Unspoken pain:

ITS ASSESSMENT IN PERSONS WITH APHASIA

Carolien (N.J.) de Vries

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Colophon

The work in this thesis was conducted at the department of Public health and Primary care of the Leiden University Medical Center.

Academic network for research in elderly care

The research in this thesis was supported by and conducted within the University Network for the Care Sector South Holland (UNC-ZH). In this network, the Leiden University Medical Center (LUMC) collaborates structurally with 13 elderly care organisations in South Holland (Marente, Pieter van Foreest, Florence, Topaz, Argos Zorggroep, Saffier, Laurens, Zonnehuisgroep Vlaardingen, Woonzorgcentra Haaglanden, Aafje, ActiVite, Haagse Wijk- en Woonzorg, Florence).

Caregivers, policy makers, researchers, students, residents, and relatives work together to improve the quality of care and quality of life for vulnerable older people. The UNC-ZH is a regional platform, inspirator and learning network for innovation in long-term care. Research, education and training, and practice are closely related.

Other elderly care organisations that participated in this researchproject are Amaris Zorggroep - Hilversum, Careyn, Silverein (Birkhoven Park) - Amersfoort, Warande - Zeist, Zorgboog - Helmond, Zorgpartners Midden-Holland (Ronssehof) - Gouda.

Topaz

The researchproject ‘Pain in aphasia: an unspoken problem’ was conducted at Topaz, a nursing home organization in the Netherlands. Topaz provides loving specialized care. What we do, we like to do well. That is why Topaz has chosen to devote time, attention, and expertise to elderly people with a focus on: non-congenital chronic physical disabilities, stroke (CVA), dementia, Huntington’s disease, and Korsakov syndrome. With 9 care locations in the Leiden and the Bollenstreek region.

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Deze namen staan symbool voor alle mensen met een afasie. In de hoop dat zij in verbinding konden blijven met de ander. Juist wanneer verbale communicatie niet vanzelfsprekend is en zeker wanneer er dan sprake is van pijn.

Table of contents

Chapter 1

General introduction

Prologue

It happened a week ago. Mrs. S. fell in the street and had a stroke. After a few days in the hospital, she is currently recovering at a Geriatric Rehabilitation department. Mrs. S. is 85 years old and has severe aphasia. She is only able to point at objects and the adequacy of her non-verbal responses to closed-ended questions varies. Mrs. is dependent on help from nurses and a hoist to get in and out of bed. During these moments she shows resistance by hitting a nurse with her arm. Mrs. S. seems to be angry. The nurses have tried everything from telling her slowly what they are going to do, to playing soft piano music. Mrs. S's resistance makes daily care difficult. The nurses wonder what to do. Could she be in pain?

This example illustrates that the identification of pain in a person with aphasia depends on the knowledge, experience and intuition of the nurses and family caregivers who support them. This immediately highlights the importance of adequate pain assessment in persons with aphasia. Especially because scientific research shows that adequate pain treatment in the acute phase after stroke is very important for rehabilitation outcomes, recovery, and independent functioning and self-reliance [1].

Stroke and its consequences

The Dutch heart foundation [2] reports that more than 38,000 persons per year and 106 persons each day suffer a stroke in the Netherlands. Approximately 376,000 persons live with the consequences of a stroke. Based on demographic developments, the number of people with stroke and the number of people who have had a stroke in a given year is expected to increase by 45% in the period 2018-2040 [3].

Stroke has a major impact on cognitive function. Cognitive impairment is common after stroke and can strongly impact daily functioning. Cognitive impairments are deficits in attention, memory, visuospatial and constructive functions, language and mathematics, and delays in information processing [4-6]. Aphasia is one of these impairments, although the aphasia may change over time after stroke. Patients undergo a period of spontaneous recovery immediately after stroke, during which dramatic improvements in language and cognitive functioning may occur [7, 8]. Stroke is the most common cause of aphasia [9-11]. Persons with aphasia often experience co-occurring non-linguistic cognitive deficits [12, 13].

Aphasia

Aphasia is an acquired language disorder resulting from brain damage, the most common of which is stroke. Aphasia occurs in approximately 30% of stroke patients [11, 14]. In addition to a stroke, aphasia can also be caused by dementia or brain trauma, such as an accident, infection or brain tumor [7]. If we include communication problems due to traumatic brain injury, primary progressive aphasia, dementia, and right hemisphere damage, the incidence and prevalence of aphasia increases [7].

Depending on the severity and location of the brain damage, some persons with aphasia are unable or barely able to communicate, or can communicate only with difficulty. The language use of persons with aphasia differs from that of persons without aphasia in both language production and language comprehension. The diagnosis of aphasia has largely evolved beyond the traditional approach of classifying patients into specific syndromes and instead focuses on individualized patient profiles [8]. These profiles include a description of clinical symptoms. The following are the most common symptoms of aphasia. It is aphasia, when one or more of these symptoms are present [8, 10, 15].

Spoken language

Usually, it is in spoken language, and especially in everyday language, that the language problems are most noticeable and most disturbing to the person and his or her environment. The problems can manifest themselves in the production of errors in the phonemes of a word or in finding the right word at the right time; also called 'word finding difficulties'. In addition, most persons with aphasia also have difficulty forming sentences. These are characterized by simplification of sentence structure and/or errors in the application of grammatical rules. In addition to these problems, persons with aphasia may exhibit other characteristics that can be summarized under the term 'automatic language use': stereotypes, language automatisms and recurring utterances, echolalia and perseverations [16].

Auditory language comprehension

Persons with aphasia may have difficulty distinguishing speech phonemes. These are the sounds of speech. A greater number of persons with aphasia experience difficulty understanding the meaning of word, and almost all persons with aphasia have difficulty understanding word sequences and complex grammatical structures [16].

Read and write

Persons with aphasia always have difficulty reading and writing [16].

Articulation disorders

Additional dysarthria in aphasia is usually the result of cortical damage in the language-dominant hemisphere and because articulatory organs are bilaterally represented, the dysarthria usually resolves quickly. Another common articulation disorder is 'apraxia of speech'. Apraxia of speech involves problems with the planning of the articulatory organs [16].

Aphasia can be classified into three levels of severity: mild, moderate, and severe [8, 16, 17]. In June 2012, the Dutch Association of Aphasia Therapists has established indications of severity based on standardized measuring instruments at the level of the disorder. In practice, individual discrepancies will occur [17]. In general, the more severe the aphasia, the more important it is to include compensatory techniques or supportive communication methods or tools [18]. The extent to which a person with aphasia will be able to independently use supportive methods is related not only to the severity of the aphasia but also to the presence of impairments in other cognitive functions, such as executive functions [19].

The conversation partner will often need to adjust his or her communication to achieve a more optimal exchange of information. Trained conversation partners are always important to facilitate the person with aphasia in his communication skills [20, 21]. In conclusion, having aphasia has considerable impact on communication with both healthcare professionals and informal caregivers or loved ones of the person with aphasia.

Pain and pain after stroke

Pain is a sensory stimulus, usually associated with tissue damage. The stimulus message is transported via nerve fibers to the spinal cord, and after some local processing at that level, is rapidly transported to the brain, where there are many areas that locate the stimulus, and bring context and perspective to that stimulus [22]. These processes have been described as two pain pathways, in which one system, the medial pain system, mediates cognitive, evaluative, memory, and motivational-affective aspects of pain and is therefore related to emotions such as 'suffering' from pain [23]. It is also in this medial pain system that words are given to pain. After a stroke, the medial pathway and the perception of pain may be disturbed [24].

The most frequently occurring post-stroke pain syndromes are headache, musculoskeletal pain, shoulder pain, complex regional pain syndrome, and central post-stroke pain [1, 25, 26]. Central post-stroke pain (CPSP) is defined as the neuropathic pain that occurs either acutely or in the chronic phase of a stroke and is a result of central lesions of the lateral pain system. The literature reports that 1 in 10 stroke patients experience CPSP, and when the lateral pain system is involved, this number increases to more than 1 in 2 patients [27]. Almost 40% experienced some degree of post-stroke pain 5 years after stroke. Of these patients, 25% felt that their pain management needs were not met. These patients also reported poorer quality

of life, self-perceived health status and recovery post-stroke [29]. Pain in patients with an inability to communicate, such as in aphasia, is not systematically assessed and is therefore undertreated [28]. The above studies confirm the importance of healthcare professionals remaining alert to pain in persons with aphasia in both the acute and chronic phases [28, 29].

Pain in aphasia

The incidence and prevalence rates of pain in persons with aphasia are unknown. However, it is known that pain is underreported in persons with this diagnosis [30-33]. The underreporting of pain indicates a gap in terms of being able to adequately report or measure pain in persons with aphasia using valid and reliable appropriate instruments. This is similar to other populations of persons with communication problems [34-36]. Studies show that pain (including shoulder pain and central pain) is just as common in stroke patients with mild to moderately severe aphasia as in stroke patients without aphasia [37, 38]. In clinical practice, it is difficult to correctly identify pain when a person with aphasia cannot indicate it verbally. The communication of pain in persons with aphasia after stroke is therefore challenging. In addition to the presence of aphasia after stroke, other cognitive impairments related to communication lead to even more challenges for the persons with aphasia and their relatives and caregivers. Persons with aphasia are dependent on the interpretation of their behavior by the healthcare professionals, legal representatives, family members and friends. However, the literature shows that they rate their relative with aphasia significantly lower in global and physical health-related quality of life, including pain [39]. This demonstrates the importance of adequate pain measurement in persons with aphasia who experience communicative impairments that limit their ability to express any pain they may be experiencing.

Self-report pain scales are considered the gold standard for measuring pain, and this also applies to stroke patients [32]. Examples of self-report pain scales are the Numerical Rating Scale (NRS; [40]), Visual Analogue Scale (VAS; [41]), and Faces Pain Scale (FPS; [42]). The use of self-report pain scales in persons with aphasia is challenging and cannot always be applied because of the comprehension and the communication problems associated with aphasia [37, 43]. In addition to aphasia, there may be other problems such as physical problems like hemiparesis in leg or arm, a hemi-inattention disorder like neglect, or hemiparesis of facial muscles. These problems also add to the difficulty of using self-report pain scales, for example, because the person does not understand the self-report pain scale correctly or cannot point to it correctly. Currently, there are few or no alternatives to measuring pain in persons with aphasia other than using a self-report pain scale. This means that a gap exists when persons are limited by communication problems, cannot complete self-report pain scales and no other instrument is available.

Observational pain scales have been used successfully as an alternative to self-report pain scales in people with advanced dementia [44-48]. The use of such a pain observation instrument may be a good alternative for people with aphasia. A pain observation instrument could serve as a proxy for measuring self-reported pain in stroke patients with aphasia. Examples of pain observation instruments are the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC [49]) the Pain Assessment in Advanced Dementia Scale (PAINAD; [50]), and Pain Assessment in Impaired Cognition (PAIC15 [48, 51]). These pain observation instruments are recommended for use in cognitively impaired elderly in acute and long-term care settings [52]. As the psychometric quality of PACSLAC-D has been previously investigated in persons with dementia and this measurement instrument is well known in Dutch nursing home institutions, a study with PACSLAC-D in persons with aphasia was conducted.

The question is whether a pain observation instrument, such as PACSLAC-D or PAIC15, which are used for people with dementia, could also be useful for people with aphasia. This research will find an answer to this question.

Outline of this thesis

This thesis describes the results of the research project **'Pain in aphasia: an unspoken problem'**. The overall aim of the 'Pain in Aphasia' project was to describe the current scientific status on pain and pain measurement in people with aphasia, and to develop a practice guideline for pain measurement specifically for people with aphasia. To achieve the above-mentioned aim of this thesis, a number of research questions are addressed. To answer these research questions, the thesis is divided into 3 parts.

- *Part 1. Pain and pain assessment in aphasia*

  Part 1 consists of two chapters describing the research questions:
  - **Which assessment instruments have been used for self-report of pain in stroke patients with communication problems?**
  - **What is known in the literature about pain and pain assessment in persons with aphasia?**

Self-report is considered the gold standard for routine assessment of symptoms such as pain. Self-report is challenging in persons with aphasia due to communication problems, although there are persons with, for example, mild aphasia who can complete these self-report scales. To gain insight into when self-report is used and when it is not in persons with aphasia, this thesis starts with a review of the literature on pain measurement in persons with aphasia. **Chapter 2** presents the results of a scoping review in which databases were searched

for an overview of what instruments are currently used for self-report pain scales in stroke patients with communication problems during hospital stay. The most common communication problem was aphasia. These findings led to the questions: how often does pain occur in persons with aphasia? Which pain measurement instruments are useful in persons with aphasia? These questions are answered by a systematic review presented in **Chapter 3**. The aim of this review was to investigate the prevalence and incidence of pain in persons with aphasia after stroke, to determine which pain assessment instruments are used, and to examine whether they are feasible, valid, and reliable.

- *Part 2. Pain observation in persons with aphasia*

  Part 2 consists of 3 chapters describing the psychometric properties of pain observation instruments in persons with aphasia. This part presents the studies that answer the question:

- **Are pain observation instruments that were developed for persons with dementia also valid, reliable and feasible for assessing pain in persons with aphasia?**

The first two chapters include studies assessing the psychometric properties of pain observation instruments in persons with aphasia. **Chapter 4** describes the psychometric properties of pain observation instrument PACSLAC-D in persons with aphasia. This study examined the construct validity, internal consistency, and test-retest reliability of the PACSLAC-D in persons with aphasia.

At the time of this observational study, the Pain Assessment in Impaired Cognition (PAIC15) observational scale was being developed and promised to be a clinically useful, valid, and reliable alternative [44]. The PAIC15 is a universal meta-tool for assessing pain in persons with cognitive impairment, developed internationally by a multidisciplinary team of experts from 16 countries [44, 48]. The PAIC15 includes the best items from existing pain scales to observe pain in persons with impaired cognition and has shown satisfactory psychometric qualities in patients with impaired cognition, mostly with dementia [46, 53]. Therefore, the PAIC15 may also be feasible for persons with aphasia. A study aimed at investigating the criterion and construct validity, as well as the reliability of the observational pain instrument PAIC15 in persons with aphasia is presented in **Chapter 5**. For criterion validity, correlations were calculated between the PAIC15 and self-report pain scales, and for construct validity, three hypotheses were tested. Reliability was determined by assessing internal consistency, and intra- and interobserver agreement. To assess whether observers find the PAIC15 user-friendly for persons with aphasia, observers who used the PAIC15 in the observational study (Chapter 5) were asked to rate the user-friendliness of the PAIC15. When self-report pain scales could be completed, most observers preferred to use the combined self-report pain scale for persons with aphasia. These results are reported in **Chapter 6**.

- *Part 3. A practice pain guideline for persons with aphasia*

  Part 3 presents the development of a practice pain guideline for persons with aphasia.

  This part answers the question:

  - **What should a clinically applicable pain guideline for recognizing pain in persons with aphasia look like - both in terms of content and design?**

Chapter 7 presents the development of a pain guideline for pain in persons with aphasia. The practice pain guideline was developed through a co-creation process in which the wishes, needs, and ideas of people with aphasia and their professional and informal caregivers were considered. Finally, **Chapter 8** provides a general discussion of all the findings. This chapter concludes with recommendations for future research and implications for practice to improve the recognition of pain in persons with aphasia.

Chapter 9 contains the summary of this dissertation and **Chapter 10** includes the Nederlandse samenvatting, Dankwoord, About the author, PhD Portfolio and Research Data Management.

References

1. Aprile, I., et al., *Pain in stroke patients: characteristics and impact on the rehabilitation treatment. A multicenter cross-sectional study.* Eur J Phys Rehabil Med, 2015. **51**(6): p. 725-36.
2. Hartstichting. *Cijfers hart-en vaatziekten*. 2022 03-05-2024]; Available from: https://www.hartstichting.nl/hart-en-vaatziekten/cijfers-hart-en-vaatziekten
3. RIVM. *Volksgezondheid en Zorg Info Beroerte Toekomst*. 2023 03-05-2024]; Available from: https://www.vzinfo.nl/beroerte/toekomst
4. Einstad, M.S., et al., *Associations between post-stroke motor and cognitive function: a cross-sectional study.* BMC Geriatr, 2021. **21**(1): p. 103.
5. El Husseini, N., et al., *Cognitive Impairment After Ischemic and Hemorrhagic Stroke: A Scientific Statement From the American Heart Association/American Stroke Association.* Stroke, 2023. **54**(6): p. e272-e291.
6. Huang, Y.Y., et al., *Post-Stroke Cognitive Impairment: Epidemiology, Risk Factors, and Management.* J Alzheimers Dis, 2022. **86**(3): p. 983-999.
7. Code, C. and B. Petheram, *Delivering for aphasia.* Int J Speech Lang Pathol, 2011. **13**(1): p. 3-10.
8. Sheppard, S.M. and R. Sebastian, *Diagnosing and managing post-stroke aphasia.* Expert Rev Neurother, 2021. **21**(2): p. 221-234.
9. Boehme, A.K., et al., *Effect of aphasia on acute stroke outcomes.* Neurology, 2016. **87**(22): p. 2348-2354.
10. Orchardson, R., *Aphasia--the hidden disability.* Dent Update, 2012. **39**(3): p. 168-70, 173-4.
11. Wu, C., et al., *Prevalence and Impact of Aphasia among Patients Admitted with Acute Ischemic Stroke.* J Stroke Cerebrovasc Dis, 2020. **29**(5): p. 104764.
12. Murray, L.L., *Attention and other cognitive deficits in aphasia: presence and relation to language and communication measures.* Am J Speech Lang Pathol, 2012. **21**(2): p. S51-64.
13. Vallila-Rohter, S. and S. Kiran, *Non-linguistic learning and aphasia: evidence from a paired associate and feedback-based task.* Neuropsychologia, 2013. **51**(1): p. 79-90.
14. Gronberg, A., et al., *Incidence of Aphasia in Ischemic Stroke.* Neuroepidemiology, 2022. **56**(3): p. 174-182.
15. Hinckley, J. and M. Jayes, *Person-centered care for people with aphasia: tools for shared decision-making.* Front Rehabil Sci, 2023. **4**: p. 1236534.
16. Bastiaanse, R., *Afasie.* 2010, Houten: Bohn Stafleu van Loghum.
17. NVAT. *NVAT Afasie Interventie Schema's* 2015 03-05-2024]; Available from: https://afasienet.com/professionals/diagnostiek-en-therapie/nais/
18. Van de Sandt-Koenderman, W.M., et al., *A computerised communication aid in severe aphasia: an exploratory study.* Disabil Rehabil, 2007. **29**(22): p. 1701-9.
19. Purdy, M. and A. Koch, *Prediction of strategy usage by adults with aphasia.* Aphasiology, 2006. **20**(2-4): p. 337-348.
20. Simmons-Mackie, N., et al., *Communication partner training in aphasia: a systematic review.* Arch Phys Med Rehabil, 2010. **91**(12): p. 1814-37.
21. Wilkinson, R. and S. Wielaert, *Rehabilitation targeted at everyday communication: can we change the talk of people with aphasia and their significant others within conversation?* Arch Phys Med Rehabil, 2012. **93**(1 Suppl): p. S70-6.

22. Achterberg, W.P., et al., *Pain management in patients with dementia.* Clin Interv Aging, 2013. **8**: p. 1471-82.

23. Scherder, E.J., J.A. Sergeant, and D.F. Swaab, *Pain processing in dementia and its relation to neuropathology.* Lancet Neurol, 2003. **2**(11): p. 677-86.

24. Haslam, B.S., D.S. Butler, and L.M. Carey, *Novel insights into stroke pain beliefs and perceptions.* Top Stroke Rehabil, 2019: p. 1-10.

25. Hansen, A.P., et al., *Pain following stroke: a prospective study.* Eur J Pain, 2012. **16**(8): p. 1128-36.

26. Klit, H., N.B. Finnerup, and T.S. Jensen, *Central post-stroke pain: clinical characteristics, pathophysiology, and management.* Lancet Neurol, 2009. **8**(9): p. 857-68.

27. Liampas, A., et al., *Prevalence and Management Challenges in Central Post-Stroke Neuropathic Pain: A Systematic Review and Meta-analysis.* Adv Ther, 2020. **37**(7): p. 3278-3291.

28. Schuster, J., et al., *Use of analgesics in acute stroke patients with inability to self-report pain: a retrospective cohort study.* Bmc Neurology, 2020. **20**(1).

29. Westerlind, E., et al., *Experienced pain after stroke: a cross-sectional 5-year follow-up study.* BMC Neurol, 2020. **20**(1).

30. Kehayia, E., et al., *Differences in pain medication use in stroke patients with aphasia and without aphasia.* Stroke, 1997. **28**(10): p. 1867-70.

31. Widar, M., et al., *Long-term pain conditions after a stroke.* J Rehabil Med, 2002. **34**(4): p. 165-70.

32. Harrison, R.A. and T.S. Field, *Post stroke pain: identification, assessment, and therapy.* Cerebrovasc Dis, 2015. **39**(3-4): p. 190-201.

33. Nesbitt, J., et al., *Improving pain assessment and managment in stroke patients.* BMJ Qual Improv Rep, 2015. **4**(1).

34. de Knegt, N.C., et al., *Pain and Cognitive Functioning in Adults with Down Syndrome.* Pain Med, 2017. **18**(7): p. 1264-1277.

35. Husebo, B.S., W. Achterberg, and E. Flo, *Identifying and Managing Pain in People with Alzheimer's Disease and Other Types of Dementia: A Systematic Review.* CNS Drugs, 2016. **30**(6): p. 481-97.

36. Oudman, E., et al., *Self-Reported Pain and Pain Observations in People with Korsakoff's Syndrome: A Pilot Study.* J Clin Med, 2023. **12**(14).

37. Benaim, C., et al., *Use of the Faces Pain Scale by left and right hemispheric stroke patients.* Pain, 2007. **128**(1-2): p. 52-58.

38. Korner-Bitensky, N., et al., *Eliciting information on differential sensation of heat in those with and without poststroke aphasia using a visual analogue scale.* Stroke, 2006. **37**(2): p. 471-5.

39. Cruice, M., et al., *Measuring quality of life: Comparing family members' and friends' ratings with those of their aphasic partners.* Aphasiology, 2005. **19**(2): p. 111-129.

40. Hjermstad, M.J., et al., *Studies comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for assessment of pain intensity in adults: a systematic literature review.* J Pain Symptom Manage, 2011. **41**(6): p. 1073-93.

41. Heller, G.Z., M. Manuguerra, and R. Chow, *How to analyze the Visual Analogue Scale: Myths, truths and clinical relevance.* Scandinavian Journal of Pain, 2016. **13**: p. 67-75.

42. Kim, E.J. and M.T. Buschmann, *Reliability and validity of the Faces Pain Scale with older adults.* Int J Nurs Stud, 2006. **43**(4): p. 447-56.

43. Closs, S.J., et al., *A comparison of five pain assessment scales for nursing home residents with varying degrees of cognitive impairment.* J Pain Symptom Manage, 2004. **27**(3): p. 196-205.

44. Corbett, A., et al., *An international road map to improve pain assessment in people with impaired cognition: the development of the Pain Assessment in Impaired Cognition (PAIC) meta-tool.* BMC Neurol, 2014. **14**: p. 229.

45. Kaasalainen, S., et al., *A Comparison Between Behavioral and Verbal Report Pain Assessment Tools for Use with Residents in Long Term Care.* Pain Management Nursing, 2013. **14**(4): p. E106-E114.

46. Lautenbacher, S., A.L. Walz, and M. Kunz, *Using observational facial descriptors to infer pain in persons with and without dementia.* BMC Geriatr, 2018. **18**(1): p. 88.

47. Lukas, A., et al., *Pain assessment in advanced dementia. Validity of the German PAINAD-a prospective double-blind randomised placebo-controlled trial.* Pain, 2019. **160**(3): p. 742-753.

48. van Dalen-Kok, A.H., et al., *Pain Assessment in Impaired Cognition (PAIC): content validity of the Dutch version of a new and universal tool to measure pain in dementia.* Clin Interv Aging, 2018. **13**: p. 25-34.

49. Zwakhalen, S.M., J.P. Hamers, and M.P. Berger, *Improving the clinical usefulness of a behavioural pain scale for older people with dementia.* J Adv Nurs, 2007. **58**(5): p. 493-502.

50. Warden, V., A.C. Hurley, and L. Volicer, *Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale.* J Am Med Dir Assoc, 2003. **4**(1): p. 9-15.

51. Corbett, A., et al., *Assessment and treatment of pain in people with dementia.* Nat Rev Neurol, 2012. **8**(5): p. 264-74.

52. Qi NG, S., Brammer, J.D., Creedy, D.K., *The psychometric properties, feasibility and utility of behaviouralobservation methods in pain assessment of cognitively impaired elderly people in acute and long-term care: A systematic review.* JBI Libr Syst Rev, 2012. **10**(17): p. 977-1085.

53. Kunz, M., et al., *The Pain Assessment in Impaired Cognition scale (PAIC15): A multidisciplinary and international approach to develop and test a meta-tool for pain assessment in impaired cognition, especially dementia.* Eur J Pain, 2020. **24**(1): p. 192-208.

PART 1

Pain and pain assessment in aphasia

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Chapter 2

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

Keywords:

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

Objective: The objective of this scoping review was to identify assessment instruments used for the self-report of pain by hospitalized patients who have had a stroke and who have communication problems.

Introduction: Pain assessment in various patient groups has received considerable attention, and a variety of pain assessment instruments exists. Nevertheless, there is a lack of consensus regarding which pain assessment instruments are used for self-report of pain in stroke patients with communication problems.

Inclusion criteria: This review included articles that focused on hospitalized adults who have had a stroke, have communication problems attributable to a stroke, and describe the use of an assessment instrument for the self-report of pain. The scoping review considered systematic reviews, quantitative and qualitative studies, and mixed method studies.

Methods: Ten databases were searched from inception to August 2020, using Embase as the key information source (it yielded 424 papers). Hand-searching of the references of the included articles yielded an additional 12 papers. Papers written in any language were considered. A data extraction table was created to record relevant information in line with the goals and results of each article, the sample studied, and the pain assessment instrument used.

Results: Ten papers were included in the review, most of which were descriptive studies. Most papers were from the United Kingdom and the United States. The most common communication problem in stroke patients was aphasia. The participants received care in various hospital settings (e.g., rehabilitation units, comprehensive stroke units, palliative care). Eleven assessment instruments were identified. In most cases, the assessment instruments focused on assessing pain presence and pain intensity. The most frequently used unidimensional pain intensity instrument was the numerical rating scale. Four instruments were multidimensional, of which two assessed health-related quality of life, including pain. The most

Abstract

thorough pain assessment instrument was the ShoulderQ, which contains ten verbal questions and three visual vertical graphic rating scales that focus on the assessment of stroke-related shoulder pain.

