Community reintegration following spinal cord injury: Insights for health professionals in community rehabilitation services in New Zealand

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ABSTRACT

When returning home following a spinal cord injury (SCI), individuals will be in contact with a range of health professionals who will be involved in their ongoing rehabilitation. This study explored the qualitative literature to determine what individuals with SCI perceive to be the barriers or facilitators to community reintegration to provide insights for health professionals working in community rehabilitation services in New Zealand. The databases of Ovid Medline, CINAHL, the Allied and Complementary Medicine Database (AMED), Cochrane Database of Systematic Reviews and PEDro were searched for relevant articles. Barriers and facilitators to community reintegration were classified into the International Classification of Functioning, Disability and Health (ICF) framework with the addition of self-management factors to further define personal factors. Of the 381 studies uncovered in the search, seven met the inclusion criteria. Findings revealed that accessibility of the environment, re-establishing self, support and connections were strong themes for reintegration. The challenge for health professionals working in the community with individuals with SCI is to be client-centred and ensure the individual's needs are suitably met to support them to re-connect with their work and community life.

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Keywords: barriers, facilitators, community reintegration, spinal cord injury

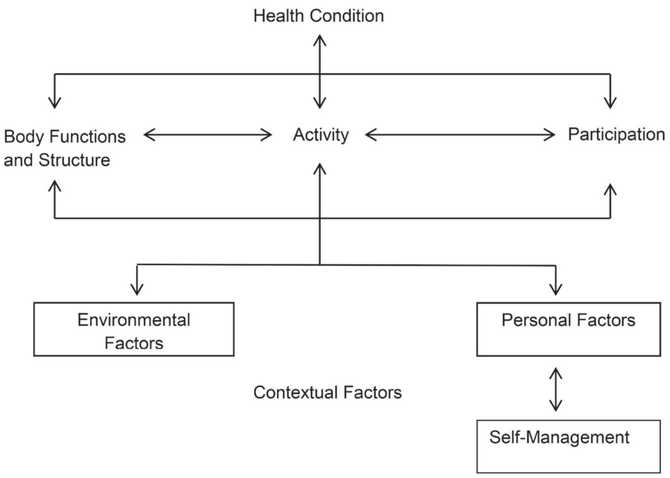
INTRODUCTION

Following a spinal cord injury (SCI), an individual will spend several weeks or months undergoing rehabilitation in a specialised facility such as a spinal unit. New Zealand has two spinal units; one in Auckland and the other in Christchurch. Considering that many people live outside of these cities, a considerable number of individuals will leave the communities in which they reside to undergo months of rehabilitation as an inpatient in one of these two units (Sinnott et al 2010). Following discharge from the spinal unit, these individuals may return to only partially accessible homes, or alternatively, be discharged to temporary accommodation such as a motel while awaiting modifications to their own house for it to be made accessible. Over the weeks and months following discharge, housing, transport and equipment issues are generally resolved together with input from a range of health professionals. Physiotherapists, occupational therapists, clinical psychologists, nurses and vocational rehabilitation providers then continue working with the individual with SCI in the months and early years post-injury, with the focus shifting to community reintegration for the individual to resume activities, leisure pursuits and work (Hay-Smith et al 2013, Kendall et al 2003). The process of reintegrating back to their local community is usually difficult and challenging (Gargaro et al 2013). Indeed, apprehension regarding discharge and a sudden transition to home from the spinal unit environment was identified as an issue for individuals with SCI in New Zealand when interviewed as part of a large international study examining the lived experience of individuals with SCI (Sinnott et al 2010). Such findings highlight the need to address the process for community reintegration for people with SCI.

Community reintegration is a broad term encompassing the process of returning home and re-establishing life following an event such as SCI. Dijkers (1998, p 5) provides this definition "Community (re-)integration (after/with (physical) impairment or disability) is acquiring/resuming age-/gender-/culture-appropriate roles/statuses/activities, including independence/interdependence in decision making, and productive behaviours performed as part of multivaried relationships with family, friends, and others in natural community settings". This definition fits well with the International Classification of Functioning, Disability and Health (ICF) when used as a bio-psychosocial framework to consider the interaction between health, function and participation and the contextual impact of the person and their environment (Figure 1) (World Health Organisation 2002). The term 'environment' encapsulates both physical factors (such as the built environment) and social factors (such as attitudes within society) that may influence a person's ability to function. Thus, the ICF could be used as a framework to assist in identifying where the complex and multifactorial barriers and facilitators to community reintegration lie for individuals with SCI.

To further investigate and identify personal factors outlined under the ICF, personal factors that allow or develop self-management skills can be added as a subset (Figure 1). This is because when individuals are discharged home, they move from

Figure 1: International Classification of Functioning, Disability and Health framework with self-management.



the relatively controlled environment of the spinal unit where systems are in place to manage SCI and health professionals are readily available, to the community where there is considerably less monitoring and oversight. The ability to make this transition and manage one's own health and physical needs associated with SCI is important. Self-management is defined as having the self-efficacy to be able to take responsibility for managing the day-to-day aspect of one's own long-term condition (Lorig and Holman 2003). Self-efficacy is described as the belief in oneself to be able to accomplish a task and self-esteem as the belief in oneself per se (Geyh et al 2012, Bandura 1977). Geyh et al (2012) linked self-efficacy and self-esteem to personal factors under the ICF framework. In a questionnaire study of 102 individuals less than five years post SCI, they found strong links between self-efficacy and self-esteem in relation to participation regardless of gender, age, level and completeness of injury. Therefore, for individuals with SCI, it appears that developing self-efficacy or confidence in their ability to manage themselves would be key to their participation in community life.

A review of the literature by Gargaro et al (2013) used the ICF model to classify environmental and personal barriers and facilitators to community reintegration following SCI. The 31 studies included in this review used questionnaires and standardised tools that examined community integration, degree of disability/function, environmental factors and quality of life. While such an approach can provide general information about the focus of the enquiry, it does not however provide or explore the more detailed and explanatory information that could be uncovered by qualitative investigation.

