Review

Heterogeneity and Its Impact on Rehabilitation Outcomes and Interventions for Community Reintegration in People with Spinal Cord Injuries

Shikha Gupta1*

1School of Rehabilitation Therapy, Queen’s University 1; 15sg48@queensu.ca

* Correspondence: 15sg48@queensu.ca; Tel.: +613-876-1780

Abstract: Evidence is lacking about the most effective interventions for community reintegration to meet the wellness needs for people living with spinal cord injuries (SCI). One among various reasons for the limited literature on effective interventions for community reintegration for people with SCI is the heterogeneity that represent this population. Heterogeneity manifested by individuals’ injury as well as personal characteristics has significant implications for SCI rehabilitation practice, specifically directed towards community reintegration, a key goal of rehabilitation interventions for people with disabilities. Therefore, this paper aims to present evidence on effect of heterogeneity in SCI population on rehabilitation outcomes and discuss the relevance of this heterogeneity to rehabilitation interventions directed at community reintegration. Available literature suggests that an array of injury-related, personal, social and environmental factors predict various rehabilitation outcomes that affect community reintegration, participation, life satisfaction, and overall quality of life of people with SCI. Therefore, approaches directed at community reintegration should involve components of physical, psychosocial, and vocational rehabilitation while considering personal and societal aspects of an individual’s life. Understanding the heterogeneity will help healthcare professionals to address the needs and concerns of people with SCI in a holistic but unique way, and help them achieve a satisfying life that they desire.

Keywords: spinal cord injury; heterogeneity; rehabilitation; community reintegration

1. Introduction

The importance of community reintegration for people with disabilities has been recognized since past few years. One of the important aspects to promote health of people with disabilities is the promotion of opportunities for participation within their community and commonly held life activities [1]. However, evidence is lacking about the most effective approaches to optimize community reintegration of people having spinal cord injury (SCI) in order to promote health and fulfill their wellness needs. One among various reasons for the limited literature on effective interventions for community reintegration for people with SCI is the heterogeneity that represent this population. Various injury characteristics such as cause, level, severity, and time since injury divide individuals with SCI into many sub-groups such as traumatic versus non-traumatic; paraplegic versus quadriplegic; complete versus incomplete; and acute versus chronic. These injury characteristics in turn determine the trajectory of neurological recovery, extent of secondary health conditions, and overall prognosis [2]. However, the impact of SCI on one’s life is multifaceted and does not solely depend on injury characteristics of an individual [3]. The aftermath of SCI ranges from premature mortality, morbidity, social exclusion and loss of independence, to full reintegration into the family including performing normal activities within the community. These consequences depend on many factors such as social and community support systems available to an individual; and individual’s personal attributes such as personality, spirituality, self-perception, or acceptance of one’s disability [4,5]. Moreover, SCI is not a static condition rather a process of continuous adaptation where various factors interact with the person’s injury to make it a complex phenomenon.
All these aspects have significant implications for SCI rehabilitation practice, specifically directed towards community reintegration [7,8]. Therefore, this paper aims to present how population with SCI differs with respect to their various injury-related, personal, social, and environmental characteristics; and present evidence on relationship of these characteristics to various rehabilitation outcomes such as independent living, social adjustment, life satisfaction, or participation that affect their community reintegration [9]. The paper then discusses the relevance of this heterogeneity to rehabilitation interventions directed at optimizing community re-integration.

2. Methods

The findings of this study are drawn from a scholarly literature review reported wherein data is analyzed thematically and reported in a narrative form [10]. A key word based search strategy was used to find pertinent journal articles. Major databases used include Medline (PubMed), CINAHL, Embase, and Google scholar that were searched from inception till May, 2017. The search terms included combination of MeSh and free text terms which include: spinal cord injury, quadriplegia, paraplegia, tetraplegia, heterogeneity, rehabilitation, health, wellness, and community reintegration. References list searching of the key articles was undertaken to identify articles that did not emerge in the initial database search. Articles considered for inclusion could be either qualitative or quantitative studies and had to be published in English. No other filters or limits were applied. To be included in the review the studies had to focus on elements related to successful community living of people with spinal cord injuries, that may have association with their community reintegration. The articles that were not available in English; did not have abstract; or full text available were excluded. Total 670 titles were reviewed out of which, 29 articles provided some evidence on how heterogeneity affects outcomes related to community reintegration.

3. Results

This section is divided into three subsections wherein each subsection discusses how population with SCI differs with respect to their various injury-related, personal, and socio-environmental characteristics; and summarizes available evidence on relationship of these differences to various rehabilitation outcomes related with community re-integration.

