

Psychological support for the patient with spinal cord injury

Panagiota Efthimiou¹, Ioannis S. Benetos², Dimitrios-Sergios Evangelopoulos³, John Vlamis⁴

¹Postgraduate Training Program, Third Department of Orthopaedic Surgery, National and Kapodistrian University of Athens, KAT Hospital, Athens, Greece

²Third Department of Orthopaedic Surgery, NKUA, KAT Hospital, Athens, Greece

³Third Department of Orthopaedic Surgery, NKUA, KAT Hospital, Athens, Greece

⁴Third Department of Orthopaedic Surgery, NKUA, KAT Hospital, Athens, Greece

Abstract

Reality after spinal cord injury (SCI) is a life-long adjustment. Although much of the effort is focused on the motor, sensory, and autonomic dysfunctions, SCI can have very serious psychosocial consequences on affected individuals. Research shows that many with sudden onset SCI will exhibit extreme negative emotions which impair psychological as well as social integration after injury. Also, people with SCI are at a higher risk of developing anxiety, depression, and post-traumatic stress disorder among others, with psychological and social factors playing a major role in incidence and progression. The purpose of this study was to review the common psychosocial consequences for people after SCI and the current psychosocial challenges within the SCI population, as well as to provide considerations that promote quality of life from a biopsychosocial perspective. A review of the current literature was performed using the online Pubmed and Google Scholar databases and the PRISMA guidelines. Relevant analyses helped to derive conclusions that may benefit the psychological rehabilitation of SCI patients. Patients with robust psychological support seem to have better physical rehabilitation rates, less emotional and behavioral problems, less alcohol/drug abuse, higher rates of reintegration and engaging in meaningful activities and less suicide attempts.

Keywords: spinal cord injury, psychological support, rehabilitation, mental health

Introduction

A spinal cord injury (SCI) damages more than the spinal cord; the lives of people with SCI as well as their support system are never the same (1, 2). Depending upon the height and severity of SCI, medical comorbidities include not only paralysis but also bradycardia, neuro-

genic orthostatic hypotension, circulatory hypokinesia, adaptive cardiomyopathy, neurogenic restrictive lung disease, neurogenic obstructive lung disease, obstructive sleep apnea, neuropathic pain, spasticity, reflex neurogenic bladder, reflex neurogenic bowel, neurogenic erectile dysfunction, neurogenic infertility, neuro-

Corresponding
Author

Panagiota Efthimiou

Postgraduate Training Program, 3rd Department of Orthopaedic Surgery, NKUA
KAT Hospital, Athens, Greece

Email: efpanagiota064@gmail.com

Tel: +30-6980960162

genic skin, neurogenic obesity, heterotopic ossification, osteopenia/osteoporosis, and the metabolic syndrome including diabetes mellitus, dyslipidemia and hypertension (3). George Engel proposed a “biopsychosocial” model, which introduced a philosophical and practical approach to clinical care (4), and, from a practical standpoint, expanded the standard medical model enabling multiple disciplines to approach the multifaceted components of the “person” and “social environment” (5) that directly affect subjective wellbeing and overall outcomes in the context of medical problems. For instance, problems with mood, relationships, or personal sense of meaning can result in maladaptive behaviors (6) (i.e. alcohol misuse) that can escalate into physical, social, and functional impairments, compounding challenges in an already difficult circumstance (7). Emotional psychosomatic complications are already under robust research, such as pain, that has already been proposed to ameliorate by psychological interventions (8).

Although bio-psycho-social components cannot be fully separated, the purpose of this study was to review the common psychosocial consequences for people after SCI and the current psychosocial challenges within the SCI population, as well as to provide considerations that promote quality of life from a biopsychosocial perspective. A review of the current literature was performed using the online Pubmed and Google Scholar databases and the PRISMA guidelines and by using the following key words: “spinal cord injury rehabilitation”, “psychological support spinal cord injury”, “psychological rehabilitation spinal cord injury”, “support group spinal cord injury”, “depression spinal cord injury”, “suicide spinal cord injury”, “mental hospitalization spinal cord injury”, “spinal cord injury mental health”. The primary search revealed 3190 titles, which were screened for relevance, eligibility and diversity, and 63 remained. Exclusion criteria included non-human subjects (6), non-English language (5) and non-full text availability (15). Finally, 37 original research articles were included in this review (Figure 1).