Conclusions: A range of both unidimensional and multidimensional self-report pain instruments was identified; however, of all the possible communication problems, most studies focused solely on patients with mild to moderate aphasia. Therefore, further research is recommended, including studies that also enroll patients with various stroke-related communication problems other than aphasia. In addition, the instruments should be translated for research in non-Western countries. Finally, apart from descriptive studies, experimental research with a robust randomized controlled trial design is needed to examine the effect of pain-inducing procedures on the perceived pain in patients with stroke-related communication problems.

Introduction

Stroke is a neurological deficit caused by acute focal damage of the central nervous system due to a disease of the blood vessels supplying the brain. Categories of stroke include cerebral ischemic stroke, intracerebral hemorrhage, and subarachnoid hemorrhage [1]. Because stroke is one of the most common causes of mortality and disability worldwide, [2] addressing health care issues relevant to this condition is paramount. In addition, it is important to devote attention to transient ischemic attack (TIA), also known as mini-stroke or transient stroke (i.e., a brief episode of neurological deficits also belonging to the category of cerebral ischemia [1] and producing the same symptoms, including pain, as a completed stroke). [3]

Although the reported prevalence of pain in patients with stroke varies due to a range of factors, such as differences in research study designs, patient characteristics, and pain assessment methods, there is evidence that pain affects patients both in the acute and chronic post-stroke phases [4]. Pain is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." [5 (para.1)] The various kinds of pain experienced by stroke patients include central post-stroke pain, spasticity- or subluxation-associated pain, painful peripheral neuropathy, complex regional pain syndrome, and headache [4]. In addition, stroke patients could have pain due to various pre-existing chronic conditions, such as musculoskeletal disorders [6]. Pain in stroke patients can hinder recovery and rehabilitation, [4] which may translate to an increased length of hospital stay. In the long-term, unresolved pain can lead to fatigue and suboptimal engagement in the activities of daily living, [7] as well as a decreased overall quality of life [4].

Despite the negative consequences of pain in patients who have had a stroke, clinicians often fail to adequately recognize and diagnose pain in this patient population, thus pain goes undertreated or even untreated [8]. Inadequate pain assessment and treatment can result from insufficient experience on the part of clinicians as well as from coexisting medical issues and impaired cognition or communication, which are common problems in patients after a stroke [4, 8, 9]. Specifically, patients can exhibit aphasia (sometimes referred to as dysphasia), an acquired language impairment caused by brain damage that can affect speaking as well as auditory comprehension, reading, and writing abilities [10]. Dysarthria, another communication sequela of a stroke, is characterized by impaired articulation due to weak or uncoordinated speech muscle control, rendering speech intelligibility suboptimal [11]. Some stroke patients may exhibit apraxia of speech, a motor speech disorder characterized by inefficient translation of speech sounds into kinematic parameters relevant to speech production [12]. Because of comprehension, expressive, or articulation difficulties, such patients might find it difficult to alert clinicians when they are in pain.

Proper pain assessment and treatment in stroke patients with communication problems is challenging because no pain instruments have yet been specifically designed and dedicated to this patient population [8]. A 2017 systematic review by De Vries et al. [9] found that most studies of pain intensity measurement only examined instruments that are also used with other patient

populations, such as the Faces Pain Scale (FPS), the Verbal Rating Scale (VRS), and the Visual Analogue Scale (VAS). Such instruments are sometimes called unidimensional (i.e., they are used to provide ratings on a single scale) [13]. De Vries et al. [9] also found that, in some studies, pain was only one subdomain in multidimensional quality-of-life instruments used in patients with various diagnoses besides stroke, such as the 36-Item Short Form Health Survey.

Compounding the problem is conflicting evidence in the scientific literature as to whether patients with stroke-related aphasia can use self-report instruments reliably. The review by De Vries et al. [9] found that most studies excluded patients with severe aphasia. These patients may not understand the instructions that accompany self-report instruments or certain specific items contained in the instruments. For these reasons, observational pain instruments, which are based on assessment of "pain-like" behavior by the clinician, may represent a more appropriate choice [9].

A preliminary search of PROSPERO, MEDLINE, CINAHL, the Cochrane Database of Systematic Reviews, and JBI Evidence Synthesis was conducted, and while no scoping reviews were identified, the search yielded two systematic reviews regarding pain assessment instruments for the diagnosis of pain in people who have had a stroke. One was the abovementioned systematic review by de Vries et al. [9] and the other was a systematic review by Edwards et al. [14]. However, the focus of these reports differs from our scoping review. Of the various communication problems, De Vries et al. [9] focused solely on aphasia, while Edwards et al. [14] did not focus on any communication problems. Further, de Vries et al. [9] included studies with proxy pain ratings, whereas our scoping review focuses solely on patient self-report.

The objective of this scoping review was to map the types and details of existing pain assessment instruments used for the self-report of pain by hospitalized stroke patients with stroke-related communication problems. Our findings synthesized various sources of information on current practice concerning the existing self-report instruments that have been used in hospital settings for stroke patients. We sought to identify any potential knowledge gaps that should be addressed through further 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

This review considered studies that included adult participants ≥18 years of age in which at least one of the studied subgroups or all participants were diagnosed with stroke, including TIA. Our chief criterion was that at least some of the participants had communication problems affecting their ability to understand language and/or produce speech (e.g., having difficulty with

understanding what other people say or not being able to produce intelligible speech). The review considered studies in which the patients' communication problems were related to a current or previous stroke, with all studies included irrespective of the type of.

Concept

This review considered studies that explored the use of assessment instruments for the self-report of pain by patients who have had a stroke and have stroke-related communication problems. These instruments could be either unidimensional (i.e., they focus on any one particular aspect of pain, such as pain intensity, pain location, or pain quality), multidimensional (i.e., they could assess several pain attributes, such as pain intensity and interference with activities), or assess other factors in addition to pain (e.g., various aspects of quality of life). The pain could be of any etiology.

Context

This review incorporated data from studies where the participants were hospitalized for any reason and any length of time and received post-stroke, inpatient care. Studies conducted in any country and any sociocultural setting were included.

Types of sources

Quantitative, qualitative, and mixed methods study designs, including validation and methodological studies, together with systematic reviews, were considered for inclusion in this scoping review. Abstracts were excluded, as these were unlikely to contain all the relevant information regarding the review question, a policy which is in line with the updated JBI methodological guidance for conducting scoping reviews [15].

Methods

This scoping review was performed in accordance with the JBI methodology for scoping reviews [15] and in accordance with an a priori published protocol, although two deviations from the protocol should be noted [16]. Articles written in any language were considered although the scoping review protocol indicated that only articles written in English would be included. The reason for this deviation was to avoid missing potentially important information in articles in languages other than English. Secondly, the data extraction table was modified during the data charting process by splitting it into two parts for easier viewing.

Search strategy

The search aimed to identify and procure both published and unpublished primary studies and reviews. The search was performed in three distinct phases. The first consisted of an initial limited search of the PubMed, CINAHL, and Nursing@Ovid data- bases to identify relevant articles. Following this, an analysis was conducted of the text words contained in the title and

abstract of the identified articles as well as of the index terms used to describe these articles. This phase informed the development of a full search strategy, including the identification of keywords and index terms, which was adapted for each information source. The full search strategy for the individual databases is shown in Appendix I. In the final phase, the reference lists of all the included articles were screened for additional articles.

The databases that were searched included: PubMed (NLM), Embase (Ovid), CINAHL (EBSCO), Nursing@Ovid, Web of Science, Scopus, and Cochrane Library. The search for unpublished articles was conducted in the following databases: ProQuest Health and Medical Collection, ProQuest Nursing and Allied Health Source, and Open Access Theses and Dissertations (OATD).

No restrictions were made concerning the year of publication. Because the information could prove relevant irrespective of publication date, all studies published from the inception of a given database to the date of the search were included (i.e., to July 2020 for the databases PubMed, Embase, CINAHL, and Web of Science, and to August 2020 for the remaining databases). As mentioned, articles published in any language were considered.

Study selection

Following the search, all identified records were collated and uploaded into the reference management program Citace PRO v.4.1 (Citace.com, s.r.o., Czech Republic), with duplicates removed. Next, two independent reviewers (PM and JK) screened the titles and abstracts for assessment against the inclusion criteria for the review. Subsequently, potentially relevant papers that met the inclusion criteria were retrieved in full, and their citation details were imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Ade- laide, Australia) [17]. The authors of three papers were contacted to request full-text content, as only the abstracts could be retrieved; however, only one author supplied the previously inaccessible article. Full-text papers that did not meet the inclusion criteria were excluded, with justifications for their exclusion provided in Appendix II. Any disagreements concerning this assessment and the inclusion or exclusion of papers were resolved through discussion between two reviewers.

Data extraction

Data were extracted from the papers included in the scoping review by two independent reviewers (PM and JK) using a draft data extraction table developed by the reviewers [16]. The data extraction table was trialed by the team to ensure that all relevant results were extracted. Minor disagreements that arose between the reviewers were resolved through discussion.

Data analysis and presentation

Appendix III contains specific details about the year of publication, country of origin, study design, study aims, the study population, communication problems (e.g., aphasia),

the context, and key findings relevant to the review question. Appendix IV contains specific details regarding the identified self- report pain instruments, such as the name (e.g., The Nottingham Health Profile), purpose, number of items, and specific content, such as what attributes of pain they focus on (e.g., pain intensity) and what aspects other than pain they assess (e.g., the Nottingham Health Profile assesses physical mobility, sleep, emotional reactions, social isolation, and energy level).

Results

Study inclusion

A total of 722 papers were identified by the search strategy (PubMed ¼ 122, Embase ¼ 424, CINAHL ¼ 26, Nursing@Ovid ¼ 9, Web of Science ¼ 58, Scopus ¼ 0, Cochrane Library ¼ 42, ProQuest Health and Medical Collection and ProQuest Nursing and Allied Health Source ¼ 40, and OATD ¼ 1), with the results shown in a PRISMA flow diagram (Figure 1) [18]. An additional 12 papers were identified through handsearching of the reference lists of all the included articles, leading to a total of 734 papers. Of these, 198 papers were duplicates and thus were excluded, leaving 536 records. In the next step, 474 additional records were excluded as irrelevant based on the screening of title and abstract. Sixty-two full text articles were retrieved, of which 52 were excluded and the reasons documented (Appendix II). The reasons for exclusion were ineligible population or context, or the papers did not contain a description of a self-report pain instrument (ineligible concept). Two records were excluded due to the inability to obtain full-text content (the authors did not respond to a request to provide the full-text paper).

In total, ten papers met the inclusion criteria and were included in the review.

Characteristics of the included studies

All included papers assessed symptoms of patients with stroke, including pain. Appendix III contains a summary of the characteristics of the papers. In three papers, the most common stroke type was ischemic stroke, followed by intracerebral hemorrhage [19-21]; the remaining papers did not specify the incidence of the individual stroke types. In two studies, the stroke type was not specified [22, 23]. None of the studies included patients with a TIA. Out of the ten papers, four focused on pain self-report instruments [9, 22, 24, 25], but this was not the main focus in the remaining studies [19-21, 23, 26, 27]. One study focused on objective pain assessment in patients with stroke-related aphasia, with the assessment compared with pain self-report [25]. The participants received care in various hospital settings, such as rehabilitation units [20, 21, 23, 27], comprehensive stroke units [22, 25], and in palliative care [26]. Descriptive research design was the most common study design identified [20, 21, 23, 24, 26, 27]. One study was a randomized controlled trial [25] and one paper was a systematic review [9].

Eleven assessment instruments were identified; in most cases, the assessment instruments focused on assessing pain presence [19-21, 23, 27] and pain intensity [9, 21-27]. The most frequently used unidimensional pain instrument was a numerical rating scale (NRS) measuring

pain intensity [9, 22, 24, 25]. One self-report pain instrument, the ShoulderQ, focused on more than one aspect of pain and was thus multidimensional [23, 27]. Three other identified instruments were multidimensional, assessing various symptoms including pain: The Nottingham Health Profile (NHP; [19, 21], The Dartmouth COOP Functional Health Assessment Charts of the World Organization of Family Doctors (COOP/WONCA; [21], and the Edmonton Symptom Assessment Scale (ESAS; [26].

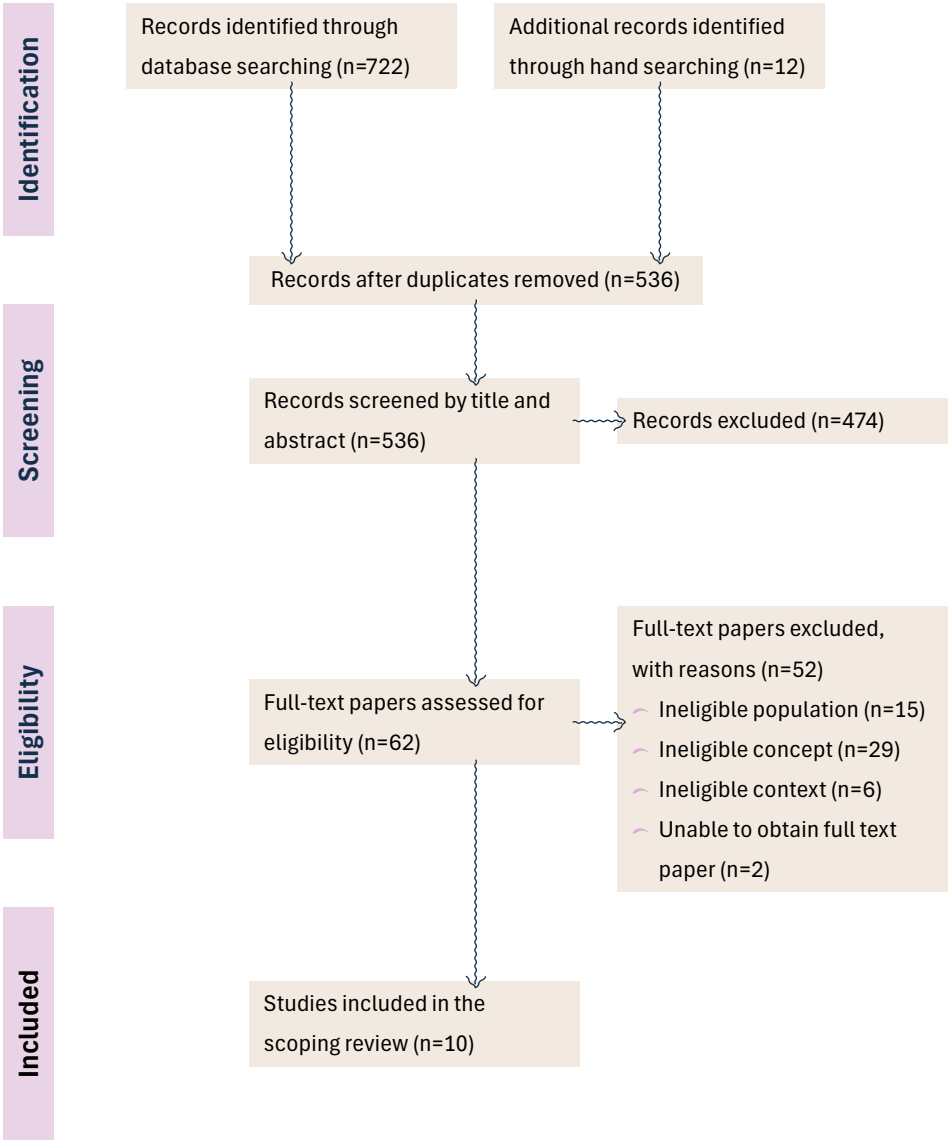

Figure 1: Search results and study selection and inclusion process [18]

Review findings

Study populations

Our scoping review focused on adult stroke patients with communication problems affecting their language comprehension and/or speech production. The most frequent communication problems were aphasia [9, 19, 21, 22, 24-26] and dysarthria [20, 22]. In two papers, the communication deficits were not specified [23, 27]. In three papers, patients with severe aphasia were excluded [19-21], and this observation was also made by De Vries et al. [9] in their systematic review. The reason used to explain this was the belief that such patients were not able to use self-report instruments [19-21]. In two studies, the patients were screened using the AbilityQ instrument to assess their capacity to respond to questionnaires with acceptable accuracy [23, 27]. None of the studies addressed other communication problems that may occur in patients with stroke, such as verbal apraxia.

Pain instruments

Overall, most papers featured unidimensional instruments. The systematic review by de Vries et al. [9] noted that a unidimensional VAS existed in several variations, including a horizontal, vertical, and mechanical VAS [9]. Horizontal and vertical VAS were defined as 10-cm lines with pain descriptors at both extremes representing "no pain" and "worst imaginable pain," and the mechanical VAS consisted of a laminated or plastic scale with a sliding marker [9]. Similarly, the ShoulderQ contained three vertical VAS, with a word descriptor at the lowest and highest ends expressing "No pain at all" (0) and "Pain as bad as it could be" (10), respectively [23, 27]. In addition, the ShoulderQ contained numerals 0 to 10 placed at 1-cm intervals [23, 27]. In contrast, de Vries et al. [9] considered NRS instruments ranging from 0 to 10, or 0 to 100. The scale could also be administered verbally, in which case it did not require the use of paper and pencil. A unidimensional 0 to 10 NRS was used in one study [25].

In another study, the 0 to 10 NRS was supplemented by a verbal no-pain-to-severe-pain scale as part of the multidimensional ESAS [26]. The ESAS included an item concerning the presence of other stroke-related symptoms without specifying what these symptoms could be. Similarly, in two studies, neither of the unidimensional pain intensity instruments (the NRS [22, 24] or the FPS [24] were specified. The FPS was also mentioned by de Vries et al. [9], who described it as an instrument containing seven photographs of facial expressions. The ShoulderQ was a multi-dimensional instrument with two variations: apart from the mentioned VAS, it contained either eight [23, 27] or ten verbal questions. The two extra questions in the longer version sought to elicit patient information about tasks associated with pain and about pain-relieving strategies. Two instruments were used to assess health-related quality of life, including pain: the NHP [19, 21] and the COOP/ WONCA [21]. The NHP had two versions: the Turkish version [19] the English version [21]. Gokkaya et al. [19] noted that the section of the instrument dealing with pain contained eight questions; however, the questions were not described.

Regarding the pain instruments used, given the previously mentioned potential problems with pro- viding self-report by stroke patients with communication difficulties, Allison [20] identified strategies that could be used to enable patients with aphasia to engage in pain self-report. These included using instruments that provided information in several formats and that contained pictures. For this reason, based on feedback obtained from clinicians and patients with stroke, Allison [20] developed and employed a simple yes/no scale accompanied by a pictographic cue (Appendix IV). Furthermore, a series of pictograms was contained in the multidimensional COOP/WONCA instrument that measured health-related quality of life, including pain, using five-point Likert scales [21]. In one study, if the patient could not communicate, patient self-report was replaced by the observation of behavioral and physiologic parameters indicative of the presence of pain [22].

The papers included in this scoping review were mainly of European origin. One limitation is that although half of the studies were from countries where English is not the official language, it is not clear whether the described instruments were translated into local languages, apart from the NHP, which contains 38 dichotomous propositions and was used in its Turkish version [19]. Translation issues can arise, especially if the instruments contain text, such as the ESAS, which was used in Switzerland and may have been used in any of the official languages of this country. Since its development in 1991, the ESAS has been translated into more than 20 languages and has been linguistically and psychometrically validated in studies conducted in various European and Asian countries [28]. Nevertheless, the instrument was initially developed for use with cancer patients, and its validity and reliability in patients with stroke have not been tested.

Discussion

The papers included in this review focused on patients who have had a completed stroke; no patients had a TIA. As patients with a TIA exhibit the same symptoms as patients with a completed stroke (i.e., they may have pain and may be hospitalized), it is recommended that future studies address this research gap. Furthermore, studies focusing on patients with stroke-related communication problems other than aphasia and dysarthria (e.g., with verbal apraxia) are needed.

One concern that affected most studies was that stroke patients with severe communication problems may not be able to use self-report instruments. The included studies used various approaches to determine whether patient communication problems were so severe that they would not be able to complete the self-report pain instrument. In some studies, patients with severe stroke underwent testing using some of the standardized tests, such as the National Institutes of Health Stroke Scale [22, 24, 25] or the Token Test [21]. In two studies, patients completed the AbilityQ, a hypothetical questionnaire providing information concerning the patient's ability to complete questionnaires and scales [23, 27]. In two studies, visual cues accompanied the pain instruments: the COOP/WONCA [21] and the instrument in Allison's study [20]. Similar efforts were

documented in other studies that involve stroke patients. Mandysova and Herr [29] used the Czech version of the Iowa Pain Thermometer-Revised, a vertical pain instrument accompanied by a visual cue, a graduated thermometer. However, it remains unclear to what extent the visual cues contribute to proper instrument use. In other studies, patients with severe stroke were excluded a priori [19-21]. This was also noted in the systematic review by de Vries et al. [9], who recommended future research using observational pain instruments, such as the Pain Assessment IN Advanced Dementia or the Pain Assessment Check- list for Seniors with Limited Ability to Communicate (PACSLAC), in situations in which the patients cannot communicate due to severe aphasia.

Of the ten studies reviewed by De Vries et al. [9], two were included in this scoping review: Mazzocato et al. [26] and Smith et al. [24]. Of the two primary studies published after the systematic review of De Vries et al. [9] that were included in this scoping review, only one study followed their recommendations and examined an observational pain instrument, the PACSLAC, together with a self-report instrument, the NRS [25]. However, none of the patients were able to complete the NRS.

One potential problem regarding instrument analysis is that there were some inconsistencies in the instruments (e.g., the ShoulderQ existed in two variations; [23, 27], making comparisons across studies difficult.

Research concerning the use of self-report pain instruments in stroke patients with communication problems has, to date, only been conducted in the USA and Europe. Given the worldwide incidence and prevalence of stroke, primary research is urgently needed in other parts of the world. For this reason, attention should be devoted to the translation of instruments into other languages. It would be especially valuable to translate multidimensional pain instruments, such as the ShoulderQ and the NHP, as these tools enable a more thorough assessment of pain than unidimensional instruments.

Finally, most studies used a descriptive design, which does not enable causal relationships to be studied. Conversely, a randomized controlled trial is considered the ideal scientific study design as it enables the prediction of cause-and-effect relations; only one included study used this design [25].

Limitations of the review

The databases were not searched on the same date (some in July 2020 and others in August 2020). It is possible that additional articles would have been identified if all the databases had been searched in August 2020. Another limitation is that we could not access two studies despite contacting the authors; therefore, we had to exclude these studies.

Conclusions

This scoping review aimed to answer the following 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 pro- duction? It is clear that over the time the included studies were conducted, various unidimensional and multidimensional self-report instruments have been used, most of which have been used with other patient populations as well. Most studies commented that stroke patients with severe communication problems may not be able to use self-report instruments. Therefore, in some studies, patients with severe aphasia were excluded, and the instruments that were used contained visual cues.

Implications for research

Based on this scoping review, it is evident that further research is needed concerning the use of self-report pain instruments in stroke patients with communication problems. In addition to descriptive studies addressing the gaps in the knowledge, another strategy that may prove highly effective is experimental research with a robust randomized controlled trial design. Such research should aim to examine the effects of painful procedures on the perceived pain in patients with stroke-related communication problems.

Stronger recommendations for practice can be made once the gaps in knowledge are addressed. Ultimately, appropriate pain assessment, as early as in the acute phase of the stroke while the patient is hospitalized, could more effectively support proper pain management as well as patient engagement in rehabilitation and could contribute to faster recovery.

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References

1. John Hopkins Medicine. [Types-of-stroke] [internet]. The Hopkins Universiy; 2021 [cited 2021 Nov 16]. Available from: https://www.hopkinsmedicine.org/health/conditions-and-diseases/stroke/types-of-stroke.
2. Katan, M. and A. Luft, *Global Burden of Stroke*. Semin Neurol, 2018. **38**(2): p. 208-211.
3. Mc Sharry, J., et al., *Delay in Seeking Medical Help following Transient Ischemic Attack (TIA) or "Mini-Stroke": A Qualitative Study*. Plos One, 2014. **9**(8).
4. Treister, A.K., et al., *Demystifying Poststroke Pain: From Etiology to Treatment*. PM R, 2017. **9**(1): p. 63-75.
5. International Association for the Study of Pain. Pain [internet]. Washington, DC: International Association for the Study of Pain; 2018 [cited 2020 Dec 19]. Available from: https://www.iasp-pain.org/PublicationsNews/NewsDetail.aspx?ItemNumber=9218
6. Klit, H., N.B. Finnerup, and T.S. Jensen, *Central post-stroke pain: clinical characteristics, pathophysiology, and management*. Lancet Neurol, 2009. **8**(9): p. 857-68.
7. Park, J., *A study on the sleep quality, pain, and instrumental activities of daily living of outpatients with chronic stroke*. J Phys Ther Sci, 2019. **31**(2): p. 149-152.
8. Delpont, B., et al., *Pain after stroke: A review*. Rev Neurol (Paris), 2018. **174**(10): p. 671-674.
9. de Vries, N.J., P.H. Sloot, and W.P. Achterberg, *Pain and pain assessment in stroke patients with aphasia: a systematic review*. Aphasiology, 2016. **31**(6): p. 703-719.
10. Brady, M.C., et al., *Speech and language therapy for aphasia following stroke*. Cochrane Database Syst Rev, 2016. **2016**(6): p. CD000425.
11. Mitchell, C., et al., *Interventions for dysarthria due to stroke and other adult-acquired, non-progressive brain injury*. Cochrane Database of Systematic Reviews, 2017(1).
12. New, A.B., et al., *Altered resting-state network connectivity in stroke patients with and without apraxia of speech*. Neuroimage-Clinical, 2015. **8**: p. 429-439.
13. Clark, C.W., et al., *Unidimensional pain rating scales: a multidimensional affect and pain survey (MAPS) analysis of what they really measure*. Pain, 2002. **98**(3): p. 241-247.
14. Edwards, S.A., et al., *Properties of Pain Assessment Tools for Use in People Living With Stroke: Systematic Review*. Front Neurol, 2020. **11**: p. 792.
15. Peters MDJ, G.C., McInerney P, Munn Z, Tricco AC, Khalil, H. . *Chapter 11: Scoping Reviews. JBI Manual for Evidence Synthesis* 2020 22 December 2020]; Available from: https://doi.org/10.46658/JBIMES-20-12.
16. Mandysova, P., et al., *Assessment instruments used for the self-report of pain by hospitalized stroke patients with communication problems: a scoping review protocol*. JBI Evid Synth, 2020. **18**(8): p. 1731-1737.
17. Munn, Z., 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): p. 36-43.
18. Page, M.J., et al., *The PRISMA 2020 statement: an updated guideline for reporting systematic reviews*. BMJ, 2021. **372**: p. n71.
19. Gokkaya, N.K., M.D. Aras, and A. Cakci, *Health-related quality of life of Turkish stroke survivors*. Int J Rehabil Res, 2005. **28**(3): p. 229-35.

