-Up*, can also introduce validity concerns by limiting the generalisability of findings. In this particular study, participants with neurological impairment self-selected to a waitlist condition or to *Shake-It-Up* – which aimed to build independent-living skills and self-confidence to set and achieve goals (Block et al., 2010). Group assignment depended on participants' requests (i.e., competing time commitments and scheduling reasons). Relative to controls, intervention participants reported significantly higher SE scores ( $d = 0.93, p = .007$ ). However, there were notable age differences between the two groups: those in the intervention group were typically younger (37.5 years,  $SD = 10.8$  vs. 52.1 years,  $SD = 13.1$ ). There is evidence that age is inversely associated with SE among chronic illness groups (e.g., heart disease; Lapiere et al., 2009), although this finding has not yet been confirmed in SCI research (Nooijen et al., 2015).

Even where randomised controlled designs are implemented, the nature of self-management interventions means that participants cannot be truly blinded to group assignment – as might otherwise occur in pharmacological studies with placebos (Munder & Barth, 2018). During a facilitated physical or psychological intervention, participants inevitably become aware that they are receiving some form of treatment and may subsequently form expectations regarding its effects, or make comparisons to other established approaches (e.g., standard medical care) (Munder & Barth, 2018). This

introduces a risk of detection bias, whereby participants' opinions about the merit or credibility of their assigned intervention could lead them to either exaggerate or downplay any perceived treatment benefits. Detection bias can, however, be mitigated by the use of comparable control conditions (e.g., attention control activities; Aycock et al., 2018).

Moreover, the randomised controlled trial is still considered the 'gold standard' for treatment evaluation in SCI rehabilitation research (Harvey, 2015).

Taken together, the mixed outcomes and methodological concerns evident across self-management interventions for psychological functioning speak to a need for a review and consolidation of the literature in this area. To date, this has not occurred. Recently, a scoping review of the SCI literature identified only seven self-management studies that focussed on depression outcomes specifically (Cadel et al., 2018). Notably, treatment estimates (i.e., standardised mean group differences) were not calculated to quantitatively compare and contrast intervention effects across these studies. Importantly, randomised controlled trials have been published in the last few years which can add to this evidence base.

## **Summary**

There is promising, albeit mixed, evidence to support the efficacy of self-management interventions to promote psychological functioning following SCI. Whilst steps have been taken to consolidate the evidence for self-management of physical symptoms and sequelae, less attention has been paid to synthesising key psychological outcomes. This is of concern given the prevalence of depression and low mood, in addition to the effects of low self-efficacy on treatment engagement and compliance, as well as the combination of both factors on quality of life in this group more broadly. Synthesising and critically reviewing the available high-quality evidence in this field is an important first step towards improving current understandings of the key components, benefits and limitations of self-management

interventions in SCI rehabilitation. This information could help to inform the development of targeted self-management approaches to supplement current mental health interventions and, in turn, reduce the symptom burden associated with SCI as a lifelong condition.

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**Self-management Interventions for Psychological Outcomes Following Spinal Cord  
Injury: A Systematic Review**

  
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**Author Note**

This article is intended for submission to *Rehabilitation Psychology*, which adheres to the APA reference style (7<sup>th</sup> edition). The article meets the Master of Clinical Psychology thesis requirement of 5000-8000 words, as well as the journal guidelines of 12 words for the Title, 250 words for the Abstract, and 200 words for the Impact statement.

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### Abstract

**Objective:** To evaluate the effects of self-management interventions on mood, self-efficacy and quality of life in adults with a spinal cord injury (SCI). **Method:** A comprehensive search of the CINAHL, Embase, PsycINFO and PubMed databases was conducted to identify randomised controlled trials (RCTs) of self-management interventions targeted to the adult SCI population. Methodological bias was assessed using the Cochrane Risk of Bias (RoB) 2.0 tool. Where data were available, Hedges'  $g$  effect sizes, with associated confidence intervals and  $p$  values, were calculated and pooled to determine both immediate and longer-term intervention effects. Heterogeneity was additionally calculated ( $I^2$ , tau). A random effects model was adopted for these analyses. **Results:** Twelve independent RCTs, comprising a pooled sample of 958 adults with SCI, were identified. Each study raised concerns across one or more RoB domains. Immediate and positive effects were noted for mood ( $g = .37$ , CI = .10 – .64,  $p = .01$ ) and self-efficacy ( $g = .88$ , CI = -.02 – 1.79,  $p = .06$ ) but not quality of life ( $g = .12$ , CI = -.31 – .54,  $p = .58$ ), although these data were based on a limited number of studies ( $N_{\text{studies}} = 6$ ). In the longer-term, large and significant improvements in quality of life were found ( $g = .89$ , CI = .51 – 1.27,  $p < .01$ ). **Conclusions:** Self-management interventions may offer an effective means of improving psychological functioning and wellbeing in SCI. Further large-scale controlled trials incorporating routine measurement and reporting of psychological outcomes are needed to confirm, and build upon, these findings.

**Keywords:** self-management, spinal cord injury, mood, self-efficacy, quality of life

### **Impact**

- This systematic review examines the effectiveness of self-management interventions for improving mood, self-efficacy and quality of life among adults living with a spinal cord injury (SCI).
- Preliminary evidence suggests that self-management interventions have the capacity to enhance psychological functioning post-SCI. However, additional randomised controlled trials with routine and repeated psychological assessments are needed to build on these findings.
- In the absence of a single ‘gold standard’ approach to delivery, a combination of flexible, multi-modal self-management interventions made available throughout the continuum of SCI care may help to optimise and maintain psychological treatment effects.

## **Self-management Interventions for Psychological Outcomes Following Spinal Cord Injury: A Systematic Review**

A spinal cord injury (SCI) is a significant and devastating neurological injury resulting from damage to the spinal cord through trauma, disease or degeneration (Ge et al., 2018; McKinley et al., 2001). Whilst the extent and impact of injury depends on the severity and location of damage to the cord, primary symptoms typically include partial or complete loss of motor, sensory and autonomic functions (Hou & Rabchevsky, 2014). More debilitating, however, are the myriad of secondary complications that often arise, including spasticity, chronic pain, pressure ulcers, urinary and bowel complications, respiratory and cardiovascular complications, osteoporosis, and obesity (Gorgey & Gater, 2007; Sezer et al., 2015). SCI can also carry a heavy emotional burden, with up to 25% of this population experiencing depressive disorders and 60% reporting low or depressed mood (Craig et al., 2009). Additional psychological concerns such as loneliness, stress, and low self-efficacy have also been noted (Geyh et al., 2012; Krause, 2007; Robinson-Whelen et al., 2016). In combination, these chronic complications increase health care utilisation, impede community participation and diminish quality of life (Boakye et al., 2012; Craig et al., 2009; Post & van Leeuwen, 2012; Sezer et al., 2015). As such, minimising the physical and psychological burden of SCI represents an important rehabilitation goal – one that can be achieved by supporting patients to self-manage their day-to-day health (Jayasuriya et al., 2001; Marks et al., 2005).

Self-management, or the ability to manage the symptoms, consequences and lifestyle changes associated with a chronic condition, is considered essential for long-term care (Barlow et al., 2002; Holman & Lorig, 2004). Given that most individuals with chronic conditions, including SCI, perform self-care at home with little direct input from health professionals, it is critical that they are supported to develop the knowledge, skills and

confidence to do so effectively (Auduly, 2013; Walker et al., 2003). Accordingly, targeted interventions aiming to facilitate chronic condition self-management have been increasingly incorporated into healthcare services (Walker et al., 2003).

Although there is currently no gold standard definition for what constitutes a 'self-management intervention,' it is recognised that a combination of medical, role and emotional management should be targeted (Lorig & Holman, 2003). To this end, self-management interventions have typically included components addressing knowledge (e.g., about the condition and management), problem solving, goal setting, coping, communication skills, lifestyle and behavioural change, self-monitoring, or decision-making (Jonkman et al., 2016; Lorig, 2003; Meade et al., 2016). Whilst the number and combination of components often varies between different self-management interventions and their target conditions, the common goal is to support people in adopting strategies to actively manage their health and optimise quality of life.

Self-management interventions have been successfully implemented with an array of chronic condition cohorts (e.g., asthma, diabetes, arthritis), with favourable outcomes reported (Barlow et al., 2002; Taylor et al., 2014; Walker et al., 2003). A growing number have also targeted SCI populations, yielding promising health outcomes including improved pain coping, reduced pressure ulcer recurrence and weight loss (e.g., Burns et al., 2013; Chen et al., 2006; Rintala et al., 2008).

Importantly, by promoting cognitive and behavioural skills, self-management interventions may also help to mitigate some of the mental health difficulties and challenges associated with SCI (Krueger et al., 2013). For example, in their non-randomised trial, Budh et al. (2006), demonstrated that a comprehensive self-management program using mindfulness and cognitive reappraisal reduced depressive symptoms among 40% of adult participants with SCI ( $n = 27$ ), compared to peers who received standard medical care ( $n =$

11). Similarly, Hughes et al.'s (2006) stress self-management program for women with SCI and other physical disabilities produced large and significant reductions in perceived stress (Cohen's  $d = -1.23$ ,  $p = .02$ ), alongside improvements in general mental health ( $d = -1.09$ ,  $p = .01$ ) relative to waitlist controls. Benefits to self-efficacy, or perceived capability to successfully perform particular behaviours – considered a key predictor of engagement in positive health practises in SCI – have also been noted (Bandura, 1977; Williams & Rhodes, 2016). For instance, self-management programs delivered via peer mentoring have yielded improvements in self-efficacy beliefs and reduced the occurrence of medical complications and rehospitalisation post-SCI (Jones et al., 2019; Ljungberg et al., 2010). Sheehy et al.'s (2013) single-subject study design, involving a nurse-coached exercise program for adults with tetraplegia, also revealed upward trajectories in participants' self-efficacy with concurrent gains in muscle strength and overall quality of life. Taken together, the aforementioned findings demonstrate the potential for self-management interventions to improve psychological wellbeing and functioning in people with SCI. It follows that these interventions may also serve to improve broader health outcomes such as quality of life (Middleton et al., 2007; Krueger et al., 2013; van Diemen et al., 2017; van Leeuwen, 2012). These findings are, however, tempered by the use of quasi-experimental designs and heterogeneous disability groups, which limit the generalisability of noted treatment effects to the broader SCI population.

