

## REVIEW

# Perceived effectiveness and mechanisms of community peer-based programmes for Spinal Cord Injuries—a systematic review of qualitative findings

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**Study design:** Systematic review and meta-synthesis of qualitative findings.

**Objectives:** To establish the perceived effectiveness and mechanisms of community peer-based programmes based on narratives of consumers with spinal cord injury (SCI).

**Methods:** Scopus, Academic Search Complete, CINAHL, Health Source, Medline, PsycARTICLES, PsychINFO, SPORTSDiscus and ProQuest were searched for articles published in English between January 1990 and December 2015. Qualitative studies referring to community peer-based interventions were included if most cases had a SCI. The results section of included studies was extracted and entered in NVivo. Data were inductively coded and analysed according to the three phases of Thematic Synthesis.

**Results:** The search yielded 1402 unique records, out of which 126 were scrutinised in full. Four studies were appraised based on eight criteria and were finally included in the analysis. Three analytical themes emerged: (1) a unique learning environment created by the right mixture of learning resources, learning processes and a can-do attitude; (2) peer mentors—a unique learning resource with high level of relatedness that eases and empowers participants; and (3) an intervention that responds to important unmet needs and unrealised potential.

**Conclusions:** Community peer-based programmes for people with SCI provide individualised training in important life areas, using a variety of learning resources and a plethora of learning processes. The high level of perceived effectiveness suggests that this type of intervention is an important tool of health systems post discharge from initial rehabilitation. Community organisations should be supported with evaluating their programmes through quality research.

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## INTRODUCTION

Spinal cord injury (SCI) has devastating consequences for the individual, their family and their community.<sup>1</sup> There is convincing evidence that comprehensive SCI systems of care result in fewer complications, better functional outcomes and lower mortality compared with general or non-systematic approaches.<sup>2–6</sup> Nevertheless, the vast majority of SCI individuals around the world are still managed through non-systematic and fragmented processes.<sup>1</sup> Only a few countries, all high income, provide comprehensive systems of coordinated care from the acute phase to life-long follow-up.<sup>1</sup> An increasing number of countries have established stand-alone Spinal Injury Units that focus on early survival and prevention of complications. Despite improvements in rehabilitation efficiency over the last 20 years, shorter rehabilitation length of stay results in lower functional outcomes on discharge.<sup>7</sup> Post-discharge follow-up, when available, may involve nursing and medical services<sup>8</sup> or consumer-driven programmes ran by non-profit organisation.<sup>1,9</sup>

Transition from in-patient care to home is a complex process that has been described as one of the most difficult aspects of life after

SCI.<sup>9–11</sup> Initial inpatient rehabilitation covers a specific set of needs relevant to the acute and early sub-acute phase, but reportedly fails to foresee needs that only become apparent when the person returns home.<sup>10,12</sup> There is compelling evidence that newly injured individuals feel unprepared physically and psychologically to transition from in-patient care to home.<sup>11,12</sup> After returning home, individuals with SCI often experience isolation, depression and low levels of physical and psychosocial functioning.<sup>9,10,13–15</sup> Low level of self-efficacy was found to have a detrimental effect on adjustment 6 months post discharge.<sup>16</sup> At the same time, social support and particularly peer support, have been reported as crucial in adjusting to post-discharge life.<sup>10,11,15,17–19</sup>

Peer-based programmes have an important role in the process of re-adjusting in the community.<sup>1</sup> For the needs of this paper, community peer-based programmes were defined as programmes located in the community that were not part of the initial in-patient or outpatient care and rehabilitation. These programmes may involve health professionals, but training is primarily led by individuals with a lived experience of disability, otherwise known as peer mentors.<sup>20</sup> World Health Organization recommended the utilisation of

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non-health professionals such as peers to assist in the delivery of a comprehensive range of health care and rehabilitation services.<sup>1</sup> To date, there is little scientific evidence exploring the effectiveness and the effect mechanisms of such interventions in SCI management. Furthermore, there is a lack of systematic reviews exploring this topic.

We therefore conducted a qualitative systematic review with the aim to assess consumer perceptions on the effectiveness of community peer-based programmes in SCI management. Furthermore, this systematic review aimed to identify and synthesise the mechanisms that contribute to the reported outcomes. Qualitative systematic reviews are considered a powerful tool for informing evidence-based policy and practice. Meta-synthesis is the type of qualitative systematic review that uses rigorous qualitative methods to synthesise and

integrate findings from existing qualitative studies in order to construct greater meanings through an interpretative process.<sup>21</sup> It is widely accepted that systematic reviews should consider diverse forms of evidence, both quantitative and qualitative.<sup>22</sup> Only then can a complete story be explored and understood.