The purpose of this paper was to review the qualitative literature to explore what individuals with SCI perceive to be the barriers or facilitators to their community reintegration. By doing so, we aimed to provide insights for health professionals to consider when working in community rehabilitation services for individuals with SCI in New Zealand.

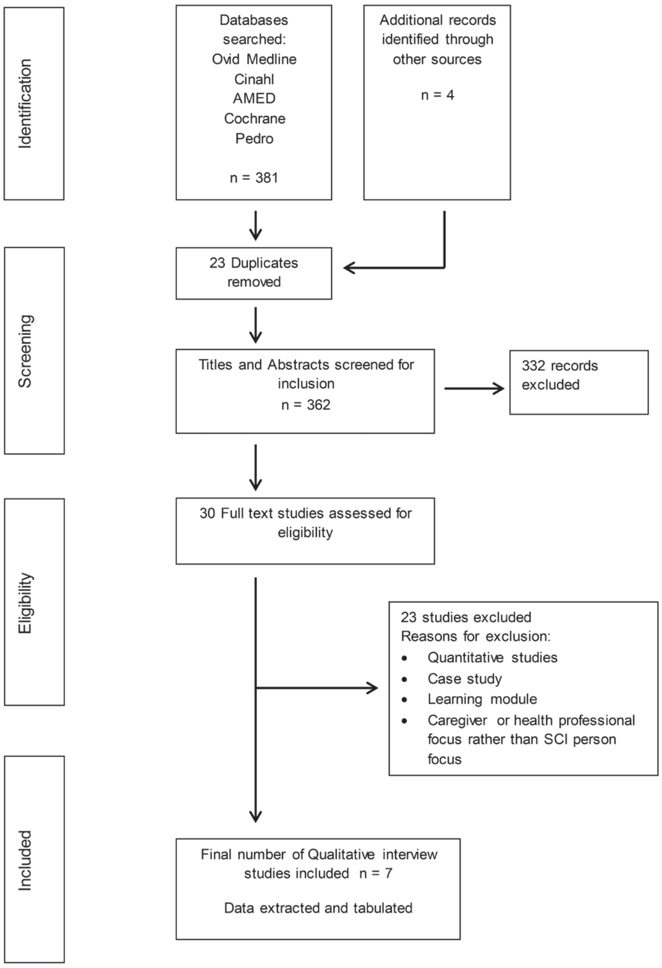
METHODS

Literature Search

A literature search was conducted using the electronic databases Ovid Medline, CINAHL, the Allied and Complementary Medicine Database (AMED), Cochrane Database of Systematic Reviews and PEDro. Search terms were: spinal cord injuries or spinal cord injur*, or SCI, or paraplegia, or quadriplegia, or tetraplegia, combined with community reintegration or community integration. Search limits included articles that were written in English and published in a peer-reviewed journal. We also confined the search to articles published since 2000 to limit the data to more recent studies which would therefore potentially be relevant to the present day context. Studies about adults with SCI that were wholly qualitative (interview or focus group) in nature or contained a qualitative component within a mixed methods study design were included. Conference abstracts, expert opinion, review studies and quantitative studies were excluded.

The search resulted in 385 articles in total; 381 were sourced from the databases with a further four articles obtained via a hand search of the references of these studies. Duplicates were removed and 362 article titles and abstracts were screened by the first author for inclusion. A further 332 articles were excluded and the full text of the remaining 30 articles was read. Following discussion between both authors, a further 23 studies were excluded as they were either quantitative studies, case studies, learning modules or had a caregiver or health professional focus rather than SCI person focus. This left seven studies that were included for review (Figure 2).

Figure 2: Flow chart of the literature search and selection process.



Assessment/Review of Quality

The Mixed Methods Appraisal Tool (MMAT) was chosen to assess the quality of methodology because this instrument can be used to appraise studies that employ qualitative, quantitative or mixed methodology (Pluye et al 2009). Criteria specific to a particular methodology are assessed and scored. For example, the qualitative domain scores the following criteria: sources of data, processes for analysis of the data in relation to the research question, consideration for how findings relate to the setting in which the data were collected, and the influence the researcher has on the findings. There are a maximum of four criteria under each domain; therefore, each criterion is worth 25%, and the final score (expressed as a percentage) indicates the level of quality for a particular study.

Data Extraction

Data that identified the barriers or facilitators to community reintegration were extracted from the seven studies and tabulated, and the MMAT rating identified (Table 1). The barriers or facilitators were then collated and transferred onto the ICF framework of domains, with factors related to personal skills for self-management added to the personal domain. Environmental factors were subdivided into physical and social categories as modelled in a publication by Mulligan et al (2012) to provide more clarity about these factors.

RESULTS

Of the seven studies included, five used only qualitative methodology and the other two incorporated qualitative components within a mixed methods approach. There were a total of 373 participants in the seven studies which were conducted in the United States of America (USA), Canada, United Kingdom, Europe, Australia and New Zealand. Appraisal of all seven studies resulted in them being rated as having similar methodological quality; therefore, similar weighting has been given to the findings from the individual studies included in this review. Figures 3 and 4 clearly demonstrate that the majority of both barriers and facilitators fall under environmental and personal factors (including self-management factors).

Barriers to Community Reintegration Following SCI

Body Function and Structure

Three studies reported loss of fitness and increasing weakness, perceived as being due to reduced therapy input and lack of access to exercise options following discharge to the community, as barriers, along with health complications (Boschen et al 2003, Dickson et al 2011, Silver et al 2012). One study also identified pain as a hindrance to daily activities and noted that this became more prevalent over time (Silver et al 2012).

Activity and Participation

Restricted mobility due to lack of suitable wheelchairs, dependence with transfers and lack of aids or independence with daily activities such as dressing and eating were barriers to community reintegration, as identified in one study (Silver et al 2012).