Discussion

Research has shown that individuals who have sustained a spinal cord injury can experience strong and abrupt variations in their emotional state (9). With regard to psychological problems, reported prevalence

rates are 14% for post-traumatic stress disorder (PTSD) (10), 20–25% for clinically significant anxiety and 30–40% for depression (11), with increased suicidal ideation in many; furthermore, these can persist over significant periods of time (12). Compared to the general population, people with SCI experience higher levels of distress and lower levels of life satisfaction on average (13). Although many patients with SCI adapt to the new realities given time, roughly 10% experience increased psychological symptoms which can possibly be mollified by early interventions emphasizing coping strategies (14). Such early adjustments have been shown to increase life satisfaction in some patients (15).

On the negative side of the spectrum, inability to adjust has been linked to mortality. Suicide is at least 3 times more common in individuals with SCI than in individuals without SCI, and anxiety and PTSD are at least twice as prevalent (16). Substance use and abuse is also significantly more prevalent (17). However, even though individuals with SCI usually have contact with health care professionals, these mental health disorders are often not recognized and therefore often not addressed optimally, perhaps because of the other more obvious physical health impairments caused by SCI and the stigma that surrounds mental health disorders (18). An important cohort of people with SCI suffering from emotional distress, mental health problems and substance abuse is the United States of America war veterans. Studies show that 40% of veterans received at least one mental disorder diagnosis, most commonly depressive disorder (19%), posttraumatic stress disorder (12%), and substance or alcohol use disorders (11%) (19). Several patient characteristics predicted mental disorders, including age, racial minority identity, non-traumatic SCI etiology, and incomplete vs. complete injury. Mental disorders were associated with greater impairment from health and mental health-related problems and less satisfaction with life (19). A 2007 study showed that among the veterans with SCI and depression diagnoses (20), 70% were also diagnosed with another psychiatric illness, with post-traumatic stress disorder and other anxiety disorders being the most common. Veterans with SCI and depression had more healthcare visits and received more pharmaceutical prescriptions than their counterparts without depression (20).

Social interactions

But the question of perception of self after SCI is not only subjective to a mirror. Social interactions, stigma and prejudice contribute to the aforementioned psychological issues. Ableism is the disability-based discrimination that results from conceptualizing able-bodied people as “normal” and superior to people with disabilities. Despite its presence, stigma and bias towards people with disabilities are studied much less frequently than other attitude-relevant domains such as age, race, or gender. Although bias can influence judgment and actions in either a positive or negative direction (21, 22), studies revealed a general negativity towards people with disabilities (23, 24)—a negative attitude that people with disabilities expressed themselves (23). Misconceptions about the lived experiences for people with SCI are regrettably common and can inadvertently influence an emotional bias (e.g., prejudice), cognitive bias (e.g., stereotype), or behavioral bias (e.g., discrimination). These can result in self-stigma, public-stigma, or professional or institutional stigma. Self-stigma is when a person sees themselves in a stigmatized way. Research shows that self-stigma appears to change over the course of injury (25). Self-stigma is most prevalent during the first two to three years of SCI (26), although the experience of stigma often persists over the course of one’s lifetime (27). Early models of disability argued that disability was a static experience, and concerns waned after one “adapted to disability” (2). Although the majority of psychosocial consequences are most intense immediately after SCI (26, 28), and they qualitatively differ between immediate and long-term effects of SCI, many psychosocial consequences remain consistent throughout one’s life. A static view of living with disability neglects the reality of dynamic and continual psychosocial challenges over time (29). SCI is a permanent condition requiring lifelong, daily adaptations for both the person with SCI and those caring for them (30).

