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SYSTEMATIC REVIEW

Exercising Choice and Control: A Qualitative Meta-synthesis of Perspectives of People With a Spinal Cord Injury

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Abstract

Objective: To systematically search the literature and construct a meta-synthesis of how choice and control are perceived by people with spinal cord injury (SCI).

Data Sources: Medline, Academic Search Premier, CINAHL, Cochrane, EMBASE, HealthSource, ProQuest, PsychInfo, SAGE, and SCOPUS were searched from 1980 until September 2018 including all languages. Reference lists of selected studies were also reviewed.

Study Selection: Eligible qualitative studies included perspectives about choice of control as reported by people with an SCI. Studies were excluded if they included perspectives from other stakeholder groups. A total of 6706 studies were screened for title and abstract and full text of 127 studies were reviewed resulting in a final selection of 29.

Data Extraction: Characteristics of the studies were extracted along with any data (author interpretations and quotes) relating to perspectives on choice and control.

Data Synthesis: First-order analysis involved coding the data in each study and second-order analysis involved translating each segment of coded data into broader categories with third-order analysis condensing categories to 2 broad overarching themes. These themes were experiencing vulnerability or security and adapting to bounded abilities.

Conclusions: Perspectives of choice and control are influenced by interrelated environmental, interpersonal, and personal contexts. From a personal perspective, participants reported a readiness for adaptation that included turning points where emotional and cognitive capacity to make choices and take control changed. Health professionals need to be responsive to this readiness, promote empowerment and foster, rather than remove, hope.

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Spinal cord injury (SCI) occurs in both traumatic and non-traumatic ways with the most common causes of traumatic SCI being motor vehicle accidents, falls, violence and sport.[1] Non-traumatic SCIs are more insidious such as development of spondylosis causing compression, vascular issues, tumors, and inflammation affecting the neural tissues in the spinal cord.[1] Injuries can occur at different levels of the spinal cord and may be incomplete or complete resulting in different experiences and classifications of resulting disability.[2,3] Across the variable classifications of disability, all individuals with SCI experience considerable change to their lives from disruption of their motor and sensory abilities.[4] Across the world, the highest population affected are men in the 15- to 32-year-old age group[4,5] who may be more exposed to the occupations that commonly result in traumatic SCI compared to women and other age groups.[6]

The central goal for a person following SCI is fulfillment of participation in life.[7] Participation is an important concept in relation to functioning, levels of disability, and maintenance of health and is defined by the World Health Organization as

"involvement in a life situation."[7(p10)] However, full participation following SCI may be compromised by limited mobility, sensation, and movement issues.[8] Participation in life depends on performing tasks such as activities of daily living, having relationships, and engaging in social activities and occupations commensurate with one's life stage, goals, and values. The capacity to participate relies in part on choice and control over one's life. Within Western cultures with individualist values there is a strong need for control that is satisfied by having power to make choices as well as access to different choices.[9] People with disabilities (including those with SCI) can frequently have their need for control undermined by physical, cultural, and institutional environments leaving them in a vulnerable position with a chronic lack of power in society.

Decades ago, the disability movement called for services to holistically approach the needs of people with a disability and to provide support without discrimination to ensure human and health rights were upheld.[9,10] As a result, policies were developed with an emphasis on equal access to services, and personalized and consumer-directed care.[11-14] The philosophies, standards, and regulations underpinning these policies and associated legislation are supported by evidence suggesting that choice and control over services enables people to be empowered and self-determining.[15] For the promotion of self-management,[16,17] there is a growing policy imperative for shared decision making between health professionals and people with disability.[16,17] However, the translation of policy into practice has been fraught with tensions[10] such as ingenuine consultation with consumers, insufficient funds for need, and difficulty procuring appropriate services.[13,14,18,19]

Greater understanding of what choice and control means to those with disability may support implementation of policy and equip health professionals with knowledge to be genuine and empathetic with consumers to meet their need for choice and rights for control in individualized and personalized ways.[13,16,19] Therefore, the purpose of this review was to synthesize the knowledge generated through a range of methodologies, samples, and interpretations on how choice and control is conceptualized by people with SCI. The question guiding this review was, "What are the views of people with SCI on their ability to exercise choice and control in their daily life?"

Methods

Our review was registered with the International Prospective Register of Systematic Reviews, PROSPERO, in May 2016. As the research was about perspectives, we chose to only include data from qualitative research.

Search strategy

Electronic databases searched were Medline, Academic Search Premier, CINAHL, Cochrane, EMBASE, HealthSource, ProQuest, PsychInfo, SAGE, and SCOPUS from 1980 until May 2016. The search was rerun from 2016 to September 2018 with EMCARE replacing CINAHL and no search in SAGE or ProQuest as these databases were no longer available to us. Papers published prior to 1980 were situated in an institutionalized context and therefore unlikely to be relevant. The operational definitions of choice and

control are based on a psychological perspective that understands choice as the opportunity to make decisions when presented with 2 or more options, while control is the opportunity to influence an action by initiating, maintaining, ceasing, or changing form, strength, or rate.[20(p5)] We used the search terms of decision making, autonomy, personal autonomy, and agency for choice; and personal control, power, and self-determination for control. These search terms were initially established in Medline (supplemental appendix S1, available online only at http://www.archives-pmr.org/), were peer reviewed by an academic librarian, and then adapted for use in each database. There were no limits on language of studies, and reference lists of relevant studies were hand searched to source additional papers.

Study selection

Selection began with removal of duplicates followed by double review of each title and abstract and full text using Covidence[a] software. A third reviewer resolved any conflicts that arose. Selection of references for inclusion in the meta-synthesis were based on the following inclusion criteria: (1) participants over 18 years, had SCI of any sort and lived in the community; (2) data from people with SCI could be separated from other participant groups (ie, health professionals, caregivers); (3) included perspectives about choice and control; and (4) qualitative research design. Exclusion criteria included (1) data from people with SCI could not be extracted from other participants and (2) did not include any data about choice and control or did not provide enough detail to inform our understanding of the concepts of choice and control.

Critical appraisal of selected papers

A critical appraisal using the McMaster criteria[21] was conducted. Two reviewers critically appraised all the selected papers and the appraisal findings were compared and discussed to reach agreement about interpretation. Appraisal decisions were based on what was included in the journal articles which may have been subject to reporting limitations.