Environmental Factors

Physical: Inaccessible housing and transportation, particularly compared to the hospital or spinal unit where the individual with SCI had come from, was identified as a barrier in three studies (Dickson et al 2011, Kuipers et al 2011, Silver et al 2012). A study based in the USA (Silver et al 2012) reported that this factor can result in discharge to a nursing facility rather than to home. In the same study, difficulty accessing information and resources regarding housing issues and returning to driving were identified (Silver et al 2012). Lack of finances or insurance to fund general expenses, caregivers, medical specialists or further therapy were also viewed as barriers (Boschen et al 2003, Silver et al 2012, Suddick et al 2009), as were costs for consumables used for dressings or for managing bowel and bladder cares along with equipment such as wheelchairs and cushions (Boschen et al 2003). Inability to return to work due to physical inaccessibility of workplaces was identified as an additional barrier to community reintegration, along with longer timeframes required by the individual to get ready for work, and health complications that can impact time available to work (Boschen et al 2003, Silver et al 2012).

Social: A lack of support from family and friends who struggle to cope with the huge change in circumstances of their loved one, as well as negative attitudes (those that were patronising or that caused a sense of inferiority) from individuals within society at large were identified as barriers in three studies (Boschen et al 2003, Dickson et al 2011, Suddick et al 2009). In addition, a lack of psychological support leading to low mood and depression was described, particularly at the time of transition from the rehabilitation unit to home (Dickson et al 2011, Suddick et al 2009). One study identified that attitudes of health professionals could compromise gains in independence when they were perceived to limit control and choice in the rehabilitation process for the individual with SCI, resulting in a sense that intervention was not client-centred (Boschen et al 2003). A different study reported that health professionals expected a certain level of function depending on the level of SCI and did not expect the individual to move beyond this to achieve more (Suddick et al 2009). The same study also identified that participants felt they were expected to be “positive in rehab” at all times; and felt not to be allowed space and time to mourn “this awful thing that has happened to you” (Suddick et al 2009, p 538).

Personal Factors

The transition from the rehabilitation hospital or spinal unit to home was reported to result in feelings of isolation (Dickson et al 2011, Suddick et al 2009). The spinal unit provided a sense of camaraderie and shared experience with others who have sustained SCI, but on returning home this sense of belonging and the peer support from being surrounded with others in a similar condition was lost. In addition, there was a personal sense of inferiority and lack of belonging to the community they were once a part of (Dickson et al 2011). Three studies reported a theme of being anxious and not psychologically prepared for returning to home and the community following discharge from the care of the hospital rehabilitation environment (Dickson et al 2011, Nunnerley et al 2013, Suddick et al 2009). Low mood, depression and suicidal thoughts on returning to the community were described (Dickson et al 2011) because of having to adjust to SCI and the struggle to cope in the ‘real world’ with a new sense of self (Nunnerley et al 2013, Suddick et al 2009). One study also described the invasion of privacy and a feeling of being exposed because of having to be dependent on caregivers to assist with personal cares, even to the extent of “when you go to the toilet” (Nunnerley et al 2013, p 1168).

Table 1: Summary of studies included for review

Author (Year)	Purpose	Design	Sample Population	Barriers/Facilitators	Quality
Boschen et al (2003)	Canadian study that examines the factors that influence community reintegration 1-6 years post SCI.	Qualitative arm of a mixed methods study. Focus groups using Grounded Theory.	n=34 71% male 65% tetraplegic 35% paraplegic 41% complete SCI 59% incomplete SCI	Barriers: Pain – barrier to daily activities Health complications Inaccessible housing, transport Return to work – physical and conceptual barriers Inaccessible physical environment Finances Sourcing supplies and equipment Societal attitudes Health professional attitudes – limiting choice/control, rehabilitation not client centred Facilitators: Independence with daily activities Support from family and friends Mentoring from peers Familiar community/neighbours Accessible housing, transport Communication – assistive technology Financial stability	75%
Dickson et al (2011)	Study based in the United Kingdom captures the lived experience of SCI from an individual perspective.	Individual semi-structured interviews. Recurrent themes analysed using IPA.	n=17 All tetraplegic; level of injury C5-C7, at least 1 year post injury 14 males 3 females Mean age=46 (26-62)	Barriers: Loss of fitness post discharge – unable to access fitness equipment Lack of psychological support Other people's reactions – feeling of inferiority Loss of camaraderie returning home from spinal unit Loss of shared experience, peer support Isolation on discharge home Loss of sense of belonging returning home Loss of safety, security returning home Depression, suicidal thoughts Not psychologically prepared for discharge Facilitators: Community resources – social work, physiotherapy, occupational therapy, nursing, psychology	75%
Kuipers et al (2011)	Australian based study which explores the concept of community as described by participants with SCI.	Telephone interviews. Open-ended questions supplied to participants in advance. Thematic analysis.	n= 269 Mean age 43 (20-76) Mean time since injury 16 years 81% male 40% ASIA A Tetraplegia 37% ASIA A Paraplegia 23% incomplete SCI	Barriers: Inaccessibility in the environment Inaccessible transport Facilitators: Relationships Familiarity with home, community Support from neighbours Independence in the community with access, transport	75%

