



CASE REPORT

The impact of personal and environmental factors on the rehabilitation of persons with neglected spinal cord injury in Malaysia

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Abstract

Introduction Managing neglected spinal cord injury (SCI) patients in a rural setting can be challenging due to a lack of resources and the unique personal and environmental contextual factors that may hinder rehabilitation. This article aims to identify the contextual factors and their impact on successful rehabilitation.

Case presentation A middle-aged man from a rural area had suffered a neglected traumatic SCI and was first seen by the rehabilitation team 17 years post injury. He had a T7 AIS A paraplegia and was bedridden with multiple secondary complications. He was admitted with goals of optimizing his health, initiating basic spinal rehabilitation and improving his functional status. By 1 month, the patient made gradual improvement of his mobility and ADL but requested discharge despite not having achieved his rehab goals. We identified the factors that contributed to his poor motivation to be more functionally independent. Personal factors include poor educational level, his background personality and erratic health-seeking behaviour. Environmental factors included poor family and financial support, physical barriers, lack of work opportunities and facilities for people with disability, poor community support and acceptance and poor healthcare facilities and expertise.

Discussion The patient's personal and environmental factors affected the delivery of SCI management, spinal rehabilitation and management of secondary comorbidities. Awareness of early spinal rehabilitation among the rural community and healthcare authorities is crucial to promote better implementation of policies, services or programs to support people with SCI.

Introduction

Spinal cord injury (SCI) is a devastating injury requiring timely acute, medical and rehabilitation management. Hence, spinal rehabilitation is a known challenge in developing countries [1]. Other than the lack of resources, different rural areas have their own unique cultural values and beliefs, which may sometimes hinder rehabilitation [2, 3].

The International Classification of Functioning, Disability and Health (ICF) framework conceptualizes functioning as a 'dynamic interaction between a person's health

condition, environmental factors and personal factors' [4]. These contextual factors need to be recognized when setting a comprehensive spinal rehabilitation plan as some are beyond the scope of the rehabilitation team and require involvement of the local community and healthcare policymakers.

This article presents a case of an unfortunate man from a small Malaysian village with neglected traumatic SCI with poor function and quality of life. The aim of this article is to illustrate how personal and environmental factors prevented him from standard SCI management and successful rehabilitation.

Case presentation

A 46-year-old man with chronic SCI was first seen in the rehabilitation clinic 17 years post-injury after being discovered by a local SCI support group. He became

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Fig. 1 The patient's bed fills the living area

paraplegic at age 28 years following a 10-foot fall from a tree. The nearest hospital was 20 km away and he only sought treatment from a traditional healer who provided massage using oils and heated stones. He became bedbound and dependent on his elderly mother for all activities of daily living (ADL). Toileting was done on the bed and he was seldom bathed. Initially he avoided movement due to back pain. Subsequently, he developed recurrent pressure ulcers around his pelvic region, which were tended by his mother using a paste made from leaves. Gradually his lower body became deformed making movement difficult. He rarely attempted sitting position and was usually supine or slightly propped up.

He had no sensation of a full bladder or rectum and could not initiate or prevent voiding. He described features of urinary retention, overflow urinary incontinence and bowel constipation. He used cloth diapers with lack of care for his neurogenic bowel and bladder. He was first seen in a rural clinic 15 years post-SCI and treated symptomatically for fever, pressure ulcer and urinary retention and was put on indwelling urinary catheter (IDUC) for the first time. Unfortunately, no further investigations or referral for rehabilitation were done.

The patient was single, illiterate and previously a village labourer. He was shy and became more socially withdrawn following SCI. He was the youngest of three siblings, all of whom live separately. His sole caregiver was his 87-year-old mother. The patient and his family did not understand his SCI, did not seek treatment due to financial and transportation constraints and had accepted his fate. He had no social motivation, no plans to have a family and there were no possible work options within his community.

They lived in a small state-subsidized house with two bedrooms and a bathroom with a squatting toilet. His bed was in the living room where he spent time watching television (Fig. 1). They have electricity but no air-conditioning

as they cannot afford a unit or the increase in electricity bill. The hot and humid weather and lack of good hygiene had resulted in recurrent pressure ulcers and fungal skin infection. During the monsoon season, his village was prone to floods. Although his house was never affected, it had made accessibility to healthcare difficult.

Accessibility and facilities for the disabled in his village were scarce and there was no nursing care facility. He received minimum monthly allowance from the Social Welfare Department. An NGO had provided him with a hospital bed, a ripple mattress and a seldom used reclining wheelchair as there was no one to help him transfer.

Upon examination, he was thin and had poor hygiene. Neurologic examination revealed a T7 American Spinal Injury Association (ASIA) Impairment Scale A paraplegia with profound musculoskeletal deformities. He had a thoracolumbar scoliosis and his lower limbs were in a wind-swept position with flexion contracture of both knees and hips and bilateral ankle equinus (Fig. 2). His pelvis was deformed with marked wasting of the glutei and pressure ulcer scars over the sacral and bilateral greater trochanters. His upper limbs had functional range of motion and muscle strength was within normal limits.