## MATERIALS AND METHODS

We followed the guidelines for Enhancing Transparency in Reporting the synthesis of Qualitative Research to report the methodology.<sup>23</sup> Based on the critical realism paradigm, we used the method of Thematic Synthesis as described by Thomas and Harden.<sup>24</sup> Thematic synthesis was developed to conduct reviews that addressed questions relating to intervention need, appropriateness and acceptability—as well as those relating to effectiveness—without compromising on key

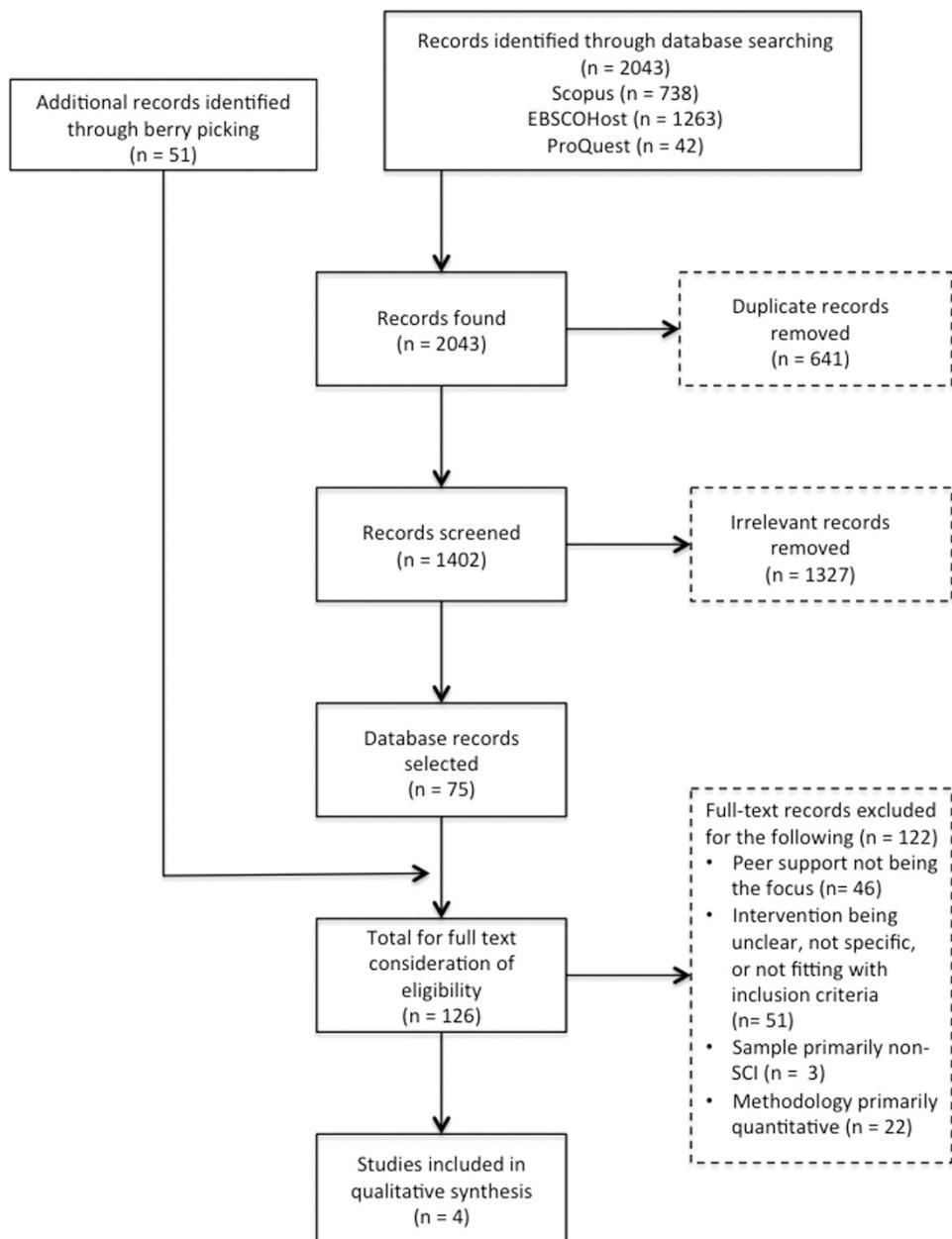


Figure 1 Flow chart of search and selection processes.

principles developed in systematic reviews.<sup>25</sup> The outcome of thematic synthesis is a list of analytical themes that go beyond the findings of the primary studies.

During the review process, the two reviewers held regular debriefing sessions in which the methodological choices and data analysis procedures and interpretations were discussed and negotiated. Any discrepancies were resolved by consensus—a process that has been described as ‘negotiated validity’ in qualitative methodology.<sup>26</sup> In our fortnightly sessions, we used a ‘think aloud’ strategy<sup>26</sup> to articulate personal perspectives and to discuss reasons for agreement or disagreement on each topic. If consensus was not reached at one meeting, the topic was moved to the following meeting until consensus was reached. We used an ‘audit trail’ format to document all major methodological decisions, as a way to better understand decision processes and to enhance reflexivity of teamwork.<sup>27</sup>

#### Inclusion and exclusion criteria

According to Sandelovski and Barroso, inclusion and exclusion criteria in meta-synthesis are reconsidered throughout the stages of the review process and are influenced by the identified studies.<sup>26</sup> Defining the criteria for our study was a dynamic process that continued into the

stage of literature search. Our final list of inclusion and exclusion criteria was as follows:

1. Qualitative studies were included independently of their design and epistemological framework; mixed-method studies were only included if the qualitative part was substantial, that is, at least equal in length and weight to the quantitative part. Studies without original quotes to support the researchers’ interpretations were excluded.
2. Studies published in English between January 1990 and December 2015.
3. Original articles and grey literature such as digital theses and research reports.
4. Studies with adequately described interventions that had the following characteristics:
  - a. Interventions offering a face-to-face, direct, real-time and mutually interactive experience.
  - b. Community interventions that were not part of the initial in-patient or outpatient care and rehabilitation.
  - c. Formal peer support interventions (that is, not incidental) that used designated peer workers in a paid or volunteer role.