Data analysis

The process of analysis and synthesis followed Noblit and Hare[22] and enabled us to arrive at findings with greater conceptual clarity than single studies alone.[23] This process is well recognized in health and accounts for all data rather than just common data across studies.[24] First-order analysis[23] involved 2 reviewers reading all the studies in full and identifying findings that related to the concepts of choice and control. Any differences in understanding of concepts were discussed and resolved by consensus. Identified data were then extracted into a single spreadsheet and each segment of data coded. Participant quotes were included against the relevant piece of coded text. The second-order analysis compared and sorted coded data from the spreadsheet into broad categories and was conducted independently by 2 authors. Third-order analysis included discussion among all authors to compare the 2 sets of categories and further synthesize and reduce the data into broad overarching themes with subthemes.

Rigor

A team of researchers were involved in this review to strengthen the findings.[25] We followed the reporting guidelines for enhancing

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List of abbreviations:

SCI   spinal cord injury

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transparency in the synthesis of qualitative research proposed by Tong et al.[26] The update of the search yielded 9 new papers for analysis and synthesis. The findings from these papers were consistent with our existing themes and subthemes and we, therefore, reached data saturation with no new findings emerging.

Findings

Search outcomes

Following removal of duplicates, there were 6706 studies for title and abstract screening which then left 127 articles for full text retrieval and review. Full text review reduced the number of included studies to 29. Reasons for exclusion are detailed in the flow chart provided in figure 1. One study was in Spanish and needed interpretation.[27]

Study characteristics

Studies included in the meta-synthesis originated in 11 different countries. The oldest study[28] was American from 1995 and the most recent[29] was published in 2018 from Australia. Overall, the studies included perspectives from 801 participants. Two studies drew their data from the same group and so their 11 participants (men) were only counted once.[30,31] Similarly, another 2 studies also drew their data from the same group and their 7 participants were only counted once.[17,32] Further details of the studies are available in table 1 with expanded information in supplemental appendix S2 (available online only at http://www.archives-pmr.org/).

Critical appraisal findings

The findings from the appraisal are available in table 2. A consistent methodological limitation across the studies was a lack of explanation of the role of the researchers, their motives for conducting the research, and whether there were existing relationships with the participants.

Meta-synthesis findings

Moving between first-, second-, and third-order analyses enabled reduction and synthesis of the data into 2 interrelated themes. The 2 themes and their subthemes are explained below. Source documents for each theme and subtheme can be found in table 3 and supporting quotes for each theme are provided in supplemental appendix S3 (available online only at http://www.archives-pmr.org/).

Theme 1: experiencing vulnerability and security

The first theme captures data about environmental and societal factors which generate vulnerability or create security following SCI. Reliance on others to feel secure at times limited choices and undermined control. Social networks including health professionals influenced opportunities and facilitated roles available to participants. The balance of power and trust between those with SCI and their paid and unpaid caregivers, their health professionals, and their friends or family were key determinants as to how vulnerability and security were experienced. To enable people with SCI genuine control over their lives, health professionals needed to listen and be responsive.
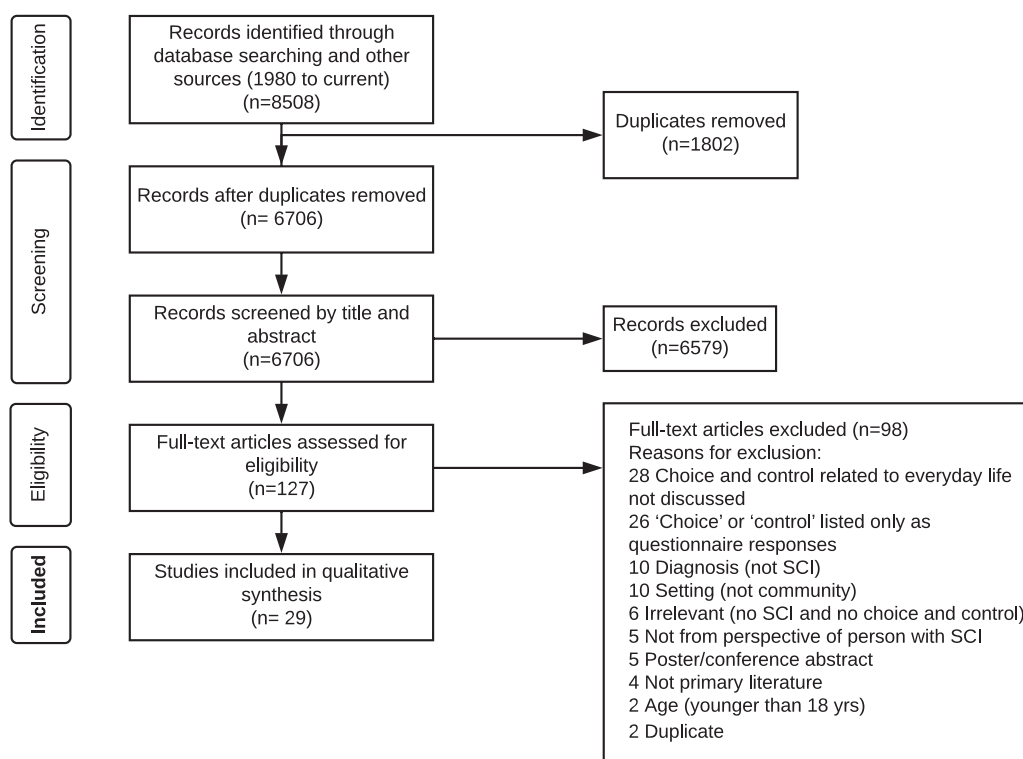

Fig 1 Flow chart of search and screening process.