Author (Year)	Purpose	Design	Sample Population	Barriers/Facilitators	Quality
Nunnerley et al (2013)	To investigate the experiences of community (re) integration of people with SCI within 12 months of discharge from a spinal unit in New Zealand.	Qualitative interviews using IPA. Initially via telephone and then face to face interviews.	n=9 7 males 2 females Mean age 36 years (20-55) All tetraplegic (C4-C7) Time since discharge 6.5-10 months	Barriers: Lack of control and reduced autonomy Loss of independence Feeling exposed – invasion of privacy Home environment not accessible like the spinal unit Anxiety about translating skills to adapt to challenges of the community environment Facilitators: Adjustment to SCI; re-establishing self, coming to terms with changed self Hope for recovery Locus of control Confidence to translate skills to community environment	100%
Silver et al (2012)	Use of the ICF to investigate barriers to community reintegration with SCI in the first year post discharge from inpatient rehabilitation. Study based in the United States of America.	Qualitative arm of a mixed methods study Recurrent interactions over a 6 month period via phone or in person done by a navigator with SCI. Followed by focus groups.	n=26 81% male 54% tetraplegic Mean age 40.6 (18-86 years) Less than 1 year post discharge from acute rehabilitation	Barriers: Restricted mobility – lack of suitable wheelchairs, aids for daily living Increasing weakness post discharge Lack of support at home Inaccessible housing Adjusting to returning home, transition to another living situation Lack of financial support for medical specialists, further therapy Access to wheelchair accessible transport Emotional coping Sourcing information, knowledge – housing, transport Dependence for activities of daily living Pain	75%
Suddick et al (2009)	To explore the lived experience of community reintegration in the United Kingdom following SCI.	Semi structured interviews using IPA.	n=7 4 males 3 females 1 tetraplegic 6 paraplegic Mean years since SCI 8.6 (5-12) Participants recruited through sports clubs and activity centres in the community	Barriers: Health professional's expectations – expect a certain level of function depending on injury; expect a constant positive attitude from person with SCI to be constantly engaged in rehabilitation. Lack of rehabilitation post discharge Lack of knowledge in community health professionals Adjustment to SCI Adjustment to leaving the spinal unit on discharge – not prepared Isolation following discharge Attitudes of family/friends Facilitators: Positive attitude Peer mentors Attitudes of family/friends Family supported rehabilitation Voluntary groups valuable for reintegration	75%

Author (Year)	Purpose	Design	Sample Population	Barriers/Facilitators	Quality
Van de Velde et al (2010)	This study from Belgium with individuals with SCI investigates perceptions of what participation means for them on transition from hospital to home.	Individual in-depth interviews using Grounded Theory. (26 interviews resulting in saturation of data).	n=11 Theoretic sampling strategy; male SCI discharged and in transition from hospital to home (2 months post discharge) Age range 25-56 years All paraplegic All married/partner	Facilitators: Sense of control Validation, endorsement Sense of importance, being valued Choosing to do an activity independently Engaging in family/community life without expectations of contributing Engaging in activities in a socio-cultural context	75%

Notes: ICF, International Classification of Functioning, Disability and Health; IPA, Interpretive Phenomenological Analysis; SCI, spinal cord injury

Self-Management Factors

A lack of personal control over the environment and of others in the environment due to physical limitations with SCI was reported in one study (Nunnerley et al 2013). These authors also described how individuals felt they wanted to take some control but were unable to due to limitations placed on them by health professionals. This loss of independence, often due to a required dependence on others for physical assistance, resulted in a sense of powerlessness and reduced self-efficacy (Nunnerley et al 2013).

Facilitators to Community Reintegration Following SCI

Activity and Participation

Independence with functional tasks as part of daily living enabled community reintegration (Boschen et al 2003). Having choice over how to do an activity, engaging in family or community life and participating in activities in a socio-cultural context such as within the work environment (regardless of whether this was paid or voluntary) were described as different aspects of participation which facilitated community reintegration (Van de Velde et al 2010).

Environmental Factors

Physical: Having accessible housing, communities and transport facilitated reintegration (Boschen et al 2003, Kuipers et al 2011). Financial resources provided stability and enabled a level of control and independence (Boschen et al 2003). Access to health professionals and psychological services were perceived to provide valuable support in the transition process (Dickson et al 2011). Assistive technology that allowed effective communication with family and friends along with access to information and resources was deemed important (Boschen et al 2003). Lastly, participating in community based voluntary groups provided constructive activity for rehabilitation and reintegration to "get on and do stuff" (Suddick et al 2009, p 539).

Social: Relationships with family, friends and the local community were identified as providing valuable support to facilitate community reintegration (Boschen et al 2003, Kuipers et al 2011, Suddick et al 2009). One study reported that those who described their community in terms of relationships were generally more positive about their community than those who described it physically (Kuipers et al 2011). Familiarity with the home and neighbourhood environment meant that individuals had knowledge of the community they were returning to (Boschen et al 2003, Kuipers et al 2011). Along with this, mentoring from peers was seen to provide support to bridge the gap from the inpatient setting to the community setting (Boschen et al 2003, Suddick et al 2009).