20. Allison, R., *Developing a longitudinal profile of the consequences of the profoundly-affected arm after stroke: a feasibility study*. 2013, University of Exeter: Available from the Open Access Theses and Dissertations database.

21. van Bragt, P.J., et al., *Predicting outcome in a postacute stroke rehabilitation programme*. Int J Rehabil Res, 2014. **37**(2): p. 110-7.

22. Schuster, J., et al., *Use of analgesics in acute stroke patients with inability to self-report pain: a retrospective cohort study*. BMC Neurol, 2020. **20**(1).

23. Turner-Stokes, L. and D. Jackson, *Assessment of shoulder pain in hemiplegia: sensitivity of the ShoulderQ*. Disabil Rehabil, 2006. **28**(6): p. 389-95.

24. Smith, J.H., et al., *Inability to self-report pain after a stroke: a population-based study*. Pain, 2013. **154**(8): p. 1281-6.

25. Soares, C.D., et al., *Experimental pain assessment in patients with poststroke aphasia*. Neurology, 2018. **91**(9): p. e793-e799.

26. Mazzocato, C., et al., *The last days of dying stroke patients referred to a palliative care consult team in an acute hospital*. Eur J Neurol, 2010. **17**(1): p. 73-7.

27. Turner-Stokes, L. and S. Rusconi, *Screening for ability to complete a questionnaire: a preliminary evaluation of the AbilityQ and ShoulderQ for assessing shoulder pain in stroke patients*. Clin Rehabil, 2003. **17**(2): p. 150-7.

28. Hui, D. and E. Bruera, *The Edmonton Symptom Assessment System 25 Years Later: Past, Present, and Future Developments*. J Pain Symptom Manage, 2017. **53**(3): p. 630-643.

29. Mandysova, P. and K. Herr, *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): p. 55-64.

Appendix I: Search strategy

PubMed (NLM)

Search conducted on July 21, 2020.

Search	Query	Records retrieved
#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 haemor- rhage"[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]	420,343
#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 "communi- cation 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]	77,801
#3	"pain"[Mesh] OR "pain*"[Ti/Ab] OR "central post-stroke pain*"[Ti/Ab] OR "complex regional pain*"[Ti/Ab] OR "head- ache"[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]	968,217
#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]	7,762,899
#5	#1 AND #2 AND #3 AND #4	122

Embase (Ovid)

Search conducted on July 24, 2020.

Search	Query	Records retrieved
#1	"cerebrovascular accident"/exp 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	571,703
#2	"aphasia"/exp 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 disorder"/exp 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	83,739

Nursing@Ovid

Search conducted on August 21, 2020.

Search	Query	Records retrieved
#1	"stroke".dw. or "stroke*".ab. or "CVA*".ab. or "cerebrovascular accident*". ab. or "cerebrovascular stroke*".ab. or "brain vascular accident*".ab. or "CNS infarction*".ab. or "CNS infarct*".ab. or "cerebral hemorrhage".ab. or "cerebral haemorrhage".ab. or "intracerebral hemorrhage".ab. or "intracerebral haemorrhage".ab. or "cerebral infarction*".ab. or "cerebral infarct*".ab. or "subarachnoid hemorrhage".ab. or "subarachnoid haemorrhage".ab. or "cerebral thrombosis".ab. or "cerebral venous thrombosis".ab. or "transient ischemic attack*".ab. or "transient ischaemic attack*".ab. or "TIA*".ab.	13,154
#2	"aphasia".dw. or "aphasia*".ab. or "aphatic*".ab. or "alogia".ab. or "anepia". ab. or "dyshasia*".ab. or "dysphatic".ab. or "agrammatism*".ab. or "agrammatic*".ab. or "communication disorders".dw. or "communication disorder*".ab. or "communica- tion problem*".ab. or "communicative problem*".ab. or "communication disability".ab. or "communication disabilities".ab. or "communicative dysfunction*".ab. or "communication dysfunction*".ab. or "speech disorder*".ab. or "language disorder*".ab. or "verbal apraxia*".ab. or "verbal problem*".ab. or "verbal dyspraxia*". ab. or "oral apraxia*".ab. or "oral dyspraxia*".ab. or "oral problem*".ab. or "phonation problem*".ab. or "phonatic problem*".ab.	1173
#3	"pain".dw. or "pain*".ab. or "central post-stroke pain*".ab. or "complex regional pain*".ab. or "headache".dw. or "headache*". ab. or "neuralgia".dw. or "neuralgia*".ab. or "neuralgic*".ab. or "neuralgetic*".ab. or "neuropathic pain*".ab. or "central pain*". ab.	62,959
#4	"pain measurement".dw. or "pain measurement*".ab. or "instrument*".ab. or "measure*".ab. or "tool*".ab. or "scale*".ab. or "questionnaire*".ab. or "assess*".ab. or "score*".ab. or "thermometer*".ab.	264,604
#5	#1 and #2	192
#6	#3 and #5	15
#7	#4 and #6	9

CINAHL (EBSCO)

Search conducted on July 24, 2020.

Search	Query	Records retrieved
S1	MW "stroke" OR AB "stroke*" OR AB "CVA*" OR AB "cerebrovascular accident*" OR AB "cerebrovascular stroke*" OR AB "brain vascular accident*" OR AB "CNS infarction*" OR AB "CNS infarct*" OR AB "cerebral hemorrhage" OR AB "cerebral haemorrhage" OR AB "intracerebral hemorrhage" OR AB "intracerebral haemorrhage"	87,618
S2	TI "stroke*" OR TI "CVA*" OR TI "cerebrovascular accident*" OR TI "cerebrovascular stroke*" OR TI "brain vascular accident*" OR TI "CNS infarction*" OR TI "CNS infarct*" OR TI "cerebral hemorrhage" OR TI "cerebral haemorrhage" OR TI "intracerebral hemorrhage" OR TI "intracerebral haemorrhage"	44,897
S3	AB "cerebral infarction*" OR AB "cerebral infarct*" OR AB "subarachnoid hemorrhage" OR AB "subarachnoid haemorrhage" OR AB "cerebral thrombosis" OR AB "cerebral venous thrombosis" OR AB "transient ischemic attack*" OR AB "transient ischaemic attack*" OR AB "TIA*"	10,487
S4	TI "cerebral infarction*" OR TI "cerebral infarct*" OR TI "subarachnoid hemorrhage" OR TI "subarachnoid haemorrhage" OR TI "cerebral thrombosis" OR TI "cerebral venous thrombosis" OR TI "transient ischemic attack*" OR TI "transient ischaemic attack*" OR TI "TIA*"	5702
S5	S1 OR S2 OR S3 OR S4	99,288
S6	MW "aphasia" OR AB "aphasia*" OR AB "aphatic*" OR AB "alogia" OR AB anepia" OR AB "dysphasia*" OR AB "dysphatic" OR AB "agrammatism*" OR AB "agrammatic*" OR MW "communication disorders" OR AB "communication disorder*" OR AB "communication problem*"	6659
S7	TI "aphasia*" OR TI "aphatic*" OR TI "alogia" OR TI anepia" OR TI "dysphasia*" OR TI "dysphatic" OR TI "agrammatism*" OR TI "agrammatic*" OR TI "communication disorder*" OR TI "communication problem*"	3179
S8	AB "communicative problem*" OR AB "communication disability" OR AB "communication disabilities" OR AB "communicative dysfunction*" OR AB "communication dysfunction*" OR AB "speech disorder*" OR AB "language disorder*" OR AB "verbal apraxia*" OR AB "verbal problem*" OR AB "verbal dyspraxia*" OR AB "oral apraxia*" OR AB "oral dyspraxia*"	1519
S9	TI "communicative problem*" OR TI "communication disability" OR TI "communication disabilities" OR TI "communicative dysfunction*" OR TI "communication dysfunction*" OR TI "speech disorder*" OR TI "language disorder*" OR TI "verbal apraxia*" OR TI "verbal problem*" OR TI "verbal dyspraxia*" OR TI "oral apraxia*" OR TI "oral dyspraxia*"	572

(Continued)

Search	Query	Records retrieved
S10	AB "oral problem*" OR AB "phonation problem*" OR AB "phonetic problem*" OR TI "oral problem*" OR TI "phonation problem*" OR TI "phonatic problem*"	100
S11	S6 OR S7 OR S8 OR S9 OR S10	8507
S12	MW "pain" OR AB "pain*" OR AB "central poststroke pain*" OR AB "complex regional pain*" OR MW "headache" OR AB "headache*" OR MW "neuralgia" OR AB "neuralgia*" OR AB "neuralgic*" OR AB "neuralgetic*" OR AB "neuropathic pain*" OR AB "central pain*"	220,171
S13	TI "pain*" OR TI "central post-stroke pain*" OR TI "complex regional pain*" OR TI "headache*" OR TI "neuralgia*" OR TI "neuralgic*" OR TI "neuralgetic*" OR TI "neuropathic pain*" OR TI "central pain*"	83,721
S14	S12 OR S13	230,106
S15	MW "pain measurement" OR AB "pain measurement*" OR AB "instrument*" OR AB measure*" OR AB "tool*" OR AB "scale*" OR AB "questionnaire*" OR AB "assess*" OR AB "score*" OR AB "thermometer*"	1,095,107
S16	AB "pain measurement*" OR AB "instrument*" OR AB measure*" OR AB "tool*" OR AB "scale*" OR AB "questionnaire*" OR AB "assess*" OR AB "score*" OR AB "thermometer*"	1,082,444
S17	S15 OR S16	1,095,107
S18	S5 AND S11 AND S14 AND S17	26

- *Cochrane Library (Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials)*

Search conducted on August 22, 2020.

Search	Query	Records retrieved
#1	MeSH descriptor: [Stroke]	9568
#2	(“stroke*”):ti,ab,kw	53,648
#3	(“CVA*”):ti,ab,kw	508
#4	(“cerebrovascular accident*”):ti,ab,kw	12,024
#5	(“cerebrovascular stroke*”):ti,ab,kw	29
#6	(“brain vascular accident*”):ti,ab,kw	0
#7	(“CNS infarction*”):ti,ab,kw	1
#8	(“CNS infarct*”):ti,ab,kw	0
#9	(“cerebral hemorrhage”):ti,ab,kw	1811
#10	(“cerebral haemorrhage”):ti,ab,kw	1811
#11	(“intracerebral hemorrhage”):ti,ab,kw	2080
#12	(“intracerebral haemorrhage”):ti,ab,kw	2080
#13	(“cerebral infarction*”):ti,ab,kw	3354
#14	(“cerebral infarct*”):ti,ab,kw	174
#15	(“subarachnoid hemorrhage”):ti,ab,kw	1906
#16	(“subarachnoid haemorrhage”):ti,ab,kw	1906
#17	(“cerebral thrombosis”):ti,ab,kw	132
#18	(“cerebral venous thrombosis”):ti,ab,kw	59
#19	(“transient ischemic attack*”):ti,ab,kw	2581
#20	(“transient ischaemic attack*”):ti,ab,kw	2580
#21	(“TIA*”):ti,ab,kw	1685
#22	[30-#21]	62,153
#23	MeSH descriptor: [Aphasia]	421
#24	(“aphasia*”):ti,ab,kw	1570
#25	(“aphatic*”):ti,ab,kw	2
#26	(“alogia”):ti,ab,kw	50

(Continued)

Search	Query	Records retrieved
#27	(“anepia”):ti,ab,kw	3
#28	(“dysphasia*”):ti,ab,kw	128
#29	(“dysphatic”):ti,ab,kw	0
#30	(“agrammatism*”):ti,ab,kw	3
#31	(“agrammatic*”):ti,ab,kw	16
#32	MeSH descriptor: [Communication Disorders]	1706
#33	(“communication disorder*”):ti,ab,kw	136
#34	(“communication problem*”):ti,ab,kw	45
#35	(“communicative problem*”):ti,ab,kw	2
#36	(“communication disability”):ti,ab,kw	8
#37	(“communication disabiiities”):ti,abzkw	1
#38	(“communicative dysfunction*”):ti,ab,kw	1
#39	(“communication dysfunction*”):ti,ab,kw	1
#40	(“speech disorder*”):ti,ab,kw	273
#41	(“language disorder*”):ti,ab,kw	73
#42	(“verbal apraxia*”):ti,ab,kw	2
#43	(“verbal problem”):ti,ab,kw	9
#44	(“verbal dyspraxia*”):ti,ab,kw	0
#45	(“oral apraxia*”):ti,ab,kw	1
#46	(“oral dyspraxia*”):ti,ab,kw	0
#47	(“oral problem*”):ti,ab,kw	5
#48	(“phonation problem*”):ti,ab,kw	0
#49	(“phonatic problem*”):ti,ab,kw	0
#50	[31-#49]	3435
#51	MeSH descriptor: [Pain]	48,548
#52	(“pain*”):ti,ab,kw	174,555

(Continued)

Search	Query	Records retrieved
#53	(“central post-stroke pain*”):ti,ab,kw	37
#54	(“complex regional pain*”):ti,ab,kw	548
#55	MeSH descriptor: [Headache]	2358
#56	(“headache*”):ti,ab,kw	30,175
#57	MeSH descriptor: [Neuralgia]	1627
#58	(“neuralgia*”):ti,ab,kw	2776
#59	(“neuralgic*”):ti,ab,kw	20
#60	(“neuralgetic*”):ti,ab,kw	0
#61	(“neuropathic pain*”):ti,ab,kw	3211
#62	(“central pain*”):ti,ab,kw	271
#63	{OR #51-#62}	197,191
#64	MeSH descriptor: [Pain Measurement]	21,082
#65	(“pain measurement*”):ti,ab,kw	22,379
#66	(“instrument*”):ti,ab,kw	10,336
#67	(“measure*”):ti,ab,kw	72,641
#68	(“tool*”):ti,ab,kw	23,192
#69	(“scale*”):ti,ab,kw	165,079
#70	(“questionnaire *”):ti,ab,kw	94,560
#71	(“assess*”):ti,ab,kw	152,681
#72	(“score*”):ti,ab,kw	158,559
#73	(“thermometer*”):ti,ab,kw	937
#74	{OR #64-#73}	480,098
#75	#22 AND #50	1042
#76	#75 AND #63	59
#77	#76 AND #74	42
#78	#22 AND #50 AND #63 AND #74	42

Web of Science

Search conducted on July 26, 2020.

Search	Query	Records retrieved
#1	AB ¼ (“cerebrovascular accident*” OR “stroke*” OR “cerebrovascular stroke*” OR “brain vascular accident*” OR “CNS infarction*” OR “CNS infarct*” OR “cerebral hemorrhage” OR “cerebral haemorrhage” OR “intracerebral hemorrhage” OR “intracerebral haemorrhage” OR “cerebral infarction*” OR “cerebral infarct*” OR “subarachnoid hemorrhage” OR “subarach- noid haemorrhage” OR “cerebral thrombosis” OR “cerebral venous thrombosis” OR “transient ischemic attack*” OR “transient ischaemic attack*”)	229,648
#2	TI ¼ (“cerebrovascular accident*” OR “stroke*” OR “cerebrovascular stroke*” OR “brain vascular accident*” OR “CNS infarction*” OR “CNS infarct*” OR “cerebral hemorrhage” OR “cerebral haemorrhage” OR “intracerebral hemorrhage” OR “intracerebral haemorrhage” OR “cerebral infarction*” OR “cerebral infarct*” OR “subarachnoid hemorrhage” OR “subarach- noid haemorrhage” OR “cerebral thrombosis” OR “cerebral venous thrombosis” OR “transient ischemic attack*” OR “transient ischaemic attack*”)	173,813
#3	#2 OR #1	316,585
#4	AB ¼ (“aphasia*” OR “aphatic*” OR “alogia” OR “anepia” OR “dysphasia*” OR “dysphatic” OR “agrammatism*” OR “agrammatic*” OR “communication disorder*” OR “communication problem*” OR “communicative problem*” OR “communica- tion disability” OR “communication disabilities” OR “communicative dysfunction*” OR “communication dysfunction*” OR “speech disorder*” OR “language disorder*” OR “verbal apraxia*” OR “verbal problem*” OR “verbal dyspraxia*” OR “oral apraxia*” OR “oral dyspraxia*” OR “oral problem*” OR “phonation problem*” OR “phonatic problem*”)	17,415
#5	TI ¼ (“aphasia*” OR “aphatic*” OR “alogia” OR “anepia” OR “dysphasia*” OR “dysphatic” OR “agrammatism*” OR “agrammatic*” OR “communication disorder*” OR “communication problem*” OR “communicative problem*” OR “communica- tion disability” OR “communication disabilities” OR “communicative dysfunction*” OR “communication dysfunction*” OR “speech disorder*” OR “language disorder*” OR “verbal apraxia*” OR “verbal problem*” OR “verbal dyspraxia*” OR “oral apraxia*” OR “oral dyspraxia*” OR “oral problem*” OR “phonation problem*” OR “phonatic problem*”)	12,369

(Continued)

Search	Query	Records retrieved
#6	#4 OR #5	24,013
#7	AB ¼ (“pain*” OR “central post-stroke pain*” OR “complex regional pain*” OR “headache*” OR “neuralgia*” OR “neuralgic*” OR “neuralgetic*” OR “neuropathic pain*” OR “central pain*”)	563,261
#8	TI ¼ (“pain*” OR “central post-stroke pain*” OR “complex regional pain*” OR “headache*” OR “neuralgia*” OR “neuralgic*” OR “neuralgetic*” OR “neuropathic pain*” OR “central pain*”)	296,373
#9	#7 OR #8	722,295
#10	AB ¼ (“pain measurement*” OR “instrument*” OR “measure*” OR “tool*” OR “scale*” OR “questionnaire*” OR “assess*” OR “score**” OR “thermometer*”)	9,942,604
#11	TI ¼ (“pain measurement*” OR “instrument*” OR “measure*” OR “tool*” OR “scale*” OR “questionnaire*” OR “assess*” OR “score**” OR “thermometer*”)	2,056,562
#12	#10 OR #11	10,920,331
#13	#3 AND #6	3742
#14	#9 AND #13	229
#15	#12 AND #14	58

Scopus

Search conducted on August 22, 2020.

Search	Query	Records retrieved
#1	TITLE-ABS (“stroke*”) OR TITLE-ABS (“CVA*”) OR TITLE ABS (“cerebrovascular accident*”) OR TITLE-ABS (“cerebrovascular stroke*”) OR TITLE ABS (“brain vascular accident*”) OR TITLE ABS (“CNS infarction*”) OR TITLE ABS (“CNS infarct*”) OR TITLE ABS (“cerebral hemorrhage”) OR TITLE ABS (“cerebral haemorrhage”) OR TITLE ABS (“intracerebral hemorrhage”) OR TITLE ABS (“intracerebral haemorrhage”) OR TITLE ABS (“cerebral infarction*”) OR TITLE ABS (“cerebral infarct*”) OR TITLE ABS (“subarachnoid hemorrhage”) OR TITLE ABS (“subarachnoid haemorrhage”) OR TITLE ABS (“cerebral thrombosis”) OR TITLE ABS (“cerebral venous thrombosis”) OR TITLE ABS (“transient ischemic attack*”) OR TITLE ABS (“transient ischaemic attack*”) OR TITLE ABS (“TIA*”)	20
#2	TITLE-ABS-KEY (“aphasia*”) OR TITLE-ABS-KEY (“aphatic*”) OR TITLE-ABS-KEY (“alogia”) OR TITLE-ABS-KEY (“anepia”) OR TITLE-ABS-KEY (“dysphasia*”) OR TITLE-ABS-KEY (“dysphatic”) OR TITLE-ABS-KEY (“agrammatism*”) OR TITLE-ABS-KEY (“agrammatic*”) OR TITLE-ABS-KEY (“communication disorder*”) OR TITLE-ABS-KEY (“communication problem*”) OR TITLE-ABS-KEY (“communi- cative problem*”) OR TITLE-ABS-KEY (“communication disability”) OR TITLE- ABS-KEY (“communication disabilities”) OR TITLE- ABS-KEY (“communicative dysfunction*”) OR TITLE-ABS-KEY (“communication dysfunction*”) OR TITLE-ABS-KEY (“speech disorder*”) OR TITLE-ABS-KEY (“language disorder*”) OR TITLE-ABS-KEY (“verbal apraxia*”) OR TITLE- ABS-KEY (“verbal problem*”) OR TITLE-ABS-KEY (“verbal dyspraxia*”) OR TITLE-ABS-KEY (“oral apraxia*”) OR TITLE-ABS-KEY (“oral dyspraxia*”) OR TITLE-ABS-KEY (“oral problem*”) OR TITLE-ABS-KEY (“phonation problem*”) OR TITLE-ABS-KEY (“phonatic problem*”)	83,875
#3	TITLE-ABS-KEY (“pain*”) OR TITLE-ABS-KEY (“central post-stroke pain*”) OR TITLE-ABS-KEY (“complex regional pain*”) OR TITLE- ABS-KEY (“headache*”) OR TITLE-ABS-KEY (“neuralgia*”) OR TITLE-ABS-KEY (“neuralgic*”) OR TITLE-ABS-KEY (“neuralgetic*”) OR TITLE-ABS-KEY (“neuropathic pain*”) OR TITLE-ABS-KEY (“central pain*”)	1,516,775
#4	TITLE-ABS-KEY (“pain measurement*”) OR TITLE-ABS-KEY (“instrument*”) OR TITLE-ABS- KEY (“measure*”) OR TITLE-ABS-KEY (“tool*”) OR TITLE-ABS-KEY (“scale*”) OR TITLE-ABS- KEY (“questionnaire*”) OR TITLE-ABS-KEY (“assess*”) OR TITLE-ABS-KEY (“score**”) OR TITLE-ABS-KEY (“thermometer*”)	19,314,809

Scopus

Search conducted on August 22, 2020.

Search	Query	Records retrieved
#1	TITLE-ABS (“stroke*”) OR TITLE-ABS (“CVA*”) OR TITLE ABS (“cerebrovascular accident*”) OR TITLE-ABS (“cerebrovascular stroke*”) OR TITLE ABS (“brain vascular accident*”) OR TITLE ABS (“CNS infarction*”) OR TITLE ABS (“CNS infarct*”) OR TITLE ABS (“cerebral hemorrhage”) OR TITLE ABS (“cerebral haemorrhage”) OR TITLE ABS (“intracerebral hemorrhage”) OR TITLE ABS (“intracerebral haemorrhage”) OR TITLE ABS (“cerebral infarction*”) OR TITLE ABS (“cerebral infarct*”) OR TITLE ABS (“subarachnoid hemorrhage”) OR TITLE ABS (“subarachnoid haemorrhage”) OR TITLE ABS (“cerebral thrombosis”) OR TITLE ABS (“cerebral venous thrombosis”) OR TITLE ABS (“transient ischemic attack*”) OR TITLE ABS (“transient ischaemic attack*”) OR TITLE ABS (“TIA*”)	20
#2	TITLE-ABS-KEY (“aphasia*”) OR TITLE-ABS-KEY (“aphatic*”) OR TITLE-ABS-KEY (“alogia”) OR TITLE-ABS-KEY (“anepia”) OR TITLE-ABS-KEY (“dysphasia*”) OR TITLE-ABS-KEY (“dysphatic”) OR TITLE-ABS-KEY (“agrammatism*”) OR TITLE-ABS-KEY (“agrammatic*”) OR TITLE-ABS-KEY (“communication disorder*”) OR TITLE-ABS-KEY (“communication problem*”) OR TITLE-ABS-KEY (“communi- cative problem*”) OR TITLE-ABS-KEY (“communication disability”) OR TITLE- ABS-KEY (“communication disabilities”) OR TITLE- ABS-KEY (“communicative dysfunction*”) OR TITLE-ABS-KEY (“communication dysfunction*”) OR TITLE-ABS-KEY (“speech disorder*”) OR TITLE-ABS-KEY (“language disorder*”) OR TITLE-ABS-KEY (“verbal apraxia*”) OR TITLE- ABS-KEY (“verbal problem*”) OR TITLE-ABS-KEY (“verbal dyspraxia*”) OR TITLE-ABS-KEY (“oral apraxia*”) OR TITLE-ABS-KEY (“oral dyspraxia*”) OR TITLE-ABS-KEY (“oral problem*”) OR TITLE-ABS-KEY (“phonation problem*”) OR TITLE-ABS-KEY (“phonatic problem*”)	83,875
#3	TITLE-ABS-KEY (“pain*”) OR TITLE-ABS-KEY (“central post-stroke pain*”) OR TITLE-ABS-KEY (“complex regional pain*”) OR TITLE- ABS-KEY (“headache*”) OR TITLE-ABS-KEY (“neuralgia*”) OR TITLE-ABS-KEY (“neuralgic*”) OR TITLE-ABS-KEY (“neuralgetic*”) OR TITLE-ABS-KEY (“neuropathic pain*”) OR TITLE-ABS-KEY (“central pain*”)	1,516,775
#4	TITLE-ABS-KEY (“pain measurement*”) OR TITLE-ABS-KEY (“instrument*”) OR TITLE-ABS- KEY (“measure*”) OR TITLE-ABS-KEY (“tool*”) OR TITLE-ABS-KEY (“scale*”) OR TITLE-ABS- KEY (“questionnaire*”) OR TITLE-ABS-KEY (“assess*”) OR TITLE-ABS-KEY (“score**”) OR TITLE-ABS-KEY (“thermometer*”)	19,314,809

- *ProQuest Health and Medical Collection and Nursing and Allied Health Database*

Search conducted on August 22, 2020.

