

Special Article

Mental Well Being, Religiosity and Spirituality among People with Spinal Cord Injury

Ismeni Serpanou, PhD

School of Human Movement and Quality of Life Sciences, Faculty of Nursing, University of Peloponnese, Tripolis, Greece

Evanthia Sakellari, PhD

Department of Public and Community Health, University of West Attica, Athens, Greece
Department of Nursing Science, University of Turku, Turku, Finland

Sofia Zyga, PhD

Vice Rector, University of Peloponnese, Tripolis, Greece

Foteini Tzavella, PhD

School of Human Movement and Quality of Life Sciences, Faculty of Nursing, University of Peloponnese, Tripolis, Greece

Despina Sapountzi-Krepia, PhD

Head of the Nursing Department, Frederick University, Nicosia, Cyprus

Correspondence: Ismini Serpanou, School of Human Movement and Quality of Life Sciences, Faculty of Nursing, University of Peloponnese, Tripolis, Greece e-mail: iser1301@gmail.com

Abstract

Spinal Cord Injury (SCI) is a medically complex and life-disrupting condition. Traumatic SCI can be mostly a result of falls, road traffic injuries, occupational and sports injuries, and violence, while, non-traumatic SCI involves an underlying pathology, musculoskeletal disease and congenital problems such as spina bifida. A complete SCI produces total loss of all motor and sensory function below the level of injury with both sides of the body affected equally. An incomplete SCI allows some function to remain below the primary level of the injury. Mental wellbeing is having the capacity to live a full and creative life, and having the flexibility to deal with life's ups and downs. The consequences of a SCI include increased levels of mental distress, which is associated with higher levels of pain and depression and lower levels of self-esteem and satisfaction. An estimated 20-30% of people with spinal cord injury show clinically significant signs of depression, which in turn has a negative impact on improvements in functioning and overall health. On the other hand, religiosity and spirituality are important aspects of people's lives. Several investigations show that religious participation is related with better outcomes for persons who are recovering from physical and mental illness, also the psychology science have committed special issues to positive correlations between religious belief and practice, mental and physical health and longevity. After a traumatic experience, great changes may occur in one's religious and spiritual life. There should be implemented psychosocial interventions among people with SCI which will allow them develop acceptance cognitions and skills in order to face their new life situation. These interventions should also integrate the benefits of religiosity and spirituality aspects which may have a positive impact on the mental well-being of people with SCI.

Keywords: mental well being, religiosity, spirituality, spinal cord injury

Introduction

Spinal Cord Injury (SCI) is a medically complex and life-disrupting condition (W.H.O., 2013a). It is a debilitating neurological condition with tremendous socioeconomic impact on affected

individuals and the health care system (Alizadeh, Dyck & Karimi-Abdolrezaee, 2019). SCI per million in Europe ranges from 8.3 in Denmark to 33.6 in Greece - the highest rate (Jazayeri et al. 2014). The global incidence of Traumatic Spinal

Cord Injury varies from 8.0 to 246.0 cases/million inhabitants per year and the global prevalence varies from 236.0 to 1,298.0 per million inhabitants (Furlan et al. 2013). According to the W.H.O. (2013a) traumatic SCI can be mostly a result of falls, road traffic injuries, occupational and sports injuries, and violence, while, non-traumatic SCI involves an underlying pathology, musculoskeletal disease and congenital problems such as spina bifida.

Those with SCI are at risk of a range of secondary conditions of circulatory system, genitourinary system, neuromusculoskeletal system, respiratory system, including pain and pressure ulcers (W.H.O., 2013a). Thus, their quality of life may deteriorate. Despite the impact on health, there are several socioeconomic consequences too. Misconceptions, negative attitudes and physical barriers to basic mobility result in the exclusion of many people from full participation in society, while there is a global unemployment rate of more than 60% among those SCI (W.H.O., 2013b). In addition, unmet needs of people with SCI include, among others, psychological needs (W.H.O., 2013a) while an earlier study highlights the complexity of mental health problems experienced by people with SCI in the community (Migliorini, Tonge & Taleporos, 2008).

The importance of both psychological and physical aspects of health appeared to be endorsed by people with SCI were found by a systematic review (Simpson et al., 2012). Hence, it is important to address the needs of people with SCI seeing them holistically and their factors associated positively with their health and not focusing only on their disabilities and the associated secondary conditions.