To date, no systematic review has consolidated the available higher-quality evidence from the 'gold standard' randomised controlled trial, to determine the effectiveness of self-management approaches on key psychological outcomes post-SCI – namely mood (e.g., depressive symptoms), self-efficacy and quality of life. Rather, previous systematic reviews have focused exclusively on physical health issues, particularly skin management and physical activity (e.g., Baron et al., 2016; Tomasone et al., 2018). A recent scoping review



identified a small sample of SCI self-management studies ( $N = 7$ ) that focussed on depression outcomes specifically (Cadel et al., 2018). However, effect size estimates were not calculated in order to quantitatively compare and contrast intervention effects across studies. Validity concerns were also introduced by the inclusion of non-randomised study designs (Cadel et al., 2018). In a recent scoping review by McIntyre et al. (2020), key psychological components of self-management interventions for SCI were identified, although the primary focus of this review was on intervention characteristics and not outcomes per se. The present systematic review with meta-analysis therefore aims to consolidate the evidence-base to answer the following research question: *in adults with SCI, are self-management interventions effective in promoting mood, self-efficacy and quality of life compared to alternative interventions, standard care and information, or waitlist comparisons?*

## Method

### Literature Search

Four electronic databases (CINAHL, Embase, PsycINFO, PubMed,) were searched using a list of key terms relating to '*self-management*' and '*spinal cord injury*' (see Appendix A for complete logic grids). Search terms were tailored to each database in consultation with an expert Research Librarian. The search period dated from database inception to the 5<sup>th</sup> of September 2019, with automatic email alerts established for each database until the 20<sup>th</sup> of July 2020 to retrieve new and potentially eligible records. Scopus citation searching was additionally used to identify related publications which had cited the included studies. Finally, the reference lists of included studies and systematic reviews examining the effectiveness of self-management interventions for physical health outcomes in SCI (i.e., skin care, physical activity) or broader disability groups (Baron et al., 2018; Baron et al., 2018; Burke et al., 2018; Matcham et al., 2014; Tomasone et al., 2018) were manually screened. Four unique records were identified through this process.

## **Eligibility Criteria**

Studies were required to fulfil the following PICO (Population, Intervention, Comparator, Outcomes) criteria (da Costa Santos et al., 2007).

### ***Population***

Eligible studies focussed on an adult sample (i.e., aged  $\geq 18$  years), diagnosed with traumatic or non-traumatic SCI, acquired at any age. Studies that included a broad group of chronic illnesses or disabilities (including SCI), but did not provide outcome data for participants with SCI separately, were excluded.

### ***Intervention***

The primary intervention focused on facilitating, supporting or enhancing participants' self-management skills and abilities. Eligible studies needed to make explicit reference to self-management, self-care, or self-monitoring in their study aims or intervention description (Walker et al., 2003) – rather than follow a specific definition (of which there are many) or subjectively determined number or combination of components (see Jonkman et al., 2016 and Pearce et al., 2016 for an overview). Studies were, however, required to include some form of education (e.g., about SCI and its impact, self-care skills, support resources etc.), as this is considered to be a core aspect of self-management (Jonkman et al., 2016; Vernooj et al., 2016). Beyond this, the delivery format and content (e.g., learning material, interactive activities, homework, feedback) was not specified in acknowledgement of the multimodal nature of self-management interventions (Pearce et al., 2016).

### ***Comparison Condition***

Eligible studies were restricted to randomised controlled trials (RCTs), wherein a self-management intervention was compared to either an active treatment (e.g., psychosocial treatment and education), usual care or waitlist control condition. RCTs are the optimal

study design for evaluating the efficacy of clinical interventions, as they minimise bias and validity concerns that may otherwise arise in uncontrolled designs (McKenzie et al., 2019).

### ***Outcomes***

Studies needed to administer self-reported or clinician-administered measures of mood (i.e., negative affect, depressive symptoms, distress), self-efficacy, or quality of life at baseline and post-intervention. Psychological measures with available psychometric data, or adaptations of established measures, were preferable. Measures that had been purposely designed for a study were also considered, provided that the authors gave sufficient information about the content of the scale items and their relevance to the study aims and/or SCI cohort.

### **Screening Process**

Database search results were imported into Covidence; a screening and data extraction tool for intervention reviews (Veritas Health Innovation, n.d.). Study screening was undertaken by the author in regular consultation with a senior researcher. To evaluate the reliability of the article selection process, an independent screener (postgraduate psychology student) reviewed a randomly selected sample of 104 articles, and inter-rater reliability was confirmed (97% agreement, Cohen's kappa = .71).

### **Data Extraction and Organisation**

Key information from each study was collated in a purposely designed Microsoft Excel spreadsheet, as per the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). These data included sample characteristics (e.g., recruitment source, mean age, SCI lesion type), and study and intervention characteristics (e.g., outcome measures, comparison condition, intervention format/duration/attrition). Where available, group means and standard deviations at each time point were also extracted to allow for the calculation of Hedges'  $g$ . Four authors of

studies with missing or unusable data were contacted (Guihan et al., 2014; Houlihan et al., 2017; Meade et al., 2016; Schulz et al., 2009), with one subsequently providing this information (Meade et al., 2016).

### **Risk of Bias Assessment**

The revised Cochrane Risk of Bias tool (RoB 2.0) was used to evaluate individual RCTs in this review (Farrah et al., 2019; Munder & Barth, 2018). The RoB 2.0 provides a series of ‘signalling questions’ to aid in identifying methodological bias arising from:

(1a) the randomisation process (failure to implement random sequence generation or allocation concealment; ‘*selection bias*’);

(1b) the recruitment process (selective recruitment of participants based on pre-existing knowledge of a cluster’s assignment to a condition; ‘*recruitment bias*’). This domain is specific to cluster-randomised studies.

(2) deviations in the delivery of intended interventions (systematic differences in the care provided to intervention and comparator groups that do not reflect usual practise; ‘*performance bias*’);

(3) missing outcome data (high dropout rates or inappropriate exclusions from analyses; ‘*attrition bias*’);

(4) measurement of the outcome of interest (assessments influenced by knowledge of intervention received; ‘*detection bias*’); and

(5) selective reporting of results (reporting outcomes based on their direction, magnitude or statistical significance; ‘*reporting bias*’).

Individual studies were assigned a rating of ‘low risk,’ ‘some concerns,’ or ‘high risk’ on each of these RoB 2.0 domains. The percentage of studies assigned each of these ratings was also calculated. Of note, RoB ratings were not used to exclude any studies, but rather to

inform judgements about the quality of evidence included in this review. The author undertook the RoB assessments in consultation with a senior researcher.

### **Statistical Analysis**

Seven studies provided sufficient data for the calculation of standardised mean group differences (Hedges'  $g$ ), allowing for direct comparisons across different self-management intervention approaches and modalities. Effect size data were entered into, and analysed using Comprehensive Meta-Analysis Software (Version 3; Borenstein et al., 2013). Both immediate (i.e., from baseline to post-intervention) and longer-term (i.e., from post-intervention to follow-up) intervention effects were calculated for each individual repeated measure, per study. Hedges'  $g$  values represent the difference between mean change scores in each condition (self-management vs. control), divided by a pooled standard deviation (SD) (Morris, 2008; Morris & DeShon, 2002). The pooled SD used in the calculation of  $g$  is weighted by each group's sample size, thereby correcting for a positive bias associated with small samples (Ellis, 2010; Turner & Bernard, 2006). The calculation of  $g$  also requires correlations between pre- and post-intervention scores to impute the within-groups standard deviation (Borenstein et al., 2009). As the majority of studies did not provide this information, a conservative estimate of  $r = 0.75$  was used. This value was derived from an average of test-retest correlations for the validated measures included in this review, obtained from psychometric studies where available (See Appendix B; Lipsey & Wilson, 2001).

Individual  $g$  values were subsequently grouped and pooled according to the psychological constructs they represented: mood, self-efficacy or quality of life. This involved first weighting each  $g$  value by its respective study's inverse variance. By doing so, studies with larger samples were given more weight in recognition of the influence of sample size on effect estimates (Dechartres et al., 2013). Where a study contributed more than one  $g$  for a single construct, data independence was ensured by averaging that study's  $g$  values prior

to pooling across studies. A random-effects model was used when pooling effect estimates. This model was deemed appropriate given the clinical heterogeneity seen in the SCI patient population, in addition to the variation in interventions and outcome measures used in the present review. The size of each effect was interpreted according to Cohen's (1998) criteria, with values of 0.2, 0.5 and  $\geq 0.8$  indicating small, medium and large-to-very large effects respectively. To ensure correct interpretation, the direction of each effect was standardised so that a positive value indicated greater improvement among participants who accessed self-management, whilst a negative value represented greater improvement among the control or comparison condition.

To identify the precision and significance of each  $g$ , 95% confidence intervals and  $p$  values were computed. In addition, Orwin's (1983) fail-safe  $N$  ( $N_{fs}$ ) was calculated for each meta-analysis to account for the influence of publication bias – wherein treatment effects may be overestimated due to preferential publishing of studies reporting significant results. The  $N_{fs}$  denotes the number of unpublished or undetected studies reporting no effects that would need to exist to reduce  $g$  to a trivial value (i.e.,  $g < 0.2$ , Orwin, 1983); larger  $N_{fs}$  values represent more reliable estimates of  $g$ . A  $N_{fs}$  was considered acceptable if its value was greater than the number of studies contributing to a pooled  $g$  (i.e.,  $N_{fs} > N_{studies}$ ).

Finally, tau ( $\tau$ ; equivalent to the standard deviation of  $g$ ) and  $I^2$  statistics were calculated to determine study heterogeneity. The  $I^2$  value represents the proportion of variance in effect sizes due to heterogeneity between studies, rather than chance (Higgins & Thompson, 2002). A significant advantage of  $I^2$  is that it is not contingent on the number of studies in a meta-analysis, and is therefore well suited to reviews with small  $N$ s relative to other heterogeneity indices (e.g., Cochran's  $Q$ ) (Higgins et al., 2003; Rucker et al., 2008).

## Results

### Study Selection

The initial literature search yielded 2315 records, of which 841 duplicates were removed. The titles and abstracts of the remaining 1474 records were subsequently screened, with 1107 off-topic studies and additional duplicates removed. Full texts of the remaining 367 records were re-screened against the eligibility criteria, from which eight articles were deemed eligible. Four additional studies were sourced from manual inspection of reference lists and topic-relevant systematic reviews (Baron et al., 2018; Baron et al., 2018; Burke et al., 2018; Matcham et al., 2014; Tomasone et al., 2018). The final sample consisted of 12 independent RCTs (see Figure 1).

