

Assessment instruments used for the self-report of pain by hospitalized stroke patients with communication problems: a scoping review protocol

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ABSTRACT

Objective: The objective of this scoping review is to systematically identify assessment instruments that are used for the self-report of pain by hospitalized stroke patients with communication problems.

Introduction: To the best of the authors' knowledge, there are no existing instruments specifically dedicated to measuring pain in stroke patients with communication problems. Pain measurement instruments currently in use may complicate pain assessment in these patients. Additionally, there is a lack of consensus regarding these patients' ability to self-report pain using existing pain instruments.

Inclusion criteria: The review will consider studies that focus on hospitalized adults where at least one subgroup has been diagnosed with stroke as well as associated communication problems attributable to a stroke. The concept of interest is assessment instruments used for the self-report of pain by these patients. The scoping review will include systematic reviews, quantitative studies of any design, and mixed methods studies.

Methods: The search will occur in three phases: an initial limited search, a full search, and a screening of the reference lists of all the included articles. The key information sources include: PubMed, CINAHL, Nursing@Ovid, the Cochrane Library, Web of Science, Scopus, and Embase. All identified citations will be uploaded to a reference management program, and the titles and abstracts screened. Full texts of studies potentially meeting the inclusion criteria will be assessed in detail, with relevant data extracted and reported in tabular as well as descriptive format that aligns with the objectives and scope of this review.

Keywords assessment instruments; communication; pain; self-report; stroke

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Introduction

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.”^{1(para.6)} Pain is a common problem in patients with stroke, although its reported prevalence varies due to differences in study design, characteristics of the selected patients, definitions of pain types, as well as pain measurement methods.²⁻⁴

Stroke is a neurological deficit attributed to an acute focal injury of the central nervous system that is caused by an interruption of the blood supply to the brain, usually because a blood vessel bursts or becomes occluded by a clot.^{5,6} Pain after stroke can be the result of the stroke itself, with the most common subtypes being central post-stroke pain,^{7,8} post-stroke shoulder pain,⁷⁻⁹ headache,^{7,10} and complex regional pain.^{7,8} Some patients experience pain secondary to stroke-related consequences, such as spasticity,^{7,8} immobility,^{11,12} and contractures.⁷ In some cases, patients with stroke experience more than one type of pain.¹³ Pain can also be present due to various pre-stroke medical conditions, such as diabetic neuropathy,

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arthritis, osteoporosis, peripheral artery disease, and depression.^{3,7,14}

Pain is often under-recognized in hospitalized patients with stroke, as they often do not express their pain verbally unless specifically asked by the health care provider, or they are unable to report pain because of stroke-related language, speech, or cognitive problems.^{3,7,14,15} This contributes to inadequate assessment and documentation of pain in this patient population,¹⁴ which may have a negative impact on pain management.^{3,12}

To the best of the authors' knowledge, no current instruments are specifically dedicated to measuring pain in stroke patients with communication problems, and hospital staff must use various general pain measurement instruments.⁷ In addition, there is a lack of consensus regarding these patients' ability to self-report pain using existing pain instruments. Smith *et al.*¹⁶ found that upon admission, as many as 86.6% of 388 patients diagnosed with acute stroke were able to provide a meaningful response using either a Faces Pain Scale (FPS) or Numerical Rating Scale (NRS); the inability to use these scales was associated with the patients' level of consciousness along with the severity of the stroke and concomitant aphasia. In contrast, according to an earlier study, only 47% to 53% of stroke patients were able to use the NRS as well as three types of the Visual Analogue Scale (VAS), and 65% were able to use the verbal 4-point rating scale ("none," "mild," "moderate," and "severe"), although patients with a reduced level of consciousness or severe aphasia were excluded from this study.¹⁷