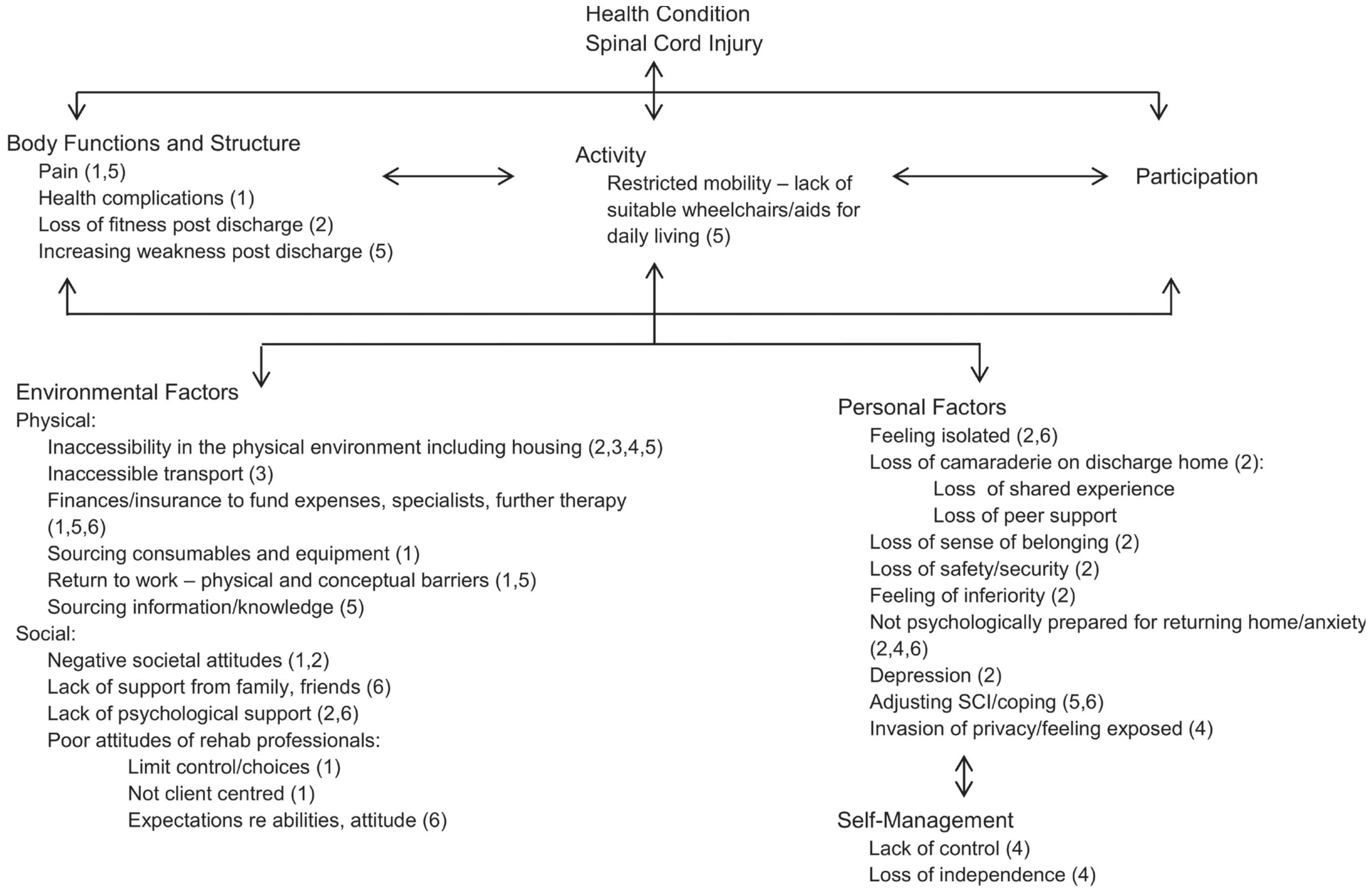
Personal Factors

Adjustment to SCI was reported in the studies with similar strong descriptors, 'rebuilding' or 'reframing life' (Boschen et al 2003), 're-establishing self' and 'coming to terms with a changed self' (Nunnerley et al 2013). Participants in one study described physical, emotional and spiritual changes as a result of their injury. This study also identified a hope for recovery as a facilitator, particularly in the first two years following SCI. However, it also identified that while this hope fosters participation in physical rehabilitation, it can hinder other aspects of reintegration such as focussing on work or other leisure pursuits (Nunnerley et al 2013). A positive attitude was perceived as being a key to facilitating smoother transition to the community (Suddick et al 2009), while a sense of importance and being valued by friends, family and the wider community provided a sense of belonging (Van de Velde et al 2010).

Self-Management Factors

Having a sense of control through independence with tasks or validation with achievement was deemed important in the coping process following SCI; this fostered autonomy and participation (Nunnerley et al 2013, Van de Velde et al 2010). Restoring independence and the confidence to adapt skills learnt in the hospital or spinal unit setting to home facilitated reintegration (Suddick et al 2009, Nunnerley et al 2013); with a participant in one study commenting "you can just do it however you want" when referring to doing activities in the

Figure 3: Barriers to community reintegration following spinal cord injury incorporated into the ICF framework. Model adapted from Mulligan et al (2012)



Notes: Study identifiers appear in parentheses: (1) Boschen et al (2003), (2) Dickson et al (2011), (3) Kuipers et al (2011), (4) Nunnerley et al (2013), (5) Silver et al (2012), (6) Suddick et al (2009), (7) Van de Velde et al (2010)

home environment as compared to the hospital environment (Nunnerley et al 2013, p 1167). Peer mentoring and modelling along with validation and endorsement by peers and others facilitated adjustment and transition to the community (Boschen et al 2003, Nunnerley et al 2013) while also improving self-efficacy and belief in one's self.