Table 1 Characteristics of included studies

Author	No. of Participants (N=801)	Study Aim
Bell and Hinjosa[28]	3	To explore perceptions of 3 men with SCIs regarding the effect of assistive devices on their daily lives.
Braff et al[29]	22	To explore the needs of people living with an SCI receiving formal caregiver and hospital services in Victoria, Australia.
Carr et al[33]	8	To determine factors associated with community participation for individuals with an SCI.
Crewe[34]	259	To describe what work means to the lives of people with an SCI.
Day[35]	1	To explore Paralympics athletes' lived experiences of becoming physically active after disability.
Dickson et al[36]	8	To explore experiences of loss after an SCI.
Duggan et al[37]	231	To identify factors associated with resilience among individuals with an SCI.
Fadyl and McPherson[38]	13	To report influences on decisions about seeking employment/resuming employment following an SCI.
Gifre et al[27]	18	To identify the factors that can facilitate or hinder the quality of life for people with an SCI.
Goodwin et al[39]	4	To understand the experience of participating in a group assisted outdoor hiking excursion.
Guilcher et al[40]	14	To understand the journey of care in the prevention and management of secondary health conditions following an SCI.
Hammell[41]	15	To explore perceptions of quality of life for people living with an SCI in the community.
Hill et al[42]	9	To understand how individuals with an SCI define function, facilitators, and barriers to function and adaptations to support function.
Ide-Okochi et al[43]	29	To explore perceptions, roles, and meanings of self-care for people with a cervical SCI.
Lindberg et al[44]	10	To explore the meaning of patient participation in care and rehabilitation from the perspective of patients with an SCI.
Lucke[45]	22	To describe rehabilitation outcomes of "nurse caring" for people with an SCI.
Molton and Yorkston[46]	13	To identify aspects of aging in the context of disability.
Munce et al[17]	7	To explore facilitators and barriers to self-management to prevent secondary complications.
Munce et al[32]	7	To identify the meaning of self-management for people with an SCI.
Nunnerley et al[47]	9	To understand the lived experience of the transition from rehabilitation to community participation.
O'Connor et al[48]	7	To examine the experience of living in the community with paraplegia and conceptualize this private experience in a sociopolitical context.
Pearcey et al[49]	14	To examine the changes that occur in personal relationships after an SCI injury and the importance of participating in relationships.
Rohatinsky et al[50]	23	To explore how the empowerment process is expressed by persons with an SCI.
Sand et al[51]	19	To describe the experiences of the rehabilitation process for people with an SCI.
Scheel-Sailer et al[52]	22	To retrospectively explore patients' views on their participation in decision making during their inpatient rehabilitation after an SCI.
Van de Velde et al[30]	11	To explore the experiences of autonomy in the transition period from hospital to home.
Van de Velde et al[31]	11	To explore "person-perceived participation" in individuals with an SCI.
Van de Velde et al[53]	12	To explore the experiences of men with paraplegia with regard to how they choose activities.
Verdonck, Nolan, and Chard et al[54]	5	To explore the subjective meaning of an environmental control unit.

Enforced passivity

Participants were forced into passivity by social expectations of compliance, overprotection, being given choices that were not genuine, and environmental barriers. Worry about being an imposition on others[30,43,48,53] or potential retribution if they were not friendly[50] diminished their power and, hence, decreased control over their life. Some participants described their experience in institutional care as being at the "mercy of staff"[41(p611)] and because of their reliance on caregivers[28,43,48] they placed their needs secondary and did not complain. Caregivers were sometimes overprotective[30,43,48] and gave or offered unnecessary assistance.[48,49] However, to ensure security, participants could also make a conscious choice to be passive and accepting.[31,42,53]

Passivity was encouraged when participants found themselves obligated to permanently adopt roles they were "steered"[53(p652)] toward by well-meaning family members or health professionals.[30,38,48,53] When participants were not properly included in decisions about role choices, they were perceived as ingenuine.[30,53] Assumptions made by health professionals could lead to the underestimation of need for services,[47,48] poor design of buildings,[27] or lack of access to technology[54] and forced participants to be dependent when they otherwise would have been autonomous. To change their environment, or to access services,[40,41,48] participants were required to "fight,"[41(p613),50(p774)] "revolt,"[53(p655)] and be "stubborn."[30(p496)] Respect for privacy was often ignored[47] with an assumption that being exposed and

vulnerable was part of their new life.[36] Similarly, there were accounts of wheelchairs limiting function[42] and the environmental design in institutions diminishing dignity, enhancing vulnerability, and negatively affecting their ability to socialize.[51]

Frustrating environmental and service barriers

Vulnerability was exacerbated by limited access to their workplace, home, or transport.[38,42] If modifications were done poorly or ramps not available, choices were diminished for accessing the community,[28,33,42,46] performing roles at home,[38] and going to work or socializing.[27,47,49] Those participants living rurally were particularly affected by access issues, which resulted in having to work harder[50] or even leaving support networks to seek marginal improvements in community mobility in the city.[40,42,48] Participants needed systems to be working in their favor to get the necessary equipment and resources to have control over reconstruction of their lives.[29,38,40,41] However, "paternalistic" policies[40(p899)] limited choice in service providers and equipment.[50] Notable inequities were observed between those who had insurance and those who relied on public services.[29,40,50]

Social (in)visibility

Being different created discomfort both for the people with SCI as well as the wider community.[49] The physical appearance in a wheelchair or using mobility aids negatively affected how others perceived their ability to make their own choices[38] and this stigma resulted in them feeling "invisible,"[36(p416)] not knowing how to behave[27] and potentially being excluded.[34] Lack of control over their own abilities as well as lack of control over community responses to their situation created limitations on choices about social options.[48] There were accounts of participants choosing to pursue certain activities to earn respect from others, but instead experiencing disapproval due to the perceived risk of harm.[30,53] Some began to withdraw socially[43] finding it difficult "to see everyone at bum level"[48(p211)] when in the wheelchair. Others found that when they ventured out, they were offered unsolicited assistance by community members and received attention that they felt was unnecessary and at times generated feelings of anger.[48]

Valuable relationships

Social networks gave participants greater control over their choices and made them feel less vulnerable.[31,36-38,43,44] Having reliable social and community networks provided both tangible (access, opportunity, resources) and nontangible (friendship, encouragement, honesty) means of support.[17,31,37,38,40,41,49,51] Loss of roles,[53] such as contributing to housework or childcare,[51] and decline in social networks[49,50] enhanced their feelings of vulnerability. Preference for family caregivers, paid caregivers, or combinations of these were variable.[29,43,49] However, there was less guilt associated with relying on paid caregivers rather than family.[29,43,44] There were grave concerns expressed about the potential for relationships to break down in the face of shifting responsibilities and participants worried about being an imposition.[48] They, therefore, ensured that those affected were included in decision making.[44]

