

Hearing the voice of caregivers to children with Spinal Cord Injury – a systematic scoping review

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INTRODUCTION

All children depend on caregiver support, which is typically provided by their parents, but for children with significant disabilities as a Spinal Cord Injury (SCI), caregivers become even more important. As a parent-researcher, I ask the question: How can we as parents use our experiences to bring change and improve the care for children? This review explores the voice of caregivers to children with SCI in research.

METHODS

The review work is in process and currently include articles published between Jan 2008-Feb 2022; from the databases CINAHL, ERIC MEDLINE, PsycINFO and Scopus; with a focus to explore the perspectives of and/or get feedback about SCI care from caregivers to children with SCI.

RESULTS

The preliminary results from 30 included articles show how the voice of caregivers to children with SCI in research is mostly represented by quantitative descriptive data from questionnaires and to a lesser extent used to actually improve care for children with SCI.

The results will be presented as a framework, showing

- 1) the reasons for including the voice of caregivers,
- 2) how the voices have been selected, collected and presented, and
- 3) the occurrence of the voice in the research process.

CONCLUSION

The framework is discussed in relation to research where people with experience participate in other ways, e.g. co-production and Integrated Knowledge Transfer. The results of the review can be used to better plan and perform research including more aspects of the voice of caregivers in all steps of the process.