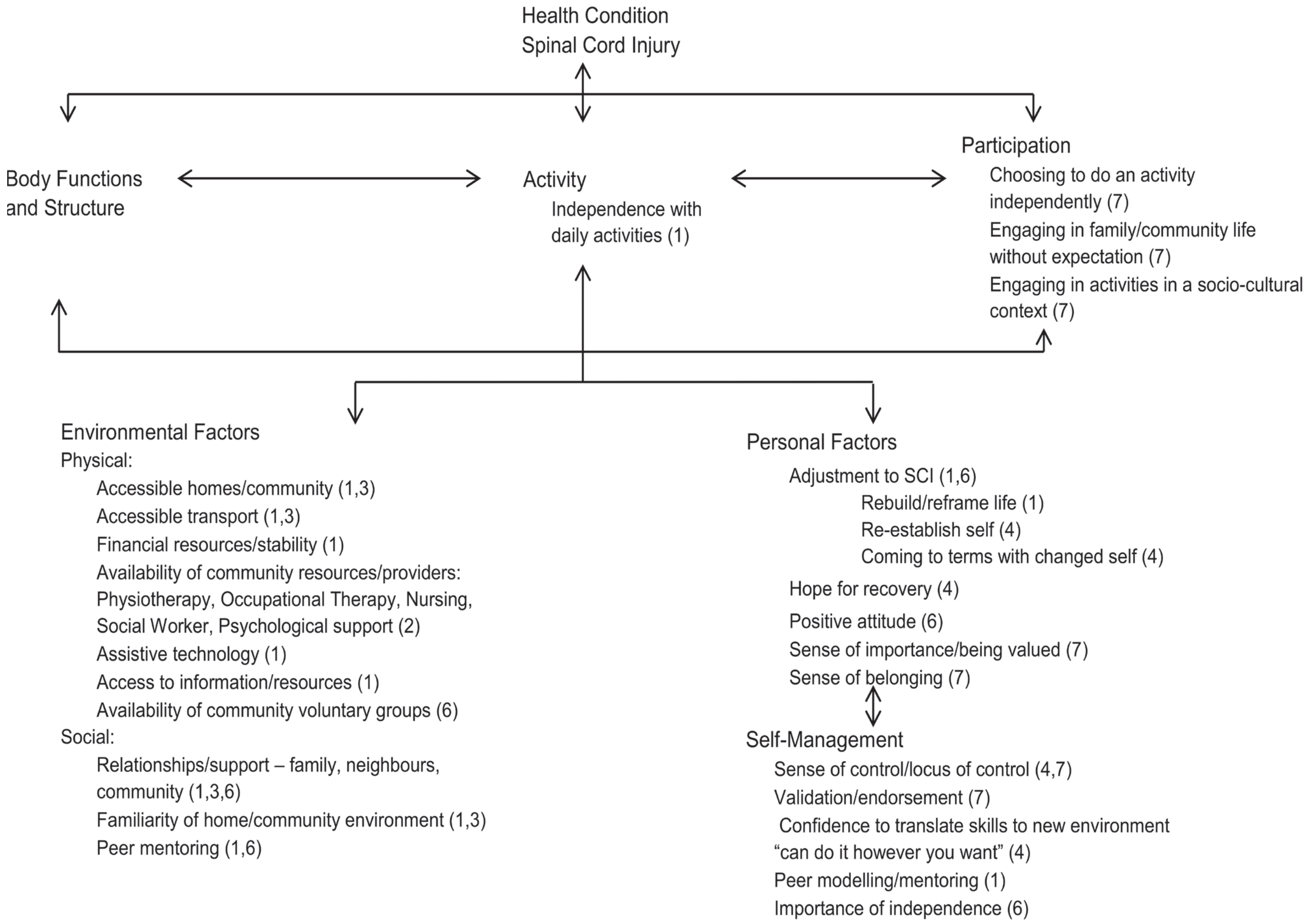
DISCUSSION

This review examined the barriers and facilitators to community reintegration following SCI as reported within the body of qualitative literature. While only a small number of studies were suitable for inclusion, the findings of these qualitative studies reflect the multifactorial components that hinder or promote reintegration. By categorising the barriers and facilitators into the ICF framework of domains, it was most apparent that contextual influences from environmental and personal factors (as opposed to factors related to body structure or function or activity level) predominated as both facilitators and barriers. Factors related to self-management (as a subset of personal factors) provided the warranted emphasis on the importance of self-efficacy in the day to day management of an individual with SCI. Personal statements reported in qualitative studies provided unique and thought-provoking insights that cannot be revealed from quantitative data.

The studies in this review came from a range of countries with similar political and economic development as New Zealand meaning they can provide insight for health professionals working in community rehabilitation services within New Zealand. However, there are distinct influences in the New Zealand environment that affect community participation following SCI which require consideration (Sinnott et al 2010). Firstly, we have the Accident Compensation Corporation (ACC) that provides a "no-fault personal injury cover to all New Zealand residents and visitors to New Zealand" (Accident Compensation Corporation 2014). The role of the ACC is within injury prevention, and treatment provision with an emphasis on return to everyday life. The ACC provides insurance cover for individuals who sustain SCI in New Zealand through injury and the Ministry of Health provides cover for those who acquire SCI through non-injury related means. The implications of this situation are examined in more depth later in the discussion.

Secondly, New Zealand identifies itself as a bi-cultural nation with Māori as the indigenous people. Statistics reveal that Māori have higher rates of incidence of SCI than New Zealand Europeans and that people of Pacific Island origin have an even greater incidence of SCI than Māori (2.4 times greater than New Zealand Europeans) (Derrett et al 2012). He Korowai Oranga is a health and disability strategy for Māori developed through the Ministry of Health, most recently updated in June 2014 (Ministry

Figure 4: Facilitators to community reintegration following spinal cord injury incorporated into the ICF framework. Model adapted from Mulligan et al (2012)



Notes:Study identifiers appear in parentheses: (1) Boschen et al (2003), (2) Dickson et al (2011), (3) Kuipers et al (2011), (4) Nunnerley et al (2013), (5) Silver et al (2012), (6) Suddick et al (2009), (7) Van de Velde (2010)

of Health 2014). This strategy describes the vision of Pae ora or healthy futures for Māori and includes three elements; mauri ora (healthy individuals), whānau ora (healthy families) and wai ora (healthy environments). These concepts of health, family and environment are certainly relevant to the factors that facilitate community reintegration following SCI identified in this review study. The health and disability strategy for Māori could therefore provide a theoretical framework to enhance or facilitate community reintegration for people with SCI if all of the three elements were addressed. Of interest is that this kind of framework also dovetails with the findings of the review by Gargaro et al (2013). Gargaro et al (2013) identified that the health of the individual with SCI was important, as was support from family and friends and an accessible and inclusive environment in which people with SCI felt welcome, valued and able to contribute. However, given the higher incidence of SCI in the Māori and Pacific Island populations in New Zealand, further exploration of the experience of community reintegration following SCI for these individuals is warranted to highlight specific issues they may face.

Health complications that individuals can be predisposed to following SCI can inhibit or interrupt community reintegration (Boshen et al 2003, Silver et al 2012). However, the review by Gargaro et al (2013) identified gaps in research pertaining to bowel and bladder function, pain and sexual health and their impact on community reintegration. Without access to ongoing appropriate resources or therapy there can be a loss of strength and fitness originally gained while undergoing initial inpatient rehabilitation leading to reduced or restricted mobility and participation in activities (Dickson et al 2011, Silver et al 2012). Such findings may be relevant especially for individuals returning to rural areas or smaller towns in the New Zealand environment where access to resources and therapy may be more limited than that which is available in cities and larger towns. Careful planning and collaboration with suitable therapy providers would therefore be prudent.