It is unknown whether certain pain assessment instruments are appropriate for use in stroke patients with communication problems. Benaim *et al.*¹⁸ studied the suitability of self-report pain scales in patients with left- or right-hemisphere stroke by comparing pain scores obtained using the FPS, VAS, and the Verbal Rating Scale (VRS). While the FPS results correlated well with those of VAS and VRS in both subgroups, the test-retest results were suboptimal in patients with right-hemispheric stroke. In fact, FPS may not be appropriate for patients with right-hemispheric stroke due to the possibility of cognitive communication deficits, such as an inability to interpret body language and facial expression.^{19,20} In contrast, FPS may be appropriate for patients with left-hemispheric stroke if they understand the verbal instructions.^{18,20}

Health care providers should consider a number of additional questions before they decide to use a specific pain assessment instrument, such as its user-friendliness and suitability in the care setting.²¹ From a global perspective, most pain assessment instruments are developed and published in English. This means that in non-English settings, such instruments need to be translated into a local language before they can be used in clinical practice.²⁰

A search of the *Cochrane Database of Systematic Reviews*, Epistemonikos, and PROSPERO was performed between January 30 and February 2, 2019, on the topic of pain in stroke patients with communication problems. De Vries *et al.*¹⁵ published a systematic review relevant to the subject explored in this scoping review; however, no scoping reviews were found.

This scoping review has been prompted by the reviewers' clinical experience with challenges encountered during pain assessment in stroke patients with communication problems. In addition, new research may have emerged in recent years, especially since the systematic review by de Vries *et al.*¹⁵ concluded that a feasible pain assessment instrument for stroke patients with aphasia was not available and recommended more research on this topic. The first author of this systematic review¹⁵ was contacted, and because the original team did not plan to conduct an update of their review or a scoping review, a new team formed to work on this manuscript. The first author of the mentioned systematic review was invited and is a member of our authorship team.

The objective of this scoping review is to map the types and details of existing assessment instruments used for the self-report of pain by hospitalized stroke patients with communication problems affecting their language comprehension and/or speech production. Data collected in this scoping review will provide a current overview of the available assessment instruments for the self-report of pain. Thus, future reviews could be guided by the results of this scoping review, and the validity and reliability of the instruments that may be used in this patient population could be compared in order to make specific recommendations for clinical practice and future research.

Review question

What assessment instruments are used for the self-report of pain by hospitalized adult stroke patients

with communication problems affecting their language comprehension and/or speech production?

Inclusion Criteria

Participants

The scoping review will consider studies that focus on adults, defined as ≥ 18 years of age. The review will consider studies in which all participants or at least one of the studied subgroups have been diagnosed with stroke and have communication problems affecting their language comprehension and/or speech production (e.g. finding it difficult to understand what other people say and feeling as if others are talking in a foreign language, not being able to form words and thus communicating only by making sounds). The scoping review will consider studies in which the participants' communication problems are attributable to a current or previous stroke, with all studies included regardless of the type of stroke.

Concept

The concept of interest is assessment instruments used for the self-report of pain by patients with stroke and communication problems. These instruments can focus on any aspect of pain, such as pain intensity, pain quality, pain character, pain location, or interference with activities of daily living. The pain can have any etiology. Instruments that also assess other factors besides pain (i.e. instruments that do not focus exclusively on pain) will be considered as well.

Context

This review will consider studies from health care settings where the participants have been hospitalized for any reason and for any length of time and where the patients have received post-stroke, inpatient care. Studies will be included regardless of country of origin or sociocultural setting.

Types of sources

This scoping review will consider systematic reviews as well as primary research studies. Furthermore, quantitative studies of any design, along with studies based on a mixed methods research design, will be considered, including validation and methodological studies.

Methods

The proposed review will be conducted in accordance with the JBI methodology for scoping reviews.²²

Search strategy

The search will seek to identify both published and unpublished studies. The search will be conducted in three phases. The first phase, which has already been completed, was an initial limited search of the PubMed, CINAHL, and Nursing@Ovid databases to identify relevant articles, followed by an analysis of the text words contained in the title and abstract of the retrieved papers, as well as of the index terms used to describe these articles. This phase informed the development of a search strategy including the identification of keywords and index terms, which will be tailored for each information source. A full search strategy for PubMed is detailed in Appendix I. Finally, the bibliographical reference lists of all the included articles will be screened to search for additional studies that will be also considered for inclusion in this scoping review.

