

PERSPECTIVE



# Comprehensive and person-centred approach in research: what is missing?

Vanesa Bochkezanian <sup>1,3</sup>✉ and Kim D. Anderson <sup>2,3</sup>

© The Author(s), under exclusive licence to International Spinal Cord Society 2021

The concept of a comprehensive and person-centred approach in healthcare is not new and it is the basic principle that is embedded in the International Classification of Functioning, Disability and Health (ICF) framework. However, the implementation of a comprehensive and person-centred approach has not been fully translated into research development in people living with spinal cord injuries (SCI). This approach in research is important as the perspectives of persons living with SCI should be equally valued drivers in any research intended to provide a direct or indirect outcome to people living with a SCI. This perspective paper will discuss some of the limiting factors and provide some examples of previous and current successful steps being taken towards the worldwide implementation of this approach. Finally, this paper will suggest some of the steps needed to implement this person-centred model in research in people with SCI.

*Spinal Cord* (2022) 60:187–189; <https://doi.org/10.1038/s41393-021-00735-0>

## INTRODUCTION

The concept of a comprehensive and person-centred approach in healthcare is not new and it is the basic principle that is embedded in the International Classification of Functioning, Disability and Health (ICF) framework. This person-centred approach provides a humanising aspect in the delivery of healthcare and puts the person's needs as a priority over tasks of care or other anonymous collective priorities [1, 2]. This approach emphasises the need of a partnership, putting the person with healthcare needs at the same level as the healthcare worker. This approach allows to having the person's voice being authentically heard, including their individual preferences, values, and beliefs, leading to co-creation, active engagement, and decision making in the healthcare context [3].

However, the implementation of a comprehensive and person-centred approach has not been fully translated into research development, and specifically in people living with spinal cord injuries (SCI). This approach appears to be relevant when research development aims to investigate new assessments, interventions, technologies, and techniques that may benefit individuals directly. The most prevalent worldwide research models in SCI appear to be detached from this person-centred approach, as the person's perspective and partnership in research seems only to be adopted occasionally, rather than systematically.

The perspectives of persons living with SCI should be equally valued drivers in any research intended to provide a direct or indirect outcome to people living with a SCI. In this case, the lived experience perspective can provide objective and practical information to strengthen the design and methods and potentially maximise the utilisation and benefits that would derive from the research outputs. This person-centred approach would help improve translation from knowledge to practice and

would allow people with SCI to have better and quicker access to research outcomes.

## LIMITING AND FACILITATOR FACTORS

Some of the limiting factors identified in the implementation of this comprehensive and person-centred approach in the healthcare setting may be similar to the limiting factors that are preventing this type of approach in the research development and academia setting. Some of these limiting factors are related to the hegemonic culture that has generated policies and procedures based on the "average" person ignoring issues such as individual's context, cultural diversity and backgrounds, structural inequalities, and environmental and social circumstances among others [3, 4]. In order to enable a comprehensive and person-centred approach, the World Health Organisation (WHO) has suggested some strategies that may need to be implemented so research development can be smoothly and quickly translated into tangible and objective outcomes and benefits for people with SCI. The WHO global strategy on integrated person-centred health services may be a model to follow to help researchers implement the inclusion of people with SCI systematically throughout the research process [5]. The first strategic goal should be directed towards empowering and engaging individuals with healthcare needs. Some of the policies that may be implemented for this previously mentioned purpose include education on the research process, shared decision making, and the implementation of partner satisfaction surveys to evaluate the level of inclusion of people with SCI in the research stages [5]. The second strategy should be focused on strengthening governance and accountability at systems and team levels, in order to formulate and

<sup>1</sup>School of Health, Medical & Applied Sciences, College of Health Sciences, Central Queensland University, Rockhampton, QLD, Australia. <sup>2</sup>Department of Physical Medicine and Rehabilitation, Metrohealth Medical Center, Case Western Reserve University School of Medicine, Cleveland, OH, USA. <sup>3</sup>These authors contributed equally: Vanesa Bochkezanian, Kim D. Anderson. ✉email: vanesabocho@gmail.com

Received: 19 July 2021 Revised: 23 November 2021 Accepted: 25 November 2021  
Published online: 3 January 2022

evaluate policies together with citizens, communities, and other stakeholders [5]. In this case, research institutes, universities, and governmental and community organisations should be collaborating with individual researchers and research teams to formulate and evaluate policies towards the common goal of a person-centred approach.