Coming to terms with having an SCI is a lengthy process. When returning to their communities, individuals with SCI are faced with adjusting to a familiar environment but with a changed self (Boschen et al 2003, Nunnerley et al 2013). This appears to lead to a sense of insecurity and of not being psychologically ready to return home (Dickson et al 2011, Nunnerley et al 2013, Suddick et al 2009). Feelings of inferiority or being viewed as different by others in the community impacts an individual's view of self (Boschen et al 2003, Dickson et al 2011, Suddick et al 2009). While a sense of hope for recovery can foster commitment to physical recovery it can defer focus on returning to other activities such as work or leisure pursuits (Nunnerley et al 2013). This review study has provided insight into key aspects that encapsulate what re-establishing self implies, that this is having a sense of control, confidence to translate skills learnt to the home environment, regaining independence and receiving validation from family, friends and health professionals about being able to manage one's own decisions and being the same person even though living with a changed physical body (Boschen et al 2003, Nunnerley et al 2013, Suddick et al 2009, Van de Velde et al 2010). Through these, self-efficacy is fostered which leads to the ability for an individual to manage his or her life (Geyh et al 2012).

Suitably modified and accessible homes, adequate transport, wheelchairs, and equipment and supplies for showering and toileting are physical supports that are essential and could reasonably be expected when someone returns home after an SCI (Dickson et al 2011, Kuipers et al 2011, Silver et al 2012). Access to ongoing rehabilitation is often required to maximise function, independence and participation in chosen activities (Dickson et al 2011, Kendall et al 2003). Rehabilitation can support access to information, resources or services that assist with returning to the workforce (Dickson et al 2011). Access to financial support is necessary for daily expenses and to fund housing modifications, equipment and therapy (Boschen et al 2003, Silver et al 2012, Suddick et al 2009). All of these contribute to facilitating community reintegration following SCI. However, disparity of funding through benefits or insurance schemes between countries will affect the level of support that is available from country to country. Even within New Zealand there is disparity between those funded through the ACC and the Ministry of Health; anecdotally individuals covered by ACC have greater financial resources for equipment, housing modifications and compensation for loss of earnings if unable to work. Further research to examine community reintegration for individuals with SCI funded under these two schemes to highlight and address disparities is warranted.

The importance of relationships and support from family, friends and the community was a recurring aspect for successful reintegration identified in this review. One study in particular identified the importance of a key figure (whether they be a family member, friend or health professional) as integral in facilitating community reintegration (Boschen et al 2003). Perhaps the inclusion of family and friends in the rehabilitation process could provide a better understanding of the impact and requirements for someone with an SCI. In addition, psychological support for the injured individual and their family would provide the opportunity to discuss adjustment and the challenging transition to returning home to local communities.

This review identified that the attitudes of health professionals impact on community reintegration; enabling an individual with SCI to have control in the rehabilitation process and choice with goals and direction via a client-centred approach facilitates this. One study identified that an expectation of health professionals working with spinal cord injured individuals was that their patients would be constantly positive and engaged in their rehabilitation; not allowing space for natural feelings of sadness and grief over their injury (Suddick et al 2009). Understanding this to be a potential barrier for their clients could help the health professional ensure that their support and care is appropriate and centred around their client's needs.

The feeling of disconnect on returning to the community following an SCI was evident in this review study. Loss of the shared experience and sense of belonging that individuals with SCI had with their peers at the spinal unit led to feelings of isolation following discharge home. Therefore, having a sense of belonging, of being a valued member of the family, community, school or workforce seems important for reintegration and participation in community. However, connecting with others in the community who have experienced SCI could be beneficial as well, as it is these individuals who understand the process of returning home and the challenges that can be encountered. This is supported in the review by Gargaro et al (2013) which comments on the importance of peer support and social networking in transition to the community. There are programmes and organisations in New Zealand, and indeed other countries, that seek to support those with SCI along with their families and friends and provide opportunities for networking and sharing of information, experiences and knowledge (for example, the New Zealand Spinal Trust or the Spinal Injuries Association in the United Kingdom). Further research would be beneficial to discover how effective these are perceived to be for individuals with SCI.

Clinical Implications

The findings from this review present implications for clinical practice by health professionals working in the community with individuals who have an SCI. These are:

1. *Re-establishing self:* Understanding that the process of adjustment to a changed self after SCI will take time and requires empathetic support. Access to psychological support for both the injured individual and family may benefit this process.
2. *Client centred:* Allowing the individual with SCI control and choice in their rehabilitation and return to community with health professionals providing appropriate support. The level of support will shift over time but health professionals should permit the individual to drive the process.
3. *Support:* Including family and friends in the rehabilitation process can facilitate reintegration for individuals with SCI into their communities. The support and attitudes of health professionals can also have a significant impact. Health professionals should therefore be sensitive and reflective in their practice as to whether they are doing the best they can to be inclusive and empathetic towards an individual with SCI and his/her family and support network.
4. *Connections:* Facilitating the linking up with others who have sustained SCI and enabling and encouraging utilisation of resources and organisations that facilitate these connections.
5. *Access:* Facilitating the process of timely and appropriate delivery of services whether it is housing modifications,

equipment, suitable transport or therapy. This requires close collaboration between the individual with SCI, the funding agency and health professionals from within both the acute spinal unit and community settings.

6. *Re-evaluation:* Barriers and facilitators to community reintegration can change over time. What may not be a barrier initially may become more of an issue later. For example, while pain was not a strong theme in the qualitative studies reviewed here, it has been identified as a significant factor impacting community reintegration in other studies, becoming more prevalent as an issue with time following SCI (Donnelly and Eng 2005, Gargaro et al 2013). Therefore, health professionals need to re-evaluate a client's situation on a regular basis.

The limitations of this review have been considered. Only a small number of studies met the inclusion criteria and the number of participants in qualitative studies tends to be small. Apart from one study which had 269 participants, the remaining studies had between 7 and 34 participants; so caution is required in applying the results to the wider population. In addition, participants in the types of studies included in this review were typically volunteers and are therefore not necessarily representative of the wider SCI population. Nevertheless, the review studies did encompass a wide age range, both sexes and a wide range of severity of injury, all of which make the findings more relevant to the population with SCI overall. This review identified similar themes to the results of quantitative studies that have investigated community reintegration following SCI (for example see Gargaro et al 2013). This suggests that the findings of this review of qualitative studies may indeed be representative of the population with SCI as a whole. Lastly, although the studies included in this review cannot be applied to a worldwide population, they are nevertheless reflective of the experiences of people with SCI in developed countries and therefore have relevance to the New Zealand context which is the focus of this review.