**Table 1** Study characteristics

First author, year, country	Participants (N, ages, M/F)	Other participants	Methodological approach	Data collection	Time of data collection	Aim
Block, USA <sup>33</sup>	19 (10 with SCI) <sup>a</sup>  M/F: 3/2 <sup>b</sup> Mean age: 44 years (range: 20-73) <sup>b</sup>	Multiple sclerosis and other neurological conditions	Content and thematic discourse analysis  Convenience sample	Semi-structured interviews, Personal activity logs (PAL), and independent living Assessments (ILAS)	6 months post intervention	Assess the influence of an intervention for capacity building and health promotion on self-efficacy and the ability to set and achieve goals, to recognise supports and to navigate barriers to goal attainment
Standal, Norway <sup>35</sup>	20 (11 with SCI)  M/F: 4/1  Mean age: 43 (age range: 26-60 years)	Other acquired neurological conditions	Situated learning framework  Phenomenological approach  Hermeneutical approach	In-depth interviews and close observations including informal interviews	Towards the end of the programme	Investigate the learning that takes place when people with disabilities interact in a rehabilitation setting
Conway, 2010, New Zealand <sup>34</sup>	Eight with SCI  M/F: 7/1 Time since injury: 1–14 years Age range: 20-63	Nil	Constructivist Grounded theory Constant comparative method Purposeful sampling	In-depth semi-structured individual interviews. Field observation notes	At the beginning of the programme and 3 months after completion of the programme	Gain an understanding of the experiences and perceptions of individuals with spinal cord injury who participate in an outdoor recreational programme in New Zealand and the influence it has on their lives
Ashton-Shaeffer 2001, USA <sup>32</sup>	15 (8 with SCI)  M/F: 3/2 Age range: 20-50 Mean time since injury: 10 years (range: 8 months–18 years)	Limb malformation, above knee amputation, below knee amputation, cerebral vascular accident, reflex sympathetic dystrophy	Constant comparison techniques with a grounded theory approach  Foucauldian framework, informed by the work of poststructural feminists	Individual, in-depth, semi-structured interviews	6 months post-intervention	Investigate the attitudes of men and women with physical disabilities towards participation in a disability sport camp

<sup>a</sup>Numbers correspond to study participants who were randomly selected for the qualitative part of the study.

<sup>b</sup>Numbers correspond to all study participants.

Studies that referred solely to patient-to-patient support were excluded.

### 5. Studies where at least half of the participants had an SCI.

#### Search and selection strategies

Overall, we conducted a comprehensive and rigorous search of the literature with an emphasis on recall rather than on precision, in order to make sure that our search was exhaustive. Electronic database searches were conducted in Scopus, EBSCOHost (Academic Search Complete, CINAHL, Health Source, Medline, PsycARTICLES, PsychINFO, SPORTSDiscus) and ProQuest. The search strategy looked in titles, abstracts and keywords for the terms listed in Supplementary Appendix S1. In addition, the two authors independently followed 'berry-picking' methods,<sup>28</sup> in order to further expand the search strategy. These involved footnote chasing, citation searching, journal run, author searching, as well as a search in websites of organisations known to run community peer-based interventions. In order to keep data analysis manageable, we only considered dissertations if there was no published article linked to the study.

#### Data evaluation

All identified studies that met the inclusion criteria were appraised for their trustworthiness and usefulness based on the set of eight criteria suggested by Rees *et al.*<sup>29</sup> First, the two reviewers independently appraised, weighted and justified the weighting of each of the studies. Then, any discrepancies were discussed and resolved through consensus. No articles were excluded on the basis of insufficient quality. Rather, the appraisal process was used to get a better understanding of the strengths and weaknesses of each article.

#### Data analysis

All included studies were entered verbatim in NVivo 10. In accordance with the recommendations by Thomas and Hardsen,<sup>24</sup> the unit of analysis for our review was the 'results' or 'findings' section of the primary sources. Thematic synthesis involved the following three stages: the coding of text 'line-by-line'; the development of 'descriptive themes'; and the generation of 'analytical themes'.<sup>24</sup>

In the first stage of analysis, we started with an inductive, open-coding process. Initially, one primary source was coded and the identified codes were then discussed between the reviewers. Subsequent primary sources were coded into pre-existing nodes, and new nodes were created when deemed necessary. Coding was an inclusive, recursive process, in which we continuously revisited previous decisions to determine whether coding was being implemented systematically and consistently.