Implementing the person-centred approach into SCI research worldwide at systems and team levels within health policies, visions and mission statements [6] is paramount to translate any advances in biomedical and engineering into generating tangible benefits and improve the quality of life of people with SCI. One step towards the direction of person-centred approach is the one used by the Swiss model [7]. This model captures a full range of relevant information that matters from people with SCI, such as usage of health services and limitations in areas of participation, and informs recommendations to the Swiss Paraplegic Foundation [8]. These recommendations can then help close the gap of what should be implemented so people with SCI get the same opportunities as the general population [7]. However, this approach did not specify if it involved people with SCI for consultation and being part of these research projects from the early stages.

Another important aspect of this person-centred approach is to adopt collaboration systematically and not just as a “ticking the box” and “fancy term” to be included in all research organisations, including education centres, such as Universities. This can be classified as tokenism and has been identified when research partnerships go against the principles of integrated knowledge translation (IKT) [9, 10]. Tokenism is a practice in which people with SCI are asked to be part of a research project without having any control over it and with the solely purpose of endorsement in such research project [11]. Therefore, to avoid tokenism it is mandatory to rigorously implement the IKT guiding principles for conducting and disseminating SCI research in partnership [12] at every organisational level starting from the educational organisations, such as tertiary level education.

### PREVIOUS, CURRENT, AND FUTURE STEPS

This person-centred model has also already been implemented in some research studies in people with SCI. Some of these research studies have implemented the collection of information based on needs and priorities of people with SCI ahead of the design of new research projects in this area [13, 14]. Recently, guiding principles were created describing how to meaningfully engage people living with SCI in research partnerships [9, 10, 12]. These examples in addition to organisations including the Swiss Paraplegic Research, the Praxis Institute, and the North American SCI Consortium, have been working to shift research from lab-based perspective to person-centred.

These examples can generate a powerful shift towards the systematic implementation of research partnerships including people with SCI as part of the research team. However, this translation into practice requires a combination of efforts from different sectors and a commitment to a plan of action, such as the IKT guidelines [12] in which the person with SCI involved in the early stages of research should have access to the potential benefits of the intended research outcomes. Creating evidence-based guidelines by themselves has very limited impact in people with SCI, as a widespread change in behaviour, cultures and implementation practices at system and team levels [6] must occur before those guidelines can make a tangible difference in multiple people's lives.

Another important aspect is how people with SCI have access to information about experimental therapies and clinical trials. A recent study revealed that only around half of people with SCI had access to SCI specialists (in the US) and that 89% of people had sought online for information about experimental therapies [15].

Thus, disseminating information online about current experimental and clinical trials seems imperative if we would like to have people with SCI involved in research for the ultimate purpose of empowering people with SCI. Some of these attempts to disseminate information among the community are based on some research Journals, which have started to implement action-oriented research for transformations in social, political, and economic systems [16]. Some others, like The Patient-Centred Outcomes Research are strictly oriented to promote development, evaluation, and implementation of therapies, technologies, and innovations towards the enhancement of the patient experience. This journal encourages articles in which the patient comments are the main focus to validate research outcomes. Thus, the next step would be to make these research articles openly available and in an easy-to-read format, such as a one-page poster or infographic. By doing this, we would allow access to this valuable information to more people in the community with an interest in physical disabilities.

Finally, some of the steps needed to implement this person-centred model in research would be as follows: [17]

- (1) Qualified researches with a strong commitment to equity and desire to collaborate with other disciplines sharing the same identity;
- (2) Research environment, infrastructure, and culture promoting collaboration and incentivising scientific training and mentorship;
- (3) Funding towards medical rehabilitation research at federal, local, and individual levels, including promotion and dissemination of funding opportunities to junior researchers that may not be aware;
- (4) Partnerships with other disciplines, institutions, academic departments, community organisations, and people with disabilities for the purpose of meaningful research;
- (5) Assessment of the research capacity to measure progress over time;
- (6) Authentic leadership by example: Train and mentor inspirational people who want to be involved in research as authentic leaders, so they can drive person-centred approach using storytelling based on their life experiences [10, 18].