CONCLUSION

In this literature review, the ICF framework with the addition of a self-management component was used to identify and structure barriers and facilitators to community reintegration following SCI. The environment and personal factors predominated, with maintenance of health, accessibility to the built environment and health services, re-establishing self and community connections being strong facilitators to reintegration. The challenge for health professionals working in the community with individuals with SCI is to be client centred and inclusive of the client's family, community and other rehabilitation providers to ensure the individual's needs are suitably met.

KEY POINTS

- The ICF framework of domains provides a useful tool to examine the barriers and facilitators to community reintegration; with the addition of self-management to further define personal factors.
- The environment and personal factors predominate as influences on community reintegration following SCI, with health and wellbeing, accessibility, re-establishing self, support and connections within the community being strong themes.
- The challenge for health professionals working in the community with individuals with SCI is to be client centred and inclusive with their families, communities and other rehabilitation providers to ensure the individual's needs are suitably met.

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REFERENCES

Accident Compensation Corporation. Retrieved from: www.acc.co.nz [Accessed 13th October 2014].

Bandura A (1977) Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review* 84: 191-215. doi: 10.1037/0033-295X.84.2.191

Boschen K A, Tonack M, Gargaro J (2003) Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research* 26: 157-164. doi: 10.1097/00004356-200309000-00001

Derrett S, Beaver C, Sullivan MJ, Herbison GP, Acland R, Paul C (2012) Traumatic and non-traumatic spinal cord impairment in New Zealand: incidence and characteristics of people admitted to spinal units. *Injury Prevention* 18: 343-346. doi: 10.1136/injuryprev-2011-040266

Dickson A, Ward R, O'Brien G, Allan D, O'Carroll R (2011) Difficulties adjusting to post-discharge life following a spinal cord injury: an interpretative phenomenological analysis. *Psychology, Health & Medicine* 16: 463-474. doi: 10.1080/13548506.2011.555769

Dijkers M (1998) Community integration: conceptual issues and measurement approaches in rehabilitation research. *Topics in Spinal Cord Injury Rehabilitation* 4: 1-15. doi: 10.1310/BJJA-2018-45KL-0VTL

Donnelly C, Eng JJ (2005) Pain following spinal cord injury: the impact on community reintegration. *Spinal Cord* 43: 278-282. doi: 10.1038/sj.sc.3101702

Gargaro J, Warren C, Boschen K (2013) Perceived barriers and facilitators to community reintegration after spinal cord injury: A critical review of the literature. *Critical Reviews™ in Physical and Rehabilitation Medicine* 25: 101-141. doi: 10.1615/CritRevPhysRehabilMed.2013007021

Geyh S, Nick E, Stirnimann D, Ehrat S, Michel F, Peter C, Lude P (2012) Self-efficacy and self-esteem as predictors of participation in spinal cord injury-an ICF-based study. *Spinal Cord* 50: 699-706. doi: 10.1038/sc.2012.18

Hay-Smith EJ, Dickson B, Nunnerley J, Sinnott KA (2013) "The final piece of the puzzle to fit in": an interpretative phenomenological analysis of the return to employment in New Zealand after spinal cord injury. *Disability and Rehabilitation* 35: 1436-1446. doi: 10.3109/09638288.2012.737079

Kendall M, Ungerer G, Dorsett P (2003) Bridging the gap: transitional rehabilitation services for people with spinal cord injury. *Disability and Rehabilitation* 25: 1008-1015. doi: 10.1080/0963828031000122285

Kuipers P, Kendall MB, Amsters D, Pershouse K, Schuurs S (2011) Descriptions of community by people with spinal cord injuries: concepts to inform community integration and community rehabilitation. *International Journal of Rehabilitation Research* 34: 167-174. doi: 10.1097/MRR.0b013e3283460e39

Lorig KR, Holman HR (2003) Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine* 26: 1-7. doi: 10.1207/S15324796ABM2601_01

Ministry of Health. He Korowai Oranga: a Māori Health Strategy. [Accessed 13th October 2014]. Retrieved from: www.health.govt.nz/publication/guide-he-korowai-oranga-maori-health-strategy

Mulligan HF, Hale LA, Whitehead L, Baxter GD (2012) Barriers to physical activity for people with long-term neurological conditions: a review study. *Adapted Physical Activity Quarterly* 29: 243-265.

Nunnerley JL, Hay-Smith EJ, Dean SG (2013) Leaving a spinal unit and returning to the wider community: an interpretative phenomenological analysis. *Disability & Rehabilitation* 35: 1164-1173. doi: 10.3109/09638288.2012.723789

Pluye P, Gagnon MP, Griffiths F, Johnson-Lafleur J (2009) A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies* 46: 529-546. doi: 10.1016/j.ijnurstu.2009.01.009

Silver J, Ljungberg I, Libin A, Groah S (2012) Barriers for individuals with spinal cord injury returning to the community: a preliminary classification. *Disability & Health Journal* 5: 190-196. doi: 10.1016/j.dhjo.2012.03.005

Sinnott A, Cassidy B, Nunnerley JL, Bourke J, Kunowski T (2010) Commentary on community participation following spinal cord injury in New Zealand. *Topics in Spinal Cord Injury Rehabilitation* 15: 63-71. doi: 10.1310/sci1504-63

Suddick K, Migliorini C, Amsters D, Balakatounis K (2009) Reintegration and rehabilitation after spinal cord injury: a small-scale pilot study. *International Journal of Therapy & Rehabilitation* 16: 535-544. doi: 10.12968/ijtr.2009.16.10.44563

Van de Velde D, Bracke P, Van Hove G, Josephsson S, Vanderstraeten G (2010) Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home. *International Journal of Rehabilitation Research* 33: 346-355. doi: 10.1097/MRR.0b013e32833cdf2a

World Health Organisation (2002) *Towards a common language for functioning, disability and health: ICF:* World Health Organisation. Retrieved from: www.who.int/classifications/icf/en/ [Accessed 31st August 2014].