Responsive professionals

The capacity of people with SCI was highly influenced by the power relationships with the health professionals they had contact with. Participants wanted to be able to take responsibility for their care[29] but to do so required courage to ask questions[52] and self-advocate with health professionals who were willing to listen.[44] There was considerable criticism of the impersonalized approach taken by health professionals who hid behind their "checklists,"[47(p1168)] had a "silo narrow minded lens,"[40(p900)] who did not listen,[34,52] introduced work options too early,[34] and were not always flexible and responsive to the needs of people following an SCI.[27,40,47,51] Health professionals were described as giving vague information[51,52] about prognosis[44] and participants did not know what to ask[51] and did not have enough information about medical status[52] or equipment.[27]

There seemed to be little accounting for changing ability to exercise choice and control. For example, participants may not have felt emotionally able to make decisions or process a lot of information early in their recovery[44,47,51,52] making it important for health professionals to judge readiness for decision making and know when to push and when to wait.[52] Unfortunately, opportunities for choice were sometimes offered before the person was ready and then not always reoffered.[35,47] However, this was not always the case, with some participants describing health professionals who were sensitive to their changing needs and to their readiness for both information and control over their choices both in rehabilitation settings[45,52] and the community.[40]

Theme 2: adapting to bounded abilities

This theme reflects the role that the ability to control change and make choices has over the process of adaptation following SCI. This process was reliant on both external resources (support and information) and gathering personal strength.

Reconciling loss

Initially participants reported strong feelings of loss,[30,35,36,46] mourned missed opportunities,[30,53] and could not bring themselves to forward plan.[47] There were significant emotional struggles,[27,43,51] feeling that life may never be as good as it used to be, and sometimes, even after several years, this feeling would return.[51] Some lacked motivation to try new things[28,43,51] and some felt despair that their life was over.[30,34] Reliance on others, loss of choices, and difficulty performing formerly valued activities resulted in frustration and a diminished sense of identity.[40,47,48,51,53]

Finding purpose

Participants expressed a desire to contribute to a greater purpose, feel useful, and give to others.[31,41] There was general agreement that the motivation to act needed to be intrinsic[33,34,41] and their choices of activities were expressions of their identity.[30,31,50,53] They were careful to pursue challenges that gave them feelings of success[31] and tested their abilities.[35] Participants chose activities for a sense of achievement such as shopping for bargains on television[31] and playing the stock market.[28]

Paid work was valued for financial outcomes and self-esteem but was often difficult to find and maintain[28,34,38] creating compromises in their work choices.[33,34,38,48,50] Participants reported difficulty consistently attending work,[41] only committing to 2 to 4 hours of work a day due to fatigue,[38] predicting early retirement due to changing function, opting for their second choice as this was easier on their body, experiencing chronic pain,[34,48] and acute and chronic health problems due to work.[34]

Expressing self

There were stories of self-expression through wheelchair sports,[30,50,53] writing, painting,[41] and music.[50] Taking control of when and how activities were done replenished normality,[30,38,41,42,46,53] security,[31,54] and self-confidence[38] and was described as pivotal to being able to self-manage.[17] Control was enhanced when participants

had the confidence to express their needs to others[38,45] and this arose from being equipped with knowledge[50] and awareness of future options.[17,29] Some participants felt that reduction in their personal control did not diminish their identity and personality, while others found the opposite.[36] Eventually, participants became accustomed to and accepted themselves.[17,36,43,47] Indeed, those who had lived with SCI for the longest gave the highest appraisals of quality of life.[41] They had a sense of themselves as being in control of the help they received[39,46] and the choices they made[31] even though physical control over their bodies was diminished.

Learning

Adaptive responses to their changed abilities included being open to new learning, new roles, and ways of thinking and doing.[28,34-37,41,50,53] However, the "real world" was more unpredictable and physically challenging[47(p1167)] than hospital environments and tangible support was needed[49] to overcome fear and to learn to trust their abilities.[27,53] Participants meticulously problem-solved to find new ways to achieve their goals and discover different options.[28,41,50,53]

Planning

Participants diligently planned outings to enable feelings of safety and to maintain control over their health. Choices to alter their established routine following their SCI were made with careful consideration due to cognitive and physical effort needed.[33,48] Attending to daily commitments was a lot more time consuming than prior to the SCI.[38] Some participants grieved over loss of their ability to be spontaneous because everything took longer[32,48] and they needed assistance,[33,36,51] which diminished their fun.[27,48,51] Scrupulous attention was given to ensure nothing went wrong[27,48] and they strove to have vigilant control over maintenance of their body to avoid issues with bowel, bladder,[29,33,43,48] pressure sores, having spasms, or dysreflexia.[32,33,41,50]

Prioritizing

As participants adjusted to their new abilities, there was an accompanying reevaluation of their goals and priorities[45,47,51,54] and decisions were made to prioritize activities that sustained rather than drained their energy.[51,54] There were new pressures and responsibilities that needed to be accounted for such as the time taken and cost for self-care and maintenance of equipment.[38,40] Participants prioritized maintaining their health as further loss of abilities, even if temporary, had significant effects on their physical and mental health, and on their caregivers.[17,43] They came to realize that accepting help was necessary[48] to avoid missing out on experiences and life milestones.[39,45]