Support system interactions

Living with SCI often forces individuals to re-evaluate and re-construct their personal and social goals and identities in their family and social systems as a result of transitioning to more dependent-functioning and changes in emotional, psychological, economic, envi-

ronmental, and social stressors (5, 30, 31, 32, 33, 34). Such physical limitations of SCI may initially disrupt the original way in which spouses or family members interact or meet traditional expectations (2, 5, 35). Despite these new and challenging stressors, individuals with SCI and their family members can better adapt to life with SCI by learning to accept the disability, staying solution focused (36, 37), accentuate abilities and values [24], and utilize socialization and supportive communication (30, 33, 34). Depression is a common problem for women with SCI, and many do not receive treatment, particularly psychological treatment (38), which can have an impact on the underlying support system. Families and friends of SCI survivors often have to work with a depressed individual.

Importantly, people with spinal cord injury (SCI) have to fight with their own and societal attitudes and stereotypes that limit sexuality to the physiological functions of genitalia, phallogocentric primacy of sexual pleasure, and sexual attractiveness of perfect bodies, thus affecting spousal connection. Research has provided with psychoeducational initiatives that try to meet the sexual needs of people with SCI and their partners, whilst providing adequate education and psychological support, involving partners, and creating a space to talk among peers (39). Results suggested that women with SCI experience greater symptom bother in certain areas, but that patterns of symptom bother across menopause and transition through menopause and age at final menstrual period (FMP) is similar to their peers. Larger studies are needed to examine menopause outcomes with respect to level of injury and completeness of injury. These findings provide a framework that women with SCI and their health care providers can use to address the menopause transition and highlights the importance of multidisciplinary involvement to maximize health and wellbeing during this transition (40).

Compared with the general population, low serum total testosterone concentration occurs earlier in life in men with SCI, at a higher prevalence by decade of life, and their age-related decline in circulating total testosterone concentration is greater (41).

Understandably, not all partners cope with SCI. Studies show a divorce rate of 17% [95% CI: 13%–20.9%] after SCI in a sample of Iranian population. The protective influence of age in maintenance of marriage

was only detected in men, which proposes existence of a sexual polymorphism in the role of age. Divorce rate was similar between two genders and injury characteristics were not related to divorce rate as well (42).

Employment

Studies have shown that life satisfaction is positively correlated with employment, regardless of income, as vocational outcomes predict life satisfaction (29) and longevity (43, 44). Employment is especially impactful on the quality of life for people with SCI (33), notably to enhance self-esteem, foster positive role model experiences, promote optimism, positive coping, and increase motivation. Moreover, people with SCI who are employed seem to advance in psychological adjustment compared to those who are unemployed (43, 45). Psychosocial problems for persons with SCI are mainly associated with financial hardship due to unemployment and the high cost of living, followed by difficulties with transportation, house modification, education, marriage, social communication, sports, and entertainment. Psychological problems include sadness, depression, irritability/anger, suicidal thoughts, and a lack of self-confidence. The levels of the aforementioned problems differ with respect to sex (46).

COVID-19

People living with SCI during the COVID-19 pandemic experienced a variety of personal physical, psychological, and social challenges, each of which could disrupt daily functioning and quality of life. Increased utilization of telehealth is recommended to support continued engagement in rehabilitation, and foster connection and community amongst others with SCI and health professionals (47). A survey of people with SCI who were in active in-patient rehabilitation from two SCI Rehabilitation Centers in Bangladesh showed that participants reported high levels of knowledge, adoption of positive attitudes, and the practice of positive health advisory behaviors related to COVID-19 prevention procedures. However, high levels of depression, anxiety, and stress were also reported, while women and younger participants were more likely to have high Knowledge, Attitude and Behavioral practices (KAP), whereas those living in rural areas and

with literacy challenges were less likely to report high knowledge scores (48). A study exploring the impacts of COVID-19 on aspects of the lives of individuals living with SCI in Nepal reported also that the pandemic has tremendously impacted the physical, mental, social, and economic aspects of the lives of individuals with SCI (49). These, in turn, could impede the functioning and well-being of this population. The utilization of telehealth to provide education, psychosocial support, social awareness programs, and the provision of essential medical supplies appears necessary to maintain and improve the well-being of individuals with SCI during this pandemic. Future studies using an in-depth interview approach and psychosocial interventions are recommended (49).