Functionally, he was only able to feed himself. He required maximum assistance to pull to sit and to transfer. His sitting tolerance lasted <2 min due to hip pain, poor endurance and poor sitting balance.

Pelvic X-ray revealed features of osteopenia and osteoarthritis. The left hip was displaced and there was evidence of right hip avascular necrosis (Fig. 3). On abdominal X-ray, there was faecal impaction up to the ascending colon. On kidney, ureters, bladder ultrasound, he was found to have bilateral renal parenchymal disease with mild bilateral hydronephrosis and nephrocalcinosis. Renal profile showed stage 3a chronic kidney disease.

He was initially reluctant to be hospitalized and not convinced that he could gain any benefit from rehabilitation. After a year and multiple counselling sessions during clinic



Fig. 2 Multiple musculoskeletal deformities of the lower limb



Fig. 3 X-ray showing evidence of right hip avascular necrosis and left hip subluxation

visits, he finally agreed and his sister was willing to commit to caregiver training. The aim of admission was to achieve safe bowel and bladder care, optimize pain control, improve upper body strength and endurance, accomplish minimally assisted wheelchair transfers and basic wheelchair skills as well as independent personal ADL with set up.

Management was multidisciplinary involving the rehabilitation team and other medical specialties. Following bowel clearance, he was taught to do alternate day glycerin enema and adopt good dietary habits. He could not commit to intermittent catheterization and was kept on IDUC with further monitoring of upper urinary tracts. Orthopaedics consult recommended conservative management of his deformities. He was put on regular Celecoxib and Paracetamol when necessary to help him tolerate movement and a cushion to provide pressure relief during sitting. After 3 weeks, he was able to sit at the edge of the bed for >2 h and no longer required regular analgesics. He could perform push ups for pressure relief satisfactorily but needed frequent reminders. He achieved minimally assisted wheelchair transfers and could propel independently for 50 m. By 1 month, his Spinal Cord Independence Measure score improved from 24 to 39 with improvements in dressing, grooming, bowel management and bed mobility.

In rehabilitation, he developed 2 urinary tract infections and new grade 2 pressure ulcers over the left greater trochanter, left gluteus and right scrotal ulcer due to his deformities, inadequate pressure relief and friction during transfers. Consequently, he developed lower limb spasms of Penn Spasm Frequency Scale 3, which disturbed his mobility. Appropriate management was initiated and the patient was counselled for preventive measures to avoid recurrent infection and pressure ulcers.

The rehab goals were made clear upon admission. A home visit and family conference were done to identify needs and ensure family support. His siblings were advised to make arrangements to assist in his care. It was planned

that he would receive a lightweight wheelchair with detachable armrest and footrest via government funding. Nevertheless, the patient became less cooperative during therapy. He was not used to moving and had poor endurance and sitting posture, therefore more effort was required of him. His Depression Anxiety Stress Scales [5] was unremarkable; however, he became more frustrated and claimed he was content with the way he was before. He had poor insight and believed that black magic was the cause of his secondary complications and could not grasp the possibility of future problems, especially with an aging mother as the sole carer. Despite counselling, he demanded to be discharged home 1 month after admission. Owing to his premature discharge and no one to assist him in wheelchair transfers, his new wheelchair prescription was withheld until further commitment was seen to avoid wastage.

He only managed to come for a follow-up clinic visit once, 4 months after discharge by getting a ride in his neighbour's car. He no longer complied with his bowel programme as he found it troublesome and had bowel accidents almost every day. He was using a Foley catheter, which was changed every 2 weeks at a rural clinic. He was mostly bedbound but occasionally pulled himself to sit with minimal assistance from his mother. His siblings still could not commit to his daily routine, thus could not help in his wheelchair transfers.

Discussion

In developed countries, SCIs can be missed acutely but are then generally treated. In developing countries, SCIs can be neglected and patients may present late without any or with inadequate treatment [2]. Studies show that in rural areas people with SCI have a higher risk of neglected care and a higher incidence of complications. These are more severe and difficult to manage, require longer hospitalization with higher cost and result in lower functional gains [1]. There is no data regarding the prevalence of neglected SCI in Malaysia. However, these patients are seen in rehabilitation clinics throughout the country and often present with various secondary complications.

