

Quality of Life of Persons Affected by Spinal Cord Injury Sequels and Advice for E-Health

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Abstract

There is a wide range of sequelae associated to spinal cord injuries and disorders, with significant impact on the individual's quality of life and well-being. Nevertheless, the incidence of traumatic spinal cord injuries is low, as well as the prevalence of people with spinal cord injuries sequels in a particular social core absolute numbers. Thus, primary care professionals may find it difficult to correctly monitor and treat health problems, sometimes specific, in these patients. The monitoring and treatment of complications, rehabilitation, psychological adaptation, sexuality, social and family integration require actions with a regular contact with the specialist. People who live far from specialized centers may have greater difficulty in receiving proper care and obtaining the necessary resources for an adequate quality of life. In recent years, assistance, training, and communication programs-such as telemedicine-have been implemented between specialized and primary care providers, as well as directly with the affected person. Here, we summarize the main environmental difficulties that influence the quality of life of spinal cord injured subjects and the proposed approaches in specialized journals, with telemedicine increasingly having greater relevance for the comprehensive care of this population.

Keywords: Spinal cord injuries; Quality of life; Telemedicine; Primary health care; Training programs

Abbreviations: SCI: Spinal Cord Injuries; QoL: Quality of Life; GP: General Practitioner; NLUTD: Neurogenic Lower Urinary Tract Dysfunction; ISCoS: International Spinal Cord Society

Introduction

Spinal Cord Injuries (SCI), involving many organs and systems, have short- and long-term effects on these patients. This type of injuries cause mobility limitations and a wide range of complications that may negatively affect patients' social relationships. People with SCI have 2.6 times higher risk of hospital readmission [1] and 2.7 times more medical visits, particularly during the first year after the initial diagnosis (~26 medical appointments per year), which decrease over the following years [2]. The incidence of traumatic SCI is low, around 10 to 25 new cases per million inhabitants/year [3]. Thus, prevalence of people with SCI sequels in a particular social environment is low in absolute numbers, but the medical complications and specific neurogenic dysfunctions in multiple body systems associated to SCI require regular follow-ups by specialists to ensure quality patient care. Several authors point out that for individuals living in rural areas, getting proper healthcare is more difficult. This implies a barrier for the well-being of the person and an additional negative impact on their Quality of Life (QoL), which is lower than that of the general population [4-6].

People with SCI usually acknowledge their General Practitioners (GPs) as their front-line physicians for medical assistance [7] and they recognize as having an adequate satisfaction level with their primary care doctors. In some countries, a rehabilitation specialist (physiatrist) may act as the primary care doctor, although this is not the common practice [8].

Thus, implementing telematic follow-up programs and resources, establishing contacts between health professionals (provider to provider - specialists to GP) or directly with the patients, is being studied and carried out with increasing interest [9]. Here, we reviewed the existing literature on the factors influenced by patients' environment that affect their QoL and discuss our experience based on voluntary surveys in outpatient clinic checkups, evaluating people's health status and medical complications.

Care Needs

The main SCI-related complications include Neurogenic Lower Urinary Tract Dysfunction (NLUTD), bowel dysregulation, chronic pain, spasticity, sexuality problems, and pressure sores [10]. Consequently, SCI patients visit the physician, the emergency department [1,2], and are readmitted to the hospital [11] more often. Guilcher and collaborators [12] suggest there is a high rate of emergency consultations by patients from rural areas, from which 66% do not require admission to the hospital, 17% are potentially preventable, and 33% were classified as low acuity. In a research carried out by Van Loo's and collaborators [10], the authors report that the GP is the most contacted healthcare worker, and 26% of the patients expressed the need for a consultation in a specialized rehabilitation center. This implies that the provided medical care is likely to be insufficient and additional treatments in cases of NLUTD (19.7%), pain (28.9%), and spasticity (26.7%) are required. They also pointed out that the information directed to the patients is scarce, particularly regarding sexual issues (16.7%). This suggests that 34% of secondary complications, mostly pressure sores (52.8%), may be preventable. In fact, the patients themselves could prevent around 30% of the pressure sores. Depending on the distribution of the population in each country, people with SCI may have more or less difficulties to access social and health services or specialized medical assistance. In a review by McColl the authors consider that psychological care, sexual and reproductive health, as well as adaptation to the society and new living conditions are insufficiently addressed [8]. There is excellent reachability with the GPs in the different studied groups in several countries, particularly over the phone, which patients may not regularly have with their specialists [7]. In Canada, GP visits are three times higher for these individuals in comparison to general population [12]. From our survey, the interviewed participants showed a level of satisfaction categorized as good for the care received from their GP and their specialist, and normal for the emergency services. In our opinion, the implementation of telemedicine programs may improve the healthcare and communication, aiming to solve different problems with the GP, and the patient's requests.