Search	Query	Records retrieved
S1	mesh(stroke) OR ab(stroke*) OR ab(CVA*) OR ab("cerebrovascular accident*") OR ab("cerebrovascular stroke*") OR ab("brain vascular accident*") OR ab("CNS infarction*") OR ab("CNS infarct*") OR ab("cerebral hemorrhage") OR ab("cerebral haemorrhage")	162,078
S2	ab("intracerebral hemorrhage") OR ab("intracerebral haemorrhage") OR ab("cerebral infarction*") OR ab("cerebral infarct*") OR ab("subarachnoid hemorrhage") OR ab("subar- achnoid haemorrhage") OR ab("cerebral thrombosis") OR ab("cerebral venous thrombosis")	18,125
S3	ab("transient ischemic attack*") OR ab("transient ischaemic attack*") OR ab(TIA*)	23,494
S4	S1 OR S2 OR S3	189,567
S5	mesh(aphasia) OR ab(aphasia*) OR ab(aphatic*) OR ab(alogia) OR ab(anepia) OR ab(dysphasia*) OR ab(dysphatic) OR ab (agrammatism*) OR ab(agrammatic*) OR mesh (communication disorders)	7205
S6	ab("communication disorder*") OR ab("communication problem*") OR ab("communicative problem*") OR ab("communication disability") OR ab("communication disabilities") OR ab("communicative dysfunction*") OR ab("communication dysfunction*") OR ab("speech disorder*") OR ab("language disorder*") OR ab("verbal apraxia*")	4399
S7	ab("verbal problem*") OR ab("verbal dyspraxia*") OR ab("oral apraxia*") OR ab("oral dyspraxia*") OR ab("oral problem*") OR ab("phonation problem*") OR ab("phonatic problem*")	331
S8	S5 OR S6 OR S7	11,540
S9	mesh(pain) OR ab(pain*) OR ab("central post-stroke pain*") OR ab("complex regional pain*") OR mesh(headache) OR ab (headache*) OR mesh(neuralgia) OR ab(neuralgia*) OR ab(neuralgic*) OR ab(neuralgetic*)	420,630
S10	ab("neuropathic pain*") OR ab("central pain*")	11,554
S11	S9 OR S10	420,630
S12	mesh(pain measurement) OR ab("pain measurement*") OR ab(instrument*) OR ab(measure*) OR ab(tool*) OR ab(scale*) OR ab(questionnaire*) OR ab(assess*) OR ab(score*) AND ab(thermometer*)	3,402,664
S13	S4 AND S8 AND S11 AND S12	40

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Search conducted on August 22, 2020.

Search	Query	Records retrieved
#1	abstract:(stroke* OR CVA* OR "cerebrovascular accident*" OR "cerebrovascular stroke*" OR "brain vascular accident*" OR "CNS infarction*" OR "CNS infarct*" OR "cerebral hemorrhage" OR "cerebral haemorrhage" OR "intracerebral hemorrhage" OR "intracerebral haemorrhage" OR "cerebral infarction*" OR "cerebral infarct*" OR "subarachnoid hemorrhage" OR "subarach- noid haemorrhage" OR "cerebral thrombosis" OR "cerebral venous thrombosis" OR "transient ischemic attack*" OR "transient ischaemic attack*" OR TIA*)	14,333
#2	abstract:(aphasia* OR aphatic* OR alogia OR anepia OR dysphasia* OR dysphatic OR agrammatism* OR agrammatic* OR "communication disorder*" OR "communication problem*" OR "communicative problem*" OR "communication disability" OR "communication disabilities" OR "communicative dysfunction*" OR "communication dysfunction*" OR "speech disorder*" OR "language disorder*" OR "verbal apraxia*" OR "verbal problem*" OR "verbal dyspraxia*" OR "oral apraxia*" OR "oral dyspraxia*" OR "oral problem*" OR "phonation problem*" OR "phonatic problem*")	1701
#3	abstract:(pain* OR "central post-stroke pain*" OR "complex regional pain*" OR headache* OR neuralgia* OR neuralgic* OR neuralgetic* OR "neuropathic pain*" OR "central pain*")	68,764
#4	abstract:("pain measurement*" OR ""instrument* "measure*" OR ""tool* "scale*" OR ""questionnaire* "assess*" OR ""score** "thermometer*")	79
#5	abstract:(stroke* OR CVA* OR "cerebrovascular accident*" OR "cerebrovascular stroke*" OR "brain vascular accident*" OR "CNS infarction*" OR "CNS infarct*" OR "cerebral hemorrhage" OR "cerebral haemorrhage" OR "intracerebral hemorrhage" OR "intracerebral haemorrhage" OR "cerebral infarction*" OR "cerebral infarct*" OR "subarachnoid hemorrhage" OR "subarach- noid haemorrhage" OR "cerebral thrombosis" OR "cerebral venous thrombosis" OR "transient ischemic attack*" OR "transient ischaemic attack*" OR TIA*) AND abstract:(aphasia* OR aphatic* OR alogia OR anepia OR dysphasia* OR dysphatic OR agrammatism* OR agrammatic* OR "communication disorder*" OR "communication problem*" OR "communicative problem*" OR "communication disability" OR "communication disabilities" OR "communicative dysfunction*" OR "communication dysfunction*" OR "speech disorder*" OR "language disorder*" OR "verbal apraxia*" OR "verbal problem*" OR "verbal dyspraxia*" OR "oral apraxia*" OR "oral dyspraxia*" OR "oral problem*" OR "phonation problem*" OR "phonatic problem*") AND abstract:(pain* OR "central poststroke pain*" OR "complex regional pain*" OR headache* OR neuralgia* OR neuralgic* OR neuralgetic* OR "neuropathic pain*" OR "central pain*") AND abstract:("pain measurement*" OR instrument* OR measure* OR tool* OR scale* OR questionnaire* OR assess* OR score* OR thermometer*)	1

Appendix II: Studies ineligible following full text review

1. Alsholm L, Axelsson C, Hagiwara MA, Niva M, Claesson L, Herlitz J, et al. Interrupted transport by the emergency medical service in stroke/transitory ischemic attack: a consequence of changed treatment routines in prehospital emergency care. Brain Behav. 2019;9(5):e01266.
   Reason for exclusion: Ineligible concept (no self-report pain instrument was used); ineligible context (no inpatient care).
2. Amort M, Fluri F, Scha¨ fer J, Weisskopf F, Katan M, Burow A, et al. Transient ischemic attack versus transient ischemic attack mimics: frequency, clinical characteristics and outcome. Cerebrovasc Dis. 2011;32:57-64.
   Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).
3. Arboix A, Garcı´a-Eroles L, Massons J, Oliveres M, Targa C: Hemorrhagic lacunar stroke. Cerebrovasc Dis. 2000;10:229-34.
   Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).
4. Axelsson K, Ahrel K, Fristro¨m A-E, Hallgren L, Nydevik I. Pain among persons living at a nursing home. Vard i Norden 2000;20(2):20-3.
   Reason for exclusion: Ineligible context (no inpatient care).
5. Baier B, Karnath H-O. Incidence and diagnosis of anosognosia for hemiparesis revisited. J Neurol Neurosurg Psychiatry. 2005;76:358-61.
   Reason for exclusion: Ineligible concept (no self-report pain instrument was used).
6. Bohannon RW, Andrews AW. Shoulder subluxation and pain in stroke patients. Am J Occup Ther. 1990;44(6):507-9.
   Reason for exclusion: Ineligible population (participants did not have communication problems); ineligible concept (no self-report pain instrument was used).
7. Bradt J, Magee WL, Dileo C, Wheeler BL, McGilloway E. Music therapy for acquired brain injury. Cochrane Database Syst Rev. 2010;(7):CD006787.
   Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).
8. Brott T, Adams HP Jr, Olinger CP, Marler JR, Barsan WG, Biller J, et al. Measurements of acute cerebral infarction: a clinical examination scale. Stroke. 1989;20(7):864-70.
   Reason for exclusion: Ineligible concept (no self-report pain instrument was used).
9. Buck D, Jacoby A, Massey A, Steen N, Sharma A, Ford GA. Development and validation of NEWSQOL, the Newcastle Stroke-Specific Quality of Life Measure. Cerebrovasc Dis. 2004;17(2-3):143-52.
   Reason for exclusion: Ineligible context (no inpatient care).
10. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer. 2000;88(9):2164-71.
    Reason for exclusion: Ineligible population (no stroke diagnosis; participants did not have Communication problems).

11. Cobley CS, Thomas SA, Lincoln NB, Walker MF. The assessment of low mood in stroke patients with aphasia: reliability and validity of the 10-item Hospital version of the Stroke Aphasic Depression Questionnaire (SADQH-10). Clin Rehabil. 2012;26(4):372-81.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

12. Cruice M, Worrall L, Hickson L. Health-related quality of life in people with aphasia: implications for fluency disorders quality of life research. J Fluency Disord. 2010;35(3):173-89.
Reason for exclusion: Ineligible context (no inpatient care).

13. Daviet JC, Bonan I, Caire JM, Colle F, Damamme L, Froger J, et al. Therapeutic patient education for stroke survivors: non-pharmacological management. Ann Phys Rehabil Med. 2012;55(9-10):641-56.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

14. Dogan SK, Ay S, Oztuna D, Aytur YK, Evcik D. The utility of the Faces Pain Scale in the assessment of shoulder pain in Turkish stroke patients: its relation with quality of life and psychologic status. Int J Rehabil Res. 2010;33(4):363-7.
Reason for exclusion: Ineligible population (participants did not have communication problems).

15. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, Laster LJ. The stroke impact scale version 2.0. Evaluation of reliability, validity, and sensitivity to change. Stroke. 1999;30(10):2131-40.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

16. El Ammar F, Ardelt A, Del Brutto VJ, Loggini A, Bulwa Z, Martinez RC, et al. BE-FAST: a sensitive screening tool to identify in-hospital acute ischemic stroke. J Stroke Cerebrovasc Dis. 2020;29 (7):104821.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

17. English JD, Fields JD, Le S, Singh V. Clinical presentation and long-term outcome of cerebral venous thrombosis. Neurocrit Care. 2009;11(3):330-7.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument); ineligible context (no inpatient care).

18. Faghri PD, Rodgers MM, Glaser RM, Bors JG, Ho C, Akuthota P. The effects of functional electrical stimulation on shoulder subluxation, arm function recovery, and shoulder pain in hemiplegic stroke patients. Arch Phys Med Rehabil. 1994;75(1):73-9.
Reason for exclusion: Ineligible population (participants did not have communication problems); ineligible concept (no self-report pain instrument was used).

19. GalarzaM, Gazzeri R. Cerebral venous sinus thrombosis associated with oral contraceptives: the case for neurosurgery. Neurosurg Focus. 2009;27(5):E5.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

20. Gall SL, Donnan G, Dewey HM, Macdonell R, Sturm J, Gilligan A, et al. Sex differences in presentation, severity, and management of stroke in a population-based study. Neurology. 2010;74(12):975-81.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

21. Greenberg E, Treger J, Ring H. Post-stroke follow-up in a rehabilitation center outpatient clinic. Isr Med Assoc J. 2004;6(10):603-6.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument); ineligible context (no inpatient care).

22. Guillan M, Alonso-Canovas A, Gonzalez-Valcarcel J, Garcia Barragan N, Garcia Caldentey J, Hernandez-Medrano I, et al. Stroke mimics treated with thrombolysis: further evidence on safety and distinctive clinical features. Cerebrovasc Dis. 2012;34(2):115-20.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

23. Halesha BR, Chennaveerappa PK, Vittal BG, Jayashree N. A study of the clinical features and the outcome of cerebral venous sinus thrombosis in a tertiary care centre in South India. J Clin Diagn Res. 2011;5(3):443-47.
Reason for exclusion: Ineligible population (age <18); ineligible concept (authors did not clearly report a self-report pain instrument).

24. HatzitoliosA, Savopoulos C, Ntaios G, Papadidaskalou F, Dimitrakoudi E, Kosmidou M, et al. Stroke and conditions that mimic it: a protocol secures a safe early recognition. Hippokratia. 2008;12(2):98- 102.
Reason for exclusion: Ineligible population (participants did not have communication problems); ineligible concept (authors did not clearly report a self-report pain instrument).

25. Hütter BO, Gilsbach JM, Kreitschmann I. Quality of life and cognitive deficits after subarachnoid haemorrhage. Br J Neurosurg. 1995;9(4):465-75.
Reason for exclusion: Ineligible context (no inpatient care).

26. Jørgensen HS, Nakayama H, Reith J, Raaschou HO, Olsen TS. Factors delaying hospital admission in acute stroke: the Copenhagen Stroke Study. Neurol. 1996;47(2):383-7.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

27. Jørgensen HS, Nakayama H, Reith J, Raaschou HO, Olsen TS. [Pattern of admissions of patients with apoplexy. Time connection between symptom onset and admission and relation to medical and social factors. The Copenhagen Stroke Study]. Ugeskr Laeger. 1998;160(6):827-30. Danish.
Reason for exclusion: Unable to obtain full-text content.

28. Kehayia E, Korner-Bitensky N, Singer F, Becker R, Lamarche M, Georges P, et al. Differences in pain medication use in stroke patients with aphasia and without aphasia. Stroke. 1997;28(10):1867-70.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

29. Ǩiǐic,: Z, Erhan B, Gündüz B, Iska Elvan G. Central post-stroke pain in stroke patients: incidence and the effect on quality of life. Turk J Phys Med Rehab. 2015;61:142-7.
Reason for exclusion: Ineligible population (participants did not have communication problems).

30. Kim SJ, Koh I. The effects of music on pain perception of stroke patients during upper extremity joint exercises. J Music Ther. 2005;42(1):81-92.
Reason for exclusion: Ineligible context (no inpatient care).

31. Korner-Bitensky N, Kehayia E, Tremblay N, Mazer B, Singer F, Tarasuk J. Eliciting information on differential sensation of heat in those with and without poststroke aphasia using a visual analogue scale. Stroke. 2006;37(2):471-5.
Reason for exclusion: Ineligible concept (the self-report instrument was used to assess temperature rather than pain).

32. Lopez-Romero LA, Riano-Carreno DM, Pachon-Poveda MY,Mendoza-Sanchez JA, Leon-Vargas YK, Moreno-Pabon A, et al. [Efficacy and safety of transcranial magnetic stimulation in patients with nonfluent aphasia, following an ischaemic stroke. A controlled, randomised and double-blind clinical trial]. Rev Neurol. 2019;68(6):241-49. Spanish.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

33. Magee WL, Clark I, Tamplin J, Bradt J. Music interventions for acquired brain injury. Cochrane Database Syst Rev. 2017;(1):CD006787.
Reason for exclusion: Ineligible population (age < 18; participants did not have communication problems).

34. Medhi G, Parida S, Nicholson P, Senapati SB, Padhy BP, Pereira VM. Mechanical thrombectomy for cerebral venous sinus thrombosis: a case series and technical note. World Neurosurg. 2020;140:148-61.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

35. Moalla KS, Damak M, Chakroun O, Farhat N, Sakka S, Hdiji O, et al. [Prognostic factors for mortality due to acute arterial stroke in a North African population]. Pan Afr Med J. 2020;35:50. French.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

36. Muresan EM, Gavre A, Lacan SM, Perju-Dumbrava L, Golea A. Emergency management of hemorrhagic stroke. A Romanian perspective on possible future improvements. Clujul Medical 2016;89:S25-29.
Reason for exclusion: Ineligible population (participants did not have communication problems); ineligible concept (no self-report pain instrument was used); ineligible context (no inpatient care).

37. 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.
Reason for exclusion: Ineligible population (authors did not clearly describe age of participants); ineligible concept (no self-report pain instrument was used).

38. Olindo S, Chardonnet M, Renou P, Coignion C, Debruxelles S, Poli M, et al. Clinical predictors of stroke mimics in patients treated with recombinant tissue plasminogen activator according to a normal multimodal computed tomography imaging. J Stroke Cerebrovasc Dis. 2018;27(2):454-9.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

39. Partridge CJ, Edwards SM, Mee R, van Langenberghe HVK. Hemiplegic shoulder pain: a study of two methods of physiotherapy treatment. Clin Rehabil. 1990;4(1):43-9.
Reason for exclusion: Ineligible population (participants did not have communication problems).

40. Philp I, Brainin M, Walker MF, Ward AB, Gillard P, Shields AL, et al., Global Stroke Community Advisory Panel. Development of a poststroke checklist to standardize follow-up care for stroke survivors. J Stroke Cerebrovasc Dis. 2013;22(7):e173-80.
Reason for exclusion: Ineligible population (no stroke participants); ineligible context (no inpatient care).

41. Pomeroy VM, Frames C, Faragher EB, Hesketh A, Hill E, Watson P, et al. Reliability of a measure of post-stroke shoulder pain in patients with and without aphasia and/or unilateral spatial neglect. Clin Rehabil. 2000;14(6):584-91.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

42. Price CI, Curless RH, Rodgers H. Can stroke patients use visual analogue scales? Stroke. 1999;30 (7):1357-61.
Reason for exclusion: Ineligible concept (the self-report instruments were used to assess blood pressure cuff tightness rather than pain).

43. Roy CW, Sands MR, Hill LD. Shoulder pain in acutely admitted hemiplegics. Clin Rehabil. 1994;8 (4):334-40.
Reason for exclusion: Ineligible population (participants did not have communication problems).

44. 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.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument).

45. Sone T, Nakaya N, Iokawa K, Hasegawa K, Tsukada T, Kaneda M, et al. [Prediction of upper limb recovery in the acute phase of cerebrovascular disease: study design and socio-demographic profiles, medical profiles, and acute symptoms of participants at baseline]. Nihon Eiseigaku Zasshi. 2015;70 (1):62-8. Japanese.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

46. Stead TG, Banerjee PR, Ganti L. Large vessel occlusion identification through prehospital Administration of stroke scales: a county-wide emergency medical services prospective research protocol. Cureus 2019;11(10): e5931.
Reason for exclusion: Ineligible context (no inpatient care).

47. Wijdicks EF, Schievink WI, Miller GM. Pretruncal nonaneurysmal subarachnoid hemorrhage. Mayo Clin Proc. 1998;73(8):745-52.
Reason for exclusion: Ineligible population (age < 18; participants did not have communication problems); ineligible concept (authors did not clearly report a self-report pain instrument).

48. Williams LS, Weinberger M, Harris LE, Clark DO, Biller J. Development of a stroke-specific quality of life scale. Stroke. 1999;30(7):1362-9.
Reason for exclusion: Ineligible population (participants did not have communication problems); ineligible concept (no self-report pain instrument was used).

49. Wolf ME, Szabo K, Griebe M, Fo¨ rster A, Gass A, Hennerici MG, et al. Clinical and MRI characteristics of acute migrainous infarction. Neurol. 2011;76(22):1911-17.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

50. Yamada S, Ohnishi H, Takamura Y, Takahashi K, Hayashi M, Kodama Y, et al. Diagnosing intracranial and cervical artery dissection using MRI as the initial modality. J Clin Neurosci. 2016;33:177-81.
Reason for exclusion: Ineligible concept (no self-report pain instrument was used).

51. Yanagida T, Fujimoto S, Inoue T, Suzuki S. Prehospital delay and stroke-related symptoms. Intern Med. 2015;54(2):171-7.
Reason for exclusion: Ineligible concept (authors did not clearly report a self-report pain instrument); ineligible context (no inpatient care).

52. Zhou N, Nan DK. Newly development of evaluation method for stroke. Chinese J Clin Rehabil. 2002;6 (13):1867-8.
Reason for exclusion: Unable to obtain full-text content.

Appendix III: Characteristics of included studies

Study	Country of origin	Study design	Study aim(s)	Population and sample size
Allison (2013)[19]	United Kingdom	Descriptive study - case series	To assess the processes of recruitment and follow-up of stroke patients	Patients with stroke (n ¼ 40); carers (n ¼ 9)
de Vries *et al*. (2017)[9]	The Netherlands	Systematic review	To investigate the prevalence of pain in stroke patients with aphasia and to establish which pain assessment instruments are used	Patients with stroke (n ¼ 1005); controls (n ¼ 162); proxies (n ¼ 30)
Gokkaya *et al*. (2005)[20]	Turkey	Case-control study	To compare health-related quality of life between stroke patients after rehabilitation and a control group	Patients with stroke (n ¼ 60); controls without stroke (n ¼ 58)
Mazzocato *et al*. (2010)[26]	Switzerland	Descriptive study - case series	To assess symptoms of patients referred to a palliative care consult team, and to review their treatment strategies	Patients dying from stroke (n ¼ 42)
Schuster *et al*. (2020)[22]	Germany	Cohort study	To assess the impact of impaired communication in stroke patients on pain assessment and treatment	Patients with stroke (n ¼ 909); patients were assigned to four groups based on their symptoms
Smith *et al*. (2013)[24]	USA	Descriptive study - case series	To assess the ability to selfreport pain after a stroke	Patients with stroke (n ¼ 388)
Soares et al. (2018)[25]	USA	Randomized controlled trial	To evaluate an observational pain instrument among stroke patients with aphasia	Stroke patients with aphasia (n ¼ 36)
Turner-Stokes and Jackson (2006)[23]	United Kingdom	Descriptive study - case series	To assess the sensitivity of the ShoulderQ to clinical improvement in shoulder pain following intervention	Patients with stroke (n ¼ 30)
Turner-Stokes and Rusconi (2003)[27]	United Kingdom	Descriptive study - crosssectional	To explore the repeatability of the ShoulderQ and ability to complete verbal and visual analogue components of the ShoulderQ	Patients with stroke (n ¼ 49)
van Bragt *et al*. (2014)[21]	The Netherlands	Descriptive study - case series	To evaluate outcome of an inpatient stroke rehabilitation program	Patients with stroke (n ¼ 250)

Stroke type	Communication problems	Context	Key findings
Ischemic stroke (90%); hemorrhagic stroke (10%)	Aphasia (35%); dysarthria (40%)	Acute and rehabilitation units	It is possible to recruit a significant number of the target population of people after stroke, even those with signifi cant physical disability.
Ischemic stroke; hemorrhagic stroke	Aphasia	Various settings including hospitals	Various pain assessment instruments were used for assessment of pain in stroke patients with mild to moderate aphasia; pain prevalence ranged from 43.8% to 87.5%.
Ischemic stroke (65%); hemorrhagic stroke (35%)	Dysphasia (50%)	Hospital setting	Improvements in disability in stroke patients were achieved. Stroke patients had a reduced health-related quality of life compared with the control group.
Ischemic stroke; intracerebral hemorrhage	Aphasia (67%)	Palliative care service in a hospital	Dyspnea and pain were the most prevalent symptoms. Most patients had problems with communication due to aphasia or altered level of consciousness.
Not specified	Severe aphasia (19%); severe dysarthria (14%)	Hospital comprehensive stroke unit	Pain is not systematically assessed and is undertreated in patients who are unable to communicate.
Cerebral infarction; intracerebral hemorrhage	Aphasia	Hospital admission records searched	86.6% of patients were able to selfreport pain.
Ischemic stroke	Aphasia (100%)	Hospital comprehensive stroke unit	An observational pain instrument was unable to differentiate patients with pain. Patients were unable to selfreport pain using a numerical rating scale.
Not specified	Communicative deficits	Regional rehabilitation center	Both verbal and visual analogue scales were sensitive to change and differentiated between the responder and non-responder groups.
Ischemic stroke; hemorrhagic stroke	Dysphasia (45%); other communicative deficits (12%)	Regional rehabilitation centers	Repeatability of the ShoulderQ was fair to moderate. A screening tool to assess technical ability to complete a questionnaire identifies those able to respond to the ShoulderQ.
Ischemic stroke (78%); hemorrhagic stroke (22%)	Aphasia (18%)	Rehabilitation center	Significant improvements were found on all outcome measures.

Appendix IV: Self-report pain instruments used in included studies for hospitalized stroke patients with communication problems

Study	Name	Number of items
Allison (2013)[19]	Not specified	1 dichotomous proposition accompanied by a visual cue
de Vries *et al*. (2017)[9]	Horizontal VAS	Horizontal 10-cm line
	Vertical VAS	Vertical 10-cm line
	Mechanical VAS	VAS with a sliding marker
	FPS	7 photographs of facial expressions
	Horizontal VAS	4 words (no pain, mild pain, moderate pain, severe pain)
Gokkaya *et al*. (2005)[20]	Nottingham Health Profile (Turkish version)	38 dichotomous propositions in 6 sections (scores for each section range from 0 ¼ no problem to 100 ¼ all problems listed are present)
Mazzocato *et al*. (2010)[26]	Edmonton Symptom Assessment Scale	10; on a numerical scale (0–10) or a verbal scale (no pain to severe pain)
Schuster *et al*. (2020)[22]	NRS	Not specified
Smith *et al*. (2013)[24]	FPS	Not specified
	NRS	
Soares *et al*. (2018)[25]	NRS	Numbers 0-10
Turner-Stokes and Jackson (2006)[23]	ShoulderQ	10 verbal questions and 3 VAS
Turner-Stokes and Rusconi (2003)[27]	ShoulderQ	8 verbal questions and 3 VAS

a The individual questions were not specified.

b The scale includes the following anchor descriptors: 0 ¼ "no pain at all" and 10 ¼ "pain as bad as it could be."

c Only those who provide an affirmative answer proceed with the rest of the questionnaire.

Purpose	Aspects of pain	Non-pain aspects
Pain presence assessment	Pain presence (yes/no)	None
Pain intensity assessment	Pain intensity	None
Health-related quality of life assessment	Pain (8 questions)[a]	Physical mobility; sleep; emotional reactions; social isolation; energy level.
Symptom assessment of pallia- tive care patients	Pain intensity	Not specified
Pain intensity assessment	Pain intensity	None
Pain intensity assessment	Pain intensity	None
Pain intensity assessment	Pain intensity	None
Shoulder pain assessment	Presence of pain (yes/no); frequency (4 grades); severity (4 grades); better/worse than last week (5 grades); night disturbance (3 grades); nighttime frequency (3 grades); interference with therapy (3 grades); amount of interference (3 grades); severity at rest (vertical 0-10 scale)[b]; severity at night (vertical 0-10 scale)[b]; severity on movement (eg, in physiotherapy; vertical 0-10 scale)[b]; tasks associated with pain (6 tasks); relieving strategies (6 strategies)	None
Shoulder pain assessment	Presence of pain (yes/no)[c]; frequency (4 grades)[a]; severity (4 grades)[a]; better/worse than last week (5 grades)[a]; night disturbance (3 grades)[a]; nighttime frequency (3 grades)[a]; interference with therapy (3 grades)[a]; amount of interference (3 grades)[a]; severity at rest (10-cm vertical VAS); severity at night (10-cm vertical VAS)[a]; severity in physiotherapy (10- cm vertical VAS)[a]	None

(Continued)

Study	Name	Number of items
van Bragt *et al*.(2014)[21]	Nottingham Health Profile	38 dichotomous propositions in 6 domains
	COOP/WONCA	6 domains (5-point scale rating accompanied by pictograms)

COOP/WONCA, The Dartmouth COOP Functional Health Assessment Charts of the World Organization of Family Doctors; FPS, Faces Pain Scale; NRS, numerical rating scale; VAS, visual analogue scale.

Purpose	Aspects of pain	Non-pain aspects
Health-related quality of life assessment	Presence of pain (yes/no)	Energy level; sleep; mobility/physical ability; social isolation; emotional reaction.
	Overall health and pain (no problems to severe problems)	Physical fitness; emotional condition; daily activities; social activities; change in health condition.