3.1. Heterogeneity based on injury characteristics

Cause. Cause of injury divide people with SCI into two groups: traumatic versus non-traumatic. Traumatic causes of injury commonly include motor vehicle accidents, falls, acts of violence, and sports related activities while the most common non-traumatic causes include spinal degenerative disorders, spinal tumours, stenosis, infections or other metastatic disorders [11,12]. While motor vehicle accidents remain the main cause of injury worldwide, spinal cord injuries due to falls; spinal degenerative diseases; and infections are rising [12,13]. Traumatic injuries mostly affect young males (15-29 years) whereas non-traumatic injuries are more prevalent in older females (>65 years) [14,15]. Injuries due to non-traumatic causes often lead to incomplete and thoracic level injuries [16] while traumatic events lead to more severe injuries or multiple injuries [15].

A large number of studies have examined the effects of cause of injury on the rehabilitation outcomes. A majority of the studies found that among clinically similar patients (matched for demographics, and level of injury), no significant differences were detected in the functional outcomes between those with traumatic versus non-traumatic causes of injury, however survival was significantly lower in those having non-traumatic SCI [14,15,17-20]. Within the group affected by non-traumatic SCI, it was found that patients with a SCI caused by infection had highest rehabilitation needs and poorer rehabilitation outcomes particularly in physical health, activities of daily living, and bowel management as compared to the patients with a SCI caused by spinal degenerative disorders [21].

Level and severity of injury. The involvement and completeness of neurological level of injury divide people with SCI into many diverse groups. For example, injuries involving high-cervical nerves (C1-C4) are the most severe leading to the paralysis of limbs and trunk where breathing along
with bowel or bladder control is affected (i.e. higher tetraplegia). In the injuries at the level of low-
cervical nerves (C5-C8), control of arms and hands is affected depending on the nerves involved but
ability to speak and breath is mostly normal (i.e. lower tetraplegia). Similarly, in the injuries at the
thoracic, lumbar or sacral regions, muscles of upper chest, abdomen, trunk, and legs are involved up
to varying degrees based on the nerve involvement, while upper limb and hand functions are usually
preserved (i.e. paraplegia). Individuals may have complete injuries (loss of motor, sensory and
autonomic functions below the level of injury) versus incomplete injuries (either or both motor and
sensory functions are preserved below the neurological level of injury) [22]. These injury
characteristics in turn determine the extent of medical complications associated with SCI [23].

In a recent study, a higher level and more severe injury along with spasticity was related with
more activity limitations [24]. Another study found that during early phases of rehabilitation, the
level of independence of patients with cervical level injuries was much more affected than in the
patients having injury at thoracic-lumbar level. Similarly, in complete injuries, the level of
independence achieved was significantly less as compared to those with incomplete injuries [25].
Barclay and associates (2016) found in their qualitative study that individuals with more severe or
higher injuries were more reliant on others to assist them to get out of the house, and to complete
household tasks for them [26]. A systematic review also reported better outcomes related to return to
work post SCI in those who had less severe injuries [27].

**Age at injury and age of injury.** Based on heterogeneity in age at injury and age of the injury
(duration or time since injury), individuals with SCI can be broadly classified into four categories- (i)
younger with acute injury (i.e. injured at a young age and are newly injured); (ii) younger with
chronic injury (i.e. injured at a young age but sustaining SCI for a long duration); (iii) older with acute
injury (i.e. incurred SCI at an old age but acquired it within last few years); and (iv) older with chronic
injury (i.e. incurred SCI at an old age and living with it for a long duration) [28]. However, it must be
noted that these are arbitrary distinctions as literature does not provide a clear classification or cutoff
to classify the acute versus chronic injuries among younger and older adults. Literature suggests that
these four sub-groups are significantly different in terms of their domains of functioning, rehabilitation needs and outcomes that they can achieve [6,29,30,31].

Examining the effects of age at injury on rehabilitation outcomes related to independence, a
study reported that younger patients showed better neurological recovery and hence higher level of
independence in bowel and bladder management and independent walking [32]. Another study
suggested that elderly patients with paraplegia were more likely to have a longer length of stay, lesser
functional and neurological status gains than younger individuals with paraplegia and tetraplegia
[33]. Some authors report that younger age at onset of injury and longer time since injury both
appeared to be positively correlated with life adjustment, securing employment post-injury, and
overall social functioning [34]. Health and activity level correlated negatively with increasing age at
onset of injury. However, a study looking at life satisfaction among older adults with long term SCI
concluded that overall life satisfaction improves as one grows or lives longer with the injury [24].