Only studies published in English will be included. No restrictions will be made regarding the year of publication. All studies published from the inception of a particular database to the present will be considered, as they may be relevant regardless of the publication date.

Information sources

The databases to be searched include: PubMed, CINAHL via EBSCO, Nursing@Ovid, Cochrane Library, Web of Science, Scopus, and Embase via Ovid. The search for unpublished articles will include ProQuest Nursing and Allied Health Source, ProQuest Health and Medical Collection, and Open Access Theses and Dissertations.

Study selection

Following the search, all identified citations will be collated and uploaded to the reference management program Citace PRO v.4.1 (Citace.com, s.r.o., Czech Republic), with duplicates removed. Subsequently, the titles and abstracts will be screened by two independent reviewers for assessment against the inclusion criteria for the review. Thereafter, full texts of the studies that may meet the inclusion criteria will be retrieved and their details imported into JBI System for the Management, Assessment, and Review of Information (JBI SUMARI; JBI, Adelaide, Australia).²³ The full text of the selected studies will be assessed by two independent reviewers in detail to determine if they meet the inclusion criteria. Studies that do not meet the inclusion criteria will be

excluded, with the reasons for the exclusion recorded and described in the final report. Any disagreements concerning this assessment and the inclusion of articles will be resolved through discussion or by arbitration with a third reviewer. The results of the search will be reported in full in the final report and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses for Scoping Reviews (PRISMA-ScR) flow diagram.²⁴

Data extraction

Data will be extracted from articles included in the review by two independent reviewers using a draft study data extraction table. The data extraction table will be trialed by the team to ensure that all relevant results are extracted, and the table will be revised and modified as necessary during the data charting process. Such modifications will be described in the full scoping review report. The authors of the primary studies will be contacted to request missing or additional data if required. The data extracted will include specific details such as author(s), year of publication, country (where the study was conducted), study design, study aims, study population (age and sex), and sample size (Appendix II). Data extracted will encompass specific details about the populations, concepts, and contexts of significance in terms of the scoping review question. Key findings that relate to the aim of this scoping review and to the scoping review question will also be compiled.

Data presentation

The extracted data will be presented in tabular form in accordance with the objective of this scoping review. The information about each identified pain instrument will include its name, purpose, and number of items. In addition, aspects of pain and non-pain aspects assessed by the instrument will be presented. The tabulated results will be accompanied by a narrative summary explaining how the results relate to the objective of the scoping review.

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References

1. International Association for the Study of Pain. Pain [Internet]. Washington, DC: International Association for the Study of Pain; 2018 [cited 2019 Mar 19]. Available from: <https://www.iasp-pain.org/PublicationsNews/NewsDetail.aspx?ItemNumber=9218>.
2. Bovim MR, Indredavik B, Hokstad A, Lydersen S, Askim T. New-onset pain in the early phase and three months following stroke – data from a multicenter study. *J Pain Res* 2018;11:1869–76.
3. Harrison RA, Field TS. Post stroke pain: identification, assessment, and therapy. *Cerebrovasc Dis* 2015;39(3–4):190–201.
4. Sommerfeld DK, Welmer A-K. Pain following stroke, initially and at 3 and 18 months after stroke, and its association with other disabilities. *Eur J Neurol* 2012;19(10):1325–30.
5. World Health Organization. Stroke, cerebrovascular accident [Internet]. Geneva, Switzerland: World Health Organization; 2020 [cited 2020 Apr 02]. Available from: <http://www.emro.who.int/health-topics/stroke-cerebrovascular-accident/index.html>.
6. Sacco RL, Kasner SE, Broderick JP, Caplan LR, Connors JJB, Culebras A, et al. An updated definition of stroke for the 21st century: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke* 2013;44(7):2064–89.
7. Delpont B, Blanc C, Osseby GV, Hervieu-Bègue M, Giroud M, Béjot Y. Pain after stroke: a review. *Rev Neurol (Paris)* 2018;174(10):671–4.
8. Treister AK, Hatch MN, Cramer SC, Chang EY. Demystifying poststroke pain: from etiology to treatment. *PM R* 2017;9(1):63–75.
9. Lindgren I, Gard G, Brogårdh C. Shoulder pain after stroke – experiences, consequences in daily life and effects of interventions: a qualitative study. *Disabil Rehabil* 2018;40(10):1176–82.
10. Oliveira FAA, Sampaio Rocha-Filho PA. Headaches attributed to ischemic stroke and transient ischemic attack. *Headache* 2019;59(3):469–76.
11. McGlinchey MP, James J, McKeivitt C, Douiri A, McLachlan S, Sackley CM. The effect of rehabilitation interventions on physical function and immobility-related complications in severe stroke-protocol for a systematic review. *Syst Rev* 2018;7(1):197.