### Study Characteristics

As seen in Table 1, the majority of included studies originated in the United States ( $N_{\text{studies}} = 7$ ). Participants were recruited from both community ( $N_{\text{studies}} = 6$ ) and inpatient ( $N_{\text{studies}} = 5$ ) settings, with Mercier et al. (2015) using a combination of both sources. Four studies identified as multisite trials (Guihan et al., 2014; Kim & Cho, 2017; Kooijmans et al., 2017; Schulz et al., 2009). Eleven of the included RCTs were primary studies, whilst Mercier et al. (2015) presented secondary analyses of data from a subgroup of participants with SCI within a larger-scale RCT, which targeted adults with chronic spinal cord dysfunction due to SCI or Multiple Sclerosis.

All studies relied on self-reported measurements, either completed by participants on their own or administered in an interview. Self-efficacy was a common outcome ( $N_{\text{studies}} = 11$ ), followed by mood or affect ( $N_{\text{studies}} = 6$ ), and quality of life ( $N_{\text{studies}} = 4$ ). Sixteen of the 21 measures had been validated, with psychometric data available. Arbour-Nicitopoulos et al. (2009) and Latimer et al. (2006) utilised self-efficacy measures that were derived from literature reviews, prior studies (e.g., Armitage & Conner, 1999), and SCI focus groups.

### **Risk of Bias Assessment**

Eleven of the 12 studies were evaluated using the RoB 2.0 tool for individually randomised trials (see Appendix C). The remaining study (Kim & Cho, 2017) was assessed according to an adapted template for cluster randomised trials (see Appendix D). Summaries of individual bias ratings within and across studies are provided in Figures 2 and 3 respectively.

Whilst most (92%) studies minimised selection bias (Criterion 1a) by using random allocation sequences (e.g., computer-generated algorithms), details pertaining to allocation concealment were rarely provided. Arbour-Nicitopoulos et al. (2009) had a single researcher assign participants and administer the intervention, resulting in a high risk of selection bias. Some concerns arose from the single cluster study (Kim & Cho, 2017) with regards to recruitment bias (Criterion 1b), as participants were recruited after the randomisation of hospitals to experimental conditions. Noted concerns regarding performance bias (Criterion 2) were expected, given that blinding of participants and personnel to intervention allocation is not feasible in psychotherapy research (Munder & Barth, 2018). Higher levels of this methodological bias were, however, mitigated by the use of active and standard/usual care comparisons in lieu of waitlist controls. A single study (Latimer et al., 2006) was identified to be at high risk of performance bias, as inappropriate analyses were used to estimate the effect of assignment to intervention (data from participants who failed to maintain fidelity to the intervention were excluded). Attrition bias (Criterion 3) was generally low, with the majority (67%) of studies reporting outcomes from their entire sample, or accounting for missing data with appropriate statistical analyses (e.g., intention-to-treat analyses). The exception was Meade et al. (2016) – here, the authors identified a significant difference in attrition between conditions (self-management > control), linked to depressive symptom severity. There were some concerns about detection bias (Criterion 4), due to the reliance on



self-assessed outcomes in all studies. Concerns regarding reporting bias (Criterion 5) were also raised for most studies, as pre-specified statistical plans were typically not reported. In addition, two studies (Guihan et al., 2014; Schulz et al., 2009) failed to report data for outcomes at pre-specified time points. To summarise, each study raised some concerns on multiple RoB domains, with five identified as being at high risk of bias on at least one domain.

### **Sample Characteristics**

The pooled sample consisted of 958 adults with SCI (472 intervention, 486 control; see Table 2). The sample were primarily middle-aged (range: 33 – 59.4) and living with a longstanding injury (time since SCI onset: 4 – 28 years). The vast majority were also male, consistent with the global epidemiological profile of SCI (Singh et al., 2014). Further socio-contextual and injury-specific variables were inconsistently reported, although both traumatic (e.g., car accident) and non-traumatic (e.g., disease) aetiologies were represented, in addition to paraplegic and quadriplegic injuries involving complete or incomplete lesions.

### **Characteristics of Self-management Interventions**

Most (75%;  $N_{\text{studies}} = 9$ ) of the self-management interventions were specifically developed for people with SCI, with various steps taken to ensure relevance to this cohort. For example, Kim and Cho (2017) developed program content from a review of the literature and existing self-management programs, a focus group needs-assessment, and consultation with healthcare professionals. Similarly, Meade et al. (2016) and Houlihan et al. (2017) followed community participatory approaches, having sought input from individuals with SCI and/or healthcare professionals. Three interventions were developed for a broad range of neurological groups (e.g., Spina Bifida, Multiple Sclerosis; Kryger et al., 2019; Mercier et al., 2015) or caregiver/care-recipient dyads (Schulz et al., 2009). However, their intervention content still addressed key SCI concerns and challenges (e.g., skincare, neurogenic bowel and

bladder, depression). Written and audio-visual materials (e.g., pamphlets, resource guides, demonstrative videos) that had been pilot-tested by consumers with SCI were also used (Arbour-Nicitopoulos et al., 2009; Houlihan et al., 2017; Kim & Cho, 2017).

Theoretical frameworks underpinning the examined self-management interventions included Bandura's (2004) Social Cognitive Theory ( $N_{\text{studies}} = 5$ ) and Ajzen's (1985) Theory of Planned Behaviour ( $N_{\text{studies}} = 2$ ), both of which highlight perceived behavioural control (self-efficacy) as a determinant of valued health behaviours. Prochaska and DiClemente's (1983) Transtheoretical Model was additionally used as a guide to positive health behaviour change ( $N_{\text{studies}} = 3$ ). Three studies made specific reference to Motivational Interviewing principles (e.g., change talk) or techniques (e.g., open questions, reflections).

Intervention components included education or information-provision, as per the inclusion criteria for this review (see Table 1). The degree to which education was incorporated within each intervention did, however, vary. For example, Meade et al. (2016) provided only a brief overview of the issues faced by individuals with SCI (e.g., skincare, bowel management, nutrition) and recommended behaviours for managing each (e.g., skin inspection, positioning, limiting calorie intake). Similarly, Arbour-Nicitopoulos et al. (2003) disseminated exercise advice and a physical activity pamphlet in a single session. In contrast, Goyaghaj et al. (2019) and Schulz et al. (2009) incorporated information about SCI, its secondary complications (e.g., pain, respiratory problems, depression), and/or recommended self-management behaviours (e.g., transfer skills, scheduling appointment reminders, connecting with family/friends) in each of their facilitated sessions.

Beyond education, skill acquisition and practise emerged as core intervention components. Each study offered opportunities for participants to develop or utilise skills in self-care and health promotion ( $N_{\text{studies}} = 7$ ), self-monitoring ( $N_{\text{studies}} = 8$ ), problem solving and decision making ( $N_{\text{studies}} = 4$ ); stress, mood or attitude management ( $N_{\text{studies}} = 4$ ),

communication and relationship-building with healthcare providers ( $N_{\text{studies}} = 4$ ), and/or goal setting, planning or organisation ( $N_{\text{studies}} = 5$ ). To promote engagement, intervention content and procedures were often customised to suit the needs of individual participants.

Specifically, personal circumstances or goals were considered ( $N_{\text{studies}} = 3$ ) and individual sessions shortened or reduced in duration to suit existing capabilities or readiness to change ( $N_{\text{studies}} = 3$ ). In one study, participants were even allowed to selectively engage with certain intervention components, depending on their personal care needs (Kryger et al., 2019).

Self-management interventions varied in duration but were typically brief (range: two weeks to nine months). Individual session duration ranged from brief 10-minute phone calls (Kim & Cho, 2017) to 2.25-hour group sessions (Kim & Cho, 2017), although this detail was not consistently reported. There was a preference for individual therapy ( $N_{\text{studies}} = 8$ ), with four studies supplementing group work with individual sessions. A combination of mediums were used to assess and monitor health status, symptoms and behaviours: face-to-face contact ( $N_{\text{studies}} = 5$ ), telecommunication technology (telephone, video conferencing, online discussion forums, automated emails, smartphone applications;  $N_{\text{studies}} = 9$ ) and/or activity trackers (e.g., accelerometers, logbooks;  $N_{\text{studies}} = 4$ ).

Facilitated input by health professionals and counsellors, peer coaches or lay leaders ensured that the interventions were relatively structured and supervised. A single study used a Telephone-Linked Computer System but incorporated professional input via a nurse coordinator, who monitored participants and provided follow-up phone calls as needed (Mercier et al., 2015). The degree to which participants completed tasks or practised skills independently outside of sessions varied. For instance, Arbour-Nicitopoulos et al. (2009) and Latimer et al. (2006) established contact with participants at the commencement of, and mid-way through their interventions to conduct assessments, provide instructions, or assist with/review goals. Participants were otherwise responsible for completing and monitoring

their own physical activity. Similarly, Kryger et al. (2019) had contact with participants at the beginning of their intervention, providing 30 minutes of training to use the *iMHere* app. Participants were subsequently free to use the app as required, with a physical therapist monitoring their data and communicating with them via app-based messaging as needed. Other interventions, such as Meade et al.'s (2016) *Health Mechanics* and Kooijmans et al.'s (2017) *HABITS*, involved more directive instruction, guidance and feedback from facilitators throughout a series of scheduled training sessions. In combination these strategies helped to engage participants; the average attrition rate was a low 13.98% (range: 0% – 42%). The higher attrition rates noted by Latimer et al. (2006) and Guihan et al. (2014) were attributed to issues maintaining fidelity to the intervention (e.g., injury-related health issues or travel restrictions; Latimer et al. 2006), reluctance to complete relatively invasive outcome assessments (e.g., submitting photographs of pressure ulcers; Guihan et al., 2014), and failure to complete follow-up phone interviews at multiple, designated time points (Guihan et al., 2014).

### **Control Conditions**

Studies used various comparison conditions, including action planning, educational resources (e.g., a pressure ulcer prevention booklet), and group meetings to discuss key health targets or behaviours (e.g., importance of an active lifestyle) ( $N_{\text{studies}} = 7$ ). Standard health care approaches, or usual medical assessment and monitoring regimes, were also utilised for comparison ( $N_{\text{studies}} = 5$ ).

### **Effectiveness of Self-management**

Six studies provided sufficient data to calculate treatment effects from pre- to immediately post-intervention. Two of these studies additionally incorporated longer-term assessments (one to six months follow-up; Goyaghaj et al., 2019; Kooijmans et al., 2017). A further study focussed solely on the longer-term effects of self-management interventions

delivered via teleconferencing, with an initial ('baseline') assessment taken immediately post-intervention and approximately 10 months thereafter (Phillips et al., 2001). Effect size data are summarised in Tables 3 and 4, grouped according to their psychological domain and rank ordered by size.