When initial coding of all primary sources was completed, the reviewers reconsidered all identified codes with the aim to condense them and subsequently group them into unique categories and sub-categories. In order to explore the effect mechanisms of the identified programmes, we used Donabedian's framework for assessment of health-care quality (that is, structure-process-outcomes), as a starting point to group the descriptive categories.<sup>30</sup> This process of reciprocal translation, synthesis of translation and grouping of categories led to the identification of overarching descriptive themes that emerged from primary data sources.<sup>24,31</sup>

In the final stage of thematic synthesis, analytical themes emerged when we related the descriptive themes to our research questions.

## RESULTS

### Included studies

Figure 1 presents a flow chart with the search and selection process. All 2043 records from database searching were entered into EndNote X7 software. After removal of duplicates, results were first screened based on title and abstract. The full article of the resulting 75 records was retrieved, and their reference lists were scrutinised to identify other relevant studies. A total of 51 records were identified through reference scrutinising and berry-picking methods. These 126 articles were then read in full by the two authors independently, and were either classified as included or excluded. The primary reason for not including an article was clearly identified and assigned into one of the four categories presented in Figure 1.

Four studies met the selection criteria and were included in this review: Ashton-Shaeffer *et al.*,<sup>32</sup> Block *et al.*,<sup>33</sup> Conway,<sup>34</sup> and Standal and Jespersen.<sup>35</sup>

### Characteristics of the included studies

Characteristics of the four included studies are presented in Table 1. Each of the four studies referred to an established peer-based programme: Wheels in Motion in Norway;<sup>35</sup> Shake it Up in USA;<sup>33</sup> Sports Camp in USA<sup>32</sup> and Back Up in New Zealand.<sup>34</sup> One of the studies included only SCI participants ( $N=8$ ), whereas the other three included an equal number of cases with SCI ( $N=35/70$ ) and cases with other neurological conditions. One study collected data towards the end of the programme, another one 3 months after completion and the other two 6 months after completion of the programme.

The key characteristics of the included programmes are presented in Supplementary Appendix S2. The two programmes from USA were collaborations between non-profit community organisations and universities. Only Wheels in Motion and Back up were residential programmes. All programmes provided a combination of outdoor activities and adapted sports, training sessions focusing on physical skills, theoretical sessions and discussions. All programmes used peer mentors, rehabilitation professionals and non-disabled assistants.

Two of the studies were assessed as high quality, one as medium to high, and one as low quality. Table 2 presents the results of the quality appraisal process.

### Descriptive themes

Analysis of the four primary sources led to the identification of the descriptive themes, categories and codes. Table 3 presents a visual representation of descriptive themes, categories and sub-categories organised in a way that could explain the effect mechanisms of the programmes. A comprehensive list of the descriptive themes is provided in Table 4.

**Table 2 Appraisal of included data sources for (a) reliability of findings and (b) usefulness of findings**

	Trustworthiness of findings			Usefulness of findings		
	Low	Medium	High	Low	Medium	High
1. Block <i>et al.</i> <sup>33</sup>	✓				✓	
2. Standal and Jespersen <sup>35</sup>				✓		✓
3. Conway <sup>34</sup>				✓		✓
4. Ashton-Shaeffer <i>et al.</i> <sup>32</sup>		✓				✓
Total	1	1	2	1		3

**Table 3 Descriptive themes, categories and sub-categories**

Mechanisms		Effects		
Learning Resources	Learning Processes & Activities	Outcomes – Cognitive and Affective level	Outcomes – Behavioral level	Significance - Impact
Curriculum <ul style="list-style-type: none"> <li>○ Structure</li> <li>○ Flexibility</li> <li>○ Content</li> </ul>	A CAN DO APPROACH	Observing	Dare to try/ push boundaries	Started work
Participants <ul style="list-style-type: none"> <li>○ Needs</li> <li>○ Expectations</li> <li>○ Goals</li> <li>○ Function</li> </ul>		Discussing	Motivate – inspire	Connected and did stuff with others
Getting together has a power		Doing	Set standard – measuring stick	Got a partner
		Comparing	Can do culture	Did not know it was possible
		Reflecting	Improve self-efficacy	Became more socially active
One's own self		Competing	Improve self-confidence	Improved community access
Peer mentors <ul style="list-style-type: none"> <li>• A living example</li> <li>• Credibility</li> <li>• Relatedness</li> </ul>		Dealing with fears	Forming identity	Managed day on their own
		Using own jargon/language	Feeling normal and accepted	Exceeded initial expectations
Engaging in stimulating activities		Individualize knowledge	Set new goals and worked towards realizing them	Learnt and practiced recreational and sports activities in the community
Health Professionals		Supporting		A unique opportunity not available elsewhere

### Analytical themes

When we related the descriptive themes to the research questions, three analytical themes emerged. The three analytical themes were: (1) a unique learning environment created by the right mixture of learning resources, learning processes and a can-do attitude; (2) peer mentors—a unique learning resource with high level of relatedness that eases and empowers participants; and (3) an intervention that responds to important unmet needs and unrealised potential. Table 4 presents the mapping of both analytical and descriptive findings with the primary sources. Supplementary Appendix S3 presents illustrative quotes for the descriptive themes under each analytical theme.