Spinal Cord Injury

The term spinal cord injury refers to damage to the spinal cord resulting from trauma (e.g. a car crash) or from disease or degeneration (e.g. cancer) (W.H.O., 2013c). A complete SCI produces total loss of all motor and sensory function below the level of injury with both sides of the body affected equally. An incomplete SCI allows some function to remain below the primary level of the injury. A person with an incomplete SCI may be able to move one arm or leg more than the other or may have more functioning on one side of the body than the

other (American Association of Neurological Surgeons, 2020).

Paraplegia refers to impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to damage of neural elements within the spinal canal. With paraplegia, arm functioning is spared, but, depending on the level of injury, the trunk, legs and pelvic organs may be involved. The term is used in referring to cauda equina and conus medullaris injuries, but not to lumbosacral plexus lesions or injury to peripheral nerves outside the neural canal (Marino et al, 2002)

Tetraplegia (preferred to “quadriplegia”) refers to impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal. Tetraplegia results in impairment of function in the arms as well as typically in the trunk, legs and pelvic organs, i.e. including the four extremities. It does not include brachial plexus lesions or injury to peripheral nerves outside the neural canal (Kirshblum et al, 2011).

Spinal cord injuries at the cervical level result to tetraplegia. Depending on the specific location and severity of trauma, limited function may be retained. Additional symptoms of cervical injuries include low heart rate, low blood pressure, problems regulating body temperature, and breathing dysfunction (Sabharwal, 2013).

Injuries at the level of T1 to T8 result in inability to control the abdominal muscles. Trunk stability may be affected; even more so in higher level injuries. The lower the level of injury, the less extensive its effects. Injuries from T9 to T12 result in partial loss of trunk and abdominal muscle control. Thoracic spinal injuries result in paraplegia, but function of the hands, arms, and neck are not affected (Weiss L, Weiss J & Pobre T, 2010).

The effects of injuries at or above the lumbar or sacral regions of the spinal cord include decreased control of the legs and hips, genitourinary system and anus. People injured below level L2 may still have use of their hip flexor and knee extensor muscles. Bowel and bladder function are regulated by the sacral region. It is common to experience sexual dysfunction after injury, as well as dysfunction of the bowel and bladder, including fecal and

urinary incontinence (Weiss L, Weiss J & Pobre T, 2010).

A systematic review on health and life priorities of individuals with SCI, identified that health, in addition to relationships, were shown to be important life areas to them. In addition, within the health domain, people with SCI identified restoration of motor, bowel, bladder, and sexual function as priorities for recovery. Restoration of arm and hand function was a specific priority for those with tetraplegia, whereas mobility function was more important to those with paraplegia (Simpson et al., 2012).

Mental well-being among people with Spinal Cord Injury

Wellbeing can be understood as how people feel and how they function, both on a personal and a social level, and how they evaluate their lives as a whole (New Economics Foundation, 2012). Mental wellbeing is having the capacity to live a full and creative life, and having the flexibility to deal with life's ups and downs (NUI Galway, 2018).

The sudden paralysis of the body and the profound change in a person's quality of life are inevitably accompanied by many psychological problems (Dezarnaulds and Ilchef, 2014: 5). The consequences of a SCI include increased levels of mental distress, which is associated with higher levels of pain and depression and lower levels of self-esteem and satisfaction Siddall et al (2017). Certain additional factors often coexist with the physical disability which have further an impact not only physically, but mentally too (Dezarnaulds and Ilchef, 2014: 6):

- Chronic pain
- Chronic fatigue
- Drug intake
- Isolation
- Bid
- Health complications and body image

People who experience physical illnesses have an increased incidence of depression in comparison to the general population (+ 10% among outpatients and up to + 15% in patients irrespectively of the diagnoses) (Katon and Schulberg, 1992). An estimated 20-30% of people with spinal cord injury show clinically significant signs of depression, which in turn has

a negative impact on improvements in functioning and overall health (W.H.O., 2013c). Furthermore, in such a dramatic change in the quality of life of people with SCI, suicide is about 5 times more common than in the general population (Dezarnaulds και Ilchef, 2014). Each person's response to the new situation, cannot be predicted, is purely personal. The following factors play an important role for the psychological status of people with SCI (Dezarnaulds and Ilchef, 2014: 6):

- Lack of private life
- Loss of independence
- Big changes in lifestyle
- Uncertainty about the future
- Feelings of incompetence
- Getting apart from family and friends
- Inability to perform basic physical functions
- Changes in physical health and functionality
- Changes in body image