12. Sackley C, Brittle N, Patel S, Ellins J, Scott M, Wright C, et al. The prevalence of joint contractures, pressure sores, painful shoulder, other pain, falls, and depression in the year after a severely disabling stroke. *Stroke* 2008;39(12):3329–34.
13. Choi-Kwon S, Choi SH, Suh M, Choi S, Cho K-H, Nah H-W, et al. Musculoskeletal and central pain at 1 year post-stroke: associated factors and impact on quality of life. *Acta Neurol Scand* 2017;135(4):419–25.
14. Nesbitt J, Moxham S, Ramadurai G, Williams L. Improving pain assessment and management in stroke patients. *BMJ Qual Improv Rep* 2015;4(1):u203375.w3105.
15. de Vries NJC, Sloot PH, Achterberg WP. Pain and pain assessment in stroke patients with aphasia: a systematic review. *Aphasiology* 2017;31(6):703–19.
16. Smith JH, Bottemiller KL, Flemming KD, Michael Cutrer F, Strand EA. Inability to self-report pain after a stroke: a population-based study. *Pain* 2013;154(8):1281–6.
17. Price CI, Curless RH, Rodgers H. Can stroke patients use visual analogue scales? *Stroke* 1999;30(7):1357–61.
18. Benaim C, Froger J, Cazottes C, Gueben D, Porte M, Desnuelle C, et al. Use of the Faces Pain Scale by left and right hemispheric stroke patients. *Pain* 2007;128(1–2):52–8.
19. McCaffrey P. Right hemisphere involvement: symptoms and diagnosis. In: McCaffrey P, editor. *The neuroscience on the web series: CMSD636 Neuropathologies of language and cognition* [Internet]. Chico, California: California State University; 1998–2008 [cited 2019 Mar 19]. Available from: <https://www.scribd.com/document/83469364/The-Neuroscience-on-the-Web-Series>
20. Mandysová P, Herr K. The translation and linguistic validation of the Revised Iowa Pain Thermometer into Czech for a clinical study involving Czech stroke patients. *Kontakt* 2019;21(1):55–64.
21. McGuire DB, Kaiser KS, Haisfield-Wolfe ME, Iyamu F. Pain assessment in noncommunicative adult palliative care patients. *Nurs Clin North Am* 2016;51(3):397–431.
22. Peters MDJ, Godfrey C, McInerney P, Baldini Soares C, Khalil H, Parker D. Chapter 11: Scoping Reviews. In: Aromataris E, Munn Z, (Editors). *JBIR Reviewer's Manual* [Internet]. Adelaide: JBI, 2017 [cited 2019 May 12]. Available from: <https://reviewersmanual.joannabriggs.org/>.
23. Munn Z, Aromataris E, Tufanaru C, Stern C, Porritt K, Farrow J, et al. The development of software to support multiple systematic review types: the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI). *Int J Evid Based Healthc* 2019;17(1):36–43.
24. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and explanation. *The PRISMA-ScR statement. Ann Intern Med* 2018;169(7):467–73.