Treating Psychological Issues in SCI- where are we now?

People with SCI first come in contact with hospital personnel - and their journey in the muddy waters of SCI reality starts there. Research suggests that even small adjustments in hospital routine, such as Nursing Assessment of Psychological Status Questionnaires, can be valid and reliable, while training nurses to use this instrument may help to enhance good emotional care of patients (50). Also, rehabilitation programs should focus on defining critical terms such as self-management and intentionally describe the components included in the self-management programs, especially those informed by theory, because this is rarely done in the current scientific literature (51). Comparative studies of different self-management programs are needed to identify those best suited to certain patient characteristics (i.e., sociodemographic, clinical), while contextual research in the form of qualitative designs will help clinicians in identifying how best to tailor self-management programs to unique clusters of individuals with SCI using effective messaging, educational, and behavioral strategies (52). Educational support should be a part of a comprehensive rehabilitation program and geared towards addressing the patients' personal and family needs, while educating the community about SCI in order to allow for reintegration into society (53). Of note, reviewed literature suggests that existing guidelines concerning mental health following SCI neglect positive processes of adjustment and sug-

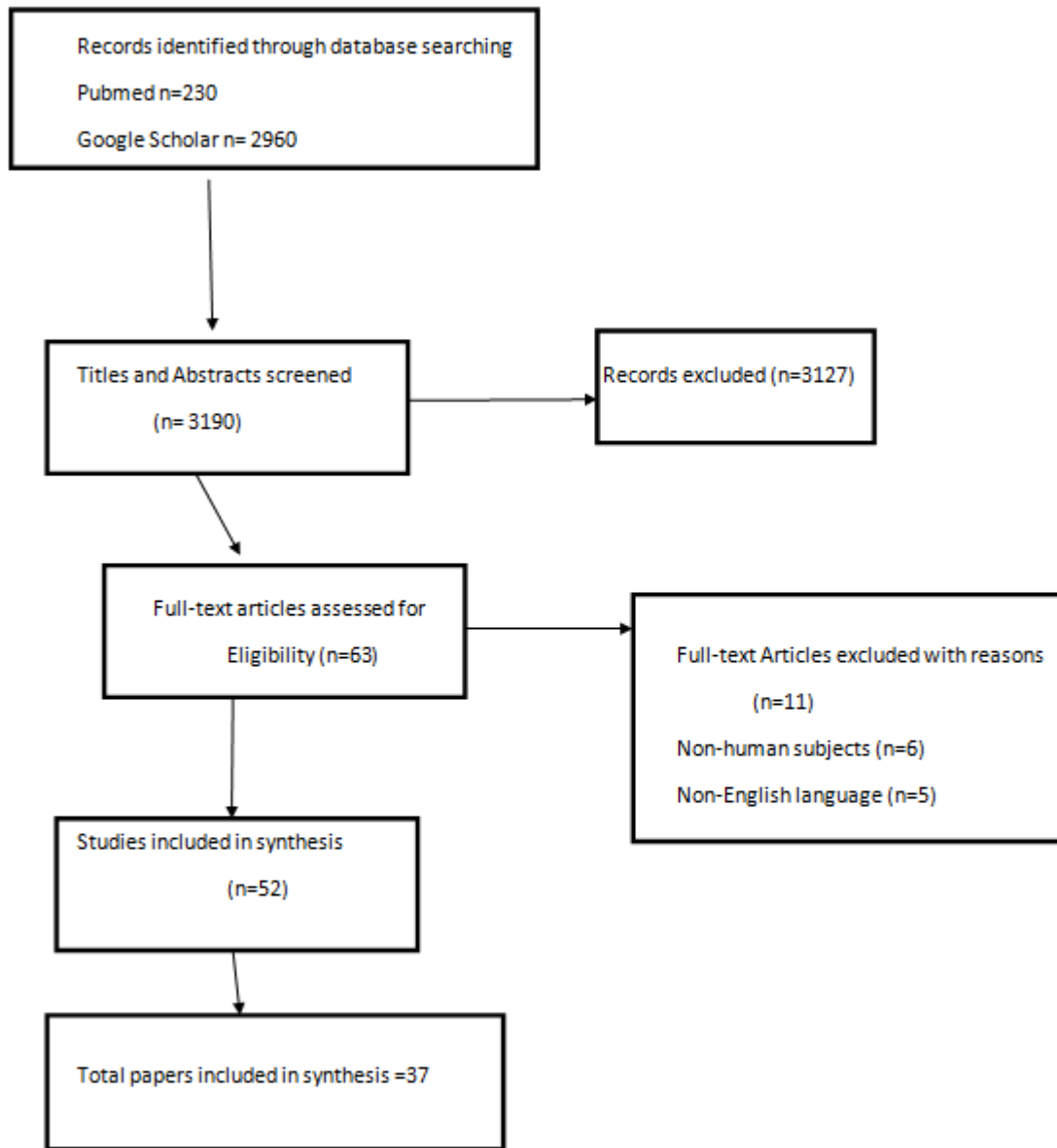


Figure 1. Flowchart of the study

gest this neglect contributes to a deficits-based view of mental health following SCI. Research into “positive” or adjustment-enhancing processes is mostly cross-sectional, heterogenous, and poorly positioned to inform future guideline-development. Researchers should achieve consensus over the operationalization of essential processes and overcome a fixation with “outcomes” to better inform management of mental

health after SCI (54). Also, patients with SCI who present with PTSD symptoms in the acute trauma care setting should be provided with specific cognitive behavioral interventions (55). Interventions for depression in SCI, including a self-management program, should target factors such as self-efficacy and mastery, which could improve secondary medical complications and overall quality of life (56). It is imperative to remain