Physical Accessibility and Transportation

Independence is closely linked to the preservation of mobility. Therefore, important aspects are the physical access to different social environments and adapted transportation services. In rural

areas, any type of environmental barriers can significantly affect the SCI individual, as concluded by Glennie from data collected using the CHIEF-SF survey. Thus, social interactions of persons living in rural areas may be constrained [13]. In a comparative study carried out by Donnelly and collaborators in three countries (UK, Canada, and USA), the authors evaluated the correlation between the physical access, overall accessibility and satisfaction with their GP and specialists [9]. They concluded that accessibility to the GP is lower in the UK and accessibility to the specialist is lower in Canada. However, the waiting time for consultation with either the GP or the specialist is quite short in the three countries, with the USA having the highest accessibility to a specialist, where a physiatrist may be contacted within one day. They also pointed out that there is a risk of duplication of the provided services. Therefore, blood tests, ultrasound of the urinary system, and urinary tests should ideally be protocolized. Existence of physical barriers, even at the consultation room, is very troubling for the patient as described by Stillman on a sample of 108 participants from different settings [14]. In a study by Bökel in Germany, the authors identified the difficulty that is the most frequent encountered by people with SCI as physical barriers, that is access and transportation barriers [4].

A model developed in the Netherlands shows a very close and frequent relationship between physical therapists, primary care nurses, and GPs [10]. However, this model does not seem feasible in all countries. Furthermore, in their study, 72% of the patients expressed the need for additional care. They also preferred specialized rehabilitation care to community care: 37% versus 13% with respect to medical care, and 19% versus 8% to nursing care [10]. In our survey, accessibility does not seem to be a significant concern for our participating patients, regardless their area of residence. However, results indicate significantly lower scores for perceived QoL in dependent people.

Contact and Training Programs

Given the problems SCI people have to get medical care, improving medical assistance is necessary for those living far from specialized SCI centers. Several authors have worked on outreach programs with GPs and rapprochement for patients. Williams highlights the benefits of learning programs and follow-ups by nurses in bowel and bladder care after SCI [15]. Other authors have also developed training and medical assistance programs on key points in the follow-up of SCI people by GPs, such as the proposal of McColl, in Canada [16]. In a survey conducted in Australia, Cox interviewed people with recognized mobility and functioning problems who were poorly followed outside hospitals [17]. Their findings suggest the importance of a multidisciplinary approach and the possibility to contact with the reference unit (preferably by phone). The patients communicated transportation problems and pointed out that their educational and working needs should be prioritized. Several studies emphasize on follow-up models and GP

treatment protocols. Programs such as transitional rehabilitation aim to create a link between hospital services, regional social support, and the participation of the family and caregivers [18].

Over the past years, telemedicine programs are being developed to help establish the contact between SCI specialists either with GP professionals or directly with the patients [19-21]. The results of these initiatives are promising in terms of satisfaction, safety, improvement of assistance received, and maybe in terms of QoL, although larger studies need to be performed. The International Spinal Cord Society (ISCoS) proposed an international panel of specialists to develop an instructional course regarding telemedicine and SCI, coining the term Tele-Spinal Cord Injury (Tele SCI) [9]. Recent publications are pointing out its benefits and proposing several subjects for intervention [22,23].