#### 1. A unique learning environment created by the right mixture of learning resources, learning processes and a can-do attitude

In community peer-based programmes, learning derived from multiple sources, it took place throughout the day and it involved a plethora of processes. Although each programme had its own characteristics, a common key theme across all the programmes was the prevailing can-do attitude.<sup>32–35</sup> Learning resources and learning processes were not linked with outcomes in a one-to-one cause–effect manner. Rather, specific outcomes were a result of a combination of resources and processes. The most important learning resources were seen as the curriculum structure, the content of the programme, the peer mentors and one's self.

Most of the curricula were described as having a flexible structure that allowed participants to engage in the scheduled activities and informal learning opportunities.<sup>32,34,35</sup> As a result, participants gained the opportunity to individualise the learning experience to their own level and needs, as well as to informally interact with peers. Overall,

most of the programmes were described as challenging, but at the same time flexible and possible to follow.<sup>32,34,35</sup>

The type of training and activities offered in each programme was yet another important resource that made it a unique learning environment. All programmes included training of physical skills, recreational activities and sports, as well as information sessions on topics such as assistive equipment, modifications and other issues relevant to living with SCI.<sup>32–35</sup>

Connecting with a peer mentor was a personal process for each participant. In most programmes, being a model for other participants was a role filled by peer workers as well as by experienced participants.<sup>32,34,35</sup> Peer workers were designated by the programme organisers prior to the programme, whereas the *experienced peers* were informally nominated by participants and emerged during the programme.

Learning also occurred between inexperienced participants who learnt from each other. Being part of a group of individuals with similar functional level and goals allowed participants to share knowledge, skills and experiences.<sup>32–35</sup> At last, learning did not always come from an external source. Participants commented that one's self was also an important source of learning.<sup>34</sup>

Observing peer mentors and other participants demonstrate skills was reported to be an important learning process.<sup>32–35</sup> On some occasions, participants then performed multiple attempts to master the skill. On other occasions, observing others was associated with comparing one's own level of injury and independence with other participants. Often, comparison led to competition, which was seen as motivating and empowering.

Discussing and negotiating were two other processes that were identified. These processes were often used to transfer knowledge, to

**Table 4 Analytical and descriptive findings: the contribution of each study**

Programmes	Project <i>shake it up</i>	Wheels in <i>motion</i>	Back up <i>New Zealand</i>	Sports <i>camp</i>
Author/s, year & country	Block <i>et al.</i> <sup>33</sup>	Standal and Jespersen <sup>35</sup>	Conway <sup>34</sup>	Ashton-Shaeffer <i>et al.</i> <sup>32</sup>
<i>Analytical themes</i>		<i>Descriptive themes</i>		
1. A unique learning environment created by the right mixture of learning resources, learning processes and a can-do attitude	✓	✓	✓	✓
1.1. Curriculum: right balance of flexibility and structure. A combination of formal sessions and informal learning opportunities		✓	✓	✓
1.2. Content: what is possible to achieve; combine autonomy in choice, exploration, competence and enjoyment	✓	✓	✓	✓
1.3. Peer mentors: peer workers and experienced peers as role models for the participants		✓	✓	✓
1.4. Participants: being part of a group with similar functional level and/or goals is a valuable learning resource	✓	✓	✓	✓
1.5. Learning from one's own self			✓	
1.6. Learning processes that facilitate self-reflection, incorporation of the knowledge into practice and build competence	✓	✓	✓	✓
1.7. Not fixing problems, but rather providing the tools			✓	
1.8. Learning processes that facilitate the relatedness with peers			✓	✓
1.9. A 'can-do' mindset that empowers and facilitates the learning processes	✓	✓	✓	✓
2. Peer mentors—a unique learning resource with a level of relatedness that empowers participants			✓	✓
2.1. Peer mentors actively involved in both formal and informal learning processes of the programme		✓	✓	✓
2.2. Peer mentors have lived it all		✓	✓	
2.3. Peer mentors versus able-bodied professionals		✓	✓	
2.4. Credible for what they can and what they cannot do		✓		
2.5. Why do they bother?		✓	✓	
3. An intervention that responds to unmet needs and unrealised potential that are important	✓	✓	✓	✓
3.1. Unmet needs related to knowledge of potential—choices, competence in abilities and relatedness with people who speak the same language		✓	✓	✓
3.2. Unrealised potentials prior to the programme. Possibilities become apparent through interaction with others		✓	✓	✓
3.3. Cognitive, affective and behavioural changes at the programmes led to realisation of needs and possibilities, and to self-determined actions (outcomes)—leading to significant outcomes that can be retained	✓	✓	✓	✓
3.4. An intervention that addresses crucial life areas for the participants	✓	✓	✓	✓
3.5. Short intervention leading to important outcomes	✓	✓	✓	✓
<i>Total contribution of each study</i>				
Analytical themes	2/3	3/3	3/3	3/3
Descriptive themes	7/19	17/19	18/19	12/19

develop a positive mindset and to strengthen the sense of belonging to the group. Participants felt that they had the opportunity to use their own language freely, which was different to that used by health professionals. This was seen as a way to reclaim their identity.