Seeing the turning points

Perceptions of ability to exert choice and control were influenced by reflective processes where participants drew on their personal resources to find strength or made self-preserving decisions to maintain control over their emotions. For example, some participants initially felt disconnected from and did not like their bodies[43] but noticed a point in which their perception shifted. Participants referred to these moments as being crucial for choosing to turn toward hope and restore control through a readiness for action.[31,45,53] This was explained in various ways including: "switching" roles from passive to active[31(p352),53]; experiencing a "reintegration of self"[45(p249)]

whereby participants explored the significance of the trauma on their lives[35]; no longer experiencing a fracture between their physical body and their sense of self thus realizing that their self-worth was not linked to physique[41]; accepting that adversity was not unique to them[41]; taking time to overcome grief associated with loss[38]; deciding to start again with life from the moment of the incident[30]; deciding to focus on their whole lifespan as one unit rather than preinjury and postinjury[30,46]; seeking continuity from their past selves and their current selves to reconstruct their identity[27,53]; accepting their "new life" in a wheelchair[52(p1136)]; deliberately making activity choices that balanced expectations of others and their personal needs[53]; deciding to stop focusing on boundaries and think about possibilities[35]; and deciding to stop fighting their disability.[51] These moments had various triggers including meeting and receiving information from people living with SCI who seemed healthy and content,[50,51] receiving explicit support for reconstruction of their lives,[27,49] becoming mobile through starting to drive again or getting employment,[34] and having the opportunity to talk about and get to know themselves better.[30]

Keeping hope

A positive adaptation was to recalibrate perspective and to focus on life satisfaction.[35,41,51,53] Participants made deliberate choices to stay positive,[17,37,46] to stay healthy,[32] to deepen and strengthen their relationships with others,[37,49,51] to find joy in life and work,[38] to notice nature, to "get in touch" with their spiritual self,[37(p612),41] and to appreciate the "luxury" of having time for thinking[41(p612)] and having time alone.[54] The multifaceted nature of these choices, illustrates that achievement of personal growth is not limited to making choices to be more physically active,[35] but can also be attributable to things like attending college, moving to a "more accessible apartment," establishing new relationships, and acting on ideas.[34(p128)]

Often taking control to achieve personal growth meant rejecting former notions of self-neglect, being busy and seeking material wealth and prestige.[41,53] This growth was contingent on experiencing success and taking some risks.[31,35,53] The social environment and the attitudes of health professionals[52] were strong influencers over obtaining and maintaining control and sometimes the expectations of others who did not value their actions[31,53] was a barrier. After a period of adjustment, some participants spoke of satisfaction with life,[37,41,51] a sense of justice,[53] enjoyment at having flexibility and contentment in their life, and becoming a stronger person than prior to their SCI.[41] They found life rewarding to the point that living with SCI was no longer something that they thought about very much.[41]

Discussion

This meta-synthesis of qualitative research has responded to the research question by translating the findings from the diverse experiences of 801 participants arising from 29 studies into 2 overarching themes that explain perspectives about the ability of people with SCI to exercise choice and control. The two themes were experiencing vulnerability and security and adapting to bounded abilities. The themes illustrate the complex interplay of systems for perceiving ability for having choice and control following SCI. These systems include internal relationships between emotional reserves, cognitive, and physical abilities and identity, societal, and environmental relationships, processes for

Table 2 Critical appraisal against McMaster criteria

Criteria	Bell and Hinjosa[28]	Braff et al[29]	Carr[33]	Crewe[34]	Day[35]	Dickson et al[36]	Duggan et al[37]	Fadyl and McPherson[38]	Gifre et al[27]	Goodwin et al[39]	Guilcher et al[40]	Hammell[41]
Study purpose:	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
1. Was the purpose and/or research question stated clearly?												
Literature:	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
2. Was relevant background literature reviewed?												
Study design:	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
3. Was the design appropriate for the study question? (ie, rationale)												
4. Was a theoretical perspective identified?	✔	ID	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
5. Are the methods congruent with the philosophical underpinnings and purpose?	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Sampling:												
6. Was the sampling method appropriate to the study purpose or research question?	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
7. Was sampling done until redundancy in data was reached?	ID	ID	ID	ID	ID	ID	X	✔	ID	ID	✔	✔
8. Was informed consent and ethical approval obtained?	ID	✔	✔	ID	ID	ID	✔	✔	✔	✔	✔	✔
Data collection:												
Descriptive clarity												
9. Clear and complete description of site?	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
10. Participants? (demographics)	✔	ID	✔	✔	ID	✔	✔	✔	✔	✔	✔	✔
11. Role of researcher and relationship with participants?	✔	X	X	✔	ID	✔	✔	ID	X	ID	ID	ID
12. Identification of assumptions and biases of researcher	✔	X	X	✔	X	X	X	X	X	X	X	X
Procedural rigor												
13. Procedural rigor was used in data collection strategies?	ID	✔	ID	ID	✔	✔	✔	✔	✔	✔	✔	✔
Data analyses:												
Analytical rigor												
14. Data analyses were inductive?	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
15. Findings were consistent with and reflective of data?	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Auditability												
16. Decision trail developed?	ID	ID	ID	✔	✔	✔	✔	✔	✔	✔	✔	✔
17. Process of analyzing the data was described adequately?	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Theoretical connections												
18. Did a meaningful picture of the phenomenon under study emerge?	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Overall rigor												
19. Was there evidence of the four components of trustworthiness?												
-Credibility	✔	ID	ID	✔	✔	ID	✔	✔	ID	✔	✔	✔
-Transferability	✔	ID	✔	✔	ID	✔	✔	✔	✔	✔	✔	✔
-Dependability	✔	✔	ID	✔	✔	✔	✔	✔	ID	✔	✔	✔
-Confirmability	✔	✔	✔	ID	✔	ID	ID	✔	✔	✔	✔	ID
Conclusions and implications												
20. Conclusions were appropriate given the study findings?	ID	✔	✔	✔	✔	✔	✔	✔	ID	✔	✔	✔

NOTE. ✔=Sufficient detail provided to meet a criterion; X=McMaster question not met; ID=Insufficient detail in regard to questions in evaluation tool.
 * Discrepancy between demographic data in text and table.