Therefore, several instruments have been developed in order to assess mental health status (Bombardier et al., 2012; Kroenke et al., 2001; Sakakibara et al., 2009), since mental health problems are developed among 42% of people with from 6 weeks to 20 years after injury (O'Donnell et al., 2005; Salyers et al., 2004). Ullrich et al. (2013) found that 20% among their study participants with post-traumatic SCI had depression the first year after injury. Similarly, in US studies, depression has been found among 22.2% of people with SCI which is three times higher than in the general population (Kessler et al., 2003; Williams and Murray, 2015). Xue et al. (2016) support that the perception of people with SCI falling off in work, social relationships and family functionality may indicate that they suffer from depression. Depression among people with SCI is often presented as a consequence of urinary tract infections and reduced mobility (Herrick et al., 1994), pain which is up to 20% among them (Ullrich et al., 2013) while it is also linked with social isolation (Fuhrer et al., 1993), higher unemployment (Scivoletto et al., 1997) and higher mortality (Krause and Reed, 2009).

Moreover, it is found that 40% of people with SCI report symptoms of stress in the first days after an injury and the diagnosis, while among 4% of them, these symptoms persist 1 month

after the traumatic event, resulting in a diagnosis of Post Traumatic Stress Disorder (PTSD). Without any treatment, 29% continue to have PTSD symptoms even 30 years later (Pollock et al., 2017:: Introduction).

Although every person with SCI reacts differently, research has shown a relationship between psychological problems and personality characteristics such as humor, optimism and self-efficacy which are associated with better prognosis (Dezarnaulds and Ilchef, 2014: 5). People with SCI and psychological symptoms preceded which have not been addressed, may suffer from depression, with the following accompanying behaviours and feelings (Khazaeipour et al., 2015; Larkin, 2010):

- getting upset with the health care staff, family members and friends who are putting pressure on them to seek proper rehabilitation treatment,
- avoiding talking about the causes of paralysis and the new reality,
- changes in appetite (either they have loss of appetite or they eat too much),
- pushing away family and friends, avoiding close relationships and new friendships,
- difficulty in concentration, remembering and making decisions,
- feeling constantly tired and without energy,
- feeling not worth living, since they cannot move as they used to
- feeling upset and restless,
- feeling useless seeing that there is no return to the previous state,
- feeling guilty of surviving the accident and ending up in a wheelchair,
- not expressing emotionally themselves,
- lose of interest in activities or hobbies that used to excite them,
- feeling constantly sad and empty
- feeling persistent pain, discomfort and other persistent physical symptoms (such as headaches, cramps and digestive problems that persist),
- having sleeping problems (either they sleep for many hours, they have insomnia, etc),
- having suicidal thoughts.

Religiosity and spirituality issues among people with Spinal Cord Injury

Religiosity and spirituality are important aspects of people's lives. Several investigations show that religious participation is related with better outcomes for persons who are recovering from physical and mental illness, also the psychology science have committed special issues to positive correlations between religious belief and practice, mental and physical health and longevity (Alves et al., 2010). Spiritual beliefs can help people find meaning in life and influence their feelings, behaviours, and overall mental health (Khoynezhad et al. 2012). Literature supports that religious belief and behaviour have a positive effect on mental and physical health (Mills 2002, Thoresen & Harris 2002). Moreover, it has been found (Berry & York 2011) a direct and protective effect over time between religiosity and/or spirituality and depression.

It is supported that there are three ways that religion affects health: i) it provides framework to cope with and reduce stress of difficult life situations, ii) it provides an outlet for social support, iii) it promotes healthier living habits (Aukst-Margeti & Margeti, 2005). Aspects of spirituality, religiosity and beliefs have high scores during the disease process and help people to face SCI (Magalhães et al., 2015). A study (Wilson et al., 2016) among 210 people with SCI, it was found that 26% had major depression and spiritual well-being was closely linked to quality of life. On the other hand, Siddall et al (2017), found that levels of spirituality among people with SCI were significantly lower compared to those without such injury.

Moreover, Jones et al. (2018) found that people with SCI and their families derive power from a number of different sources of spirituality including religious belief. Although their spirituality sources have often been tested and the intensity may have decreased for some families, they are linked to three main outcomes; gratitude, hope, and a deeper relationship with others which help families during their journey with SCI. Similarly, Xue et al. (2016) study among people with SCI who have depressive symptoms, showed that spirituality and religiosity can protect to some extent from depression.