Participants acknowledged that getting together with others who were in a similar situation and faced similar issues was empowering.<sup>34,35</sup> The sense of safety, support and collegiality facilitated the relatedness of the participant with peers. In such a learning environment, seeing others dealing with fears, motivated participants to push their own boundaries. Participants commented that instead of being given the solutions to their problems, they had to learn how to solve problems.<sup>34</sup>

## 2. Peer mentors—a unique learning resource with high level of relatedness to participants that eases and empowers

Although peer mentors were highly involved in training and education, their role extended much further than that.<sup>32,34,35</sup> They worked with motivating the participants to develop a positive mindset and persistence.<sup>32,34,35</sup> Peer mentors were described as having credibility because 'they have lived it all' and because they developed high level of relatedness with the participants.<sup>34,35</sup> These attributes were described as unique to peer mentors, as these could not be offered by non-disabled health professionals.<sup>34,35</sup>

Peer mentors were described as a living example of what the participants could achieve and a resource for how to achieve it. At the same time, sharing openly their own limitations made participants feel comfortable with the idea of not being able to manage everything. Therefore, peer mentors were credible both for what they could and could not achieve.<sup>35</sup> Peer mentors undertook their role either because they had a sense of duty to help those in need, or because they had similar personal experiences in the past, or lastly, because they benefitted personally through that role.<sup>34,35</sup>

## 3. An intervention that responds to important unmet needs and unrealised potential

Some participants admitted having vital unmet needs prior to the programme. They knew why they attended the programme and what they wanted to get out of it.<sup>32,34,35</sup> Unmet needs were often related to lack of skill and motivation to perform physical activities. Others reported that they lacked the confidence to be in less-protective environments than their homes or the rehabilitation centre.

Some other participants had not realised their full potential, as they did not know what was possible to achieve, particularly in relation to major life areas, such as living independently without a personal assistant, being able to travel, socialise effectively and get a partner.<sup>32,34,35</sup> These potentials only became apparent to them during the programme through observing and interacting with peers.<sup>32,34,35</sup> Many participants reported not knowing that it was possible to perform so many activities and live an active life after injury. Some participants reported that they were missing the relatedness with others in a similar condition, and they saw the programme as a unique opportunity to do so.<sup>32,34,35</sup>

For the participants, gaining a better understanding of what was possible to achieve and being encouraged to explore boundaries contributed to developing a can-do culture.<sup>32–35</sup> This positive mentality and the availability of the peer mentors' and the other participants' living example motivated individuals to accomplish their own goals.<sup>32–35</sup> This in turn led to higher perceived self-efficacy and self-confidence.<sup>32–35</sup>

Changes occurring at cognitive, affective and behavioural levels during the programme led to realisation of needs and opportunities,

which in turn led to more self-determined actions.<sup>29,31–33</sup> As a consequence, self-determined actions led to outcomes that were more likely to be retainable in the future. Participants reported improvements in wheelchair skills, community access, being more socially active, being able to enjoy activities that they always liked, achieving higher self-confidence and independence.<sup>32–35</sup> Overall, they were able to increase their level of physical activity by getting involved in recreational activities and sports that they had tried during the programme.

Overall, participation in the programme was a transformational experience for many participants and a transition point for achieving higher level of functioning, well-being and identity rebuilding.<sup>32–35</sup> For some of them, the programme was the first time they performed activities as advanced as doing kayaking, or as basic as leaving their house. An illustrative quote from one of the participants stated 'I (had not) left my house in 3 years before I met you guys' (Dora).<sup>33</sup> However, for Carla, a 41-year-old physical education teacher, it was return to work that she achieved through the skills and the confidence she had gained in the programme.<sup>32</sup>

## DISCUSSION

This is the first attempt to systematically identify and synthesise findings of qualitative studies in order to explore the mechanisms and perceived effectiveness of community peer-based programmes in SCI management. Our findings suggest that community peer-based programmes result in positive outcomes for community-dwelling individuals with SCI. Exploration of the effect mechanisms revealed a plethora of learning resources and processes, and highlighted the role of peer mentoring.

### 1. A unique learning environment created by the right mixture of learning resources, learning processes and a can-do attitude

Learning occurred during formal (that is, scheduled sessions) and informal opportunities (interactions with peers and peer mentors), involved various processes (for example discussing, observing, doing, incorporating, following), and came from various directions (that is, from experienced peers, peer workers, inexperienced peers, health professionals). This is a unique learning environment, different to other settings or programmes, such as inpatient rehabilitation,<sup>36</sup> therapeutic recreation,<sup>37</sup> leisure activity programmes,<sup>38</sup> wheelchair sports,<sup>39</sup> support groups,<sup>20</sup> non-face-to-face or one-to-one peer mentoring programmes.<sup>40</sup>

The first and foremost mechanism of the community peer-based programmes could be summarised by what Perlan called in his dissertation 'Gathering has a power'.<sup>41</sup> In the case of Project Quila in Mexico described in Perlan's study, gatherings of local people with disability at a local hotel resulted in the development of a consumer-led rehabilitation centre.<sup>41</sup> In the case of community peer-based programmes, gathering of many people with a SCI became a transformational experience for those attending. Community peer-based programmes are an effective form of participatory learning.