Change of Address

The above-mentioned factors, mostly the struggle to get medical assistance and accessibility problems, has pushed the SCI population to move to better connected areas with more services (cities) and closer to specialized healthcare centers, as communicated by Canadian and Swiss authors. In Glennie's work with SCI subjects in diverse settings, 13% of the patients migrated to urban areas after their injury [13]. This group tended to be younger and with lower QoL scores. However, no differences in the characteristics of the injury or life satisfaction scores were identified. It is notable that the participants in this study living in the city reported more problems with depression and a lower score in the mental health domain (SF36V2 questionnaire) than patients from rural areas. Another survey by Ronca in Switzerland reports that the likelihood of moving to be closer to a specialized SCI center increases with age [24]. The language spoken in the region, as well as social and labor factors, may also influence this decision. In our survey, we found no cases of patients that changed their address or expressed a need to move.

Conclusion

People with SCI have significant difficulties in maintaining adequate standards of health and QoL, which may worsen in areas with difficult access to health care and social resources. In our community, people do not perceive living in rural areas as a negative factor, and patients report a high level of satisfaction with the received health assistance. However, mobility, dependency, and accessibility are the main concerns of SCI individuals, which can undermine their QoL. Furthermore, GPs do not always address properly the health struggles that this population may encounter, such as bladder and bowel management problems, scars, or spasticity. Direct communication programs between specialized centers and primary care should exist. We believe that telemedicine programs (i.e., Tele SCI), being developed in different modalities and in different countries, may be very useful tools in this field. Direct

connections between health providers through different routes (derivation protocols from GP, direct communication lines, etc) are necessary to maintain the standard of health in this population. Additionally, direct contact from specialized centers with the patient may provide improvements in the care and prevention of the conditions that affect SCI people. These measures may be more effective than proximity or setting, as they play relevant roles in other aspects that influence QoL, such as social integration, employment and study opportunities. Therefore, further studies should be carried to assess the needs of people in every aspect that society can offer (job opportunities, sports, social activities, healthcare assistance in rehabilitation centers, etc), regardless of the person's residence.

References

1. Dryden DM, Saunders LD, Rowe BH, May LA, Yiannakoulis N, et al. (2004) Utilization of health services following spinal cord injury: a 6-year follow-up study. *Spinal Cord* 42(9): 513-525.
2. Munce SEP, Guilcher SJT, Couris CM, Fung K, Craven BC, et al. (2009) Physician utilization among adults with traumatic spinal cord injury in Ontario: A population-based study. *Spinal Cord* 47(6): 470-476.
3. Montoto-Marqués A, Ferreiro-Velasco ME, Barrera SS, Balboa-Barreiro V, Rodríguez-Sotillo A, et al. (2017) Epidemiology of traumatic spinal cord injury in Galicia, Spain: Trends over a 20-year period. *Spinal Cord* 55(6): 588-594.
4. Bökel A, Dierks M-L, Gutenbrunner C, Weidner N, Geng V, et al. (2020) Perceived environmental barriers for people with spinal cord injury in Germany and their influence on quality of life. *J Rehabil Med* 52(8): 1401-1410.
5. Barker RN, Kendall MD, Amsters DI, Pershouse KJ, Haines TP, et al. (2009) The relationship between quality of life and disability across the lifespan for people with spinal cord injury. *Spinal Cord* 47(2): 149-155.
6. Goodridge D, Rogers M, Klassen L, Jeffery B, Knox K, et al. (2015) Access to health and support services: perspectives of people living with a long-term traumatic spinal cord injury in rural and urban areas. *Disabil Rehabil* 37(16): 1401-1410.
7. Donnelly C, McColl MA, Charlifue S, Glass C, O'Brien P, et al. (2007) Utilization, access and satisfaction with primary care among people with spinal cord injuries: A comparison of three countries. *Spinal Cord* 45(1): 25-36.
8. McColl MA, Aiken A, McColl A, Sakakibara B, Smith K (2012) Primary care of people with spinal cord injury: Scoping review. *Can Fam Physician* 58(11): 1207-1216.
9. Irgens I, Rekand T, Arora M, Liu N, Marshall R, et al. (2018) Telehealth for people with spinal cord injury: A narrative review. *Spinal Cord* 56(7): 643-655.
10. Loo MA, Post MWM, Bloemen JHA, Asbeck FWA (2010) Care needs of persons with long-term spinal cord injury living at home in the Netherlands. *Spinal Cord* 48(5): 423-428.
11. Jaglal SB, Munce SEP, Guilcher SJ, Couris CM, Fung K, et al. (2009) Health system factors associated with rehospitalizations after traumatic spinal cord injury: A population-based study. *Spinal Cord* 47(8): 604-609.
12. Guilcher SJT, Craven BC, Calzavara A, McColl MA, Jaglal SB (2013) Is the emergency department an appropriate substitute for primary care for persons with traumatic spinal cord injury? *Spinal Cord* 51(3): 202-208.
13. Glennie RA, Batke J, Fallah N, Cheng CL, Rivers CS, et al. (2017) Rural and urban living in persons with spinal cord injury and comparing environmental barriers, their health, and quality-of-life outcomes. *J Neurotrauma* 34(20): 2877-2882.