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Chapter 3

Pain and pain assessment in stroke patients with aphasia: a systematic review

Keywords:

stroke;
stroke care;
aphasia;
pain;
assessment;
quality of life

Abstract

Background: Persons with aphasia (PWA) after stroke are less able or unable to communicate about their pain due to language, speech and/or cognitive impairment. Most commonly pain rating scales are used for the assessment of pain in PWA, which could not be applied to any patient aphasia because of their inability to communicate verbally their pain.

Aims: This review aims to investigate the prevalence and incidence of pain in PWA after stroke, establish which pain assessment instruments are used, and examine whether they are feasible, valid and reliable. Methods & procedures: A systematic literature search was made to identify studies on pain and pain assessment in PWA and persons without aphasia after stroke, or in patients with right and left hemispheric stroke. The COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) checklist was used to evaluate the methodological quality of the studies and the properties of the measurement scales used.

Outcomes & results: The search yielded ten articles. The vertical, mechanical and horizontal Visual Analogue Scale, Faces Pain Scale, Verbal Rating Scale, Numeric Rating Scale, categorical site-of-pain scale, and a pictorial scale of pain intensity were used to assess pain, as were the Short-Form 36 Health Survey and the Dartmouth COOP Charts Quality of Life Scales that each have one pain item. Prevalence of pain in PWA after stroke was reported in two studies and ranged from 43.8–87.5%. Most studies described pain assessment in PWA after stroke with mild-to-moderate aphasia, while patients with severe aphasia were excluded. Various pain assessment tools were used but their feasibility, validity and reliability were generally of low methodological quality.

Conclusions: A feasible, reliable and valid instrument is not available for PWA after stroke.

Introduction

Stroke survivors experience significant pain, especially headache, shoulder pain, pain from increased muscle stiffness and central post-stroke pain. Post-stroke pain is a chronic neuropathic disorder after lesions in the central somatosensory system. It may occur not only directly after stroke but also years after [1]. Joint pain is equally common in patients with or without post-stroke pain [2]. Shoulder pain and central post-stroke pain are distressing sequelae of stroke, with shoulder pain occurring in 19–74% and central post-stroke pain in 11% of patients [3, 4]. However, pain in persons with aphasia (PWA) after stroke is not well described due to difficulty with self-report assessment and (often) the inability of these patients to describe and communicate their pain [5]. It is unclear if this leads to under identification and under treatment of pain in PWA [6]. Therefore, it is important that clinicians address the presence of pain in aphasia more appropriately. Registering the presence of pain with a self-report scale is particularly challenging in PWA. Self-report pain scales generally require respondents to understand verbal information to understand the instructions of the pain assessment instruments. Therefore, conducting self-report pain scales in patients with severe aphasia is not seldomly suitable because of the inability to understand the instructions to report whether they experience pain or able to rate their pain. For example, the Visual Analogue Scale (VAS) [7] requires patients to point to the position on the line to indicate how much pain they are currently feeling. Similar instructions are provided for the Numeric Rating Scale (NRS) [8] and the Faces Pain Scale (FPS) [9]. A description of traditionally used pain rating scales and their instructions are reported in Table 1. The combination of the inability to communicate pain because of aphasia, and the high prevalence of pain after stroke, suggests a need for adequate assessment of pain in this vulnerable population. Therefore, a systematic review was performed to evaluate the incidence and prevalence of pain among PWA and to establish which pain measurement instruments are being used. The main goal of this review was to examine whether these pain instruments are feasible, reliable and valid in PWA.

Methods

Search

A systematic search guided by the PRISMA guidelines was conducted in June 2015 in the following databases PubMed (Medline), PsychInfo, Chinahl, Embase, Web of Science and Cochrane. Search strategies relevant to the database (using MeSH heading when appropriate) were developed to identify appropriate studies [10]. Search terms included “stroke, cerebrovascular accident”, “aphasia, language, speech or communication disorder” and “pain, ache, pain measurement, pain assessment, pain scale”. Combined MeSH terms and text words for stroke, aphasia and pain are presented in Supplemental Material. Subsequently, relevant articles were included based on a three-step process; (1) screening based on the title, (2) screening based on the abstract and (3) screening based on the full-text of the articles. After screening the titles, all abstracts were read. Full-text was also reviewed, when it was not possible to assess eligibility based on abstract alone. Two reviewers (WA/CDV) independently selected studies based on title

and abstract, and full-text papers were independently scrutinized by two reviewers (PS/CDV). The selected studies were compared and final inclusion was based on consensus between three reviewers (WA/CDV/PS).

Table 1: Pain rating scales

Pain rating scale	Description	Scoring	Author(s)
Horizontal VAS	This VAS is presented as a 10-cm line, whose ends are labelled as the extremes of pain, for example: "no pain" and "worst imaginable pain". The patient is asked to mark the 10-cm line to indicate pain intensity	The distance in centimetre from "no pain" and to the mark made by the patient represents that patient's pain intensity scores	Jensen, et al. (1986) [11]
Vertical VAS	This is a vertical 10-cm line labelled at the bottom with "no pain" and at the top with "worst imaginable pain". The patient is asked to mark the 10-cm line to indicate pain intensity	The distance from "no pain" and to the mark made by the patient represents that patient's pain intensity scores	Scott and Huskisson (1979) [7]
Mechanical VAS	Usually consists of laminated or plastic VAS scales with a sliding marker with which the patient is asked to rate their pain intensity. The side with the sliding marker is facing the patient. The reverse side indicates numerically, usually in millimetres, how far the patient has moved the marker from the "no pain" end towards the "worst imaginable pain". An additional cue, such as graduations of colour from pale pink on "no pain" to dark red on "worst imaginable pain", can be provided	After the patient rates his or her pain, the researcher or clinician examines the other side of the scale to obtain the intensity score	Jensen et al. (1986) [11]
FPS	Horizontal 7-point scale of photographs, line drawings or "smileys" that illustrate facial expressions of persons experiencing different levels of pain severity. Patients select the face that best describes their present state of pain	Face 0 represents "no pain", and face 6 represents "the worst possible pain ever". *NB. Additional FPS tools are available with less or more than 7 faces or smileys*	Wong and Baker (1988) [9]
NRS	The NRS involves asking the patients to rate their pain from 0 to 10 (an 11-point scale) or from 0 to 100 (a 101-point scale). A verbal NRS does not require paper and pencil	The number that is indicated by the patient is the pain intensity score	Jensen et al. (1986) [11]
VRS	Usually lists the adjectives in rank order of pain intensity and assigns each one a score as a function of its rank. The 4 points consist of: "no pain", "mild pain", "moderate pain" and "severe pain"	No pain is given a score of 0, mild pain a score of 1, moderate pain a score of 2 and severe pain a score of 3. NB. Additional VRS tools are available with less or more points to rate the patient's pain	Seymour (1982) [12]

The Categorical site-of-pain scale (shoulder) and the Scale Pain INtensity (SPIN) do not appear in Table 1, because they could not be evaluated using COSMIN. VAS: Visual Analogue Scale; FPS: Faces Pain Scale; NRS: Numeric Rating Scale; VRS: Verbal Rating Scale.

Selection criteria

Studies meeting the following criteria:

- Participants: adult stroke survivors (aged ≥ 18 years) at any stage after stroke and in any setting.
- Participants: PWA or part of a cohort that included PWA and persons without aphasia.
- Intervention and/or outcomes: reported outcomes of pain, pain measurement or pain assessment, or prescribed or used pain medication.

Exclusion criteria:

- No aphasia.
- No pain, pain assessment or interventions.
- Both no aphasia, aphasia assessment or interventions and no pain, pain assessment or interventions.

No other restrictions (such as language or publication date) were utilized for the inclusion of articles.

Data extraction

A data extraction form was designed and tested before actual data extraction. Two reviewers (WA/CDV) independently extracted data on (1) characteristics of the study samples (e.g., sample size, setting, age, stroke); (2) presence of aphasia, outcome of the aphasia examination; (3) prevalence of pain and pain measurement scales used or assessment instruments and/or pain intervention; (4) findings of the included studies and (5) score of the methodological quality.

Quality assessment

The results of the review were organized to (a) describe the methodological quality of the studies and (b) summarize the measurement properties of the instruments utilized to measure pain taking into account the methodological quality.

The Consewnsus-based Standards for the selection of health status Measurement Instruments (COSMIN) checklist was used to critically evaluate and compare the measurement properties of the measurement instruments used and the methodological quality of the studies reporting use of those tools [13]. The measurement properties contain the domains reliability, validity and responsiveness. In addition, the interpretability and feasibility was evaluated. The COSMIN checklist consists of nine boxes with 5–18 items concerning methodological standards for how each measurement property should be assessed. Each item was scored on a 4-point rating scale (i.e., “poor”, “fair”, “good” or “excellent”); this is an additional feature of the COSMIN

checklist (see http://www.cosmin.nl). An overall score for the methodological quality of a study is determined for each measurement property separately, by taking the lowest rating of any items in a box. The methodological quality of pain assessment instruments was evaluated per measurement property. Assessment of the methodological quality was performed by two reviewers (CDV/PS) independently. In case of any disagreement, a third reviewer (WA) was consulted to achieve consensus.

Best evidence synthesis: levels of evidence

The results of this review were organized and presented to describe the methodological quality of the studies. Second, the results summarize all the evidence on the measurement properties of the different used instrument, taking into account the methodological quality of the studies. Similarly, the possible overall rating for a measurement property was defined as "positive", "indeterminate" or "negative", accompanied by levels of evidence, as proposed by the Cochrane Back Review Group [14, 15]. Level of evidence (LOE) "strong" indicates consistent findings in multiple studies of good methodological quality, or in one study of excellent methodological quality. LOE "moderate" indicates consistent findings in multiple studies of fair quality, or in one study of good methodological quality. LOE "Limited" corresponds with one study of fair methodological quality. The LOE "conflicting" corresponds with conflicting findings, and the level "unknown" indicates that only studies of poor methodological quality are present.

The criteria to assess the results of the measurement properties reliability, content validity, criterion validity and responsiveness were based on Terwee et al. [16] and De Vet et al. [17]. The quality criteria of the measurement properties were as follow:

- A positive reliability was based upon reports of intra-class correlation coefficient of weighted Kappa ≥0.70 or Pearson's r ≥ 0.80 [16].
- Content validity indicates that all items of the measurement are relevant for the application of the measurement instrument. Questions about discrimination (to distinguish between persons at one point in time), evaluation (to assess change over time) or prediction (to predict future outcomes) were answered with the COSMIN checklist [16].
- A positive criterion validity indicates a correlation between the results of both the pain scale used and the gold standard pain measurement instrument [16].
- Responsiveness corresponds with a correlation with an instrument measuring the same construct ≥0.50 or at least 75% of the results are in accordance with the hypotheses or area under the curve ≥0.70, and correlation with related constructs is higher than with unrelated constructs [16, 17].

Results

Search

The initial search strategy yielded 829 results: 224 from PubMed (Medline), 149 from PsychINFO, 125 from CINAHL, 192 from EMBASE, 62 from Web of Science and 83 from Cochrane. Of these, 493 references were excluded based on the title and 46 were excluded based on the abstract. Finally, ten studies met all three inclusion criteria and were included in the present review (Figure 1 and Table 2).

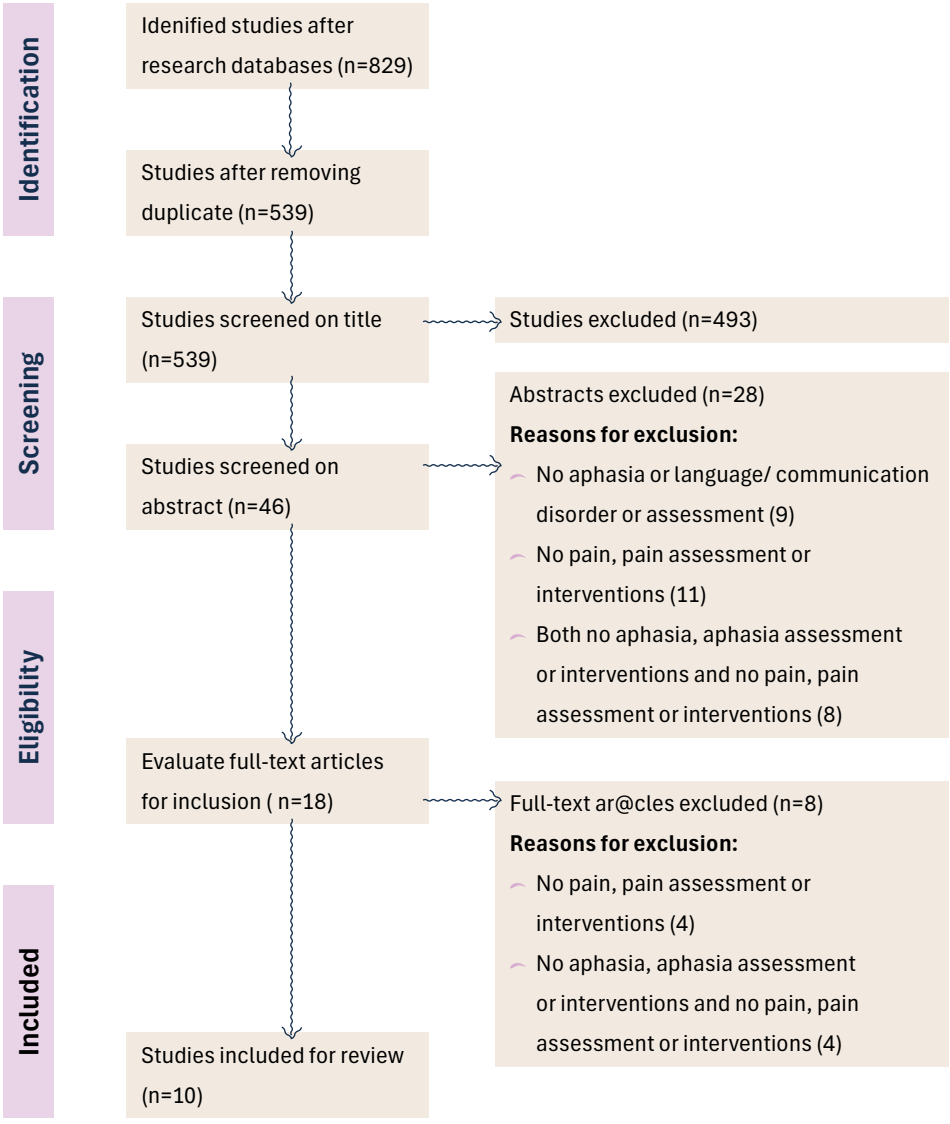

Figure 1: PRISMA flow chart of study selection

Study characteristics

The included studies were published between 1997 and 2015. Two articles reported data from the same original research [18, 19]. Five studies were conducted at a stroke unit of a university or general hospital [5, 6, 20-22] and one and one study at a rehabilitation center [23].

Data from three studies were collected at a community setting [19, 24]. Most of the included studies used a prospective cohort design; of the ten articles, three described a retrospective cohort study [6, 19, 21]. The studies including PWA consisted of sample sizes of 33–388 participants [5, 24]. The number of PWA varied from 13 to 138 PWA. The following types of aphasia were reported in the studies included in the review mild–moderate aphasia, receptive aphasia, severe aphasia, aphasia with severe expressive deficits and aphasia with both comprehension and expressive deficits [6, 20, 24]. Four of the ten studies used a control group. Control groups including individuals with stroke, aphasia and the presence of cognitive or psychiatric disorders or neurological disease were excluded from the review [18-20, 25]. Mean age ranges from 43 to 84 years, where the youngest patient is 36 and the oldest 92 years [6, 21, 23].

Table 2: Characteristicso f included articles.

Author (year of publication)	Country	Design	Setting	Sample (size)
1. Pomeroy *et al.*, (2000)	United Kingdom	Prospective cohort study	Community	*n* = 33 Groups: 1: Without aphasia and neglect (12) 2: Receptive aphasia (8) 3: Neglect (8) 4 4: Receptivea phasia + neglect (5)
2. Benaim *et al*, (2007)	France	Prospective cohort study (2001-2006)	Rehabilitation unit	*n* = 127 Groups: 1: 21 Controls 2: LHSP (63) 3: RHSP (64) 82% (104) ischemia, 18% (23) haemorrhage
3. Korner-Bitensky *et al.*, (2006)	Canada	Prospective cohort study	University hospital	*n* = 90 Groups: 1: 18 Controls 2: Stroke, without aphasia (20) 3: mild-moderate aphasia (23) 4: Aphasia severe expressive deficits (12) 5: Aphasia comprehension and expressive deficits (17)
4. Price *et al.*, (1999)	United Kingdom	Prospective cohort study	General hospital	*n* = 96 + 48 controls
5. Kehayia and Korner-Bitensky (1997)	Canada	Retrospective cohort study (1988-1993)	Rehabilitation hospital	*n* = 207 Groups: 1: Without aphasia (69) 2: Mild-moderate aphasia (69) 3: Severe aphasia (69)
6. Cruice et al. (2010)	Australia	Prospective cohort study (1999-2001)	Community	*n* = 105 aphasic *n* = 30 + 75 controls

Mean age (range) (years)	Mean post onset time (range) (months)	Exclusion criteria	Prevalence of aphasia/inability to communicate	Prevalence of pain
74 (S7-89)	42 (7-360)	-	39.4 % (13/33)	78.8% (26/33) Groups: 1: 83.3% (10/12) 2: 75% (6/8) 3: 87.5% (7/8) 4: 60% (3/5)
63 (18-80)	2.3	7.9% (5/63) of LHSP could not participate because of severe language disorders affecting comprehension (BDAE: 0-2/5)	60% (38) of LHSP presented aphasia	-
Groups: 1: 65.1 (37-86) 2: 73.7 (48-86) 3: 74.4 (35-89) 4: 73.8 (59-85) 5: 75.1 (43-90)	Groups: 2: 1.1 (0.2-3) 3: 3.1 (0.3-37) 4: 1.16 (0.1-4.2) 5: 2.8 (0.2-15.5)	Those with insufficient cognltive status to understand the purpose	Groups: 3: 20.7% (23) mild-moderate aphasia 4: 9.9% (12) severe expressive deficit 5: 15.3% (17) severe comprehension and expressive deficits	-
72.5	<6	Those too drowsy or dysphasic to understand simple motor command and further instructions. Severe aphasia was excluded	33% (32/96)	-
Groups: 1: 70.4 (50-92) 2: 67 (36-92) 3: 65.7 (27-88)	Groups: 1: 2.4 (0.4-1.6) 2: 3.1 (0.4-6.3) 3: 2.9 (0.5-5.6)	With severe cognitive and/ of psychological problems	Groups: 2: 33.3% (69/207) 3: 33.3% (69/207)	Pain medication in groups: 1: 15.9% (*n* = 11) 2: 23.2% (*n* = 16) 3: 19.3% (*n* = 13)
70.1 (57-88)	41.1 (10-108)	Those who cannot self-report and had no moderate comprehension ability	28.6% (30/105) mild-moderate aphasia	-

(Continued)

Author (year of publication)	Country	Design	Setting	Sample (size)
7. Cruice *et al.*, (2005)	Australia	Rerrospective cohort study	Community	Aphasic *n* = 30 + 30 proxies
8. Mazzocato *et al*. (2010)	Switzerland	Retrospective cohort study (2000-2005)	Hospita!	*n* = 42
9. Jackson *et al.*, (2006)	United Kingdom	Case study	Rehabilltation centre	*n* = 1
10. Smith *et al.*, (2013)	United States of America	Prospective cohort study (2008-2012)	Hospital	*n* = 388 inpatients and outpatients Groups: 1. 85% (331) infraction 2. 15% (57) haemorrhage

LHSP: left hemisphere stroke patient;

RHSP: right hemisphere stroke patient;

BDAE: Boston Diagnostic Aphasia Examination [26].

Mean age (range) (years)	Mean post onset time (range) (months)	Exclusion criteria	Prevalence of aphasia/inability to communicate	Prevalence of pain
70.7 (57-88)	41 (10-108)	-	100% mild-moderate aphasia. Fluent + good auditory comprehension 15 anomic, 8 conduction, 3 Brocas, 3 Wernicke, 1 transcortical sensor	-
84	0.4 (0.1-3.8)	-	38.1% (16/42) unable to communicate	69% (29/42). Specify pain type: 45% (13/29). Pain on inability communicate: one pain 43.8% (7/16). Two or more pains 56.2% (9/16)
43	2.3	-	Used hand gestures and able to indicate Y + N and understandp icturese asier than words; severe aphasia + significant semantic impairment+ verbal dyspraxia	-
Groups: 1. 78 (66-86) 2. 75 (63.5-835)	-	-	-	-

Outcomes

Pain measurement

The pain assessment instruments used in the studies involving PWA were the vertical, horizontal and mechanical VAS [20, 22, 24, 25], the FPS [25], the NRS [22], the Verbal Rating Scale (VRS) [22, 25, 27], a categorical site-of-pain shoulder scale [24] and the Scale Pain Intensity (SPIN) for patients with communication impairments [23]. Parallel to pain measurement instruments, the studies with pain registered as a subdomain of quality of life also used different quality of

life instruments the International Quality of Life Assessment (IQOLA) SF-36 Health Survey [28] and the Dartmouth COOP Charts [29]. Studies on pain measurement in specific patients with an inability to communicate used the FPS and NRS to measure pain [5, 21]. A summary of pain scales, the methodological quality and their accompanying LOE is presented in Table 3. The use of self-report pain scales in individuals with severe aphasia after stroke was not possible in some studies due to their inability to two studies included individuals with severe aphasia [5, 6, 19, 20, 22, 25].

Four articles, evaluating four pain measurement scales and two quality of life scales, were assessed with the COSMIN checklist to evaluate methodological quality for each pain measurement instrument and measurement property [19, 20, 24, 25]. There were no methodological studies evaluating the internal consistency, measurement error, structural validity, hypotheses testing and cross-cultural validity of the following pain measurement instruments; only the items of Reliability, Content validity, Criterion validity and Responsiveness could be rated. The methodological quality of the ten studies is presented in Table 4 for each scale and measurement property. The following section presents the results of the methodological quality per used pain measurement instrument. These results are summarized in Table 3.

Visual Analogue Scale

The (vertical, mechanical or horizontal) Visual Analogue Scale is an ordinal validated pain rating instrument [6]. A feasibility study of the usability of the VAS in stroke patients reported that 13.5% (15/111) were excluded because of drowsiness or severe aphasia [22]. There is limited positive evidence for the reliability of the VAS vertical in LHSP and RHSP, because both inter-rater and intra-rater reliability are adequate (LHSP: ICC = 0.72 and 0.78, respectively; RHSP: ICC = 0.86 and 0.90, respectively) [25]. One study of excellent methodological quality presented a positive rating result in strong positive evidence for content validity [25]. There was limited positive evidence for criterion validity of the VAS vertical in LHSP and RHSP (r = 0.82 and 0.72, respectively) [25]. An examination of responsiveness across studies showed conflicting findings. Two studies of fair methodological quality confirmed a positive rating [24, 25] and one study of poor quality reported a negative rating [20]. Regarding generalizability of the results, no disease characteristics (e.g., severity, duration and symptoms of the stroke patients in which VAS was evaluated) were described. No floor or ceiling effects were detected [20, 24, 25].

Faces Pain Scale

The FPS is designed to measure pain and disability [9]. Scores on the FPS were highly correlated with scores on the VAS and VRS in both left and right hemisphere stroke patients [25]. Patients who suffer from a left hemisphere stroke, 60% of PWA, preferred the FPS to the VAS and VRS with a significant difference compared to RHSP. A second study found that, when patients were unable to self-report, nurses rely on their own observations to assess pain and that of the research population. Of the participants, 13.4% (52/388) were unable to fill out the FPS and NRS and 30.1% of 388 patients suffered from left hemisphere stroke [5]. The study utilized the FPS by LHSP and

Table 3: Quality of measurement properties per scale

Pain scale	Reliability	Content validity	Criterion validity	Responsiveness
VAS vertical	+	+++	+	±
FPS	LHSP: ± RHSP: –	+++	++	+
VRS	LHSP: – RHSP: –	+++		–
Quality of Life scale used by proxy respondents Short Form 36 Health Survey			–	
Dartmouth COOP Charts			–	

VAS: Visual analoque scale;
FPS: faces pain scale;
LHSP: left hemisphere stroke patient;
RHSP: right hemisphere stroke patient;
VRS: verbal rating scale.
The categorical site-of-pain scale (shoulder) and the Scale Pain INtensitye (SPIN) do not appear in Table 1, because they could not be evaluated using COSMIN.

Table 4: Methodological quality of each study per measurement property and pain scale

Study:	Reliability	Content validity	Criterion validity	Responsiveness
VAS vertical Pomeroy et al. (2000)	Fair			Fair
Benaim et al. (2007)	Fair	Excellent	Good	Fair
Korner-Bitensky et al. (2006)				Poor
FPS Benaim et al. (2007)	Fair	Excellent	Good	Fair
VRS Benaim et al. (2007)	Fair	Excellent		
Validity of proxy respondents: Short Form 36 Health Survey Cruice et al. (2005)			Poor	
Dartmouth COOP Charts Cruice et al. (2005)			Poor	

VAS: Visual analoque scale; FPS: faces pain scale; VRS: verbal rating scale.

RHSP found that 7.9% (5/63) of the left hemisphere stroke patients could not participate (fill out the FPS) due to severe language disorders [25].

There was limited evidence that the reliability of the FPS in RHSP is inadequate (interrater reliability: K = 0.44; intra-rater reliability: K = 0.53). Inter-rater reliability of the FPS in LHSP was inadequate (K = 0.64), while only intra-rater reliability of the FPS in LHSP was adequate (K = 0.74) [25]. One study of excellent methodological quality reported positive ratings results in strong positive evidence [25]. There was moderate positive evidence for criterion validity, because one study of good methodological quality described a positive result. One study of fair methodological quality reported positive evidence for responsiveness [25]. No floor or ceiling effects were detected; no information was available on other aspects of generalizability.

Verbal Rating Scale

The VRS is a pain rating scale in rank order of pain intensity and assigns each one a score as a function of its rank. The 4 points consist of: “no pain”, “mild pain”, “moderate pain” and “severe pain” [12]. Results on the VRS showed limited evidence for both inter-rater and intra-rater reliability of the VRS in LHSP (K = 0.46 and K = 0.39, respectively) and both inter-rater and intra-rater reliability are inadequate in RHSP (K = 0.52 and K = 0.57) [25]. There was strong positive evidence for content validity: one study of excellent methodological quality reported positive results [25]. For responsiveness, there were conflicting findings: two studies of fair methodological quality and one study with poor methodological quality [20, 24, 25].