Our analysis demonstrated that through the prevalent can-do attitude in the programmes, participants developed a high level of perceived efficacy in performing tasks that were important for them. This is important given that higher level of self-efficacy has been reported to improve resilience and to reduce the risk for depressed mood in people with SCI after discharge.<sup>42,43</sup> According to Bandura,<sup>44</sup> self-efficacy beliefs are an important aspect of human motivation and behaviour and influence the actions that can affect one's life. Furthermore, personal accomplishments, vicarious experience, verbal persuasion and physiological feedback build self-efficacy beliefs and set

the base for expectations and actions in one's life.<sup>44</sup> The programmes provided many opportunities for participants to experience success and to overcome failures. Mastering a skill has been considered as the most influential source on efficacy.<sup>44</sup> By observing what their peers achieved, participants were able to improve their self-efficacy beliefs through what Bandura describes as vicarious experience.<sup>44</sup> Furthermore, verbal persuasion was more effective as it came from the sources that were considered credible, that is, peer mentors, as compared with non-disabled instructors.

In addition, the programmes offered a dynamic learning environment that facilitated the satisfaction of the three basic needs postulated in self-determination theory, that is, the need for autonomy, competence and relatedness.<sup>45-47</sup> According to self-determination theory, satisfaction of these needs fosters an internalised motivation for changes in behaviour, which makes it more likely for the person to achieve long-term adherence.<sup>45-47</sup> Participants of the programmes became more internally motivated, because they felt competent in performing a certain behaviour, they were provided with choices on how to accomplish it and they felt connected with significant others.

The learning environment was also described as supportive and flexible, offering a plethora of learning resources and processes. Such an environment helped participants to feel safe, overcome their fears, encouraged them to try activities and led them to push their own boundaries. The relationship between learning resources, processes and outcomes was not linear or pre-determined. Rather, from the available learning resources and processes, the participants picked the ones that best suited their needs. That unique combination differed from participant to participant, that is, learning resources and processes that worked for one participant did not necessarily work for another. Therefore, the available set of learning resources and processes could be seen as a toolbox, where participants pick the tools that work best for them. It was the flexibility of the programme that facilitated participants to pick and choose the right tools for themselves, and thus to customise the intervention to their personal needs. Client-centredness can be seen as an integral part of community peer-based programmes.

## 2. Peer mentors—a unique learning resource with high level of relatedness that eases and empowers participants

The availability of peer mentors (for example, designated peer workers and emergent experienced peers) as a source of learning made the programmes a hive of observational learning. Although the exact roles and responsibilities of peer mentors were somewhat different, modelling of behavioural skills was a common process in the programmes. Peer mentors are considered credible because their lived experience makes them convincing, live representations of what participants could achieve if they wanted and made the effort. According to Bandura, modelling is much more than mimicry, as it involves higher level processes that allow the observer to extract the rules governing specific judgments and actions, in order to generate new courses of behaviour that go beyond what was seen or heard.<sup>48</sup>

In addition to being a credible learning resource, as noted above, peer mentors have high degree of relatedness with participants. Relatedness is considered a result of acceptance, understanding and taking responsibility for the well-being of others.<sup>45,46</sup> Peer mentors understand the needs of participants and respect their feelings primarily because of their common lived experience of disability. In this way, participants feel valued and accepted. Furthermore, by using a language that is built on their common experiences, participants feel

understood and connected with peer mentors. The feeling of relatedness helps participants find relevance in what peer mentors represent, it makes learning worthwhile, and it positively influences learning efficacy.

Furthermore, the peer mentors' role was characterised as motivational. It has been suggested that through cognitive representation of future outcomes, individuals can generate current motivators of behaviour.<sup>44,49</sup> According to a systematic review by Ginis *et al.*<sup>49</sup> peer mentors are an important source of social influence that can impact theoretically relevant motivational determinants of behaviour such as self-efficacy, perceptions of competence and self-determination. The availability of peer mentors with different characteristics and socio-cultural backgrounds suited participants with differing needs and learning styles.

The three key features of peer mentoring, that is, credible learning resource, high degree of relatedness and motivators, make peer mentors a unique learning resource.

## 3. An intervention that responds to important unmet needs and unrealised potential

During the chronic phase of SCI, there are factors that facilitate (that is, self-efficacy, motivation, access to learning resources in an appropriate learning environment, access to peers) and factors that hinder (for example, fear, lack of knowledge, isolation, lack of basic skills, depression) the achievement of outcomes.<sup>15,50</sup> The current review found that community peer-based programmes endorsed the facilitating factors and minimised the hindering factors through a plethora of learning processes. Participants achieved positive outcomes in significant life areas, such as independent living, employment, leisure and social life.