### CONCLUSION

In conclusion, there are many challenges to implementing a comprehensive and person-centred approach at a research development level, but one of the main challenges is to start considering a new structure, organisation, and mindset of how we think about people living with SCI. They are not just patients waiting to be healed. They are experts in living with a chronic disease.

### REFERENCES

1. McCormack B, Borg M, Cardiff S, Dewing J, Jacobs G, Janes N, et al. Person-centredness—the ‘state’ of the art. *Int Pract Dev J.* 2015;5:1–15.
2. Cook NF, McCance T, McCormack B, Barr O, Slater P. Perceived caring attributes and priorities of preregistration nursing students throughout a nursing curriculum underpinned by person-centredness. *J Clin Nurs.* 2018;27:2847–58.
3. Phelan A, McCormack B, Dewing J, Brown D, Cardiff S, Cook N, et al. Review of developments in person-centred healthcare. *Int Pract Dev J.* 2020;10:1–29.
4. Rock D, Cross SP. Regional planning for meaningful person-centred care in mental health: context is the signal not the noise. *Epidemiol Psychiatr Sci.* 2020;29:e104.
5. World Health Organisation. WHO global strategy on integrated people-centred health services 2016–2026. Geneva, Switzerland: World Health Organisation; 2015.
6. Edgar DA, Wilson VJ, Moroney T. Which is it person-centred culture, practice or care? It matters. *Int Pract Dev J.* 2020;10:8-1-8-17.

7. Stucki G, Reinhardt JD, Cieza A, Brach M, Celio M, Joggi D, et al. Developing Swiss paraplegic research: building a research institution from the comprehensive perspective. *Disabil Rehabil.* 2008;30:1063–78.
8. Stucki G, Bickenbach J. Editorial. *Spinal Cord.* 2021;59:361–2.
9. Hoekstra F, Gainforth HL. Principles and related strategies for spinal cord injury research partnership approaches: a qualitative study. *Evid Policy.* 2021. <https://doi.org/10.1332/174426421X16161715996124>.
10. Hoekstra F, Schaefer L, Athanasopoulos P, Gainforth HL. Researchers' and Research Users' Experiences With and Reasons for Working Together in Spinal Cord Injury Research Partnerships: A Qualitative Study. *Int J Health Policy Manag.* 2021. <https://doi.org/10.34172/ijhpm.2021.35>.
11. Woodill G, Willi V. Independent living and participation in research: A critical analysis. Canada: Centre for Independent Living Toronto (CILT); 2006.
12. Gainforth HL, Hoekstra F, McKay R, McBride CB, Sweet SN, Martin Ginis KA, et al. Integrated knowledge translation guiding principles for conducting and disseminating spinal cord injury research in partnership. *Arch Phys Med Rehabil.* 2021;102:656–63.
13. Anderson KD. Consideration of user priorities when developing neural prosthetics. *J Neural Eng.* 2009;6:055003.
14. Anderson KD. Targeting recovery: priorities of the spinal cord-injured population. *J Neurotrauma.* 2004;21:1371–83.
15. Farrehi C, Pazzi C, Capron M, Anderson K, Richardson B, Stillman M. How individuals with spinal cord injury in the United States access and assess information about experimental therapies and clinical trials: results of a clinical survey. *Spinal Cord Ser Cases.* 2020;6:103.
16. Bradbury H, Glenzer K, Apgar M, Embury DC, Friedman V, Kjellström S, et al. Action Research Journal's seven quality choicepoints for action oriented research for transformations. *Action Res.* 2020;18:3–6.
17. Frontera WR, Fuhrer MJ, Jette AM, Chan L, Cooper RA, Duncan PW, et al. Rehabilitation medicine summit: building research capacity— executive summary. *Phys Ther.* 2006; 86:285–98.
18. Rokstad AM, Vatne S, Engedal K, Selbaek G. The role of leadership in the implementation of person-centred care using Dementia Care Mapping: a study in three nursing homes. *J Nurs Manag.* 2015;23:15–26.

#### COMPETING INTERESTS

The authors declare no competing interests.

#### ADDITIONAL INFORMATION

**Correspondence** and requests for materials should be addressed to Vanesa Bochkezanian.

**Reprints and permission information** is available at <http://www.nature.com/reprints>

**Publisher's note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.