vigilant in the health profession and acknowledge the need for possible education and training (e.g., coping strategies, communication skills training) as well as counseling prior to discharge to assist individuals with SCI and family caregivers with adaptation to a new life post-injury (34).

Psychological support is imperative in people with SCI. Mental health providers are the cornerstone of such approaches, and research demonstrates the practicality of cognitive behavioral therapy, which consists of educating patients about their pain, focusing in techniques on how to cope with their pain, such as relaxation training, and how to implement these cognitive coping techniques in real-life situations (57). This form of psychological therapy has been shown to successfully reduce depression and anxiety symptoms in individuals with SCI (9, 58, 59, 60). Several studies have examined if cognitive behavioral therapy is a useful treatment for reducing pain after SCI (58, 59, 61, 62). Heutink *et al.*, carried out a multicenter randomized control trial on the use of cognitive behavioral therapy for 10 weeks in individuals with SCI-induced neuropathic pain (62). They assessed pain intensity and pain-related disability as well as anxiety, depression, and life satisfaction before treatment and 3- and 6-months after the intervention started. They found that the intervention group, but not the control group, displayed a significant decrease in pain intensity and pain-related disability at the 3-month timepoint. The intervention group also displayed a decrease in anxiety and an increase in participation in activities at the 3- and 6-month timepoints compared to baseline. Importantly, the participants stated they would recommend this type of treatment program to others but suggested it be offered earlier following SCI. Burns *et al.*, measured the influence of 10-weeks of cognitive behavioral therapy paired with either group exercise or guided relaxation in individuals with SCI-induced neuropathic pain (61). They found that although this treatment program did not reduce pain severity, it did help individuals cope with their pain, lessened pain interference with daily activities, and improved their sense of control. Many of the studies using cognitive behavioral therapy as a treatment for SCI-induced pain, anxiety, and/or depression suggest that “refresher” courses to reinforce skills learned during the treatment program

are important to maintain efficacy of this treatment.