With SCI being a condition that, in most instances, leads to life-long disability, affected individuals have extensive needs that, if not addressed appropriately, can create an unbearable burden for the health-care system, the family and the individual. Following initial discharge, SCI individuals are reported to have more than double the number of hospital visits and three times longer hospitalisation duration per person per year as compared with the general population.<sup>51</sup> Despite all four programmes taking place in countries with well-developed and well-functioning systems of care for SCI (USA, Norway, New Zealand), participants reported significant unmet needs prior to the programmes. Many of these needs, that involved major life areas, were satisfied through participation in the community peer-based programmes. In well-functioning systems of care, community peer-based programmes fill an important service gap in long-term SCI management. It may be possible that these programmes fill even bigger service gaps in countries with less well-functioning systems.

## Need for more research evidence about community peer-based interventions

As modern health-care costs are rising, health systems strive for becoming more evidence-based.<sup>52</sup> Policy makers need solid and convincing proof that an intervention is effective and that it saves money in the short and long term. The current systematic review found that only a very small number of community peer-based programmes for individuals with SCI have been evaluated systematically. More specifically, the systematic literature search yielded a number of small-scale papers that lacked robust methodological design or a clear description of the intervention. We therefore face a paradoxical situation, where there are many community-based interventions, a lot of anecdotal evidence on their effectiveness, very

little quality research on these programmes, low level of integration in health-care systems and limited funding of these programmes.

Given that community peer-based programmes are usually offered by not-for-profit organisations, there are many possible factors contributing to this paradox. These organisations focus and allocate their limited resources on finding participants and funding. Often, they are dependent on volunteers with expertise but with limited time. In other instances, the programmes may be very labour intensive and with limited number of hands, there is not enough time and energy to conduct research. Also, standardisation or even detailed description of the intervention is often lacking, making it even more difficult to perform any meaningful and generalisable research. Perhaps, exploring the effectiveness and cost-efficiency has not been made an explicit requirement for not-for-profit organisations. Finally, a lack of expertise in designing and conducting quality research might be a major deterring factor.

### Research implications

In agreement with previous studies, this review highlights the importance of collaboration between community organisations and universities as a solution to the paradox and its contributing factors.<sup>53</sup> Universities often have the interest and the expertise in conducting quality research and in securing research funding. At the same time, community organisations are engaged with the consumers, and they can identify important real-life problems that need solutions. A great example of multidisciplinary community–university partnership was implemented in Canada.<sup>53</sup> Action Canada is a partnership of university (researchers) and a community-based organisation with the goal to increase physical activity among adults with SCI. That study concluded with a description of challenges, opportunities and lessons learned through this community–university partnership.<sup>53</sup>

### Policy implications

Even in the presence of comprehensive systems of care, community peer-based programmes are needed to cover unmet needs in important life areas. Often, peer support programmes have an ancillary role to medical rehabilitation and treatment. In some instances, these interventions are not part of the formal system of care, which means that they are not subsidised accordingly. Findings of this review suggest that the high levels of perceived effectiveness necessitate the higher integration of community peer-based programmes in health-care systems, and the provision of adequate long-term funding.

Associating funding with evidence-based outcomes relevant to the goals of the organisation and the population they serve could be a way to encourage community organisations to evaluate the effectiveness and cost-efficiency of their programmes. At the same time, making community engagement an explicit expectation for university funding could make collaboration between universities and community organisation become a higher priority for both parties. That could galvanise the interest of the universities to conduct quality and meaningful research, and can make a difference for the community.

### Clinical implications

Flexibility of the programmes was found to be a key characteristic that allowed participants to customise the intervention to their own needs and learning style. Flexibility was also found to facilitate formal and informal learning through a range of processes. Community peer-based programmes should strive to offer rich learning environments with learning resources (that is, content and structure of the

programme, peer mentors, participants, non-disabled members) that fit the needs of the participants.

### Limitations of the review

Similar to other systematic reviews on community-based programmes,<sup>8</sup> there is a strong possibility of publication bias in our study. Community peer-based programmes tend to be under-reported, under-described and under-researched. Furthermore, inclusion of studies published in English may potentially be another factor contributing to publication bias. Last, this systematic review included four studies that satisfied the inclusion criteria, all from high-income countries. Therefore, caution needs to be practiced when relating the conclusions of the current review to programmes in mid- and low-income countries.

### CONCLUSIONS

Community peer-based programmes provide individualised active training in important life areas, using a variety of learning resources. A distinct feature of these programmes is the role and contribution of peer mentors. It appears to be the interplay between the learning resources and the plethora of learning processes in a can-do attitude that create the unique learning environment of the community peer-based programme. It is this interplay that can make this type of intervention a useful tool in the continuum of SCI care, irrespective of the level of comprehensiveness of the system of care. This type of community-based intervention is distinctly different from others and needs to be recognised as such. Because of the high level of perceived effectiveness, these programmes deserve to be better integrated in health-care systems and adequately funded. As most of the community peer-based programmes have not been adequately researched, service providers should be encouraged and supported to explore the effectiveness and cost-efficacy of these interventions.

### DATA ARCHIVING

There were no data to deposit.

### CONFLICT OF INTEREST

The authors declare no conflict of interest.

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