### ***Mood***

Four studies examined the impact of self-management interventions on feelings commonly experienced after a SCI, including depression and distress (Table 3). The pooled effect was small-to-medium and significant: participants typically reported improved mood immediately after completing a self-management intervention. This finding can, however, only be considered tentative ( $N_{\text{studies}} = N_{\text{fs}}$ ). On examining individual effects, some dispersion (i.e., wide confidence intervals) was evident, likely reflecting within-study variability in individual symptom reporting. Large to very large reductions in symptoms of psychological distress were apparent, in addition to improved wellbeing amongst intervention participants (Kooijmans et al., 2017; Meade et al., 2016). However, those who accessed usual care also reported greater symptom improvement (as measured by the Patient Health Questionnaire; PHQ-9; Meade et al., 2016). Two studies reported small and non-significant group differences, albeit in favour of self-management (Kryger et al., 2019; Mercier et al., 2015).

Only two studies measured longer-term effects up to 10 months post-intervention (Table 4). Both identified greater improvements among their standard medical care and information-only control groups, relative to those who accessed self-management delivered via video or phone conferencing (Phillips et al., 2001), or face-to-face (Kooijmans et al., 2017). The resulting pooled effect was medium in magnitude, negative and significant. This overall estimate was also susceptible to publication bias ( $N_{\text{fs}} < N_{\text{studies}}$ ).

### *Self-efficacy*

Four studies examined the immediate effects of self-management interventions on self-efficacy beliefs, contributing to a pooled effect that was large, robust, and neared significance (Table 3). This included very large and positive effects favouring self-management (Goyaghaj et al., 2019; Kim & Cho, 2017), but also non-significant and even negligible effects for exercise self-efficacy, self-reported coping competency, and disability management in general (Kooijmans et al., 2017, Meade et al., 2016). Significant between-study variability was evident, as demonstrated by the wide-ranging  $g$  values ( $g$  range:  $-.03 - 1.84$ ) and heterogeneity statistics.

Two studies examined the longer-term impact of self-management on self-efficacy beliefs, with variable and imprecise results ( $g$  range:  $.00 - 1.93$ ; Table 4). Consequently, the pooled estimate was large but not statistically significant. Despite the high  $N_{fs}$  value, this finding was based on very limited data. Intervention participants reported large and significant improvements in their perceived ability to perform functional activities of daily living, and engage in exercise up to six months post-intervention (Goyaghaj et al., 2019; Kooijmans et al., 2017). However, they reported similar levels of perceived competency to cope with their SCI as did peers in the control group (Kooijmans et al., 2017).

### *Quality of Life*

The immediate effects of self-management interventions on quality of life were not apparent (Table 3). Of the two studies that assessed this psychological construct, both produced small- to-medium and non-significant effects, including satisfaction with health, daily activities, relationships, and general living conditions as measured by the World Health Organization Quality of Life assessment scales (Kooijmans et al., 2017; Kryger et al., 2019). Further research is needed to confirm these results ( $N_{fs} < N_{studies}$ ).

In comparison, self-management interventions demonstrated positive and highly significant longer-term benefits to quality of life (Table 4). Indeed, the two studies providing these data both reported medium to very large gains for intervention participants up to 10 months post-intervention, in comparison to information-only (Kooijmans et al., 2017) or standard medical care (Phillips et al., 2001). Again, however, this pooled estimate needs to be interpreted cautiously given the limited data.

The mixed results of the aforementioned meta-analyses are supported by the five studies that did not contribute data to calculate effect size estimates. Schulz et al. (2009) reported “relatively small” (p. 10) rates of change in depressed mood at six months (i.e., immediate intervention effects). Similarly, Guihan et al. (2014) indicated that intervention effects across various measures of self-efficacy were non-significant. Conversely, Houlihan et al. (2017) reported greater improvements in quality of life ratings amongst self-management intervention participants across multiple time points (two, four and six months). A further two studies, both of which used purposely-designed measures of self-efficacy, reported varied findings. Both Arbour-Nicitopoulos et al. (2009) and Latimer et al. (2006) observed greater confidence to schedule physical activity amongst their intervention participants ( $p < .05$ ). However, whilst Arbour-Nicitopoulos et al. (2009) noted gains in participants’ confidence to overcome salient barriers (e.g., pain) to physical activity ( $p < .01$ ), Latimer et al. (2006) did not. Moreover, no perceived benefits in participants’ self-confidence to overcome physical environmental barriers to exercise were observed (Arbour-Nicitopoulos et al., 2009).

### **Discussion and Implications**

The present systematic review evaluated the effects of self-management interventions on key psychological outcomes for adults with SCI. Of the 12 independent trials identified, six provided effect size data. The combined findings are promising, albeit preliminary: self-

management interventions contributed to immediate and large gains in mood and self-efficacy, with longer-term improvements in quality of life noted up to 10 months post-intervention. These results do need to be considered in the context of study quality, with concerns regarding methodological rigour identified across all 12 studies.

The small number of studies identified in this review highlights a lack of high-quality, randomised controlled trials (RCTs) in the SCI self-management literature – particularly trials that target psychological outcomes. This is a clear research gap that must be addressed. It is well-established that poor psychological functioning and wellbeing are not only inter-related and common secondary complications in SCI, but represent important and modifiable treatment targets in SCI rehabilitation (Bandura, 1986; Chen et al., 2015; Craig et al., 2013; Dorstyn et al., 2010). It would be remiss to neither confirm nor capitalise on the utility of self-management interventions in this space. The potential for self-management interventions to produce meaningful improvements in mood, self-efficacy and quality of life has been demonstrated with other chronic illness and disability groups, including individuals with an acquired brain injury following stroke, diabetes or arthritis (Fryer et al., 2016; Knittle et al., 2010; Steed et al., 2003). Further larger-scale RCTs which incorporate routine and repeated psychological assessments are needed to determine the combined extent of their efficacy in persons with SCI.

Firm conclusions about longer-term intervention effects cannot be made given the limited data. Importantly, the longer-term benefits to quality of life noted by two studies (Kooijmans et al., 2017; Phillips et al., 2001) are consistent with the wider self-management literature (Cochran & Conn, 2008; Kidd et al., 2017). Estimating meaningful and reliable change over time in a complex, multi-dimensional index of wellbeing such as quality of life is difficult. Ideally, both individual-item and total quality of life scale scores should be considered (Tractenberg et al., 2013). SCI is also associated with a plethora of



environmental, social, physical and psychological challenges which take time to mitigate. Routine evaluation of longer-term (i.e., beyond 12 months) psychological outcomes is needed to confirm whether self-management interventions can deliver long lasting effects; it is these interventions that will offer the greatest benefit to people with SCI as they navigate their lifelong condition, and appeal most to health providers considering implementation (Eaton et al., 2015; Kidd et al., 2017).

In delineating the characteristics of interventions that were most effective over the short term, several themes emerged. Evidence-based behavioural components, such as problem solving and goal setting, were associated with the largest gains in mood (Kooijmans et al., 2017; Meade et al., 2016). Interestingly, the delivery of these interventions also reflected features of traditional cognitive behaviour therapy (CBT), including structured and intensive facilitator guidance supplemented with face-to-face, individualised support (Wright et al., 2017). These observations are consistent with a compelling body of evidence supporting the effectiveness of CBT in optimising psychological adjustment following SCI (Dorstyn et al., 2010; Perkes et al., 2014).

It follows that future self-management interventions targeting mood or emotional adjustment post-SCI would be well-served by drawing on core elements of CBT in both their components and approaches to delivery. Such interventions could even be applied via telecommunication technology. Notably, the few studies included in the present review that relied predominantly on smartphone applications, or video or telephone-based interventions, placed little emphasis on CBT-based skill development or the establishment of therapeutic relationships (Kryger et al., 2019; Mercier et al., 2015; Phillips et al., 2001). Given that many people with SCI have expressed a preference for accessible technology-based programs (Allin et al., 2018; Munce et al., 2014), investigating the efficacy of these mediums with greater integration of CBT skills training and structured guidance (e.g., weekly video

discussions with a health professional) would be a worthwhile endeavour. Indeed, the efficacy of internet-based CBT, including mobile health applications, has been demonstrated both in the general population and among chronic condition cohorts (e.g., fibromyalgia, diabetes) (Mehta et al., 2018; Newby et al., 2016; Rathbone et al., 2017; Twomey & O'Reilly, 2017).

The present findings also emphasise the importance of underpinning theoretical frameworks when designing self-management interventions for SCI, particularly to enhance self-efficacy. It was encouraging to note that self-efficacy showed the largest – albeit non-significant – immediate improvement, given its known influence over other physical and psychological health outcomes in SCI (Bandura, 1977; Craig et al., 2013; van Diemen et al., 2017). The substantial variability in individual effect sizes associated with this particular construct perhaps reflects the diversity in the operationalisation of self-efficacy. This included individual measures of general self-efficacy – which target a broad sense of personal competence across a range of issues encountered in adjustment after SCI (e.g., Moorong Self-Efficacy Scale; Middleton et al., 2003) – as well as measures targeting self-confidence in the management of SCI-specific tasks (e.g., engagement in physical activity; SCI exercise self-efficacy scale; Nooijen et al., 2013). Intervention characteristics may have also rendered some programs more effective than others. In particular, the self-management intervention that produced the strongest immediate improvement drew heavily on the tenets of Bandura's self-efficacy theory, with core components and content focussed on providing participants with mastery experiences (e.g., skill practise), modelling (e.g., demonstrations of self-care), social persuasion (e.g., support from health professionals) and attention to affective states (e.g., via counselling) (Bandura, 1986; Kim & Cho, 2017). It is argued that self-management program developers must more explicitly consider the intersection of their components with

psychological theory, such that they are intentionally embedded to provide avenues for meaningful change in behaviour in the longer-term (McIntyre et al., 2020).

The effectiveness of a self-management program can be further enhanced by recognising and acknowledging that patients are likely to have different levels of health literacy. Many people with SCI do not always possess a basic knowledge and understanding of their injury, and thus may not believe in their ability to successfully manage their care (Farley, 2020). The need to assess a patient's educational needs and tailor an intervention accordingly is demonstrated by Goyaghaj et al.'s (2019) training program for veterans with SCI, which produced impressive gains in self-efficacy by tailoring content to participants' pre-identified, self-reported needs in relation to self-care, illness and SCI complications.