Appendix I: Search strategy

PubMed

Search conducted on December 16, 2019, from database inception (1996) to present.

Search Query

1. “stroke”[Mesh] OR “stroke”[Ti/Ab] OR “CVA”[Ti/Ab] OR “cerebrovascular accident”[Ti/Ab] OR “cerebrovascular stroke”[Ti/Ab] OR “brain vascular accident”[Ti/Ab] OR “CNS infarction”[Ti/Ab] OR “CNS infarct”[Ti/Ab] OR “cerebral hemorrhage”[Ti/Ab] OR “cerebral haemorrhage”[Ti/Ab] OR “intracerebral hemorrhage”[Ti/Ab] OR “intracerebral haemorrhage”[Ti/Ab] OR “cerebral infarction”[Ti/Ab] OR “cerebral infarct”[Ti/Ab] OR “subarachnoid hemorrhage”[Ti/Ab] OR “subarachnoid haemorrhage”[Ti/Ab] OR “cerebral thrombosis”[Ti/Ab] OR “cerebral venous thrombosis”[Ti/Ab] OR “transient ischemic attack”[Ti/Ab] OR “transient ischaemic attack”[Ti/Ab] OR “TIA”[Ti/Ab] (313,634)
2. “aphasia”[Mesh] OR “aphasia”[Ti/Ab] OR “aphatic”[Ti/Ab] OR “alogia”[Ti/Ab] OR “anepia”[Ti/Ab] OR “dysphasia”[Ti/Ab] OR “dysphatic”[Ti/Ab] OR “agrammatism”[Ti/Ab] OR “agrammatic”[Ti/Ab] OR “communication disorders”[Mesh] OR “communication disorder”[Ti/Ab] OR “communication problem”[Ti/Ab] OR “communicative problem”[Ti/Ab] OR “communication disability”[Ti/Ab] OR “communication disabilities”[Ti/Ab] OR “communicative dysfunction”[Ti/Ab] OR “communication dysfunction”[Ti/Ab] OR “speech disorder”[Ti/Ab] OR “language disorder”[Ti/Ab] OR “verbal apraxia”[Ti/Ab] OR “verbal problem”[Ti/Ab] OR “verbal dyspraxia”[Ti/Ab] OR “oral apraxia”[Ti/Ab] OR “oral dyspraxia”[Ti/Ab] OR “oral problem”[Ti/Ab] OR “phonation problem”[Ti/Ab] OR “phonatic problem”[Ti/Ab] (69,534)
3. “pain”[Mesh] OR “pain”[Ti/Ab] OR “central post-stroke pain”[Ti/Ab] OR “complex regional pain”[Ti/Ab] OR “headache”[Mesh] OR “headache”[Ti/Ab] OR “neuralgia”[Mesh] OR “neuralgia”[Ti/Ab] OR “neuralgic”[Ti/Ab] OR “neuralgetic”[Ti/Ab] OR “neuropathic pain”[Ti/Ab] OR “central pain”[Ti/Ab] (796,878)
4. “pain measurement”[Mesh] OR “pain measurement”[Ti/Ab] OR “instrument”[Ti/Ab] OR “measure”[Ti/Ab] OR “tool”[Ti/Ab] OR “scale”[Ti/Ab] OR “questionnaire”[Ti/Ab] OR “assess”[Ti/Ab] OR “score”[Ti/Ab] OR “thermometer”[Ti/Ab] (2,683,201)
5. #1 AND #2 (6195)
6. #5 AND #3 (314)
7. #6 AND #4 (49)
8. #7 AND English [La] (43)

Appendix II: Study data extraction table

Author(s)	Year of publication	Country of origin	Study design	Study aim(s)	Study population	Sample size	Stroke type	Communication problems	Context	Key findings	Pain instrument				
											Name	Purpose	Number of items	Aspects of pain	Non-pain aspects