14. Stillman MD, Frost KL, Smalley C, Bertocci G, Williams S (2014) Health care utilization and barriers experienced by individuals with spinal cord injury. *Arch Phys Med Rehabil* 95(6): 1114-1126.
15. Williams KS, Assassa RP, Cooper NJ, Turner DA, Shaw C, et al. (2005) Clinical and cost-effectiveness of a new nurse-led continence service: A randomised controlled trial. *Br J Gen Pract* 55(518): 696-703.
16. McColl MA, Aiken A, Smith K, McColl A, Green M, et al. (2015) Actionable nuggets: Knowledge translation tool for the needs of patients with spinal cord injury. *Can Fam Physician* 61(5): 240-248.
17. Cox RJ, Amsters DI, Pershouse KJ (2001) The need for a multidisciplinary outreach service for people with spinal cord injury living in the community. *Clin Rehabil* 15(6): 600-606.
18. Booth S, Kendall M (2007) Benefits and challenges of providing transitional rehabilitation services to people with spinal cord injury from regional, rural and remote locations. *Aust J Rural Health* 15(3): 172-178.
19. Houlihan BV, Jette A, Friedman RH, Paasche-Orlow M, Ni P, et al. (2013) A pilot study of a telehealth intervention for persons with spinal cord dysfunction. *Spinal Cord* 51(9): 715-720.
20. Newman SD, Toatley SL, Rodgers MD (2019) Translating a spinal cord injury self-management intervention for online and telehealth delivery: A community-engaged research approach. *J Spinal Cord Med* 42(5): 595-605.
21. Tyagi N, Goel SA, Alexander M (2019) Improving quality of life after spinal cord injury in India with telehealth. *Spinal Cord Ser Cases* 5(1): 1-5.
22. Hatch MN, Martinez RN, Etingen B, Cotner B, Hogan TP, et al. (2021) Characterization of telehealth use in veterans with spinal cord injuries and disorders. *PM R* 13(10): 1094-1103.
23. Irgens I, Bach B, Rekand T, Tornas S (2020) Optimal management of health care for persons with disability related to spinal cord injury: Learning from the Sunnaas model of telerehabilitation. *Spinal Cord Ser Cases* 6(1): 88.
24. Ronca E, Brunkert T, Koch HG, Jordan X, Gemperli A (2018) Residential location of people with chronic spinal cord injury: The importance of local health care infrastructure. *BMC Health Serv Res* 18(1): 657.