That immediate gains in both mood and self-efficacy were associated with both brief (e.g., two weeks; Goyaghaj et al., 2019) and extensive self-management programs delivered over six months (e.g., Meade et al., 2016) is also noteworthy. Interestingly, the strongest gains were associated with interventions delivered during inpatient rehabilitation and on a regular and intensive schedule (Kim & Cho, 2017; Goyaghaj et al., 2019). People with SCI have expressed mixed views with regards to the timing of self-management interventions. Some have expressed a preference for programs to be introduced early during rehabilitation, when there is greater scope to capitalise on motivation and utilise available multi-disciplinary resources (Munce et al., 2014). In contrast, others have argued for delayed intervention, citing difficulties engaging with content and learning during the emotionally charged early-adjustment period (Allin et al., 2018; Hirsche et al., 2011). The present findings suggest that there is both a capacity and clinical justification for catering to both inpatient and outpatient settings. Future research might explore the comparative value of integrating self-management strategies into existing inpatient rehabilitation processes and patient-provider

interactions, with less resource-intensive, more cost-effective community-based approaches to support or maintain psychological gains in the longer term.

No overall preference for intervention mode emerged, with significant improvements in mood and self-efficacy noted in individualised interventions (Goyaghaj et al., 2019; Meade et al., 2016) as well as those that incorporated adjunct group support (Kim & Cho, 2017; Kooijmans et al., 2017). Previous research has highlighted benefits to both formats for people with SCI; individuals experiencing an emotional crisis, or who may feel overwhelmed or anxious in group settings, may benefit from intensive and tailored support, whereas group programs provide an opportunity to connect with and learn from peers (Barlow et al., 2002; Hirsche et al., 2011; Munce et al., 2014). Given that group-based approaches do, however, offer a potentially less resource-intensive alternative with wider reach, further research efforts should be made to establish and compare the efficacy of group versus individual-based interventions.

The variable attrition rates reported across the studies (range: 0% – 42%) also indicate that further efforts to enhance the accessibility of self-management intervention are needed. One possible option is to incorporate peer mentors alongside trained health professionals and counsellors. There is a growing body of evidence supporting the efficacy of peer-led interventions in SCI (Jones et al., 2019; Ljungberg et al., 2010). This includes Houlihan et al.'s (2017) reported improvements following their peer-led, telephone-based empowerment intervention. Future RCTs should seek to further substantiate and compare the psychological merit of these approaches. It may also be important for peer facilitators to be trained in basic psychotherapeutic skills (e.g., active listening, reflection) and provided with supervision or adjunct support from trained professionals, given the effectiveness of CBT-informed strategies as demonstrated in the present review.

## Limitations

The present findings must be considered in the context of several methodological limitations encountered throughout data sourcing and extraction. First, restrictive eligibility criteria may have failed to capture all relevant studies. This included the requirement that studies needed to make explicit reference to self-management, self-care, or self-monitoring in their aims or intervention descriptions. Whilst this approach facilitated objective and systematic screening given the lack of consensus regarding an operational definition for ‘self-management,’ it is possible that interventions which upheld the principles of self-management or included key self-management components, but did not refer to the term itself, were missed as a consequence.

Furthermore, only articles written in English and published in peer-reviewed journals were included; thus the findings are likely subject to some degree of language and publication bias. Including grey literature may have increased the number of eligible studies, although this would have presented challenges with regard to maintaining a rigorous, transparent and replicable review process (Mahood et al., 2014; Paez, 2017).

Finally, this review included multiple self-report outcome measures which differed in their psychometric properties and responsiveness to meaningful change in the SCI population. This included valid and reliable measures which captured content pertinent to the unique concerns and experiences of persons with SCI (e.g., Moorong Self-Efficacy Scale; Middleton et al., 2003), but also measures that contained generic content which, although used among chronic illness groups, still require psychometric evaluation within an SCI sample (e.g., Utrecht Proactive Coping Competence Scale; Bode et al., 2008). To facilitate accurate and clinically meaningful conclusions regarding efficacy, future interventions should consistently employ recommended, SCI-appropriate measurement tools (for examples with comments and recommendations, see Miller et al., 2013).

**Conclusion**

The findings from the present systematic review are promising; self-management interventions have the capacity to enhance psychological functioning in persons with SCI. Interventions that draw on evidence-based theory and therapeutic strategies, such as CBT, may yield the best outcomes. However, it is important to note that no single approach to delivery can meet the individualised psychological needs or preferences of persons with SCI across time. Rather, a combination of multi-modal interventions made available throughout the continuum of SCI care and including flexible delivery approaches may help to optimise and maintain treatment effects. Additional RCTs with greater methodological rigour can build on these findings and, importantly, contribute to an agreed upon set of core outcome measures to be routinely utilised in the SCI self-management literature.

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**Tables**

**Table 1**  
*Study Characteristics*

Lead author (date)	Sample			Country	Recruitment source	Psychological measures	Attrition (%) <sup>d</sup>	Self-management				Control condition/s
	Total <sup>a</sup>	I	C					Primary target outcomes	Core components	Contact & timeframe	Medium	
Arbour-Nicitopoulos (2003)	46	23	23	Canada	Community	General barriers SE Facility barriers SE Scheduling SE	17	Physical activity + SE	Skill development and practise, information + resources	Single phone session (20-30 mins) + interviews at 5 and 20 weeks	Phone	Action planning
Goyaghaj (2019)	60	30	30	Iran	Inpatient	MSES	0	SE	Education + skill development and practise	6 (45-60 min) sessions over 2 weeks	Face-to-face	Usual care
Guihan (2014)	144	72	72	USA	Inpatient	SE scale/s (Lorig et al., 2001) <sup>b</sup>	42	Skin-protective behaviours	Education + skill development and practise + peer support + counselling	7 (45-60 min) conference calls + 8 phone calls over 6 months	Internet + phone	Education
Houlihan (2017)	84	42	42	USA	Community	SCI QoL-BDS	10	Health self-management	Education + information and resources + skill development + peer coaching + external referral	Tapered phone calls (average 21.8 mins -(weekly, biweekly, monthly) over 6 months + optional text or email messaging	Phone	Usual care
Kim (2017)	51	26	25	Korea	Inpatient	Korean SE scale <sup>c</sup>	8	SE + pressure ulcers	Education + skill development and practise + counselling	Contact staggered across 8 weeks. 2.25-hour group session in week 1 + face-to-face counselling in week 5 + phone counselling (10-15 mins) in weeks 3 and 7	Face-to-face + phone + internet	Information
Kooijmans (2017)	64	33	31	Netherlands	Inpatient	SCI-ESES UPPC MHI-5 WHOQOL-5	14	Physical activity	Education + skill development and practise + peer support + information and resources	Home visit + 5 (2.25 hour) group sessions + 5 individual sessions	Face-to-face	Information



**Table 1** (cont.)

Lead author (date)	Sample				Psychological measures	Attrition (%) <sup>d</sup>	Self-management				Control condition/s	
	Total <sup>a</sup>	I	C	Country			Recruitment source	Primary target outcomes	Core components	Contact & timeframe		Medium
Kryger (2019)	38	19	19	USA	Community	BDI-II, WHOQOL- BREF	13	Health outcomes	Information and resources + skill development and practise + healthcare advice	30 min app training + as- needed communication over 9 months	Mobile app	Usual care
Latimer (2006)	54	26	28	North America	Community	Perceived behavioural control Scheduling SE Barrier SE	31	Physical activity	Skill development and practise, information + resources	Phone session + interviews at weeks 4 and 8	Phone	Information + standard goal setting & monitoring
Meade (2016)	27	19	8	USA	Community	SCI-SCS distress PHQ-9 DMSES	19	Health outcomes	Education + skill development and practise	Between 3-10 (45 min) sessions over 6 months	Face-to- face	Usual care
Mercier (2015)	106	53	53	USA	Mixed	PHQ-9	4	Health outcomes	Education + skill development and practise + healthcare advice + counselling	Tapered automated calls (average 12.6 mins -weekly, fortnightly) over 6 months + optional dial-in	Phone	Usual care + information
Phillips (2001)	111	36	36 (C1) 39 (C2)	USA	Inpatient	CESD-20 QWB	0	Health outcomes	Education + skill practise + clinical advice and referrals	5 weekly video or phone sessions (30-40 mins) + 2 fortnightly video or phone sessions over 9 weeks	Video OR phone	Usual care
Schulz (2009)	173	57	56 (C1) 60 (C2)	USA	Community	CESD-10	10	Quality of life	Education + skill development and practise + peer support	7 at-home sessions (60-90 mins) + 2 phone sessions (60- 90 mins) + 5 phone support group sessions over 6 months	Face-to- face + phone	(1) Caregiver intervention (2) Information

<sup>a</sup> number of participants allocated at baseline; I = Self-management intervention; C(1) = 1<sup>st</sup> control or comparison group; C(2) = 2<sup>nd</sup> control or comparison group; <sup>b</sup> no further information provided by authors; <sup>c</sup> modified from the self-efficacy subscale of the Skin Care Belief Scale (King et al., 2012); <sup>d</sup> percentage of participants who did not complete post-treatment measurements. Measure abbreviations: SE = self-efficacy; MSES= Moorong Self-Efficacy Scale; SCI QoL-BDS= Spinal Cord Injury Quality of Life Basic Data Set; SCI-ESES= Spinal Cord Injury Exercise Self-Efficacy Scale; UPPC= Utrecht Proactive Coping Competence scale; MHI-5= Mental Health Inventory (5 items); WHOQOL-5= World Health Organisation Quality of Life assessment (5 items); BDI-II= Beck Depression Inventory (2<sup>nd</sup> edition); WHOQOL-BREF= World Health Organisation Quality of Life assessment (26 items); SCI-SCS= Spinal Cord Injury Secondary Conditions Scale (distress subscale); PHQ-9= Patient Health Questionnaire (9-item depression module); DMSES = Disability Management Self-Efficacy Scale; CESD-20= Center for Epidemiological Studies Depression scale (20 items); QWB= Quality of Wellbeing scale; CESD-10= Center for Epidemiological Studies Depression scale (10 items).