Categorical site-of-pain scale (shoulder)

The categorical site-of-pain scale (shoulder) contains the four categories no pain, pain easy to pinpoint in one localized spot of the shoulder, pain generalized all around the shoulder area and diffuse pain radiating away from the shoulder joint area [24]. One study of fair methodological quality evaluated the content validity and responsiveness of the categorical site-of-pain scale. For both measurement properties, there was limited negative evidence. Results on inter-rater reliability and intra-rater reliability were poor (K = 0.156–0.385 and K = 0.300–0.559, respectively) [24].

IQOLA SF-36

The SF-36 is a multi-purpose, short-form health survey which contains 36 questions. It yields an 8-scale profile of scores as well as summary physical and mental measures. The IQOLA Project was established in 1991 to translate the SF-36 Health Survey and to validate, norm and document the translations as required for their use internationally [28]. There is limited negative evidence for criterion validity of the Australian version of the SF-36 completed by proxy respondents. One study of poor methodological quality described positive correlations between aphasic and proxy respondent on the item Body Pain of the IQOLA SF-36 (ICC = 0.75) [19]. Proxy respondents of PWA rated their partners’ pain with the IQOLA SF-36 significantly lower

than the PWA's score (ICC = 0.75). Depending on the item, exact agreement ranged from 25% to 91% [19]. In addition, PWA who could self-report at interview and had moderate comprehension ability at the time of interviewing were included. However, the number of excluded participants is unknown [18].

Dartmouth COOP charts

The Dartmouth COOP Charts is a measurement system of individual scales for each measure which are displayed on a chart which is a direct indicator of function in the domain. COOP charts for adults contains the domains physical function, emotional function, daily activities, social activities, social support, change in health, overall health, pain and quality of life. A 5-point scale with descriptors and cartoon illustrations of levels 1–5, rating of "1" = no impairment and "5" = most impaired, was used [29]. The study on the use of the Dartmouth COOP Charts to measure pain describes that proxy respondents showed a significant negative bias in rating their aphasic partners' pain. There was limited negative evidence for criterion validity as it was reported by only one study of fair methodological quality (ICC = 0.54) [19].

SPIN for patients with communication impairments

The SPIN of patients with communication disorders is based on a total communication approach which was established and serial pain ratings made by the patient were found to be consistent with independent clinical records. The SPIN appears to have potential as a method for quantifying pain severity in people with limited communication [23]. The aim of the study on a pictorial scale of pain intensity was to develop and characterize a step-by-step process for introducing this new scale. Because the article describes a single case study, the COSMIN checklist could not be completed. No specified examination of aphasia was used. The patient was able to indicate yes or no and understand pictures easier than words and used hand gestures to respond [23]. Results concerning validity yield outcomes of good validity (SPIN-VAS r = 0.79; SPIN-NRS r = 0.92; NRS-VAS r = 0.87). Self-reported pain ratings showed daily fluctuations, but the overall pattern reflected an increase in medication and was consistent with the documented reports [23].

Prevalence of pain

Two studies reported prevalence of pain in PWA after stroke, ranging from 43.8% to 87.5% [21, 24]. A prospective study reported higher prevalence of pain in stroke patients without aphasia (83.3–87.5%) compared with PWA after stroke (60–75%) [24]. Another study reported a prevalence of pain in 69% of the 42 stroke patients. Out of the total population, 38.1% (16/42) had difficulties communicating; for 15 of these participants, this was due to aphasia or altered level of consciousness. Of these 38.1%, the prevalence of one-location pain was 43.8% (7/16) and of two or more pain locations was 56.2% (9/16), as measured with the National Institutional Health Stroke Scale [21].

Pain intervention

A study on pain intervention reported a significant difference in prescribed dosages and actually used pain medication in PWA and persons without aphasia after stroke; 88% of patients without aphasia were prescribed pain medication and 56% actually used this medication. Of the PWA with mild-to-moderate aphasia, 51% were prescribed medication and 29% actually used this medication; for PWA with severe aphasia, the percentage was 55% and 27%, respectively [6]. Patients with severe cognitive and/or psychological problems, as indicated in the neuropsychology report (percentage not mentioned), were excluded [6]. A retrospective cohort study including 42 stroke patients reported that 69% of their study population were treated with opioids [21].

Discussion

This is the first systematic review to document the incidence and prevalence of pain, and the measurement properties of pain assessment instruments, in PWA after stroke. The broad search strategy resulted in only ten relevant publications that actually described pain or pain assessment or pain medication in PWA or patients with inability to communicate after stroke. There were no studies that reported the incidence of pain. Five studies explicitly excluded PWA with severe aphasia after stroke because of the inability to complete pain measurement instruments [6, 18, 20, 22, 25]. One article reported a significant difference in prescribed proportions and actually used pain medication in PWA and persons without aphasia after stroke [6]. These findings underline the difficulty of identifying pain in PWA after stroke. None of the ten studies reported incidence rates of pain in this specific population. The few studies that described prevalence of pain in PWA after stroke with mild-to-moderate aphasia or difficulty to communicate reported a prevalence of 43.8–87.5%. There is strong positive evidence for content validity, moderate positive evidence for criterion validity and limited positive evidence for responsiveness of the FPS in LHSP and RHSP. Regarding reliability, there are conflicting findings in LHSP and limited negative results in RHSP. In addition, patients with a left hemispheric stroke prefer the FPS to the VAS or VRS [25]. The VAS vertical showed limited positive evidence for reliability and criterion validity and strong positive evidence for content validity [25]. In contrast to the conflicting findings reported for the responsiveness of the VAS vertical [20, 24, 25], there is strong positive evidence for content validity of the VRS in contrast to limited negative evidence for reliability and responsiveness [25]. Regarding the feasibility, reliability and validity, four studies were evaluated on their methodological quality. Reliability, content validity and responsiveness rates were judged to be fair [24, 25], and poor ratings were observed on criterion validity and responsiveness [19, 20, 22]. The study utilizing the FPS in LHSP and RHSP scored excellent rating on content validity and good rating on criterion validity [25]. Additionally, quality assessment revealed that studies with good or fair methodological quality reported poor methodological quality of the measurement properties of the pain assessment tools VRS, Categorical site-of-pain scale, IQOLA

SF36 and the Dartmouth COOP Charts. Poor quality was reported because of missing items (or no report for reasons for missing items), no adequate sample size or the lack of a gold standard.

A strength of the present study is the sensitive search string and the various databases used. In addition, the PRISMA guidelines provide a transparent methodology. Another strength is that, by using the COSMIN method, a meta-analysis could be performed on the quality of the measurement properties of the pain instruments in the different studies. A limitation of the study is that, due to the scarcity of the number of studies on pain in aphasia and their heterogeneity, a meta-analysis of the results was not possible. Our findings stress that more research is required on how to effectively measure pain in aphasia. For example, instead of (or in addition to) a self-report pain scale, the use of an observational instrument might be helpful to reliably assess symptoms of pain in PWA after stroke. Although several such instruments have been developed for people with dementia [30], they have not been tested in PWA. Therefore, assessment of psychometric properties of these observational instruments in PWA is warranted. Based on our findings, the vertical VAS and FPS are recommended for pain assessment in PWA. When it is impossible to use a self-report pain scale because of total inability to communicate, an observation scale for pain used in patients with dementia (e.g., the PAINAD Pain Assessment IN Advanced Dementia or the PACSLAC-D: Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dementia) might be considered [31]. This study confirms that most of the studies on pain assessment in PWA after stroke focus on mild-to-moderate aphasia. Of the various pain assessment tools used, the feasibility, validity and reliability generally show low quality. The pain scales VAS vertical and FPS provide the best results on methodological quality. Patients with a left hemispheric stroke prefer the use of FPS rather the VAS and VRS.

In summary, a feasible, reliable and valid pain assessment instrument is not yet available for PWA after stroke. Therefore, future research is needed to facilitate a valid, feasible and reliable pain assessment tool in PWA after stroke.

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References

1. Mulla, S.M., et al., *Management of Central Poststroke Pain: Systematic Review of Randomized Controlled Trials*. Stroke, 2015. **46**(10): p. 2853-60.
2. Klit, H., N.B. Finnerup, and T.S. Jensen, *Central post-stroke pain: clinical characteristics, pathophysiology, and management*. Lancet Neurol, 2009. **8**(9): p. 857-68.
3. Kim, J.S., *Post-stroke pain*. Expert Rev Neurother, 2009. **9**(5): p. 711-21.
4. Raffaeli, W., et al., *Population-based study of central post-stroke pain in Rimini district, Italy*. J Pain Res, 2013. **6**: p. 705-11.
5. Smith, J.H., et al., *Inability to self-report pain after a stroke: a population-based study*. Pain, 2013. **154**(8): p. 1281-6.
6. Kehayia, E., et al., *Differences in pain medication use in stroke patients with aphasia and without aphasia*. Stroke, 1997. **28**(10): p. 1867-70.
7. Scott, J. and E.C. Huskisson, *Vertical or horizontal visual analogue scales*. Ann Rheum Dis, 1979. **38**(6): p. 560.
8. Hjermstad, M.J., et al., *Studies comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for assessment of pain intensity in adults: a systematic literature review*. J Pain Symptom Manage, 2011. **41**(6): p. 1073-93.
9. Wong, D.L. and C.M. Baker, *Pain in children: comparison of assessment scales*. Pediatr Nurs, 1988. **14**(1): p. 9-17.
10. Moher, D., et al., *Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement*. Ann Intern Med, 2009. **151**(4): p. 264-9, W64.
11. Jensen, M.P., P. Karoly, and S. Braver, *The measurement of clinical pain intensity: a comparison of six methods*. Pain, 1986. **27**(1): p. 117-126.
12. Seymour, R.A., *The use of pain scales in assessing the efficacy of analgesics in post-operative dental pain*. Eur J Clin Pharmacol, 1982. **23**(5): p. 441-4.
13. Mokkink, L.B., et al., *The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes*. J Clin Epidemiol, 2010. **63**(7): p. 737-45.
14. Furlan, A.D., et al., *2009 updated method guidelines for systematic reviews in the Cochrane Back Review Group*. Spine (Phila Pa 1976), 2009. **34**(18): p. 1929-41.
15. van Tulder, M., et al., *Updated method guidelines for systematic reviews in the cochrane collaboration back review group*. Spine (Phila Pa 1976), 2003. **28**(12): p. 1290-9.
16. Terwee, C.B., et al., *Quality criteria were proposed for measurement properties of health status questionnaires*. J Clin Epidemiol, 2007. **60**(1): p. 34-42.
17. De Vet, H., Terwee, C.B., Mokkink, L.B., Knol, D.L., *Measurement in Medicine. A Practical Guide.*, ed. P.g.t.B.a. Epidemiology. 2011, Cambridge: Cambridge University Press.
18. Cruice, M., L. Worrall, and L. Hickson, *Health-related quality of life in people with aphasia: Implications for fluency disorders quality of life research*. J Fluency Disord, 2010. **35**(3): p. 173-189.
19. Cruice, M., et al., *Measuring quality of life: Comparing family members' and friends' ratings with those of their aphasic partners*. Aphasiology, 2005. **19**(2): p. 111-129.
20. Korner-Bitensky, N., et al., *Eliciting information on differential sensation of heat in those with and without poststroke aphasia using a visual analogue scale*. Stroke, 2006. **37**(2): p. 471-5.

21. Mazzocato, C., et al., *The last days of dying stroke patients referred to a palliative care consult team in an acute hospital*. Eur J Neurol, 2010. **17**(1): p. 73-7.

22. Price, C.I.M., R.H. Curless, and H. Rodgers, *Can stroke patients use visual analogue scales?* Stroke, 1999. **30**(7): p. 1357-1361.

23. Jackson, D., et al., *Development of a pictorial scale of pain intensity for patients with communication impairments: initial validation in a general population*. Clin Med (Lond), 2006. **6**(6): p. 580-5.

24. Pomeroy, V.M., et al., *Reliability of a measure of post-stroke shoulder pain in patients with and without aphasia and/or unilateral spatial neglect*. Clin Rehabil, 2000. **14**(6): p. 584-91.

25. Benaim, C., et al., *Use of the Faces Pain Scale by left and right hemispheric stroke patients*. Pain, 2007. **128**(1-2): p. 52-8.

26. Goodglass, H., E. Kaplan, and B. Barresi, *Boston Diagnostic Aphasia Examination. 3rd ed. (BDAE-3)*. 2001, Austin, TX: Pro-Ed.

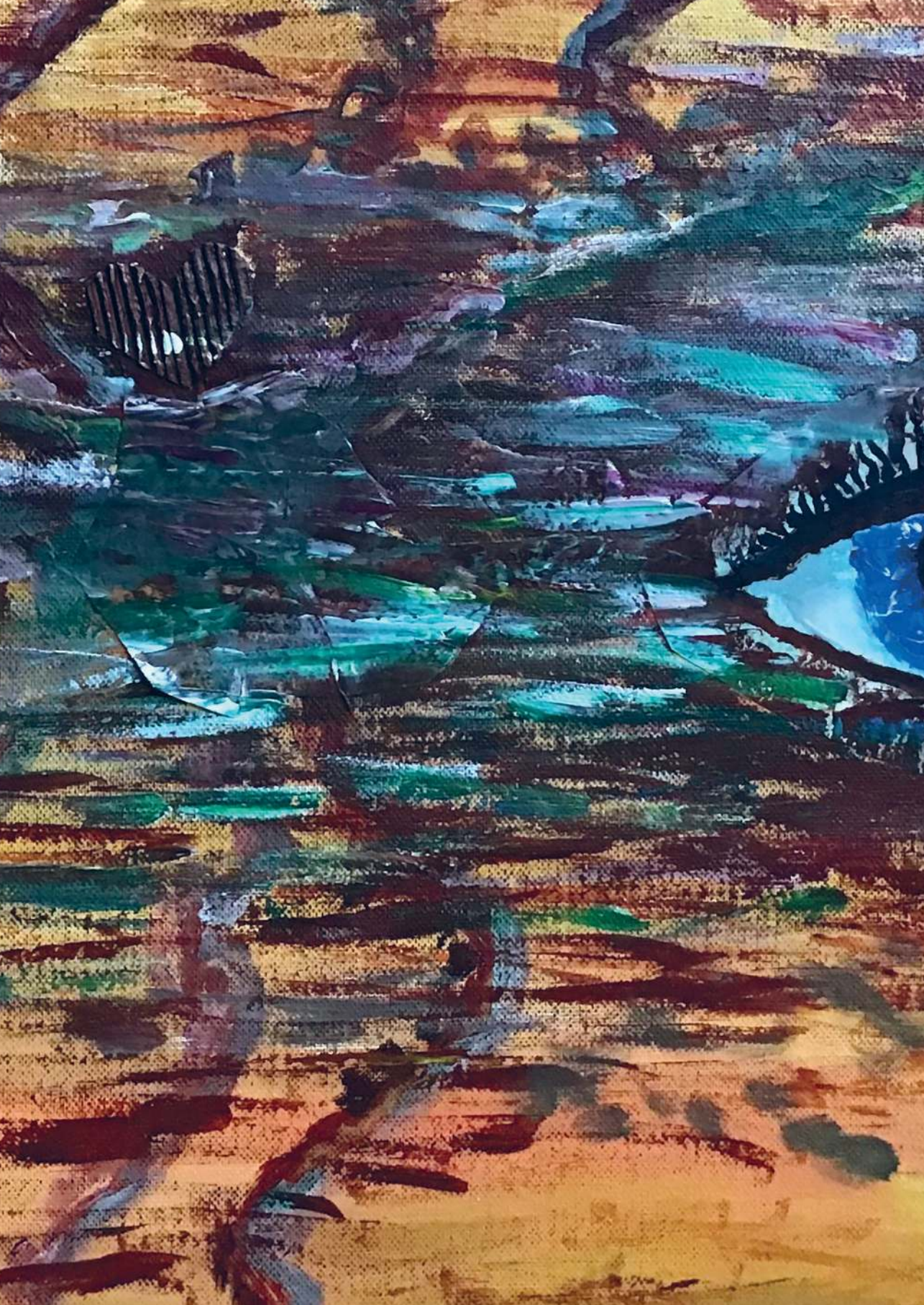
27. Herr, K.A., et al., *Pain intensity assessment in older adults: use of experimental pain to compare psychometric properties and usability of selected pain scales with younger adults*. Clin J Pain, 2004. **20**(4): p. 207-19.

28. Ware, J.E., Jr. and B. Gandek, *Overview of the SF-36 Health Survey and the International Quality of Life Assessment (IQOLA) Project*. J Clin Epidemiol, 1998. **51**(11): p. 903-12.

29. Nelson, E., et al., *Assessment of function in routine clinical practice: description of the COOP Chart method and preliminary findings*. J Chronic Dis, 1987. **40 Suppl 1**: p. 55S-69S.

30. Corbett, A., et al., *An international road map to improve pain assessment in people with impaired cognition: the development of the Pain Assessment in Impaired Cognition (PAIC) meta-tool*. BMC Neurol, 2014. **14**: p. 229.

31. Zwakhalen, S.M., et al., *Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools*. BMC Geriatr, 2006. **6**: p. 3.



PART 2

Pain observation in persons with aphasia

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Chapter 4

Measuring Pain in Aphasia: Validity and Reliability of the PACSLAC-D

Abstract

Background: Post-stroke pain in patients with an inability to communicate is not systematically assessed and therefore not sufficiently treated. This stresses the need to study pain assessment instruments that do not require good communication skills.

Aim: To examine the validity and reliability of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version (PACSLAC-D) in stroke patients with aphasia.

Methods: sixty stroke patients (mean age 79.3 years, SD 8.0), of whom 27 had aphasia were observed during rest, activities of daily living (ADL), and physiotherapy using the PACSLAC-D. The observations were repeated after two weeks. To examine convergent validity, correlations between the PACSLAC-D, self-report pain scales and the clinical judgement of a healthcare professional (pain present yes/no) were used. To examine discriminative validity, differences in pain were investigated between rest and ADL, in patients who use pain medication and those who do not, and in patients with and without aphasia. Internal consistency and test-retest reliability were assessed to determine reliability.

Results: Convergent validity failed to meet the acceptable threshold during rest but was adequate during ADL and physiotherapy. Discriminative validity was only adequate during ADL. The internal consistency was 0.33 during rest, 0.71 during ADL, and 0.65 during physiotherapy. Test-retest reliability varied from poor during rest (ICC= 0.07; 95% CI: -0.40- 0.51) to excellent during physiotherapy (ICC= 0.95; 95% CI: 0.83- 0.98).

Conclusions: the PACSLAC-D captures pain in patients with aphasia who are unable to self-report, during ADL and physiotherapy, but may be less accurate during rest.

Background

Different types of pain are common after stroke [1], for instance headache, shoulder and central post-stroke pain (CPSP) [2]. CPSP, for example, affects 11% of stroke patients [3]. Almost 40% of stroke survivors (n=281) experienced pain to some degree 5 years post-stroke, with 15% reporting frequent pain, and 25% felt that their needs for pain treatment were not met [4]. These rates are comparable with other common types of pain in older adults without stroke, who reported musculoskeletal pain (40%), peripheral neuropathic pain (40%), and chronic joint pain [5].

Self-report pain scales are considered the gold standard to measure pain, including in stroke patients [6]. Examples of self-report pain scales are the Numerical Rating Scale (NRS) [7], Visual Analogue Scale (VAS) [8] and Faces Pain Scale (FPS) [9]. However, the use of self-report pain scales can be difficult for stroke patients with aphasia and other cognitive deficits. An estimated 30% of stroke patients develop aphasia [10-12]. Most stroke patients with aphasia or communication problems are unable to complete self-report pain scales [13, 14].

A pain observation instrument score can serve as a proxy for measuring self-reported pain in stroke patients with aphasia. Pain observation instruments are regularly used in people with dementia who also have cognitive and communication problems [15-18]. The Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) [19] is an example of a pain observation instrument. This originally Canadian instrument consists of 60 items. The PACSLAC has shown adequate psychometric qualities for cognitively impaired older people in acute and long-term care settings [17, 19-22]. The PACSLAC was revised into a 31-item version, the PACSLAC-II [23-25]. It differentiates between painful and non-painful states in older long-term care residents with dementia and older adult outpatients without dementia [25, 26]. Several studies with translations in different languages, indicate that it is a valid and reliable observation instrument for the measurement of pain in older adults with dementia [16, 27-33].

The PACSLAC-D was developed based on the 60-item original Canadian PACSLAC instrument: [34]. Zwakhalen et al. [34] validated the reduced 24-item PACSLAC-D.

Post-stroke pain in patients with an inability to communicate is not systematically assessed and therefore not sufficiently treated [13]. This stresses the need to study the psychometric properties and feasibility of assessment instruments that do not require good communication skills. The aim of this study is to determine the validity and reliability of PACSLAC-D, an observational instrument, in stroke patients with aphasia.

Methods

Design and study population

This study employed a prospective observational design. Data were collected from July 2014 to December 2018. Patients who met the following selection criteria were invited by a speech and language therapist to participate in the study: ≥18 years old and staying at the stroke

unit of a Geriatric Rehabilitation Care center in The Netherlands. Patients with dementia or delirium were not eligible. Patients who were able to communicate gave oral informed consent for participation in this study. If patients were not able to give verbal informed consent or if there were doubts about the patient's communication abilities, the legal representative also provided verbal informed consent. Stroke patients, both with and without aphasia, were included. If aphasia was suspected; aphasia was diagnosed by a speech and language therapist using TokenTest [35] or ScreeLing [36]. A score of ≥ 7 on the TokenTest or a score of ≤ 68 on ScreeLing indicates the presence of aphasia. If tests could not be taken, the clinical judgement of the speech and language therapist was decisive.

A sample size with a minimum of 50 patients is recommended for validation studies and for the analysis of reliability [37].

Measurement instruments

To assess the presence of pain, the PACSLAC-D, was used because of good psychometric properties in Dutch persons with dementia [34]. The 24 items are related to face, resistance/defense, and social emotional/mood. The observer indicated for each item whether it was observed (1) or not (0). The total score ranges from 0 to 24, with a higher score indicating more pain. A score of 4 or higher may indicate the presence of pain [38].

Further, two self-report pain scales were used to measure pain. The FPS consists of six vertically placed faces, with face 1 (no pain) at the bottom and face 6 (maximum pain) at the top [9]. These 6 faces are assigned the following scores: 0 (no pain), 2, 4, 6, 8 and 10 (worst imaginable pain). Patients were asked to select the face that represents their experienced pain. The combined vertical NRS and VAS consists of a 10-centimeter vertical line with scores of 0 to 10, anchored by two extremes of pain: no pain (0) and extreme pain (10). Appendix A includes the FPS and the NRS/VAS combined scale.

For the clinical judgement of pain during ADL, the nurse, and during physiotherapy the physiotherapist, were asked the question 'Is there pain?' Their Yes or No response was recorded by the observer as judgement nurse and judgement physiotherapist.

Assessment of measurement properties

Construct validity

For construct validity, the subtypes convergent and discriminative validity were determined.

Convergent validity

Moderate correlations between the PACSLAC-D and self-report pain scales were expected for the convergent validity. Similarly, moderate correlations with the clinical judgement of the presence of pain of the nurse and physiotherapist were hypothesized.

Discriminative validity

Three a-priori hypotheses were tested to examine discriminative validity: 1) More pain is expected in patients with aphasia during ADL compared with rest. In persons with dementia, more pain is observed during ADL compared to rest [23, 33, 39]. Second hypothesis: more pain is expected in patients with aphasia using pain medication than in those who use no pain medication. Persons with dementia who used pain medication have more pain than those who did not use pain medication [40]. Also, a study of hospitalized persons with dementia found that 60% (of n=108) of persons who demonstrated pain received pain medication compared to 40% who did not receive pain medication [41]. Third hypothesis: more pain is expected in patients with aphasia compared to patients without aphasia. Stroke patients with aphasia received significantly less pain medication compared to patients without aphasia and those with moderate to severe aphasia are often excluded from pain research [42].

Reliability

For reliability, an acceptable internal consistency of PACSLAC-D in patients with aphasia was expected, and moderate test-retest reliability.

Procedure

After inclusion, the following sociodemographic characteristics were collected: gender, age, native language, hand dominance, stroke type, date of injury, stroke localization, analgesic medication and the presence of aphasia. Hand dominance is related to the localisation of language in the brain and, also with the localisation of the stroke. In most cases, language is in the left hemisphere located and, sometimes in the right hemispere [43, 44].

All patients, not blinded for aphasia, were observed by one observer on one day during rest, activities of living (ADL), and physiotherapy using the PACSLAC-D pain observation instrument for five to ten minutes. The observer was a speech and language therapist with a university education level Master of Arts. Subsequently, the observer asked the patient to indicate the degree of experienced pain using the self-report pain scales FPS [9], and a combination of the NRS [7] and VAS [8]. 'Not applicable' was noted if the participant was unable to self-report using (one of) these scales. After the observation during ADL and physiotherapy, the nurse and physiotherapist respectively, with no knowledge of the PACSLAC-D score, were asked to use clinical judgement if the patient had experienced pain. After two weeks, the measurements were repeated.

Statistical analysis

An overview of the characteristics of the patients was prepared using descriptive statistics. Group comparisons were obtained with t-test, Pearson chi-square test or Fisher's exact test. To examine the convergent validity of PACSLAC-D in patients with aphasia, Pearson correlation coefficients were calculated between the PACSLAC-D, self-report pain scales and the clinical judgement of the nurse and physiotherapist. To describe the strength of the correlation we

used: '.00-.19'= very weak; '.20-.39'= weak; '.40-.59'= moderate; '.60-.79'= strong; '.80-1.0'= very strong [45]. Additionally, a 95% confidence interval using bootstrapping (number of samples: 1,000) of the correlations was calculated. To investigate discriminative validity, the three hypotheses were tested. First, a non-parametric Wilcoxon signed-rank test was used to examine whether more pain was observed during rest than ADL (paired test) in patients with aphasia. Second, a Kruskal-Wallis test was used to investigate if patients with aphasia who use pain medication experienced more pain than those without pain medication. Third, to examine whether patients with aphasia had more pain than patients without aphasia, a Mann-Whitney U test was used.

The reliability of the PACSLAC-D was examined using Cronbach's alpha. Cronbach's α-values ranging from 0.70 to 0.95 are generally considered acceptable [46].

In addition, test-retest reliability were assessed using intraclass correlation coefficient (ICC). Based on the 95% confident interval of the ICC, a value between 0.50 and 0.75 indicates moderate reliability, between 0.75 and 0.90 good reliability, and higher than 0.90 excellent reliability [47, 48]. The analyses were performed using IBM SPSS Statistics version 25 for Windows, 2018.

Ethical considerations

The study was performed in accordance with the Dutch Healthcare Quality, Complaints and Disputes Act (WKKGZ). Article 7 of this Act states that the institution should improve regular care and to that purpose should gather data. Patient participation was voluntary and took place with their consent and in compliance with data protection.