On a different note, mindfulness-based interventions are different from cognitive behavioral therapy as these interventions aim to facilitate present-moment awareness and acceptance, rather than attempting to change behavioral and psychological responses (63). A systemic review by Streijger *et al.*, on the use of mindfulness-based interventions in individuals with SCI pain found a variation in results on this therapy’s efficacy in the 5 studies reviewed (63). One study reported a significant reduction in SCI pain, while the others reported no change. Additionally, 4/5 studies reported a significant reduction in symptoms of depression while 3/5 reported reductions in anxiety. Authors suggest that while mindfulness might not improve SCI pain, it could be used to reduce incidence of depression and anxiety in individuals with SCI-induced co-morbid pain and mood disorders. However, two recent studies using different forms of mindfulness interventions [meditation (64) and yoga (65)] in individuals with SCI, demonstrated positive outcomes on pain, anxiety, and depression. Zanca *et al.*, used a 4-week clinical meditation and imagery program, which included mindfulness, meditation, and guided imagery in individuals with chronic nociceptive and/or neuropathic SCI pain (64). They measured pain outcomes as well as depressive symptomology and perceived stress. Their results indicated that the intervention group showed a greater decrease in depressive symptomology and worst pain intensity over the last week and a greater increase in perceived control over pain. Although their results did not reach statistical significance, the authors note that it was a pilot study and that their sample size was small. Chalageri *et al.*, used 1 month of *raja yoga*, which is a meditation technique, and found a significant decrease in numeric pain rating, anxiety and depression, and perceived stress scale in individuals with SCI that received the *raja yoga* treatment compared to those that received conventional rehabilitation (65). Additionally, they saw a significant increase in quality-of-life scores in the intervention group. Importantly, SCI patients that have developed neurogenic bowel and/or neurogenic bladder report psychological distress, anxiety, and embarrassment about their abdominal pain, constipation, incontinence, or need for catheterization. Prescribing cognitive behavioral therapy, meditation,

or yoga/exercise may improve the mental strain of neurogenic bowel and neurogenic bladder inhibiting the hyperactive autonomic nervous system as suggested by functional gastrointestinal disorders models, such as irritable bowel syndrome (57). Interestingly, in an era of microbiome and epigenetics, studies show the importance of understanding the mechanisms underlying the relationship between SCIs, gut dysbiosis and psychological stress, which could contribute to the development of novel therapeutic strategies to improve SCI patients' quality of life (66).

Although age and education do not seem to significantly influence psychological empowerment, self-esteem can have a direct effect on psychological empowerment, whereas physical impairment duration, functional ability, and social support had indirect effects through self-esteem. These four predictors explained 64% of the total variance in a model of psychological empowerment for people with spinal cord injury (67), and these findings can be used as a guideline for developing appropriate interventions to promote psychological empowerment among patients with spinal cord injury (67).

In conclusion, rehabilitation is a lifelong journey for people with SCI. Psychological support and mental health is a balance that should never be lost. Research has shown that rehabilitation professionals have a central role in promoting purpose in life as a means of increasing longevity, since by assessing personality

factors predictive of specific causes of mortality, those at risk may be targeted for cause-specific prevention strategies (68). Specific targets and socioeconomic groups, such as attempts to improve the outcomes of Veterans with SCI, should focus on a tailored approach that emphasizes patients' demographic, medical, and psychosocial assets (e.g., building their sense of self-esteem or increasing their feelings of mastery), while providing services targeted to their specific limitations (e.g., reducing depression and anxiety) (69). Also, disability-sensitive and affordable depression treatment must be made available to everyone, especially women with SCI (38). Studies of testosterone replacement therapy in men with SCI should assist in determining the possible functional and clinical benefits from reversing low serum total testosterone concentration (41). As far as the COVID-19 pandemic is concerned, future studies using an in-depth interview approach and psychosocial interventions are recommended (49). SCI deeply affects multiple dimensions of a person's psychological and social well-being, with vast consequences. Health care providers are first contacts of newly acquired SCI people; so, the accountability to mindfully consider the individuality and associated psychosocial traits remains imperative.

Conflict of interest

The authors declare no conflicts of interest.

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