**Table 2***Demographic and Injury Characteristics*

Variable	Self-management					Control				
	$N_{studies}$	$N_{participants}$	Mean (SD)	Median	Range	$N_{studies}$	$N_{participants}$	Mean (SD)	Median	Range
Sample size <sup>a</sup>	12	472	36.31 (15.95)	33	19 – 72	12	486	37.38 (18.41)	31	8 – 72
Age (years)	12	461	45.32 (6.89)	45.80	35 – 59.4	12	473	46.73 (14.19)	47.5	33 – 59
Time since injury (years)	9	302	15.69 (7.83)	15.73	8.8 – 28.32	9	287	14.43 (6.41)	12.1	5.49 – 24
			N (%)					N (%)		
Gender										
Male	12	461	353 (76.57)			12	473	351 (74.21)		
Female	12	461	108 (23.43)			12	473	122 (25.79)		
Ethnicity/race										
White	6	251	185 (73.71)			6	310	239 (77.10)		
Non-white	5	251	66 (26.29)			5	310	71 (22.90)		
Employment status										
Employed	7	296	67 (22.64)			7	344	82 (23.84)		
Unemployed	7	296	229 (77.36)			7	344	262 (76.16)		
Education										
≤ High school	8	321	150 (46.73)			8	368	148 (40.22)		
> High school	9	321	171 (53.27)			9	368	220 (59.78)		
Relationship status										
Married/partnered	9	352	151 (42.90)			9	308	144 (46.75)		
Single/not partnered	9	352	201 (57.10)			9	308	164 (53.25)		
Aetiology of injury										
Traumatic	3	85	80 (94.12)			3	73	72 (98.63)		
Nontraumatic	3	85	5 (5.88)			3	73	1 (1.37)		
Injury level										
Paraplegia	6	182	97 (53.30)			6	184	103 (55.98)		
Quad/tetraplegia	6	182	85 (46.70)			6	184	81 (44.02)		
Lesion										
Complete	8	285	152 (53.33)			8	334	190 (56.89)		
Incomplete	8	285	133 (46.67)			8	334	144 (43.11)		

Note:  $N_{studies}$  = number of participants allocated at baseline;  $N_{participants}$  = number of participants who provided data across category (where there were multiple comparison conditions in a study, data for these conditions were combined).

**Table 3**

*Immediate Effects Associated with Self-management Interventions*

Construct	Measure	<i>N</i> <sub>studies</sub>	<i>N</i> <sub>participants</sub>	Time (months)	<i>g</i>	95% CI		SE	<i>p</i>	<i>N</i> <sub>fs</sub>	$\tau$	<i>I</i> <sup>2</sup>	Lead author (date)
						L	U						
Mood	SCI-SCS distress	1	27	6	1.27	.40	2.14	.44	<.01				Meade (2016)
	PHQ-9	1	27	6	-1.08	-1.93	-.22	.44	.01				Meade (2016)
	MHI-5	1	55	~4	.79	.22	1.35	.29	.01				Kooijmans (2017)
	PHQ-9	1	106	6	.28	-.10	.66	.19	.15				Mercier (2015)
	BDI-II	1	38	9	.26	-.37	.88	.32	.42				Kryger (2019)
	Total	4	226		.37	.10	.64	.14	.01	4	0.00	0.00	
Self-efficacy	Korean SE scale	1	47	~2	1.84	1.17	2.52	.34	<.01				Kim (2017)
	MSES	1	60	~0.5	1.52	.95	2.09	.29	<.01				Goyaghaj (2019)
	SCI-ESES	1	55	~4	.31	-.24	.87	.28	.27				Kooijmans (2017)
	DMSSES	1	27	6	-.03	-.83	.77	.41	.94				Meade (2016)
	UPCC	1	55	~4	.00	-.55	.55	.28	1.00				Kooijmans (2017)
	Total	4	189		.88	-.02	1.79	.47	.06	15	.86	87.63	
Quality of life	WHOQOL-BREF (Environmental)	1	38	9	-.31	-.94	.32	.32	.33				Kryger (2019)
	WHOQOL-5	1	55	~4	.25	-.33	.82	.29	.40				Kooijmans (2017)
	WHOQOL-BREF (Social)	1	38	9	.25	-.38	.87	.32	.44				Kryger (2019)
	WHOQOL-BREF (Physical)	1	38	9	-.24	-.86	.39	.32	.46				Kryger (2019)
	WHOQOL-BREF (Psychological)	1	38	9	.17	-.45	.79	.32	.59				Kryger (2019)
	Total	2	93		.12	-.31	.54	.22	.58	1	0.00	0.00	

Note: *N*<sub>studies</sub> = number of studies contributing data; *N*<sub>participants</sub> = number of participants contributing data; Time = assessment interval from baseline, with approximate values (~) converted from weeks to months; *g* = Hedges' *g*; CI = confidence interval with lower (L) and upper (U) limits; *N*<sub>fs</sub> = fail-safe *N*;  $\tau$  = between-study variance; *I*<sup>2</sup> = proportion of between-study heterogeneity. Measure abbreviations: MHI-5= Mental Health Inventory (5 items); BDI-II= Beck Depression Inventory (2<sup>nd</sup> edition); SCI-SCS= Spinal Cord Injury Secondary Conditions Scale (distress subscale); PHQ-9= Patient Health Questionnaire (9-item depression module); WHOQOL-5= World Health Organisation Quality of Life assessment (5 items); WHOQOL-BREF= World Health Organisation Quality of Life assessment (26 items); MSES= Moorong Self-Efficacy Scale; SCI-ESES= Spinal Cord Injury Exercise Self-Efficacy Scale; UPPC= Utrecht Proactive Coping Competence scale; DMSSES = Disability Management Self-Efficacy Scale.

**Table 4**

*Longer-term Effects Associated with Self-management Interventions*

Construct	Measure	$N_{studies}$	$N_{participants}$	Time (months)	$g$	95% CI		SE	$p$	$N_{fs}$	$\tau$	$I^2$	Lead author (date)
						L	U						
Mood	CESD-20	1	75	~10	-1.00	-1.47	-.52	.24	<.01				Phillips (2001) - video
	CESD-20	1	75	~10	-.46	-.91	-.01	.23	.05				Phillips (2001) - phone
	MHI-5	1	55	~6	-.24	-.84	.35	.30	.42				Kooijmans (2017)
	Total	2	166		-.52	-.10	-.05	.24	.03	1	.21	37.13	
Self-efficacy	MSES	1	60	1	1.90	1.30	2.51	.31	<.01				Goyaghaj (2019)
	SCI-ESES	1	55	~6	.78	.17	1.39	.31	.01				Kooijmans (2017)
	UPCC	1	55	~6	.00	-.60	.60	.30	1.00				Kooijmans (2017)
	Total	2	115		1.15	-.34	2.63	.76	.13	10	1.03	91.69	
Quality of life	QWB	1	75	~10	1.37	.87	1.87	.26	<.01				Phillips (2001) - phone
	WHOQOL-5	1	55	~6	.74	.13	1.36	.31	.02				Kooijmans (2017)
	QWB	1	75	~10	.59	.13	1.04	.23	.01				Phillips (2001) - video
	Total	2	166		.89	.51	1.27	.19	<.01	7	.00	0.00	

Note:  $N_{studies}$  = number of studies contributing data;  $N_{participants}$  = number of participants contributing data; Time = assessment interval from post-intervention, with approximate values (~) converted from weeks to months;  $g$  = Hedges'  $g$ ; CI = confidence interval with lower (L) and upper (U) limits;  $N_{fs}$  = fail-safe  $N$ ;  $\tau$  = between-study variance;  $I^2$  = proportion of between-study heterogeneity. Measure abbreviations: MHI-5= Mental Health Inventory (5 items); CESD-20= Center for Epidemiological Studies Depression scale (20 items); WHOQOL-5= World Health Organisation Quality of Life assessment (5 items); QWB= Quality of Wellbeing scale; MSES= Moorong Self-Efficacy Scale; SCI-ESES= Spinal Cord Injury Exercise Self-Efficacy Scale; UPPC= Utrecht Proactive Coping Competence scale.

Figures

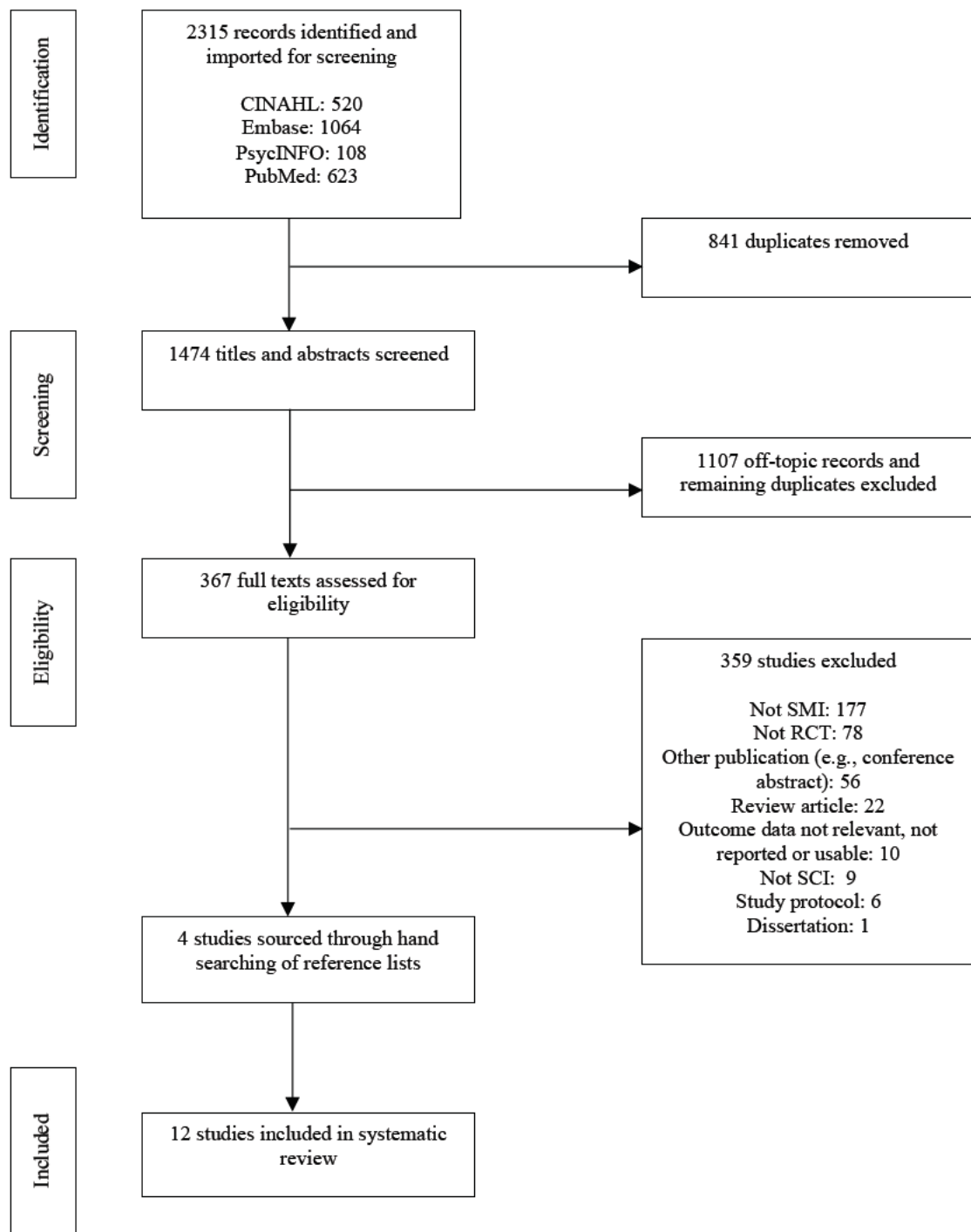


Figure 1. PRISMA Flow Diagram outlining Study Selection Procedure (Moher et al., 2009).