Results

This study included 60 stroke patients, of whom 43% (n= 26) were female. Their age ranged from 59 to 99 years, with a mean age of 79.3 years (SD 8.0). Of the 60 stroke patients, 27 (45%) had aphasia. Seven stroke patients (12%) were unable to complete the self-report pain scales. Six of these seven stroke patients had aphasia. The patient without aphasia had other cognitive and motor damage, including severe dysarthria due to basal nuclei stroke in the right hemisphere (Table 1).

Table 2 describes the PACSLAC-D and self-report pain scale scores during rest, ADL, and physiotherapy. All 60 patients were observed during during rest and ADL. Of these 60 stroke patients, 49 patients were observed during physiotherapy.

A small proportion of the patients (12%) could not complete all self-report pain scales, during the observations in different conditions.

Almost no pain was observed with PACSLAC-D during rest and most patients (75%) completed the self-report pain scales with the lowest possible score of 0. During ADL and physiotherapy more pain was observed using PACSLAC-D and some patients rate their pain with the self-report pain scales.

Significantly more pain was observed in stroke patients unable to self-report during ADL (*n* = 7, mean 3.0, SD 1.7) and physiotherapy (*n* = 4, mean 2.5, SD 1.0) compared to 53 stroke patients (88%) who were able complete the self-report pain scales, ADL: *n* = 53, mean 0.54, SD 1.53; *t*(58)= -3.6, *p* < .05; physiotherapy: *n* = 45, mean 0.42, SD 1.03; *t*(47)= -3.9, *p* < .05. During rest, there was no difference in observed pain between patients who were unable (*n* = 7, mean 0.1, SD 0.38) and those who were able to complete self-report pain scales (*n* = 53, mean 0.2, SD 0.57); *t*(58)= 0.4, *p* =.971.

Convergent validity

Table 3 shows the associations between the PACSLAC-D, self-report pain scales, and clinical judgement of pain by the nurse and physiotherapist in patients with aphasia. During rest and ADL, we found no significant correlations between PACSLAC-D and self-report pain scales. During ADL, we reported only a moderate positive correlation between PACSLAC-D and the judgement of the nurse. During physiotherapy, the PACSLAC-D was only strongly positively associated with the NRS/VAS. We found no significant correlations between the PACSLAC-D and the FPS or judgement of physiotherapist.

Table 1: Patients' characteristics

		Total (N=60)
Age (years)	Mean (SD) Range	79.3 (8.0) 59.1 – 99.1
Gender (female)	n (%)	26 (43%)
Type of stroke	*Ischemic, n(%)* Left Hemisphere Right Hemisphere Brainstem Cerebellar *Haemorrhage, n(%)* Left Hemisphere Right Hemisphere Other	*52 (87%)* 26 (43%) 22 (37%) 2 (3%) 2 (3%) *8 (13%)* 1 (2%) 1 (2%) 6 (10%)
Pain medication	Mean (SD)	1.4 (0.5)
Unable to complete self-report pain scales[b]	N (%)	7 (12%)

a p<.05;

b ≥ 2 self-report pain scales not completed during Rest, Activities of Daily Living and Physiotherapy. SD = standard deviation.

Discriminative validity

No difference in pain is observed during ADL (median 1) compared to rest (median 0); $T = 25$, $z = -1.93$, $p = .053$.

Also, we found no difference in observed pain in patients with aphasia who used pain medication during rest (median = 0) and physiotherapy (median = 0) compared to those who did not use pain medication during rest (median = 0) and physiotherapy (median = 0); rest $H(1) = 0.49$, $p = .483$; physiotherapy $H(1) = 1.39$, $p = .238$. Only during ADL, significantly more pain is observed in patients with aphasia who used pain medication (median = 1) than those who did not use pain medication (median = 0); $H(1) = 6.33$, $p < .05$.

During rest, we found no difference in pain in patients with aphasia (median = 0) compared to non-aphasia patients (median = 0); $U = 437$, $z = -0,26$, $p = .792$. Significantly more pain was observed during ADL in patients with aphasia (median 1) compared to patients without aphasia (median = 0); $U = 310$, $z = -2,37$, $p = <.05$. During physiotherapy, no difference in pain was observed between patients with aphasia (median = 0) and without aphasia (median = 0); $U = 258$, $z = -0,86$, $p = .388$.

Stroke patients with aphasia (n=27)	Stroke patients without aphasia (n=33)	Group comparisons t(df), *p* *X*2(df), *p* or two tailed, *p* (Fisher's exact test)
79.3 (9.0) 59.1 – 92.7	79.4 (7.1) 67.1 – 99.1	$t(58) = -0.02$, $p = 0.98$
14 (52%)	20 (61%)	$X^2(1) = 0.46$, $p = 0.49$
24 (89%) 21 (78%) 3 (11%) 0 0	*28 (85%)* 5 (15%) 19 (58%) 2 (6%) 2 (6%)	$X^2(1) = 0.21$, $p = 0.64$
3 (11%) 0 1 (4%) 2 (7%)	*5 (15%)* 1 (3%) 0 4 (12%)	two tailed, p= 0.72
1.3 (0.5)	1.4 (0.5)	$t(58) = -1.02$, $p = 0.31$
6 (22%)	1 (3%)	two tailed, $p = 0.04^{a}$

Table 2: Descriptive statistics of PACSLAC-D and self-report pain scales during rest, Activities of Daily Living, and physiotherapy

	Total (N=60)			With aphasia (n=27)		
	N	Mean (SD)	Range	N	Mean (SD)	Range
Rest						
PACSLAC-D	60	0.15 (0.55)	0-3	27	0.11 (0.43)	0-2
NRS/VAS	55	0.84 (2.13)	0-8	22	0.09 (0.30)	0
FPS	55	0.84 (2.07)	0-8	22	0.27 (0.94)	0
ADL						
PACSLAC-D	60	1.00 (1.71)	0-8	27	1.41 (1.70)	0-5
NRS/VAS	53	1.77 (2.87)	0-9	21	1.33 (1.96)	0-7
FPS	53	1.64 (2.66)	0-8	21	1.24 (1.61)	0-4
Physiotherapy						
PACSLAC-D	49	0.59 (1.17)	0-4	20	0.80 (1.36)	0-4
NRS/VAS	45	1.36 (2.58)	0-8	16	0.75 (1.30)	0-3
FPS	45	1.24 (2.40)	0-8	16	0.75 (1.44)	0-4

PACSLAC-D = Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version;
NRS/VAS = Numeric Rating Scale/ Visual Analogue Scale;
FPS = Faces Pain Scale;
ADL = Activities of Daily Living

Table 3: Correlation matrix PACSLAC-D and self-report pain scales in patients with aphasia

		Rest	
Patients with aphasia (n= 27)		NRS-VAS	FPS
PACSLAC-D	Pearson Corr.	-0.07	-0.07
	Sign. (2-tailed)	0.76	0.77
	n	22	22
	95% CI	-0.17 - -0.05	-0.16 - -0.05

ADL = Activities of Daily Living, NRS/VAS = Numeric Rating Scale / Visual Analogue Scale, FPS = Faces Pain Scale, Judgement nurse = the nurse was asked to judge if any pain was present during ADL; Judgement physiotherapist = physiotherapist was asked to judge if any pain was present during physiotherapy, CI = confidence interval.

Without aphasia (n=33)			Group comparisons
N	Mean (SD)	Range	Mann-Whitney U test
33	0.18 (0.64)	0-3	*U*= 437.00, *z*= -0.26, *p*=.79
33	1.33 (2.64)	0-8	*U*= 301.00, *z*= -1.58, *p*=.11
33	1.21 (2.51)	0-8	*U*= 304.50, *z*= -1.50, *p*=.14
33	0.67 (1.67)	0-8	*U*= 310.00, *z*=-2.37, *p*=.02*
32	2.06 (3.34)	0-9	*U*= 330.00, *z*= -0.13, *p*=.90
32	1.91 (3.16)	0-8	*U*= 329.00, *z*= -0.15, *p*=.88
29	0.45 (1.02)	0-4	*U*= 258.00, *z*= -0.86, *p*=.39
29	1.69 (3.03)	0-8	*U*= 225.00, *z*= -0.21, *p*=.84
29	1.52 (2.77)	0-8	*U*= 216.00, *z*= -0.49, *p*=.63

ADL			Physiotherapy		
NRS-VAS	FPS	Judgement nurse	NRS-VAS	FPS	Judgement physiotherapist
0.11	0.22	0.44*	0.64**	0.49	0.49
0.65	0.35	0.05	0.01	0.054	0.054
21	21	21	16	16	16
-0.27 - 0.64	-0.22 - 0.69	0.00 - 0.85	0.04 - 0.98	-0.25 - 0.94	0.21 - 1.00

* $p < .05$,

** $p < 0.01$; PACSLAC-D = Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version,

Reliability

Table 4 presents the internal consistency of the PACSLAC-D in patients with aphasia and without aphasia. In patients with aphasia, Cronbach's alpha varied between 0.33 (rest) and 0.71 (ADL). In patients without aphasia, from 0.69 (rest) to 0.86 (ADL).

The test-retest reliability during rest was poor; ICCconsistency= 0.07 (95% CI: -0.40 - 0.51). By contrast, the test-retest reliability during ADL was good; ICCconsistency= 0.88 (95% CI: 0.71-0.95) and it was excellent during physiotherapy; ICCconsistency= 0.95 (95% CI: 0.83- 0.98).

Table 4: Internal consistency of PACSLAC-D based on observations day 1 and 2

	Group	Cronbach's alpha
Rest	Patients with aphasia	0.33
	Patients without aphasia	0.69
ADL	Patients with aphasia	0.71
	Patients without aphasia	0.86
Physiotherapy	Patients with aphasia	0.65
	Patients without aphasia	0.73

PACSLAC-D = Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version; consists of 24 items, ADL = Activities of Daily Living

Discussion

The present study investigated the convergent and discriminative validity and reliability of PACSLAC-D in stroke patients with aphasia.

The PACSLAC-D and self-report pain scales showed poor correlations (Table 3). Van der Steen et al. (2021) also reported this finding in a study with patients with dementia who were observed with the pain observation instrument Pain Assessment in Impaired Cognition (PAIC15) [49].

When we compared stroke patients who were unable to self-report pain to those who were able self-report their pain, more pain was observed in patients who were unable to self-report during ADL and physiotherapy. This is in line with research in persons with dementia, in which pain was observed using PACSLAC-D and where patients with pain all tended to be more severely cognitively impaired and had difficulty with self-report scales [15, 17, 38].

A moderate positive correlation was found between PACSLAC-D and the clinical judgement of the nurse during ADL, and a strong positive correlation was found between PACSLAC-D and NRS/VAS during physiotherapy. Contrary to our expectations and other studies that found associations

between the PACSLAC-D and FPS in cognitively impaired participants [16, 50], in this study the PASCLAC-D showed no to weak correlation with the self-report pain scales. We found only a moderate positive correlation with the judgement of the nurse during ADL, and a strong correlation with the NRS during physiotherapy. These results provide some evidence for the convergent validity of PACSLAC-D in patients with aphasia during activities, but not during rest. This may be explained by the fact that relatively few signs of pain where observed during rest, possibly because of the composition of the sample. The sample consists of patients who had no fractures, injuries or painful disorders.

The discriminating validity of the PACSLAC-D was adequate in patients with aphasia. No difference in pain was observed with the PACSLAC-D during ADL compared to rest. This result is in contrast with previous studies in which less pain is observed during rest compared to during activities [16, 51]. Second, results were in accordance with the hypothesis that patients with aphasia who used pain medication experienced significantly more pain than patients with aphasia who did not use pain medication during ADL. Not surprisingly, the many 0 scores during rest and physiotherapy mean no significant difference was found in observed pain between both groups. A possible explanation during physiotherapy might be that the movements and exercises are more structured and guided by the physiotherapist, who may try to limit potentially painful movements while still working on therapeutic goals. Consistent with expectation in the third hypothesis, significantly more pain was observed in patients with aphasia compared to non-aphasia patients during ADL. More pain during ADL seems to be consistent with other research which found that aphasic participants score higher on body pain and general health [52]. Adequate discriminative validity of the PACSLAC-D in this study population was supported by previous relevant research of pain observation in older people with communication problems [16, 53].

The reliability of PACSLAC-D in patients with aphasia is particularly good during activities but insufficient during rest. The acceptable internal consistency during ADL and physiotherapy is in line with studies using the PACSLAC-D in patients with dementia [16, 17, 50]. Test-retest reliability was good during ADL and excellent during physiotherapy. This is in line with outcomes of test-retest reliability of PACSLAC-D in elderly with communication problems [33, 53].

Limitations of the current study include the relatively small sample size that was restricted to older stroke patients with aphasia in one geriatric rehabilitation center. This limits the generalizability of results. The order of the self-report pain scales was not randomized, the researcher who observed the patients with aphasia was not blinded and was also their speech and language therapist. Next to these limitations, the current study also has several strengths. This is the first study to examine psychometric properties of a pain observation instrument to measure pain in patients with aphasia in a clinical setting, comparing aphasia with non-aphasia patients, and in several active states.

Conclusions

The PACSLAC-D might be a useful observational instrument and alternative to screen for the presence of pain in stroke patients with aphasia, a population in which pain occurs regularly, pain is triggered by movement, and where pain management may be suboptimal due to communication difficulties.

Implications for nursing education, practice and research

More pain was observed in patients who were unable to self-report during potentially painful activities. This means that pain management in patients with aphasia and other communication difficulties may not optimal, highlighting the fact that alternatives to screen for pain are essential for these patient groups. The PACSLAC-D might be a suitable alternative to screen for the absence and presence of pain in patients with aphasia who are unable to self-report during activities. The use of a pain observation instrument could help healthcare professionals to substantiate their opinion on whether pain is present and to evaluate whether pain interventions were successful. Notwithstanding its limitations, this study supports that a pain observation instrument might be a good alternative when self-reporting pain is not possible because of impaired cognition and/or communication problems [15-17]. However, more research is required on how to measure pain in persons with aphasia in a valid and reliable manner, for example by comparing various observation instruments using larger sample sizes.

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References

1. Delpont, B., et al., *Pain after stroke: A review.* Rev Neurol (Paris), 2018. **174**(10): p. 671-674.
2. Hansen, A.P., et al., *Pain following stroke: a prospective study.* Eur J Pain, 2012. **16**(8): p. 1128-36.
3. Liampas, A., et al., *Prevalence and Management Challenges in Central Post-Stroke Neuropathic Pain: A Systematic Review and Meta-analysis.* Adv Ther, 2020. **37**(7): p. 3278-3291.
4. Westerlind, E., et al., *Experienced pain after stroke: a cross-sectional 5-year follow-up study.* BMC Neurol, 2020. **20**(1).
5. Jones, M.R., et al., *Pain in the Elderly.* Current Pain and Headache Reports, 2016. **20**(4).
6. Harrison, R.A. and T.S. Field, *Post stroke pain: identification, assessment, and therapy.* Cerebrovasc Dis, 2015. **39**(3-4): p. 190-201.
7. Hjermstad, M.J., et al., *Studies comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for assessment of pain intensity in adults: a systematic literature review.* J Pain Symptom Manage, 2011. **41**(6): p. 1073-93.
8. Heller, G.Z., M. Manuguerra, and R. Chow, *How to analyze the Visual Analogue Scale: Myths, truths and clinical relevance.* Scandinavian Journal of Pain, 2016. **13**: p. 67-75.
9. Kim, E.J. and M.T. Buschmann, *Reliability and validity of the Faces Pain Scale with older adults.* Int J Nurs Stud, 2006. **43**(4): p. 447-56.
10. Engelter, S., *[Aphasia in stroke patients: frequency and significance].* Praxis (Bern 1994), 2006. **95**(13): p. 489-92.
11. Mitchell, C., *Prevalence of aphasia and dysarthria among inpatient stroke survivors: describing the population, therapy provision and outcomes on discharge.* Aphasiology, 2020. **7**(950-960).
12. Wu, C., et al., *Prevalence and Impact of Aphasia among Patients Admitted with Acute Ischemic Stroke.* J Stroke Cerebrovasc Dis, 2020. **29**(5): p. 104764.
13. Schuster, J., et al., *Use of analgesics in acute stroke patients with inability to self-report pain: a retrospective cohort study.* Bmc Neurology, 2020. **20**(1).
14. Smith, J.H., et al., *Inability to self-report pain after a stroke: a population-based study.* Pain, 2013. **154**(8): p. 1281-6.
15. Coca, S.M. and R.A.A. Zuniga, *Instruments for pain assessment in patients with advanced dementia: A systematic review of the evidence for Latin America.* Palliative & Supportive Care, 2020. **18**(6): p. 741-747.
16. Haghi, M., Fadayevatan, R., Alizadeh-Khoei, M., Kaboudi, B., Foroughan, M., Mahdavi, B., *Validation of Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II (PACSLAC-II) in Iranian older adults with dementia living in nursing homes.* Psychogeriatrics, 2020. **20**: p. 278-287.
17. Natavio, T., et al., *A Comparison of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) and Pain Assessment in Advanced Dementia Scale (PAINAD).* Pain Manag Nurs, 2020. **21**(6): p. 502-509.
18. Van Dalen-Kok, A.H., et al., *The impact of pain on the course of ADL functioning in patients with dementia.* Age and Ageing, 2021. **50**(3): p. 906-913.
19. Kaasalainen, S., et al., *A Comparison Between Behavioral and Verbal Report Pain Assessment Tools for Use with Residents in Long Term Care.* Pain Management Nursing, 2013. **14**(4): p. E106-E114.
20. Collins, J.T., et al., *Chronic pain in people living with dementia: challenges to recognising and managing pain, and personalising intervention by phenotype.* Age Ageing, 2023. **52**(1).

21. Fuchs-Lacelle, S. and T. Hadjistavropoulos, *Development and Preliminary Validation of the Pain Assessment Checklist for Seniors With Limited Ability to Communicate (PACSLAC).* Pain Manag Nurs, 2004. **5**(1): p. 37-49.

22. Qi NG, S., Brammer, J.D., Creedy, D.K., *The psychometric properties, feasibility and utility of behaviouralobservation methods in pain assessment of cognitively impaired elderly people in acute and long-term care: A systematic review.* JBI Libr Syst Rev, 2012. **10**(17): p. 977-1085.

23. Hadjistavropoulos, T., et al., *Pain assessment in elderly adults with dementia.* Lancet Neurol, 2014. **13**(12): p. 1216-1227.

24. Ruest, M., et al., *Can We Quickly and Thoroughly Assess Pain with the PACSLAC-II? A Convergent Validity Study in Long-Term Care Residents Suffering from Dementia.* Pain Manag Nurs, 2017. **18**(6): p. 410-417.

25. Chan, S., et al., *Evidence-based development and initial validation of the pain assessment checklist for seniors with limited ability to communicate-II (PACSLAC-II).* Clin J Pain, 2014. **30**(9): p. 816-24.

26. Hadjistavropoulos, T., et al., *Pain in severe dementia: A comparison of a fine-grained assessment approach to an observational checklist designed for clinical settings.* Eur J Pain, 2018. **22**(5): p. 915-925.

27. Aubin, M., et al., *[Validity 'and Utilities' clinic of a grid observation (PACSLAC-F) to evaluate the pain in seniors with dementia's living in the Long-Term Care].* Can J Aging, 2008. **27**(1): p. 45-55.

28. Büyükturan, Ö., et al., *Reliability and validity of the Turkish version of Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC-T).* Turk J Med Sci, 2018. **48**(4): p. 805-810.

29. Kim, E.K., et al., *[Validity and reliability of the Korean version of the pain assessment checklist for seniors with limited ability to communicate].* J Korean Acad Nurs, 2014. **44**(4): p. 398-406.

30. Takai, Y., et al., *Developing and validating a Japanese version of the Assessment of Pain in Elderly People with Communication Impairment.* Archives of Gerontology and Geriatrics, 2013. **57**(3): p. 403-410.

31. Thé, K.B., et al., *Pain assessment in elderly with dementia: Brazilian validation of the PACSLAC scale.* Einstein (Sao Paulo), 2016. **14**(2): p. 152-7.

32. van Nispen tot Pannerden, S.C., et al., *An item response theory-based assessment of the pain assessment checklist for Seniors with Limited Ability to Communicate (PACSLAC).* J Pain, 2009. **10**(8): p. 844-53.

33. Zwakhalen, S.M., J.P. Hamers, and M.P. Berger, *The psychometric quality and clinical usefulness of three pain assessment tools for elderly people with dementia.* Pain, 2006. **126**(1-3): p. 210-20.

34. Zwakhalen, S.M., J.P. Hamers, and M.P. Berger, *Improving the clinical usefulness of a behavioural pain scale for older people with dementia.* J Adv Nurs, 2007. **58**(5): p. 493-502.

35. Doesborgh, S.J., et al., *Linguistic deficits in the acute phase of stroke.* J Neurol, 2003. **250**(8): p. 977-82.

36. El Hachioui, H., et al., *The ScreeLing: occurrence of linguistic deficits in acute aphasia post-stroke.* J Rehabil Med, 2012. **44**(5): p. 429-35.

37. De Vet, H., Terwee, C., Mokkink, L., & Knol, D., *Measurement in Medicine: A Practical Guide (Practical Guides to Biostatistics and Epidemiology).* 2011, Cambridge, UK Cambridge University Press.

38. Zwakhalen, S.M., et al., *The prevalence of pain in nursing home residents with dementia measured using an observational pain scale.* Eur J Pain, 2009. **13**(1): p. 89-93.

39. Lints-Martindale, A.C., et al., *A Comparative Investigation of Observational Pain Assessment Tools for Older Adults With Dementia.* Clinical Journal of Pain, 2012. **28**(3): p. 226-237.

40. Rajkumar, A.P., et al., *Epidemiology of Pain in People With Dementia Living in Care Homes: Longitudinal Course, Prevalence, and Treatment Implications.* J Am Med Dir Assoc, 2017. **18**(5): p. 453 e1-453 e6.

41. Boltz, M., et al., *Pain Incidence, Treatment, and Associated Symptoms in Hospitalized Persons with Dementia.* Pain Management Nursing, 2021. **22**(2): p. 158-163.

42. de Vries, N.J., P.H. Sloot, and W.P. Achterberg, *Pain and pain assessment in stroke patients with aphasia: a systematic review.* Aphasiology, 2016. **31**(6): p. 703-719.

43. Carey, D.P. and L.T. Johnstone, *Quantifying cerebral asymmetries for language in dextrals and adextrals with random-effects meta analysis.* Front Psychol, 2014. **5**: p. 1128.

44. Vingerhoets, G., *Phenotypes in hemispheric functional segregation? Perspectives and challenges.* Phys Life Rev, 2019. **30**: p. 1-18.

45. Evans, J.D., *Straightforward statistics for the behavioral sciences.* 1996, Pacific Grove, CA: Brooks/Cole Publishing.

46. Bland, J.M. and D.G. Altman, *Cronbach's alpha.* Bmj, 1997. **314**(7080): p. 572.

47. Koo, T.K. and M.Y. Li, *A Guideline of Selecting and Reporting Intraclass Correlation Coefficients for Reliability Research.* J Chiropr Med, 2016. **15**(2): p. 155-63.

48. Kunz, M., et al., *The Pain Assessment in Impaired Cognition scale (PAIC15): A multidisciplinary and international approach to develop and test a meta-tool for pain assessment in impaired cognition, especially dementia.* Eur J Pain, 2020. **24**(1): p. 192-208.

49. van der Steen, J.T., et al., *Probable Pain on the Pain Assessment in Impaired Cognition (PAIC15) Instrument: Assessing Sensitivity and Specificity of Cut-Offs against Three Standards.* Brain Sci, 2021. **11**(7).

50. Liu, J.Y.W., M. Briggs, and S.J. Closs, *The Psychometric Qualities of Four Observational Pain Tools (OPTs) for the Assessment of Pain in Elderly People with Osteoarthritic Pain.* Journal of Pain and Symptom Management, 2010. **40**(4): p. 582-598.

51. van Herk, R., et al., *Observation scales for pain assessment in older adults with cognitive impairments or communication difficulties.* Nurs Res, 2007. **56**(1): p. 34-43.

52. Cruice, M., L. Worrall, and L. Hickson, *Health-related quality of life in people with aphasia: Implications for fluency disorders quality of life research.* J Fluency Disord, 2010. **35**(3): p. 173-189.

53. Thé, K.B., et al., *Pain assessment in elderly with dementia: Brazilian validation of the PACSLAC scale.* Einstein (São Paulo), 2016. **14**(2): p. 152-157.

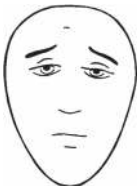
Appendix A: Faces Pain Scale (FPS)

10.  **ten = most worse pain**

8.  **eight**

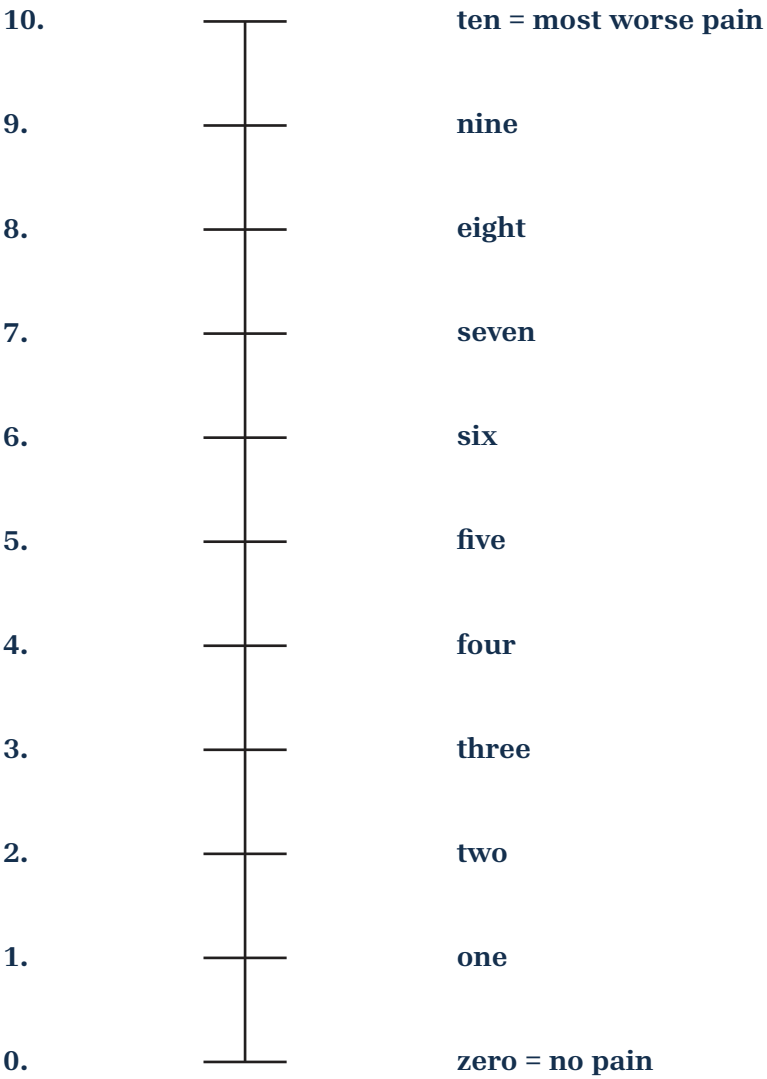
6.  **six**

4.  **four**

2.  **two**

0.  **zero = no pain**

Numeric Rating Scale / Visual Analogue Scale (NRS/VAS)



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Chapter 5

Validity and reliability of the Pain Assessment in Impaired Cognition 15 (PAIC15) observation scale in persons with aphasia

Keywords:

- *aphasia;*
- *self-report pain;*
- *pain scales;*
- *pain observation instrument*

Abstract

Background: The use of self-report pain scales in persons with aphasia can be challenging due to communication and cognitive problems, while for assessing pain self-report pain is considered the gold standard [1]. An observational scale may be used as an alternative. This study examines the validity and reliability of the observational Pain Assessment in Impaired Cognition (PAIC15) scale in persons with aphasia.