Table 2 *Continued*

Hill et al[42]	Ide-Okochi et al[43]	Lindberg et al[44]	Lucke[45]	Molton and Yorkston[46]	Munce et al[17]	Munce et al[32]	Nunnerley et al[47]	O'Connor et al[48] 2004	Pearcey et al[49] 2007	Rohatinsky et al[50] 2017	Sand et al[51] 2006	Scheel-Sailer et al[52] 2017	Van de Velde et al[30] 2012	Van de Velde et al[31] 2010	Van de Velde et al[53] 2013	Verdonck et al[54] 2017
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
✔	✔	ID	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
✔	✔	✔	✔	ID	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
ID	✔	✔	ID	ID	✔	✔	ID	X	X	X	✔	X	✔	✔	✔	X
✔	✔	✔	✔	✔	✔	✔	✔	ID	ID	✔	✔	✔	✔	✔	✔	✔
ID	✔	ID	✔	ID	✔	✔	✔	ID	✔	✔	✔	ID	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔*	✔	ID	✔	✔	✔	✔	✔	✔	✔
ID	ID	ID	X	X	ID	ID	✔	ID	ID	ID	✔	✔	X	X	X	ID
X	X	X	ID	X	X	X	✔	X	✔	ID	X	X	X	X	X	ID
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	ID	✔	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	X	✔	✔	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
✔	✔	✔	ID	✔	✔	✔	✔	✔	✔	✔	ID	✔	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	ID	✔	✔	✔	ID
✔	✔	✔	✔	✔	✔	✔	✔	✔	ID	✔	✔	ID	✔	✔	✔	✔
✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	ID	✔	✔	✔	✔	✔	✔
ID	✔	✔	ID	✔	✔	✔	✔	✔	✔	ID	✔	✔	✔	✔	✔	✔
✔	ID	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔

Table 3 Themes with source documents

Themes and Subthemes	No. of Studies	Studies
Theme 1: Experiencing vulnerability or security		
Enforced passivity	17	(27, 28, 30, 31, 33, 36, 38, 40-43, 47-51, 53, 54)
Frustrating environmental and service barriers	13	(27-29, 33, 38, 40-42, 46-50)
Social (in) visibility	9	(27, 30, 34, 36, 38, 43, 48, 49, 53)
Valuable relationships	15	(17, 29, 31, 36-38, 40, 41, 43, 44, 48-51, 53)
Responsive professionals	10	(27, 29, 34, 35, 40, 44, 45, 47, 51, 52)
Theme 2: Adapting to bounded abilities		
Reconciling loss	13	(27, 28, 30, 34-36, 40, 43, 46-48, 51, 53)
Finding purpose	11	(28, 30, 31, 33-35, 38, 41, 48, 50, 53)
Expressing self	15	(17, 29-31, 36, 38, 39, 41-43, 45-47, 50, 53)
Learning	10	(28, 34-37, 41, 47, 49, 50, 53)
Planning	10	(27, 29, 32, 33, 36, 38, 41, 48, 50, 51)
Prioritizing	11	(17, 35, 36, 38-40, 43, 47, 48, 51, 54)
Seeing the turning points	15	(27, 30, 31, 34, 35, 38, 41, 43, 45, 46, 49-53)
Keeping hope	12	(17, 32, 34, 35, 37, 38, 41, 46, 49, 51, 53, 54)

conservation of resources and readiness for reclaiming personal power.

Participants clearly described a personal or innermost system sitting at the heart of this dynamic process of coming to terms with altered choices and physical control over and within their own bodies. Previous research has conceptualized this as a process of self-reconstruction[55]—how the person with SCI relates to his or her own changed (and changing) physical, emotional, cognitive, and social self. Getting to know, understand, and accept the new or emergent self requires a reexamination of all societal and environmental relationships: between self and family, friends, professional supporters, peers, and colleagues,[56] in the broadening circles of home, work, and community environments. This includes a recognition of options or seeing options that are new and unfamiliar. Understanding the nature of the constraints affecting options seems to be an important facilitatory part of the process of adaptation to the new self.[57] For example, arranging the need for meaningful participation[7] within the constraints of fatigue and physical impairment can lead to creative solutions in the choice of dependency and assistance for activities. However, this process is predicated on having some level of decision making and the support of surrounding people and environment to accommodate the choice.[58] In these instances, external circumstances can become the constraints that are beyond the individual's control and overcoming stigma may require more than personal embodiment of identity as a wheelchair user.[59] Some of these external constraints may be attitudinal (as expressed by work colleagues, or institutionalized thinking) and arising from education and exposure; others, such as physically inaccessible environments, require change at a policy, or building code level.

Overlaying this systems perspective from the personal, to the interpersonal, to the societal and environmental, is the passage of time and balance of power. The time that participants needed to adapt to and recognize the boundaries to their new abilities varied. After the initial trauma of SCI, participants began to discover what was possible accompanied by new perspectives on choice and control within their lives. The capacity to exercise choice and control is dynamic and any services invested in supporting people with SCI need to maintain an agility of responsiveness to accommodate and support the emergence of empowerment.

Agility might manifest as flexibility in working with people and being prepared to frequently renegotiate goal setting, planning actions, and making decisions as the person changes and adapts at different stages of readiness and integration of self.

Implications for practice and recommendations

Health professionals and people in support positions need to be vigilant for the thresholds of readiness for choice and control where power and influence need to be reestablished or reassigned. Enablers for promoting readiness include a willingness to listen and be guided by the person with SCI. This practice may sensitize health professionals to recognize when the feelings, attitudes, and actions of people with SCI are turning toward adaptation and hope. This requires an emphasis in rehabilitation on fostering psychological coping strategies.[60] As participants in the included studies experienced a connection between the building of capacity for control and choice, they began to develop hope for their future, and notice their capacity for growth. This building of personal power and capacity to cope is obviously highly individual and needs to account for the interactions occurring between the environmental, interpersonal, and personal systems. Finally, it is worth highlighting that despite (or because of) the unique constraints experienced by people with SCI, these can proffer an emergent ability to adapt, problem solve, and be creative.

Health professionals working with people following SCI need to understand the systemic processes described above that are both ubiquitous and unique. There needs to be a balance of service provision that ensures people's rights to self-determination and informed decision to control their own choices.[41,45] As power is central to having choices,[61] health professionals need to contemplate who is holding the power in the therapeutic relationship, be sensitive and responsive to the turning points that indicate readiness for having choice, and control and enable people to attain and retain this right. Adjustment to new abilities requires time and the information and space to take control incrementally through developing new or adapted skills. Providing and sharing information and knowledge seems to be key, as well as being sensitive to changing emotional, cognitive, and occupational needs and preferences.