3.2. **Heterogeneity based on personal characteristics**

**Demography.** Age, gender, race, ethnicity, education, marital status, employment status, and
income divide individuals with SCI into many subgroups. Studies examining worldwide literature
report that there is a bimodal distribution in the age of onset of SCI where it mostly affects those
between 15-29 years and >65 years [2,13]. There is an increase in the age of SCI onset with incidence
of non-traumatic SCI increasing steadily with age [11,12,35,36]. Overall, the incidence of SCI is higher
for males than females regardless of age, and in black than whites; though the trend towards injury
in females is rising [35].

A large number of studies have examined the effects of age on rehabilitation needs and outcomes
[6,29-31]. Some investigators suggest that a person with SCI experiences functional declines from
aging that are superimposed on their disability [37,38]. A research study found that older adults had
more susceptibility towards having co-morbidities, that also had an impact on their rehabilitation
care pathways [39]. Having higher independence, higher income, employment and insurance
coverage at the time of injury, and better education were reported having positive effects on
vocational gains after SCI [27,40]. However, none of studies reported that these factors were significantly related to rehabilitation outcomes. Similarly, neither gender nor race were found to be significantly affecting rehabilitation outcomes such as discharge destination, rehabilitation length of stay or functional status gains [33].

**Physical or mental illness and other co-morbidities.** Presence or absence of physical or psychological comorbidities along with SCI make individuals with SCI diverse in terms of their overall health status, and hence pose a substantial effect on the rehabilitation gains or outcomes that an individual can have. For example, a study reported that presence of psychological and medical complications was related to decreased community participation and reintegration [41]. Another systematic review reported that cognitive impairment was significantly predictive of poorer rehabilitation gains [42]. Likewise, patients who experienced complications such as neuropathic and musculoskeletal pain, pressure ulcers, urinary tract infections, bowel problems, autonomic dysreflexia, and depression had higher rehabilitation needs [37]. Another recent study reported that physical limitations such as pain, fatigue, spasticity and decreased muscle strength were the major reasons cited by the participants with SCI for not participating in active recreation [43].

**Personal skills and attitude towards disability.** People with SCI are also found to be different based on their personal skills and perceptions; and attitude towards their disability [44], which affect their overall adjustment with the injury [45]. For instance, a systematic review found that self-efficacy and self-esteem were associated with higher well-being and better mental health; and spirituality and purpose in life were the potential determinants of adjustment outcomes in long-term SCI [44]. Another study from Switzerland found that self-efficacy and self-esteem were significant predictors of participation of people living with SCI [46].

### 3.3. Heterogeneity based on socio-environmental factors

**Access to formal and informal social support.** Characteristics of people living with SCI place them on a spectrum where on one side of the spectrum, few individuals have better access to resources and social support, while on the other side, people have very limited access to income resources and have little or no social support at all. Based on the policies, the available funding or community resources vary from individual to individual that affect their access to services and subsequently influence life-long outcomes [26,47,48].

Evidence on the role of informal social support has also been well-established in the successful rehabilitation of people with SCI [49,50]. Social relationships and availability of informal social networks were found as one of the most significant factors that improved participation; helped dealing with secondary health conditions; and overall management of life with SCI [50,52]. Another systematic review found positive relationship between social support to both physical and mental health such as dealing with depression or pain; adjustment with injury; and overall life satisfaction post having a SCI. Having positive social relationships also lead to reduced likelihood of experiences related to depression, suicidal ideation, psychosocial disability and post-traumatic stress disorder in people with SCI [53].

**Environment.** People with SCI are also diverse based on the frequency and magnitude of environmental barriers that they do (or do not) face in the community. Several studies report the influence of environmental factors on the experiences of community reintegration and participation of people with SCI [8,26]. A qualitative study exploring the factors affecting participation among people with SCI revealed that mobility aids, transportation and home accessibility were identified as most influential factors [54]. In a study including African Americans living with SCI, authors found that after natural environment, government policies; transportation; and availability of health care services were the topmost barriers perceived by the participants affecting their community reintegration [55]. In another study, accessible transportation, community access, and adapted and special equipment were found the most significant factors to improve participation in physical and social activities after SCI [52].
4. Discussion

Implications of heterogeneity in SCI population for interventions directed at community reintegration

Overall, evidence presented above indicates that successful community integration of individuals with SCI is a combined function of their injury related as well as their personal and social factors. Consequently, rehabilitation interventions directed towards community reintegration should involve a multidisciplinary approach that may include components of physical, psychosocial, and vocational rehabilitation directed at personal and environment level [56]. All three types of approaches are interrelated and have their direct or indirect impact on community reintegration of individuals with SCI [57].