This case highlights how personal and environmental factors affected this patient's rehabilitation and functional outcome. Personal factors are large and diverse and are not listed in the ICF [4]. Studies have found educational level to be a significant predictor for community participation along with age at the time of injury, level of injury, time since injury, chronological age, gender, marital status and employment status [6]. Educational level together with cultural values, social upbringing and personal attitudes may also influence one's health insight and health-seeking behaviour, self-efficacy and motivation for social

participation. Environmental factors include products and technology; natural and man-made environments; support and relationships; attitudes; and services, systems and policies [4]. Spinal rehabilitation in low-resourced areas is challenging in view of these environmental factors, which include lack of experience of rural healthcare staff, limited availability of specialized investigations, treatment, services or equipment, lack of transportation, physical and architectural barriers and slow healthcare reform [7].

In Malaysia, SCI awareness is promoted by local NGOs via social media but has not reached the community at large. Thus there is poor understanding of SCI as a cause of paralysis. Interestingly, seeking traditional treatment is seen in both rural and urban areas. Many SCI patients have tried a myriad of traditional treatments that can be potentially harmful. These include traditional massage provided by untrained practitioners using oils or heated river stones applied with slight pressure on the back and limbs to 'optimize blood flow' and 'relieve patients from wind trapped in their limbs' to resolve paralysis. [8]. Also popular are herbal remedies and commercial health drinks that claim to cure a variety of illnesses, including paralysis. Their widespread false advertisement and absence of stringent regulations from authorities have further influenced the health-seeking behaviour of the community.

Malaysia has yet to have a care pathway for patients with SCI [9]. Patients are managed by the orthopaedic or neurosurgical teams before being referred for rehabilitation available in tertiary hospitals. Following inpatient rehabilitation, patients are discharged to their home or to a general nursing facility. ADL assistance is provided by family members or paid caregivers. Maintenance of healthcare is usually provided by the rehabilitation clinic of the tertiary hospital.

Malaysia has a healthcare facility within every 5 km radius allowing easy access to the rural community [10]. Domiciliary services are also available to provide home care to bedbound patients. Cases requiring specialist review are referred to the state tertiary hospital. Designated district hospitals have scheduled visiting specialist clinics to improve accessibility to specialist care. Unfortunately patients are still missed as the rural healthcare staff are not familiar with SCI. This adds to patient frustration, hence the appeal of traditional healers who claim to provide cure. A local study examining the equity in access to healthcare in a rural population found that inequity in unmet need exists attributable to personal reasons rather than geographical and financial barriers. It was postulated that this was likely due to the lack of responsiveness in healthcare rather than a lack of physical access [11].

Telemedicine has the potential to provide access to specialty care for the SCI population [12]. In Malaysia, telemedicine allows a rural healthcare provider to consult a

specialist remotely; however, this is only seen in critical cases. The Ministry of Health has initiated various online applications to promote dissemination of knowledge and information among all healthcare workers but this has yet to be fully implemented [13]. Tele-consultation between patient and healthcare provider is still foreign in our public health setting. Telecommunication devices such as cell phones and computers are not considered 'medical equipment', hence is not funded by the government including their associated utility bills. Additionally, some rural areas do not have access to internet connections.

Malaysia has a tropical rainforest climate with heavy seasonal monsoon rains. Structural measures to prevent floods have been undertaken [14]. However, measures such as improvement of drainage mainly occur in urban cities, whereas drainage in rural areas is still inadequate. In rural areas, the government provides funding to build and repair homes as part of the Housing Assistance Program [15]. However, the homes are standard with basic facilities, which may not suit the needs of people with SCI.

Worldwide, people with SCI have reported that rehabilitation does not adequately prepare them for community living [1]. In regards to equipment, only 5–15% of people with disabilities in low- and middle-income countries have access to assistive devices [16]. In Malaysia, there are limited beds and facilities for basic inpatient spinal rehabilitation. Therefore, simulation of the patients' actual living situation may not be possible. Prescription of basic assistive equipment for the needy is usually funded by the government that is bounded by a ceiling price and has a waiting time ranging from a month to a year. However, some equipment may not be appropriate for use due to poor social support, environmental barriers and unavailability of maintenance services.

Community support encourages participation post-SCI as it helps people develop strong coping skills, creates a feeling of autonomy, motivates patients to stay healthy and relieve stress by facilitating healthy behaviours [6]. Unfortunately, awareness regarding the need to empower people with SCI is still lacking as evident by the shortage of opportunities for community reintegration. Malaysia has enacted the Persons with Disabilities Act (PWDA) in 2008 and signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2010. To date, the PWDA has led to the promotion of rights but PWDs continue to face many barriers in their daily encounters and denied equal participation in the community. This is due to the lack of enforcement and absence of penalties for non-compliance to the PWDA [17].

In conclusion, personal and environmental factors profoundly influence spinal rehabilitation in developing countries. Research exploring these contextual factors is necessary to identify the disease burden, inadequacy of

current services and possible measures that may provide sustainable positive impacts towards spinal rehabilitation. Awareness is necessary to encourage health-seeking behaviours to empower people with SCI in the community, improve the knowledge and competency of healthcare providers and to initiate and strengthen collaborations that facilitate the needs and participation of the SCI population.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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