Study limitations

As with any systematic review, our review is subject to some known limitations. Study selection was limited to 1980 onwards and some misinterpretation of meaning from the study that was translated from Spanish may have occurred.[27] The predominance of Western-based studies and the high ratio of participants who were men may mean that the views expressed do not fully capture alternate perceptions. For example, the ability to adapt and to readopt choice and control are expected to vary across cultures. We recommend that future research include participants from different cultural groups. Future research would also benefit from including collaboration with consumers so that they are included in the research process and have influence over interpretation of findings. It is also recommended that the concepts of changing choice and control be explored in those populations that experience insidious onset of disability (such as multiple sclerosis) to see if this is different from traumatic onset.

Conclusion

Exercising choice and control requires a complex interplay of systems from personal development through to the environmental—each containing different sets of constraints or challenges that afford altered opportunities. People with SCI need support in understanding and accepting these dynamic processes and to become aware of options and make decisions. Likewise, external barriers require attention in terms of changing attitudes in the people around the person with SCI (health professionals, family, support people) as well as at a societal and environmental level.

Supplier

a. Covidence software; Covidence.

Keywords

Cognition; Emotions; Hope; Humans; Interpersonal relations; Power (psychology); Rehabilitation

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References

1. Van den Berg ME, Castellote JM, Mahillo-Fernandez I, de Pedro-Cuesta J. Incidence of spinal cord injury worldwide: a systematic review. Neuroepidemiology 2010;34:184-92.

2. Kirshblum SC, Burns SP, Biering-Sorensen F, et al. International standards for neurological classification of spinal cord injury (revised 2011). J Spinal Cord Med 2011;34:535-46.

3. Roberts TT, Leonard GR, Cepela DJ. Classifications in brief: American Spinal Injury Association (ASIA) Impairment Scale. Clin Ortho Relat Res 2017;475:1499-504.

4. Lee BB, Cripps RA, Fitzharris M, Wing PC. The global map for traumatic spinal cord injury epidemiology: update 2011, global incidence rate. Spinal Cord 2013;52:110.

5. Norton L. Spinal cord injury, Australia 2007-2008. Canberra, Australia: Australian Institute of Welfare; 2010.

6. Turner C, McClure R. Age and gender differences in risk-taking behaviour as an explanation for high incidence of motor vehicle crashes as a driver in young males. Inj Control Saf Promot 2003;10: 123-30.

7. World Health Organization. International classification of functioning, disability and health. Geneva, Switzerland: World Health Organization; 2001.

8. Lund ML, Nordlund A, Bernspang B, Lexell J. Perceived participation and problems in participation are determinants of life satisfaction in people with spinal cord injury. Disabil Rehabil 2007;29:1417-22.

9. Hurst R. The International Disability Rights Movement and the ICF. Disabil Rehabil 2003;25:572-6.

10. Kendrick M, Ward M, Chenoweth L. Australia's national disability insurance scheme: looking back to shape the future. Disabil Soc 2017; 32:1333-50.

11. NDIS Independent Advisory Council. Choice and control: reflections on the implementation of the principle of choice and control under the NDIS2013. Available at: https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b1a015a0e2e727770ffac25/1528430941741/Choice%2Band%2BControl.pdf. Accessed March 13, 2019.

12. Lifetime Support Authority. Lifetime support authority of South Australia's strategy. Available at: http://lifetimesupport.sa.gov.au/wp-content/uploads/LSA-Strategy.pdf. Accessed January 4, 2018.

13. Ottmann G, Laragy C, Haddon M. Experiences of disability consumer-directed care users in Australia: results from a longitudinal qualitative study. Health Soc Care Community 2009;17:466-75.

14. Owens J, Mladenov T, Cribb A. What justice, what autonomy? The ethical constraints upon personalisation. Ethics Soc Welfare 2017;11:3-18.

15. Dickinson H, Needham C, Sullivan H. Individual funding for disability support: what are the implications for accountability? Aust J Publ Admin 2014;73:417-25.

16. Lord J, Hutchison P. Individualised support and funding: building blocks for capacity building and inclusion. Disabil Soc 2003;18:71-86.

17. Munce SE, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. BMC Neurology 2014;14:48.

18. Clarke J. Consumers, clients or citizens? Policy, politica and practice in the reform of social care. Eur Soc 2006;8:423-42.

19. Fleming P, McGilloway S, Barry S. The successes and challenges of implementing individualised funding and supports for disabled people: an Irish perspective. Disabil Soc 2016;31:1369-84.

20. Gerrig R, Zimbardo PG, Campbell AJ, Cumming SR, Wilkes FJ. Psychology and life. 2nd ed. Frenchs Forrest, Australia: Pearson Australia; 2012.

21. Letts L, Wilkins S, Lam M, Stewart D, Bosch J, Westmorland M. Critical review form — qualitative studies version 2.0. Available at: https://www.unisa.edu.au/contentassets/72bf75606a2b4abcaf7f17404af374ad/7b-mcmasters_qualreview_version2-01.pdf. Accessed March 13, 2019.

22. Noblit GW, Hare RD. Meta-ethnography: synthesising qualitative studies. Newbury Park: SAGE Publishing; 1998.

23. Murray C, Stanley M. Meta-synthesis de-mystified: connecting islands of knowledge. In: Nayar S, Stanley M, editors. Qualitative research methodologies for occupational science and therapy. Abingdon, Oxon: Taylor & Francis; 2015. p 174-89.

24. Thorne S. Metasynthetic madness: what kind of monster have we created? Qual Health Res 2017;27:3-12.

25. Lee RP, Hart R, Watson R, Rapley T. Qualitative synthesis in practice: some pragmatics of meta-ethnography. Qual Res 2014;15:334-50.

26. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Med Res Methodol 2012;12:181.

27. Gifre M, del Valle A, Yuguero M, Gil A, Monreal P. [Quality of life improvement in people with spinal cord injury: the transition from rehabilitation hospital to the everyday life from users' perspective] [Spanish]. Athenea Digital 2010;18:3-16.

28. Bell P, Hinojosa J. Perception of the impact of assistive devices on daily life of three individuals with quadriplegia. Assist Technol 1995; 7:87-94.

29. Braaf SC, Lennox A, Nunn A, Gabbe BJ. Experiences of hospital readmission and receiving formal carer services following spinal cord injury: a qualitative study to identify needs. Disabil Rehabil 2018;40: 1893-9.