a) Physical interventions: The heterogeneity manifested through individuals’ injury-related and personal characteristics determine the approaches to physical rehabilitation for community reintegration. Depending on these factors, the goals for rehabilitation may be varied and can be achieved through the outpatient or community based physiotherapy, occupational therapy (OT) services, a fitness center, assistive technology support, and other health services related to urology, obstetrics, gynecology and sexual health [47]. For example, in case of less severe injuries (or paraplegia), rehabilitation goals can range from maintaining or improving walking, regaining motor control, and facilitating performance in the tasks such as transfers, or pushing a wheelchair [4]. In case of moderate level of injuries such as at the higher thoracic regions, maintaining or improving reach, grasp and manipulation, bowel or bladder continence, and ameliorating neuropathic pain can be of importance. In case of more severe injuries such as higher tetraplegia, attaining independence in breathing, and optimizing spasticity would be more important [47,58]. Likewise, individuals who are older at the time of injury and have complete or more severe injuries will have different (and probably more) rehabilitation needs than those who are younger and have less severe injuries. The interventions for improving functioning in important areas such as mobility or bladder functions will also depend on their personal and other lifestyle factors. For example, individuals with paraplegia will most likely need to use a manual wheelchair; or be able to learn to drive a modified car; or stand in a standing frame, or walk with braces. Similarly, each individual will need a customized bladder management program that is appropriate to their sex, bladder control, mobility, and lifestyle [4].

b) Psychosocial interventions: The psychosocial rehabilitation of an individual with SCI often involves a comprehensive approach of building a supportive environment involving family members; and helping patients accessing and navigating legal, federal, or provincial resources or services available to them, such as those related to accommodation, housing, insurance, health or other disability benefits [59,60]. The extent, nature, and frequency of these interventions will depend on the availability of formal and informal social support such as family or other caregivers; and eligibility for funding or other resources (i.e. attendant care services) [56]. In cases where family support is available, a comprehensive evaluation of the family is required where family’s understanding of the injury and expectations for the future are assessed. Potential caregivers are identified and educated about rehabilitation needs of an individual with SCI and resources available in the community [60, p.27]. In case of individuals living alone, special attention should be given to improve social participation of an individual (e.g. health promotion activities in the community) to the maximum extent possible, and provide appropriate information to improve their access to various community resources [62,63]. Social skills and recreational training can be of particular importance to promote ones physical and psychological health and provide avenues for reintegration into the society [64]. Likewise, depending on the individual’s mental health needs, rehabilitation interventions may include individualized or a group-based programs involving education and counselling, cognitive behavior therapy (CBT), psychotherapy, or a coping effectiveness training (CET) by a psychologist or psychiatrist if needed [45,65].
c) **Vocational interventions:** Return to work (including both vocational and avocational activities) has been the key to independent living and has a significant impact on life satisfaction, quality of life and overall mental health of people with SCI [66]. Evidence presented above suggest that along with health-related issues, various personal, environmental and policy related factors affect return to work or initiating employment after incurring SCI [47]. Therefore, keeping these factors into consideration, several approaches to vocational rehabilitation can be considered for a person for whom return to work is an important goal. Some of these approaches include program-based, supported employment and case-coordinated approaches [67]. The critical components within each of these approaches will vary according to individual needs and most likely include job readiness assessments and work preparedness programs to evaluate and improve person’s ability to perform the job demands; evaluating environmental factors such as transportation, accessibility of the work premises or availability of an attendant; knowing employer’s expectations and addressing concerns related to worksite modifications, equipment, or flexible work schedule; and providing ongoing support to both individual and the employer [47,68,69]. In situations where return to work or school is not a primary or feasible goal for an individual, efforts can be geared towards improving meaningful engagement in self-directed activities, such as resuming hobbies, home-making activities, exploring options for volunteer work, adapted sporting, or continuing education, to improve the feelings of self-worth and increase avenues for social interaction and involvement [70,71].

5. **Conclusion**

Heterogeneity within SCI population poses significant implications on the rehabilitation needs and outcomes, and hence interventions targeted at community reintegration. Available literature on SCI rehabilitation suggest that an array of injury-related, personal, social and environmental factors interact with each other and predict the community reintegration, participation, life satisfaction, and overall quality of life of people with SCI. Therefore, rehabilitation approaches directed at optimizing community-reintegration may involve components of physical, psychosocial, and vocational rehabilitation while considering injury related, personal and societal aspects of an individual’s life. Understanding the heterogeneity posed by these aspects will help rehabilitation professionals to address the needs and concerns of people with SCI in a holistic but unique way, and help them achieve a satisfying life that they desire.

**Acknowledgments:** No funding was received for this study.

**Conflicts of Interest:** There are no conflict of interests to declare.

**References**