Lead author (date)	(1a) Randomisation process (selection bias)	(1b) Recruitment within clusters (recruitment bias)	(2) Intended intervention (performance bias)	(3) Outcome data (attrition bias)	(4) Outcome measure (detection bias)	(5) Reporting of results (reporting bias)	Overall bias
Arbour-Nicitopoulos (2009)	High risk of bias	N/A	Some concerns	Low risk of bias	Some concerns	Some concerns	High risk of bias
Goyaghaj (2019)	Some concerns	N/A	Some concerns	Low risk of bias	Some concerns	Some concerns	Some concerns
Guihan (2014)	Low risk of bias	N/A	Some concerns	Low risk of bias	Some concerns	High risk of bias	High risk of bias
Houlihan (2016)	Some concerns	N/A	Some concerns	Low risk of bias	Some concerns	Some concerns	Some concerns
Kim (2017)	Low risk of bias	Some concerns	Some concerns	Low risk of bias	Some concerns	Low risk of bias	Some concerns
Kooijmans (2017)	Some concerns	N/A	Some concerns	Low risk of bias	Some concerns	Some concerns	Some concerns
Kryger (2019)	Some concerns	N/A	Some concerns	Low risk of bias	Some concerns	Some concerns	Some concerns
Latimer (2006)	Some concerns	N/A	High risk of bias	Low risk of bias	Some concerns	Some concerns	High risk of bias
Meade (2016)	Some concerns	N/A	Some concerns	High risk of bias	Some concerns	Some concerns	High risk of bias
Mercier (2015)	Some concerns	N/A	Some concerns	Low risk of bias	Some concerns	Some concerns	Some concerns
Phillips (2001)	Some concerns	N/A	Some concerns	Low risk of bias	Some concerns	Some concerns	Some concerns
Schulz (2009)	Low risk of bias	N/A	Some concerns	Low risk of bias	Some concerns	High risk of bias	High risk of bias

N/A	
Low risk of bias	
Some concerns	
High risk of bias	

Figure 2. Cochrane Risk of Bias 2.0 Evaluation Ratings Within Studies.

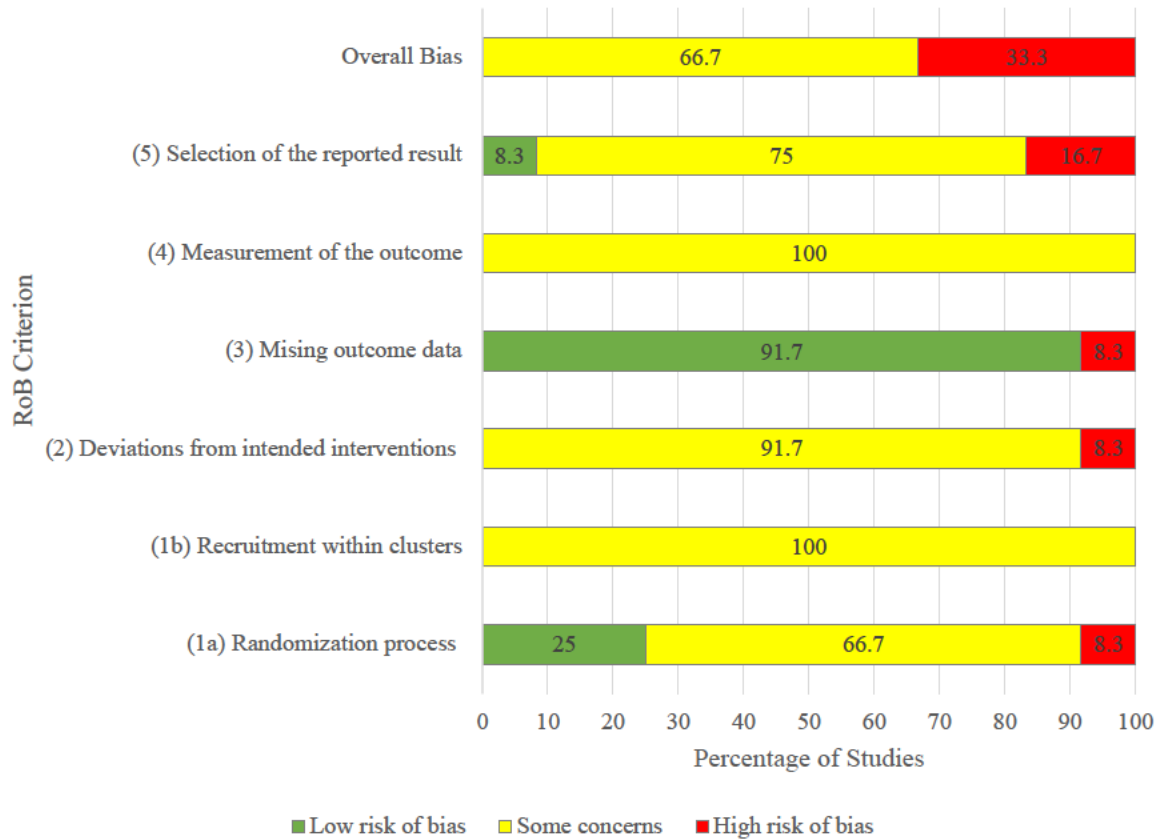


Figure 3. Cochrane Risk of Bias 2.0 Evaluation Ratings Across Studies.

## Appendix A

Key search terms and Boolean operators used in database searches.

### CINAHL Logic Grid

Self-management programs **AND** → Spinal Cord Injury

Self-management	Spinal Cord Injury
MH Self Care OR TI “self care” OR AB “self care” OR MH Self-Management OR TI “self manag*” OR AB “self manag*” OR TI “self help” OR AB “self help” OR TI “self monitor” OR AB “self monitor” OR TI “self rehabilitation” OR AB “self rehabilitation” OR TI “self led” OR AB “self led” OR TI “self directed” OR AB “self directed”	MH Spinal Cord Injuries+ OR MH Spinal Injuries OR TI “spinal cord injur*” OR AB “spinal cord injur*” OR TI “spinal injur*” OR AB “spinal injur*” OR TI “spine injur*” OR AB “spine injur*” OR TI “spinal cord trauma*” OR AB “spinal cord trauma*” OR TI “spine trauma*” OR AB “spine trauma*” OR TI “spinal trauma*” OR AB “spinal trauma*” OR MH Spinal Fractures OR TI “spinal fracture*” OR AB “spinal fracture*” OR TI “spine fracture*” OR AB “spine fracture*” OR MH Paraplegia+ OR TI parapleg* OR AB parapleg* OR MH Quadriplegia OR TI quadripleg* OR AB quadripleg* OR TI tetrapleg* OR AB tetrapleg* OR TI “traumatic myelopath*” OR AB “traumatic myelopath*” OR TI “spinal cord transection*” OR AB “spinal cord



transection\*" OR TI "spinal cord  
transsection\*" OR AB "spinal cord  
transsection\*" OR TI "spinal cord  
laceration\*" OR AB "spinal cord  
laceration\*" OR TI "spinal cord  
contusion\*" OR AB "spinal cord contusion"  
OR TI "spinal cord compression\*" OR AB  
"spinal cord compression\*" OR TI "spinal  
cord transverse lesion\*" OR AB "spinal  
cord transverse lesion\*" OR TI "central  
cord syndrome" OR AB "central cord  
syndrome" OR MH Autonomic Dysreflexia  
OR TI "autonomic dysreflexia" OR AB  
"autonomic dysreflexia" OR TI "Brown-  
Sequard Syndrome" OR AB "Brown-  
Sequard Syndrome" OR TI "vertebra  
compression\*" OR AB "vertebra  
compression\*" OR TI "vertebral  
compression\*" OR AB "vertebral  
compression\*" OR TI "vertebra  
dislocation\*" OR AB "vertebra  
dislocation\*" OR TI "vertebral  
dislocation\*" OR AB "vertebral  
dislocation\*" OR TI "vertebra fracture\*"  
OR AB "vertebra fracture\*" OR TI

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“vertebral fracture\*” OR AB “vertebral fracture\*”

### PubMed Logic Grid

Self-management programs AND → Spinal Cord Injury

Self-management	Spinal Cord Injury
“self management”[mh] OR “self care”[mh:noexp] OR self manag*[tiab] OR self care[tiab] OR self help[tiab] or self monitor*[tiab] OR self rehabilitation[tiab] OR self led[tiab] OR self directed[tiab]	“spinal cord injuries”[mh] OR “spinal injuries”[mh] OR spinal cord injur*[tiab] OR spinal injur*[tiab] OR spine injur*[tiab] OR spinal cord trauma*[tiab] OR spine trauma*[tiab] OR spinal trauma*[tiab] OR spinal fracture*[tiab] OR spine fracture*[tiab] OR “paraplegia”[mh] OR parapleg*[tiab] OR “quadriplegia”[mh] OR quadripleg*[tiab] OR tetrapleg*[tiab] OR traumatic myelopath*[tiab] OR spinal cord transection*[tiab] OR spinal cord transsection*[tiab] OR spinal cord laceration*[tiab] OR spinal cord contusion*[tiab] OR spinal cord compression*[tiab] OR spinal cord transverse lesion*[tiab] OR central cord syndrome[tiab] OR autonomic dysreflexia[tiab] OR Brown-Sequard Syndrome[tiab] OR vertebra

compression\*[tiab] OR vertebral  
 compression\*[tiab] OR vertebra  
 dislocation\*[tiab] OR vertebral  
 dislocation\*[tiab] OR vertebra  
 fracture\*[tiab] OR vertebral fracture\*[tiab]

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### PsycINFO Logic Grid

Self-management programs AND → Spinal Cord Injury

Self-management	Spinal Cord Injury
self management.sh OR self	spinal cord injuries.sh OR spinal cord
management.ti,ab OR self care skills.sh OR	injur*.ti,ab OR spine injur*.ti,ab OR spinal
self care.ti,ab OR self help.ti,ab OR self	injur*.ti,ab OR spinal cord trauma*.ti,ab OR
monitor*.ti,ab OR self rehabilitation.ti,ab	spine trauma*.ti,ab OR spinal trauma*.ti,ab
OR self led.ti,ab OR self directed.ti,ab	OR spinal fracture*.ti,ab OR spine
	fracture*.ti,ab OR paraplegia.sh OR
	parapleg*.ti,ab OR quadriplegia.sh OR
	quadripleg*.ti,ab OR tetrapleg*.ti,ab OR
	traumatic myelopath*.ti,ab OR spinal cord
	transection*.ti,ab OR spinal cord
	transsection*.ti,ab OR spinal cord
	laceration*.ti,ab OR spinal cord
	contusion*.ti,ab OR spinal cord
	compression.ti,ab OR spinal cord transverse
	lesion*.ti,ab OR central cord syndrome.ti,ab
	OR autonomic dysreflexia.ti,ab OR Brown-