30. Van de Velde D, Bracke P, Van Hove G, Josephsson S, Devisch I, Vanderstraeten G. The illusion and the paradox of being autonomous, experiences from persons with spinal cord injury in their transition period from hospital to home. Disabil Rehabil 2012;34:491-502.

31. Van de Velde D, Bracke P, Van Hove G, Josephsson S, Vanderstraeten G. Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home. Int J Rehabil Res 2010;33:346-55.

32. Munce SEP, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Meaning of self-management from the perspective of individuals with traumatic spinal cord injury, their caregivers, and acute care and rehabilitation managers: an opportunity for improved care delivery. BMC Neurology 2016;16:11.

33. Carr JJ, Kendall MB, Amsters DI, et al. Community participation for individuals with spinal cord injury living in Queensland, Australia. Spinal Cord 2017;55:192-7.

34. Crewe N. A 20-year longitudinal perspective on the vocational experiences of persons with spinal cord injury. Rehabil Couns Bull 2000; 43:122-33.

35. Day M. The role of intial physical activity experiences in promoting posttraumatic growth in Paralympic athletes with an acquired disability. Disabil Rehabil 2013;35:2064-72.

36. Dickson A, Allan D, O'Carroll R. Biographical disruption and the experience of loss following a spinal cord injury: an interpretative phenomenological analysis. Psychol Health 2008;23:407-25.

37. Duggan C, Wilson C, DiPonio L, Trumpower B, Meade MA. Resilience and happiness after spinal cord injury: a qualitative study. Top Spinal Cord Inj Rehabil 2016;22:99-110.

38. Fadyl J, McPherson K. Understanding decisions about work after spinal cord injury. J Occup Rehabil 2010;20:69-80.

39. Goodwin D, Peco J, Ginther N. Hiking excursions for persons with disabilities: experiences of interdependence. Ther Recreation J 2009; 43:43-55.

40. Guilcher SJT, Craven BC, Lemieux-Charles L, Casciaro T, McColl MA, Jaglal SB. Secondary health conditions and spinal cord injury: an uphill battle in the journey of care. Disabil Rehabil 2013;35: 894-906.

41. Hammell KW. Quality of life among people with high spinal cord injury living in the community. Spinal Cord 2004;42:607-20.

42. Hill JN, Balbale S, Lones K, LaVela SL. Starting a new conversation: engaging veterans with spinal cord injury in discussions of what function means to them, the barriers/facilitators they encounter, and the adaptations they use to optimize function. Disabil Health J 2017; 10:114-22.

43. Ide-Okochi A, Tadaka E, Fujimura K. The meaning of self-care in persons with cervical spinal cord injury in Japan: a qualitative study. BMC Neurology 2013;13:115.

44. Lindberg J, Kreuter M, Taft C, Person LO. Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. Spinal Cord 2013;51:834-7.

45. Lucke KT. Outcomes of nurse caring as perceived by individuals with spinal cord injury during rehabilitation. Rehabil Nurs 1999;24:247-53.

46. Molton IR, Yorkston KM. Growing older with a physical disability: a special application of the successful aging paradigm. J Gerontol B 2017;72:290-9.

47. Nunnerley JL, Hay-Smith EJ, Dean SG. Leaving a spinal unit and returning to the wider community: an interpretative phenomenological analysis. Disabil Rehabil 2013;35:1164-73.

48. O'Connor DL, Young JM, Saul MJ. Living with paraplegia: tensions and contradictions. Health Soc Work 2004;29:207-18.

49. Pearcey TE, Yoshida KK, Renwick RM. Personal relationships after a spinal cord injury. Int J Rehabil Res 2007;30:209-19.

50. Rohatinsky N, Goodridge D, Rogers MR, Nickel D, Linassi G. Shifting the balance: conceptualising empowerment in individuals with spinal cord injury. Health Soc Care Community 2016;25:769-79.

51. Sand A, Karlberg I, Kreuter M. Spinal cord injured persons' conceptions of hospital care, rehabilitation, and a new life situation. Scand J Occup Ther 2006;13:183-92.

52. Scheel-Sailer A, Post MW, Michel F, Weidmann-Hügle T, Baumann Hölzle R. Patients' views on their decision making during inpatient rehabilitation after newly acquired spinal cord injury—a qualitative interview-based study. Health Expect 2017;20:1133-42.

53. Van de Velde D, Bracke P, Van Hove G, Josephsson S, Vanderstraeten G. How do men with paraplegia choose activities in the light of striving for optimal participation? A qualitative study, based on a phenomenological—hermeneutical method. Disabil Soc 2013;28: 645-59.

54. Verdonck M, Nolan M, Chard G. Taking back a little of what you have lost: the meaning of using an environmental control system (ECS) for people with high cervical spinal cord injury. Disabil Rehabil Assist Technol 2018;13:785-90.

55. Lennon A, Bramham J, Carroll À, et al. A qualitative exploration of how individuals reconstruct their sense of self following acquired brain injury in comparison with spinal cord injury. Brain Inj 2014;28: 27-37.

56. Chemtob K, Caron JG, Fortier MS, Latimer-Cheung AE, Zelaya W, Sweet SN. Exploring the peer mentorship experiences of adults with spinal cord injury. Rehabil Psychol 2018;63:542-52.

57. Frank G. The concept of adaptation as a foundation for occupational science research. Philadelphia: F.A. Davis; 1996.

58. Williams TL, Smith B, Papathomas A. The barriers, benefits and facilitators of leisure time physical activity among people with spinal cord injury: a meta-synthesis of qualitative findings. Health Psychol Rev 2014;8:404-25.

59. Papadimitriou C. Becoming en-wheeled: the situated accomplishment of re-embodiment as a wheelchair user after spinal cord injury. Disabil Soc 2008;23:691-704.

60. Pollard C, Kennedy P. A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: a 10-year review. Br J Health Psychol 2010;12: 347-62.

61. Inesi ME, Botti S, Dubois D, Rucker DD, Galinsky AD. Power and choice: their dynamic interplay in quenching the thirst for personal control. Psychol Sci 2011;22:1042-948.