Jones et al. (2016) found in their systematic review that spirituality is positively associated

with life satisfaction, quality of life, mental health and resilience among people with SCI. Thus, those who find religiosity or spirituality as an essential aspect of their lives, it should be given the opportunity to practice their 'beliefs' in the way they consider appropriate. Given the fact that there is variety and diversity of each person's 'beliefs', more time should be devoted in identifying and addressing those needs (Sulmasy, 2009). Health professionals may reinforce the role of spirituality that plays in recovery by integrating the spiritual beliefs of individuals and their family members in assessing and intervention processes.

Discussion and conclusions

Literature supports that suboptimal functional outcomes associated with poor emotional health are reported in a variety of orthopaedic specialties (Ayers, Franklin & Ring, 2013). It is found (Migliorini, Tonge & Taleporos, 2008) the vulnerability of the population with spinal cord injury to emotional disorders and the complexity of mental health problems experienced that people with SCI. Rehabilitation should include emotional and social support (Rabeh & Caliri, 2010) which is also supported by a recent study (Serpanou et al., 2019) with participants supporting that it is essential to address the patients' mental health issues since patients.

While earlier the research about SCI rehabilitation focused on physical and functional outcomes and the medical issues, it is now claimed that a thorough appreciation of the psychological and social factors associated with adjustment is crucial for optimal rehabilitation outcomes following SCI (Dezarnaulds and Ilchef, 2014).

After a traumatic experience, great changes may occur in one's religious and spiritual life (Şimşir, Boynueğri & Dilmaç, 2017). Moreover, the coping strategies to physical and psychological adjustment in people with disabilities include religious and spiritual approaches (Johnstone, Glass & Oliver, 2007). It is concluded that religiosity and/or spirituality help people with SCI cope, give them meaning, and they a source of happiness in their lives (Marini & Glover-Graf, 2011). Thus, Wilson et al., (2016), suggested spirituality assessment, along with other more traditional psychological measurements, should be considered for diagnosis and treatment, since it is found that during rehabilitation, spiritual beliefs can help

improve quality of life and mild depressive symptoms that often accompany chronic illnesses and disabilities.

In conclusion, even though better understanding may be needed about how to address the challenges during SCI rehabilitation, there should be implemented psychosocial interventions among people with SCI which will allow them develop acceptance cognitions and skills in order to face their new life situation. These interventions should also integrate the benefits of religiosity and spirituality aspects which may have a positive impact on the mental well-being of people with SCI.

References

- Alizadeh A., Dyck S.M. & Karimi-Abdolrezaee S. (2019) Traumatic Spinal Cord Injury: An Overview of Pathophysiology, Models and Acute Injury Mechanisms. *Frontiers in Neurology*, 10: 282.
- Alves R.R.N., Alves H.N., Duarte Barboza R.R. & de Medeiros Silva Souto W. (2010) The influence of religiosity on health. *Ciência & Saúde Coletiva*, 15(4): 2105-2111.
- American Association of Neurological Surgeons (2020) Spinal Cord Injury. Available at: <https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Spinal-Cord-Injury> (Accessed: 01.03.20)
- Aukst-Margeti B. & Margeti B. (2005) Religiosity and Health Outcomes: Review of Literature. *Collegium antropologicum*, 29(1): 365-371.
- Ayers D.C., Franklin P.D. & Ring D.C. (2013) The role of emotional health in functional outcomes after orthopaedic surgery: extending the biopsychosocial model to orthopaedics. *Journal of Bone and Joint Surgery*, 95: e165 (1-7).
- Berry D.M. & York K. (2011) Depression and religiosity and/or spirituality in college: A longitudinal survey of students in the USA. *Nursing and Health Sciences*, 13, 76–83.
- Furlan J.C., Sakakibara B.M., Miller W.C. & Krassioukov A.V. (2013) Global incidence and prevalence of traumatic spinal cord injury. *Canadian Journal of Neurological Sciences*, 40: 456-464.
- Jazayeri S.B., Beygi S., Shokraneh F., Hagen E.M. & Rahimi-Movaghar V. (2015) Incidence of traumatic spinal cord injury worldwide: a systematic review. *European Spine Journal*, 24: 905-918.
- Johnstone B., Glass B.A. & Oliver R.E. (2007) Religion and disability: clinical, research and training considerations for rehabilitation professionals. *Disability and Rehabilitation*, 29: 1153–1163.