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Sequard Syndrome.ti,ab OR vertebra  
 compression\*.ti,ab OR vertebral  
 compression\*.ti,ab OR vertebra  
 dislocation\*.ti,ab OR vertebral  
 dislocation\*.ti,ab OR vertebra  
 fracture\*.ti,ab OR vertebral fracture\*.ti,ab

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### Embase Logic Grid

Self-management programs AND → Spinal Cord Injury

Self-management	Spinal Cord Injury
'self care'/de OR 'self care agency'/de OR	'spinal cord injury'/exp
'self care':ti,ab OR 'self help'/de OR 'self	OR 'spine injury'/exp OR 'spinal cord
help':ti,ab OR 'self management':ti,ab OR	injur*':ti,ab OR 'spine injur*':ti,ab OR
'self monitor*':ti,ab OR 'self	'spinal injur*':ti,ab OR
rehabilitation':ti,ab OR 'self led':ti,ab OR	'spinal cord trauma*':ti,ab OR 'spine
'self directed':ti,ab	trauma*':ti,ab OR 'spinal trauma*':ti,ab
	OR 'spinal fracture*':ti,ab OR 'spine
	fracture*':ti,ab OR 'paraplegia'/de OR
	'parapleg*':ti,ab OR 'quadriplegia'/de OR
	'quadripleg*':ti,ab OR 'tetrapleg*':ti,ab OR
	'traumatic myelopath*':ti,ab OR 'spinal
	cord transection*':ti,ab OR 'spinal cord
	transsection*':ti,ab OR 'spinal cord
	laceration*':ti,ab OR 'spinal cord
	contusion*':ti,ab OR 'spinal cord

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compression'/de OR 'spinal cord  
compression':ti,ab OR 'spinal cord  
transverse lesion\*':ti,ab OR 'central cord  
syndrome':ti,ab OR 'autonomic  
dysreflexia'/de OR 'autonomic  
dysreflexia':ti,ab OR 'Brown-Sequard  
Syndrome':ti,ab OR 'vertebra  
compression':ti,ab OR 'vertebral  
compression\*':ti,ab OR 'vertebra  
dislocation\*':ti,ab OR 'vertebral  
dislocation\*':ti,ab OR 'vertebra  
fracture\*':ti,ab OR 'vertebral  
fracture\*':ti,ab

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**Appendix B**

Sources of psychometric data for pre-post correlations.

<b>Outcome Measure</b>	<b>Used by: Lead Author (Date)</b>	<b>Reference for Psychometric Data</b>	<b>Test-retest Correlation</b>
Beck Depression Inventory-II	Kryger (2019)	Wang and Gorenstein (2013)	.85
Center for Epidemiologic Studies Depression Scale-20	Phillips (2001)	Radloff et al. (1977)	.49 (median)
Disability Management Self-Efficacy Scale	Meade (2016)	–	–
Korean Self-Efficacy Tool	Kim (2017)	King et al. (2012)	.51 (median)
Mental Health Inventory-5	Kooijmans (2017)	Fuh et al. (2000)	.77
Moorong Self-Efficacy Scale	Goyaghaj (2019)	Middleton et al. (2003)	.74
Patient Health Questionnaire-9	Meade (2016) Mercier (2015)	Kroenke et al. (2001)	.84
Quality of Well-Being Scale	Phillips (2001)	Seiber et al. (2008)	.60
SCI Exercise Self-Efficacy Scale	Kooijmans (2017)	Nooijen et al. (2013)	.81
SCI Secondary Conditions Scale - Distress	Meade (2016)	Kalpajian et al. (2016)	.71 (median)
Utrecht Proactive Coping Competence scale	Kooijmans (2017)	Tielemans et al. (2014)	.64 (median)
WHOQOL*-5	Kooijmans (2017)	Harper and Power (1998)	.75 (median)
WHOQOL – Physical			.66
WHOQOL – Psychological	Kryger (2019)	Harper and Power (1998)	.72
WHOQOL – Social			.76
WHOQOL – Environment			.87

\* Measure abbreviation: WHOQOL = World Health Organisation Quality of Life assessment

## Appendix C

Rationales for RoB 2.0 ratings assigned to individually randomised trials per domain.

	Low	Some concerns	High
<b>Randomisation process</b>	<p>Evident that studies concealed the allocation sequence, used a random allocation sequence and produced comparable groups at baseline.</p> <p><i>“Participants were randomly assigned at discharge from hospital by the Hines Data Coordinating Center. Randomisation was 1:1 blocked.”</i></p> <p><i>“Participants randomly allocated using block randomisation...done by an independent investigator who will not be involved in the interventions, measurements or analyses of data.”</i></p>	<p>Method of concealment was not described or not described in sufficient detail to allow a definite judgement.</p> <p>However, studies either:</p> <p>a) Used a random allocation sequence and produced groups comparable at baseline or differing in size per the randomisation pattern (e.g., 2:1 block)</p> <p><i>“Participants were randomized using a random number generator in Microsoft Excel...no significant differences were detected at baseline between control and intervention groups.”</i></p> <p>b) Mentioned the use of random allocation, but provided insufficient information to confirm that the sequence was genuinely</p>	<p>Clearly stated that the researcher who administered an intervention also generated the randomisation sequence, with no mention of materials or efforts for concealment.</p> <p><i>“The researcher used a random numbers table to randomly assign participants to either...condition.”</i></p>

		<p>random. Groups nonetheless comparable at baseline.</p> <p><i>“Patients were randomly assigned to one of three telehealth intervention groups.”</i></p>
<p><b>Deviations from intended interventions</b></p>	<p>Participants, carers or personnel likely aware of intervention allocation during the trial (even where blinding was attempted)</p> <p>Insufficient information re: deviations in intended intervention due to experimental context, but exclusion of waitlist control conditions may have mitigated high risk.</p> <p>Appropriate analyses used to estimate effects of assignment to intervention.</p> <p><i>“We applied constrained longitudinal data analysis to examine differences in mean change scores...following intention to treat.”</i></p>	<p>Exclusion of participants who could have contributed data to analyses.</p> <p><i>“Only data from participants who maintained fidelity to the intervention were included in the final analysis.”</i></p>
<p><b>Missing outcome data</b></p>	<p>Data provided from most (&gt;95%) participants or, where data missing:</p> <p>a) authors reported appropriate</p>	<p>Authors identified a relationship between scores on an index of psychological functioning and rate of attrition in one condition, where there</p>



	<p>analyses conducted to account for bias, e.g., ITT analyses</p> <p><i>“Analyses were conducted using the ITT procedure.”</i></p> <p>b) authors provided information about dropout reasons which did not clearly indicate that missingness in the outcome was dependent on its true value</p> <p><i>“2 participants died (not related to the study) during the study and several participants dropped out of the study because of illness or secondary complications.”</i></p>		<p>was a significant difference in attrition rates between conditions.</p> <p><i>“Of the 19 individuals randomized to the experimental intervention, 5 withdrew from the study...individuals who showed fewer depressive symptoms were more likely to drop out of the study.”</i></p>
<p><b>Measurement of the outcome</b></p>		<p>Measures validated or informed by relevant research.</p> <p>Outcomes assessed via self-report, with potential for participants to have formed judgements about interventions. Possible that ratings could have been influenced by knowledge of the intervention, but judged unlikely.</p>	
<p><b>Selection of the reported result</b></p>	<p>Data analysed align with a pre-specified plan, and unlikely to have been selected</p>	<p>Insufficient information re: pre-specified analyses plans, but analyses</p>	<p>Outcomes taken across multiple specified timepoints not reported, or</p>

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from multiple measures or analyses.	include all expected outcomes based on the article methods.	reported only for selected timepoints.
<i>Protocol: "Multilevel regression analysis will be the main statistical technique to test for differences."</i>	<i>Method: "self-efficacy was measured using the Moorong self-efficacy scale..."</i>	<i>"Because the rates of change at 6 months were relatively small, we do not show 6-month values."</i>
<i>Article: "linear mixed models analyses...were performed."</i>	<i>Results: MSES outcomes reported for both conditions.</i>	

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## Appendix D

Rationales for RoB 2.0 ratings assigned to cluster randomised trial per domain.

Low	Some concerns	High
<b>Randomisation process</b>	<p>Evident that a random allocation sequence was used, but method of concealment not described to allow a definite judgement about potential subversion.</p> <p><i>“...hospitals were randomly allocated...by having their representatives choose a red or a white ball from a container.”</i></p> <p>Baseline characteristics not reported at the cluster level, but no significant differences observed between conditions across sites at baseline.</p> <p><i>“...no significant differences between the experimental group and the control group with regard to baseline demographic or clinical characteristics...”</i></p>	
<b>Identification or recruitment of individual participants within cluster</b>	<p>Participants recruited after randomisation of hospitals to conditions. However, unclear as to whether hospital representatives involved in randomisation were also involved in recruitment, or conveyed allocation details to the recruiting sites.</p> <p>Baseline characteristics not reported at the cluster level, but no significant differences observed</p>	

	between conditions across sites at baseline.
<b>Deviations from intended interventions</b>	<p>Participants and/or personal likely aware of allocation to intervention.</p> <p>Insufficient information to determine whether deviations in intended intervention occurred or affected outcomes, but outcomes assessed for participants in their correct groups.</p>
<b>Missing outcome data</b>	<p>Data not available for all participants, but similar proportions of missing data across groups.</p> <p><i>SMI: dropout = 2</i> <i>Control: dropout = 2</i></p>
<b>Measurement of the outcome</b>	All outcomes assessed via self-report, with potential for participants to have formed judgements about interventions. Possible that ratings could have been influenced by knowledge of the intervention, but judged unlikely.
<b>Selection of the reported result</b>	<p>Insufficient information re: pre-specified analyses plans, but analyses include all expected outcomes based on the article methods.</p> <p><i>Method: "self-efficacy was measured by using a Korean version of the self-efficacy tool modified from the...Skin Care Belief Scale..."</i></p> <p><i>Results: Self-efficacy outcomes reported for both conditions.</i></p>

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