- Kirshblum S., Burns S., Biering-Sorensen F., Donovan W., Graves D., Jha A., Johansen M., Jones L., Krassioukova A., Mulcahey MJ., Schmidt-Read M., Waring W. (2011) International standards for neurological classification of spinal cord injury (Revised 2011). *J Spinal Cord Med.* 2011 Nov; 34(6): 535–546.
- Khoynezhad, G., Rajaei, A.R., & Sarvarazemy, A. (2012). Basic religious beliefs and personality traits. *Iranian Journal of Psychiatry*, 7, 82-86.
- Magalhães S.R., de Figueiredo Carvalho Z.M., de Andrade L.M., Bezerra Pinheiro A.K. & Studart R.M.B. (2015) Influence of spirituality, religion and beliefs in the quality of life of people with spinal cord injury. *Text Context Nursing*, 24(3): 792-800.
- Marini I. & Glover-Graf N.M. (2011) Religiosity and spirituality among persons with spinal cord injury: attitudes, beliefs, and practices. *Rehabilitation Counseling Bulletin*, 54 (2): 82-92.
- Marino RJ., Barros T., Biering-Sorensen F., Burns SP., Donovan WH., Graves DE., Haak M., Hudson LM., Priebe MM; ASIA Neurological Committee 2002. (2003) International standards for neurological classification of spinal cord injury. *J Spinal Cord Med*, Spring; 26 Suppl 1:S50-6.
- Migliorini C., Tonge B. & Taleporos G. (2008) Spinal cord injury and mental health. *Australian and New Zealand Journal of Psychiatry*, 42(4): 309-314.
- Mills P.J. (2002) Spirituality, religiousness, and health: from research to clinical practice. *Annals of Behavior Medicine*, 24, 1–2.
- New Economics Foundation (2012) *Measuring Wellbeing: A guide for practitioners*, London: New Economics Foundation. Available at: <https://neweconomics.org/2012/07/measuring-wellbeing> (Accessed: 01.03.20)
- NUI Galway (2018) *Defining Mental Wellbeing*. Available at: http://www.nuigalway.ie/human-resources/employee_wellbeing/defining_mental_wellbeing/ (Accessed: 01.03.20)
- Rabeh S.A., Caliri M.H.L. (2010) Functional ability in individuals with spinal cord injury. *Acta Paulista de Enfermagem*, 23: 321-327.
- Sabharwal Sunil (10 December 2013). *Essentials of Spinal cord Medicine*. Demos Medical Publishing. ISBN 978-1-936287-38-3
- Serpanou I., Sakellari E., Psychogiou M., Zyga S. & Sapountzi-Krepia D. (2019) Physical therapists' perceptions about patients with incomplete post-traumatic paraplegia adherence to recommended home exercises: a qualitative study. *Brazilian Journal of Physical Therapy*, 23(1): 33-40.
- Simpson L.A., Eng J.J., Hsieh J.T.C., Wolfe D.L. & the Spinal Cord Injury Rehabilitation Evidence (SCIRE) Research Team (2012) The Health and Life Priorities of Individuals with Spinal Cord Injury: A Systematic Review. *Journal of Neurotrauma*, 28(8): 1548-1555.
- Spinal Cord Injuries Australia (2020) What is Spinal Cord Injury. Available at: <https://scia.org.au/what-is-a-spinal-cord-injury/> (Accessed: 01.03.20)
- Şimşir, Z., Boynueğri, S. B., Dilmaç, B. (2017). Religion and spirituality in the life of individuals with paraplegia: spiritual journey from trauma to spiritual development. *Spiritual Psychology and Counseling*, 2: 89–110.
- Weiss, L.D., Weiss, J.M., Pobre, T. (15 Marc 2010) *Oxford American Handbook of Physical Medicine and Rehabilitation*. Oxford University Press, USA. ISBN 978-0-19-970999-1
- W.H.O. (2013a) International perspectives on Spinal Cord Injury. Available at: https://apps.who.int/iris/bitstream/handle/10665/94190/9789241564663_eng.pdf?sequence=1 (Accessed: 06.01.20)
- W.H.O. (2013b) Spinal Cord Injury. Key facts. Available at: <https://www.who.int/en/news-room/fact-sheets/detail/spinal-cord-injury> (Accessed: 06.01.20)
- W.H.O. (2013c) Spinal cord injury. Available at: <https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury> (Accessed: 01.03.20)