Methods: Persons with aphasia were observed during rest and transfer by two observers using the PAIC15. The PAIC15 comprises 15 items covering the three domains of facial expressions, body movements, and vocalizations. When able, the participant completed four self-report pain scales after each observation. The observations were repeated within one week. For criterion validity, correlations between the PAIC15 and self-report pain scales were calculated and for construct validity, three hypotheses were tested. Reliability was determined by assessing internal consistency, and intra- and interobserver agreement.

Results: PAIC15 observations were obtained for 71 persons (mean age 75.5 years) with aphasia. Fair positive correlations (rest: 0.35-0.50; transfer: 0.38-0.43) were reported between PAIC15 and almost all self-report pain scales. Results show that significantly more pain was observed in persons with aphasia during transfer than during rest. No differences were found for observed pain between persons with aphasia who use pain medication and those without, or persons who have joint diseases compared to those without. Results showed acceptable internal consistency. Intra- and interobserver agreement was high for most PAIC15 items, particularly for the domains body movements and vocalizations during rest and transfer.

Conclusions: Recognition of pain in persons aphasia using the PAIC15 showed mixed yet promising results.

Introduction

Self-report pain scales are commonly used to assess pain in patients with aphasia. Examples are the the Numerical Rating Scale (NRS) [2], the Visual Analog Scale (VAS) [3] and Faces Pain Scale (FPS) [4]. Self-report pain scales require the person to be able to understand verbal and written instructions and to apply this information in his or her response, which limits the use in persons with aphasia. Persons with moderate to severe aphasia are also often excluded from pain research, which makes interpretation of applicability, usefulness and best practices in pain assessment in aphasia difficult, although very relevant [5, 6]. However, stroke patients with mild to moderately-severe aphasia have pain just as often as stroke patients without aphasia (e.g. due to shoulder pain and central pain) [7].

Smith and Bottemiller [8] found that 14% of stroke patients were not able to complete the FPS or NRS. Capacity to complete these scales was associated with the severity of stroke and severity of aphasia. Most studies focused on patients with mild to moderate aphasia [9]. Also, despite varied self-report pain scales, stroke patients are less likely than age-matched controls to be able to complete these pain scales [1, 10]. Evidently, an appropriate alternative method of assessment of the presence of pain in persons with aphasia who are unable to self-report is needed. An alternative to self-report could be the observation of a person's behavior, as is common in patients with cognitive impairment [11, 12]. Observational pain scales have been used successfully as an alternative to self-report pain scales in people with advanced dementia [13].

In 2011, a European Cooperation in Science and Technology (EU-COST) initiative collaborated to improve pain assessment in persons with impaired cognition. This international multidisciplinary team of experts from 16 countries developed a universal meta-tool for the assessment of pain in persons with cognitive impairment. This meta-tool, the Pain Assessment in Impaired Cognition (PAIC15), is an observational instrument that includes the best items from existing pain scales to observe pain in persons with impaired cognition. The PAIC15 has shown satisfactory psychometric qualities in patients with impaired cognition, mostly with dementia [14, 15]. This pain observation instrument is available in ten languages and comes with an internet-based E-learning module in three languages (German, Dutch, and English: https://paic15.com/en/e-training-en/). The PAIC15 is therefore a potentially suitable alternative for assessing pain in patients who are unable to self-report, such as those with aphasia [16]. This study aims to answer the following research question: 'What is the validity and reliability of the Dutch version of PAIC15 in persons with aphasia?'

Methods

Study design

The current study was an observational cohort study to determine the validity and reliability of the Dutch version of PAIC15 in persons with aphasia. Persons with aphasia were observed using PAIC15 during rest and transfer. Rest situations could be lying in bed or sitting in a (wheel)chair. Transfer situations include physical moves from bed to (wheel)chair, repositioning in bed or a

short walk. Observations were conducted by two observers and repeated within one week. The data were collected during the COVID19-pandemic between May 2019 and July 2021.

Participants

Speech and language therapists from 19 nursing home organizations in the Netherlands invited the persons with aphasia to participate in the study. The nursing home organizations participated in the University Network for the Care sector – South Holland (UNC-ZH). Further, we used personal networks to invite nursing homes to participate in the study. Inclusion criteria were residing in a nursing home in a geriatric rehabilitation department or a unit for patients with chronic physical impairments, age 18 years or older, sufficient comprehension of the Dutch or English language before onset of aphasia and diagnosed with aphasia regardless of cause or severity. A score of ≤ 68 on the ScreeLing [17] or ≥ 7 on the TokenTest [18] implies aphasia. If diagnostic examination was not possible, the speech and language therapist's clinical judgement was decisive. Persons were excluded if they had a delirium, severe psychiatric disease, dementia, or a life expectancy ≤ 6 months according to the primary responsible physician.

Instruments

Questionnaires 1 and 2

Characteristics of persons with aphasia were assessed with two questionnaires. An informal caregiver or legal representative or the speech and language therapist, if possible, together with the person with aphasia, completed the brief questionnaire 1 with questions about persons, hand dominance, and length of stay in the nursing home. Questionnaire 1 is showed in Additional file 1 [see Additional file 1]. The speech and language therapist collected demographic characteristics and reported other more medical characteristics of the aphasia and pain treatment using questionnaire 2. Questionnaire 2 is showed in Additional file 2.

Pain observation scale

Pain symptoms were observed for five to a maximum of ten minutes using the validated Dutch version of the PAIC15 [15, 16]. The PAIC15 includes fifteen items: five in each of the three domains of facial expressions, body movements and vocalizations. Scoring options are 'not at all' (0), 'slight degree' (1), 'moderate degree' (2), 'great degree' (3) and 'not scoreable' (X). For example, the first item 'frowning' is described as moving eyebrows downwards and contracting them. 'Not at all' is scored when frowning does not occur during the observation. If this item cannot be assessed (e.g., the person turns their head away), it is rated as: 'not scoreable'. 'Slight degree' (1) is scored when frowning is observed but only briefly or with little intensity; 'great degree' (3) when frowning is observed frequently or continuously, 'moderate degree' (2) when this item is not constantly observed, but more frequent than briefly. The PAIC15 e-learning provides clear instructions on how to score each item.

Summed total scores range from 0 to 45; 0-15 for each domain. For the statistical analysis, all scores X (not scorable) were regarded as 0 [19, 20]. The observers were students of clinical neuropsychology or medicine, and nurses or speech and language therapists. They received 1.5 hours of instruction and completed the PAIC15 e-learning (https://paic15.com/en/e-training-en/).

Self-report pain scales

The four self-report pain scales used were: the vertical NRS, VAS, FPS and a combined scale. The NRS ranges from 0 (no pain) to 10 (worst pain imaginable) [2]. The VAS consists of a 10-centimetre line with extremes labelled 'no pain' and 'unbearable pain'. The person is asked to locate the pain intensity on the line. Half a centimetre is rounded up to whole numbers, e.g., 3.5 is counted as 4 centimetres [3]. The FPS comprises six coloured cartoon-faces with expressions no pain (dark green smiling face) to worst pain (dark red sad face) with the values 0, 2, 4, 6, 8, and 10 [4]. An additional file shows the self-report combined pain scale. This combined scale combines the self-report pain scales FPS and NRS [see Additional file 3]. This scale consists of the numbers zero to ten, coloured smiley faces, and written expressions of pain displayed along a vertical line. All self-report pain scales were offered in a vertical form for use in case of visual problems such as neglect or hemianopsia post stroke. The order of the first three scales was randomized, and the final self-report scale was always the combined scale.

Procedure

Questionnaires 1 and 2 were completed on paper before the observations and returned in a closed envelope. Persons with aphasia were observed during rest and transfer twice within 7 days by the same two observers. The observations were performed by trained research assistants who were not familiar with the person with aphasia.

Each observation was performed by two observers (A and B) independently (blinded). The observers were also blind with respect to the questionnaires and self-report pain scales. First, the participant's language comprehension was checked using the FPS. The participant was asked: *'Imagine you have no pain now, could you indicate which face on this scale fits this experience?'* and *'Imagine you have a severe headache at this moment, which face on this scale fits this situation?'.* If these questions were answered correctly, language comprehension to complete the self-report pain scales was assumed to be sufficient. If these questions could not be answered and self-report pain scales could not be completed, only PAIC15 was used during the observations. Next, the observers observed the participant for a minimum of five and a maximum of ten minutes during rest and completed the PAIC15 form independently. Afterwards, if applicable, the participant completed the four self-report pain scales. This procedure was repeated during transfer. The participants were observed during transfer for a minimum of 5 minutes, even when the transfer sometimes took less time.

The procedure was repeated within 7 days by the same observers. After both observations on measurement 1, the observers discussed the independent observations during rest and transfer and jointly completed a new observation form. This new observation form, with the consensus scores of PAIC15, was completed to minimize the risk of behaviour being overlooked and for quality purposes. If the observation during transfer was carried out first, the observation during rest took place after 30 minutes, to prevent the transfer influencing the observation during rest.

Statistical Analysis

Descriptive statistics of the PAIC15

First, we perform general descriptive statistics of the PAIC15 consensus scores and the self-report pain scales if these were used. Because of non-normal distribution, data were expressed as medians with interquartile range (IQR). Second, the presence of responses of the individual PAIC15 items of the consensus scores were examined, and reported in percentages, during rest and transfer. Floor or ceiling effects are defined as ≥ 15% of PAIC15 total scores scored the lowest (0: not at all) or highest possible score (3: great degree) [21]. More than 5% missing scores of items per observation form were discussed, reported, and are not imputed. No PAIC15 observation form and no person was excluded.

Criterion validity

Regarding criterion validity, we expected moderate correlations between PAIC15 and the four self-report pain scales. Because the data was not normally distributed, Spearman's correlation coefficient and a 95% confidence interval (CI) were used to calculate the correlations between the PAIC15 consensus scores and the four self-report pain scores of measurements 1 in order to determine criterion validity. To describe the strength of the correlation we used: less than 0.30 is poor, 0.3 to 0.5 is fair, 0.6 up to 0.8 moderately strong, and 0.80 and higher is very strong [22]. See Table 1 for the definitions of types of validity adapted from COnsensus based Standards for the selection of health Measurement INstruments (COSMIN) as applied in this study [23].

Table 1: Definitions of types of validity

Measurement property + adapted COSMIN definition	
Criterion validity	The degree to which the score on PAIC15 is an adequate reflection of another well-established self-report pain measure.
Construct validity/ hypotheses testing	The degree to which the PAIC15 scores are consistent with hypotheses (for instance, relationships to scores of other measures or observer report,

Construct validity

To determine construct validity, 3 hypotheses were tested:

1) *More pain is expected during transfer compared to rest in persons with aphasia.*
To assess the degree to which the PAIC15 is capable of measuring pain in persons with aphasia, we compared results of the PAIC15 between rest and transfer. Similar research in persons with dementia reported more observed pain during ADL compared to rest [24-26].

2) *More pain is expected when persons with aphasia used pain medication compared to persons who did not use pain medication.*
Also, research on pain in dementia reports more observed pain in persons who used pain medication compared to persons who do not used pain medication [27, 28] Persons still experience pain, even when they receive pain medication. Additionally, a study of hospitalized persons with dementia (n = 108) who experienced pain (assessed with Pain Assessment in Advanced Dementia (PAINAD)) found that 60% of those persons had received pain medication compared to 40% who did not receive pain medication [29].

3) *More pain is expected in persons with aphasia who have joint disease such as osteoarthritis or rheumatism versus those without joint disease.*
Osteoarthritis was the most common joint disease, and joint pain was among the most frequent pain syndromes in Europe [30-32]. It is expected that persons with aphasia and joint disease will have more pain than persons without joint disease, due to the risk of increased pain from joint problems and the difficulty in communication due to aphasia.

First, a non-parametric Wilcoxon signed rank (paired) test was used to examine whether more pain was observed during rest than during ADL. Subsequently, Mann-Whitney U tests were used to investigate if patients with aphasia who use pain medication experienced more pain than those without pain medication, and whether patients with aphasia and joint pain had more pain versus those without joint pain.

Reliability

The reliability of PAIC15 in persons with aphasia was determined by assessing internal consistency, intraobserver and interobserver agreement.

Internal consistency

The internal consistency of the PAIC15 of observers A and B together, during measurement 1, measurement 2, and measurements 1 and 2 together (consensus scores) was examined using Cronbach's alpha. Cronbach's α-values ranging from 0.70 to 0.95 are generally considered acceptable [24].

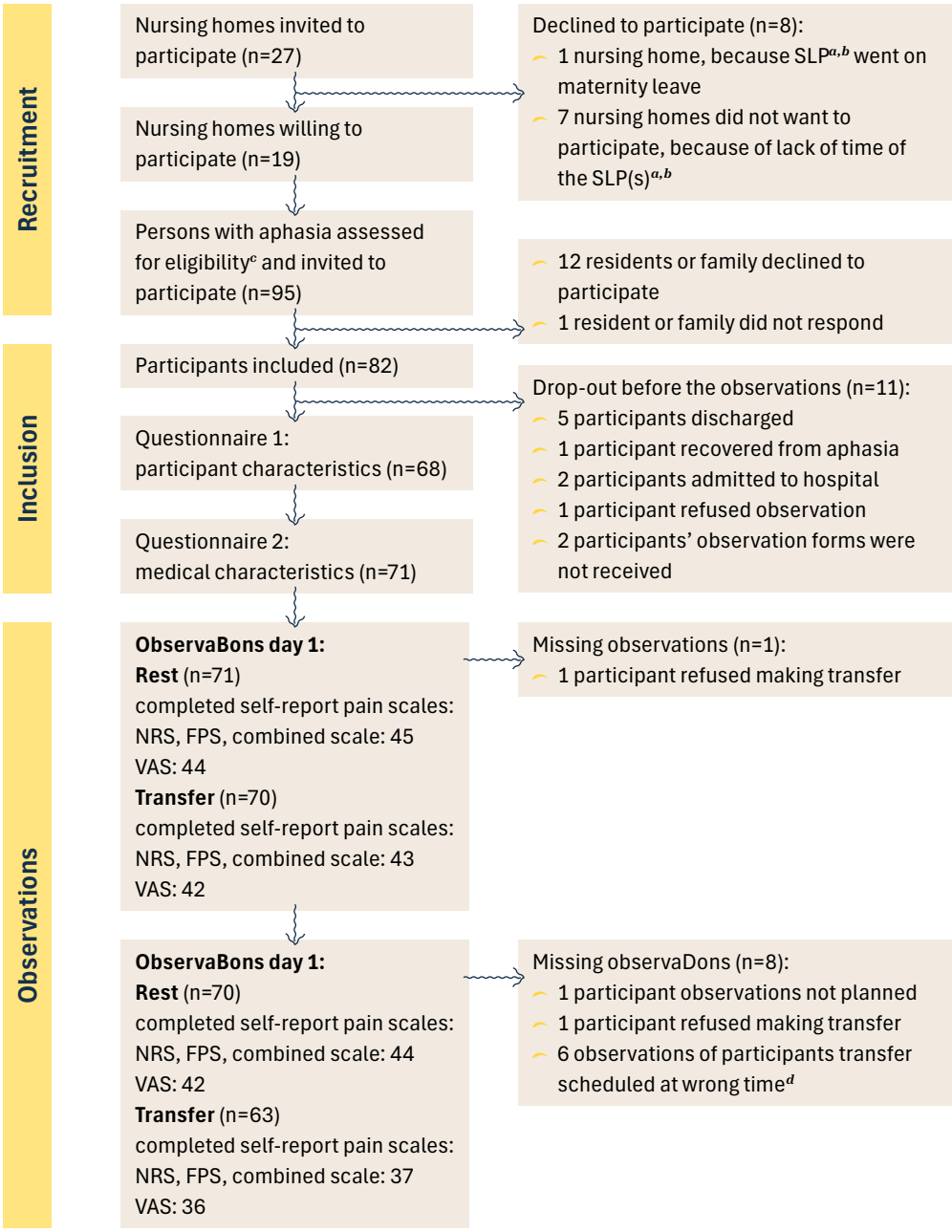
Intraobserver and interobserver agreement

The intraobserver and interobserver agreement of the individual items of PAIC15 were analysed using percentage agreement [21, 33, 34]. Percentage agreement is more suitable than for example Cohen's kappa and interpretation by clinicians is more straightforward [34]. Cohen's kappa is a relative measure of reliability, whereas percentage agreement is an absolute measurement. In clinical practice, the probability that another rater gives the same answers is of interest to healthcare professionals. Therefore, to assess intraobserver agreement, percentage agreement was calculated between the responses of each of the observers on measurements 1 and 2 during rest and transfer. Interobserver agreement was examined using percentage agreement between the PAIC15 4-point scores of observer A on measurements 1 and 2 compared to the scores of observer B on measurements 1 and 2 during rest and transfer. Percentage agreement was also calculated with dichotomized scores (0= absent; 1,2,3 = present) of the PAIC15 scores of both observers on both measurements during rest and transfer. These percentage agreements of the dichotomized scores were compared with the percentage agreements of the PAIC15 scores using the 4-point scale. Percentage agreement below 70% was regarded as poor and percentage agreement of ≥ 70% was considered high [34]. The analyses were performed using IBM SPSS Statistics version 29 for Windows, 2022.

Results

The study flowchart is presented in Fig. 1 [see Fig. 1]. Data was collected during the COVID-19 pandemic and inclusion of persons with aphasia and collecting data took longer than expected due to the closure of a department of participated nursing homes or quarantine. Speech and language therapists of 14 nursing home organizations invited 95 persons with aphasia to participate; 82 persons with aphasia were included. Pain observations were performed by trained speech and language therapists (N= 4), nurses (N= 8), and trained master's students (N=7).

The sample characteristics of the persons with aphasia are shown in Table 2. Almost two-thirds of the persons received pain medication (62%) and were able to complete at least one self-report pain scale (65%). Osteoarthritis or rheumatism were present in 9 (13%) patients (See Table 2).



a = SLP= Speech Language Pathologist often called speech and language therapist;
b = nursing homes participated if one or two speech language therapists participated;
c = Persons with aphasia without a diagnosis of aphasia, psychiatric disorder, or delirium;
d = observations took place at a time when no transfer took place (for example because the person was in bed or wheelchair).
NRS = Numeric Rating Scale; FPS = Faces Pain Scale; VAS = Visual Analogue Scale.

Figure 1: Flowchart inclusion of nursing homes and persons with aphasia

Table 2: Characteristics of the 71 participating persons with aphasia

		Mean [SD] range, or % (n)
Age		75.5 [10.6] 40-92 (n=71)
Sex	female male	63 (45) 37 (26)
Nationality	Dutch Western migration background Non-western migration background Missing	91 (62) 7 (5) 1 (1) (3)
Level of education[a]	Lower Medium High Missing	49 (33) 21 (14) 30 (20) (4)
Cause of aphasia[b]	Stroke Tumor Trauma	97 (69) 1 (1) 1 (1)
Hand dominance	Right Left Missing	93 (62) 10 (5) (4)
Total duration of hospitalization (months)	(n=66)	11.8 [24] 3-123
Pain medication	Yes No Missing	63 (44) 39 (26) (1)
Joints diseases (osteoarthritis/ rheumatism)	Yes No Missing	14 (9) 86 (55) (7)
Complete self-report pain scales	Yes No Missing	66 (46) 34 (24) (1)

a = International Standard Classification of Education (ISCED): Lower= 8 years of primary and special primary education; prevocational secondary education; lower secondary vocational training and assistant's training. Medium= upper secondary education, (basic) vocational training, middle management and specialist education. Higher= higher education, 4-year education at universities of applied sciences and research universities; doctoral degree programs at research universities (UNESCO, 2012).

b = the percentages do not always sum up to 100, due to rounding to whole decimal places.

Descriptive statistics of the PAIC15

The descriptive statistics of PAIC15, based on the PAIC15 consensus scores of measurements 1, and the self-report pain scales in persons with aphasia are presented in Table 3. See Additional file 4 for the descriptive statistics of the individual observations using PAIC15 of observers A and B [see Additional file 4]. Table 4 shows the presence of responses on the individual

PAIC15 consensus scores in percentages during rest and transfer. During rest, prevalence of all PAIC15 items was low except for the facial expression item 'opening mouth', which had a prevalence of ≥30%. More items with higher prevalence were found during transfer; three items in the domain's facial expressions and one item in the domain vocalizations showed a prevalence of ≥ 30%. All other items had a lower prevalence than 30%, during rest and during transfer (See Table 4). In most cases, the item 'resisting care' was 'not scoreable' during rest because healthcare professionals were often not present or not providing care. Both during rest and transfer, there is a floor effect with frequencies higher of 15% on score '0-not at all'. No ceiling effect emerged. Less than 5% of responses were missing.

Table 3: Descriptive statistics of the PAIC15[a] consensus scores[b] and self-report pain scales[c] in persons with aphasia during assessment 1.

Instrument	N	Median (IQR)	Observed Range
During rest:			
PAIC15 total score (range 0-45)	71	1 (1-3)	0-21
Self-report pain scales (range 0-10)			
FPS	46	2 (0-4)	0-10
NRS	46	2 (0-4)	0-10
VAS	45	1 (0-4)	0-8
Combination scale	46	2 (0-4)	0-10
During transfer:			
PAIC15 total score (range 0-45)	70	3 (2-6)	0-18
Self-report pain scales (range 0-10)			
FPS	43	2 (0-4)	0-10
NRS	43	2 (0-4)	0-9
VAS	42	1 (0-4)	0-9
Combination scale	43	2 (0-4)	0-9
Days between assessment 1 and 2	62	3 (2-5)	1-7

a = Pain Assessment in Impaired Cognition with 15 items, subdomain ranges of 0-15 and a total range of 0-45.

b = the consensus scores of PAIC15 was based on consensus after discussing scores after independent observations during rest and transfer on day 1. c: the range of self-report pain scales is: 0-10.

IQR = Interquartile Range;

FPS = Faces Pain Scale;

NRS = Numeric Rating Scale;

VAS = Visual Analogue Scale.

Table 4: Scores per item of PAIC15[a] consensus scores (in percentages) during rest (N= 71) and during transfer (N=70) in patients with aphasia

Score: / Items:	Not scoreable		0 - not at all		1 - slight degree		2 - moderate degree		3 - great degree	
Facial expressions	**Rest n=71**	**Transfer n=70**	**Rest n=71**	**Transfer n=70**	**Rest n=71**	**Transfer n=70**	**Rest n=71**	**Transfer n=70**	**Rest n=71**	**Transfer n=70**
1 Frowning			70	49	27	38	3	11		
2 Narrowing eyes			87	70	11	23	1	6		
3 Raising upper lip			93	68	4	28	3	3		
4 Opening mouth			54	31	42	55	3	13	1	
5 Looking tense			69	45	28	41	1	13	1	
Body movements										
6 Freezing			94	72	4	25	1	1		
7 Guarding		1	90	87	7	6	1	4	1	
8 Resisting care	70	43	30	54		3				
9 Rubbling			93	93	3	3	3	3	1	
10 Restlessness			89	90	9	7	3	1		
Vocalizations				**n=69**		**n=69**		**n=69**		**n=69**
11 Using pain-related-words			97	80	1	7	1	4		
12 Shouting			96	93	3	3			1	1
13 Groaning			94	55	6	34		7		1
14 Mumbling			89	83	10	11	1	3		
15 Complaining			96	93	4	4	3			

a = PAIC15: Pain Assessment in Impaired Cognition with 15 items.

Validity

Criterion validity

Correlations between PAIC15 consensus scores and the self-report pain scales of measurement 1 during rest and transfer are shown in Table 5. The PAIC15 had fair positive correlations with NRS, VAS, FPS, and the combined scale during rest (ranging from 0.35 with NRS to 0.50 with VAS). During transfer, the correlations between PAIC15 and the NRS, VAS and the combined scale were fair positive, varying from 0.38 (combined scale) to 0.43 (VAS). The PAIC15 correlated poorly with FPS (0.26).

Table 5: Correlation of PAIC15[a] consensus scores[b] versus self-report pain scales total scores in patients with aphasia during rest and during transfer

Instrument	Spearman's rho	PAIC15	FPS	NRS	VAS	Combination scale
Rest						
PAIC15	Correlation Coefficient N	1 71	0.43** 45	0.35* 45	0.50** 44	0.44** 45
FPS	Correlation Coefficient N		1 45	0.69** 45	0.63** 44	0.84** 45
NRS	Correlation Coefficient N			1 45	0.84** 44	0.79** 45
VAS	Correlation Coefficient N				1 44	0.71** 44
Transfer						
PAIC15	Correlation Coefficient N	1 70	0.26 43	0.40** 43	0.43** 42	0.38* 43
FPS	Correlation Coefficient N		1 43	0.73** 43	0.87** 42	0.92** 43
NRS	Correlation Coefficient N			1 43	0.84** 42	0.81** 42
VAS	Correlation Coefficient N				1 42	0.92** 42

* = $p < .050$

** = $p < .010$

a = Pain Assessment in Impaired Cognition with 15 items, subdomain ranges of 0-15 and a total range of 0-45.

b = the consensus scores of PAIC15 was based on consensus after discussing scores after independent observations during rest and transfer on day 1.

FPS = Faces Pain Scale; possible range 0-10.

NRS = Numeric Rating Scale; possible range 0-10.

VAS = Visual Analogue Scale; possible range 0-10. Combination scale: possible range 0-10

Construct validity

For the construct validity, the results of the 3 hypotheses that were tested show that significant more pain was observed in persons with aphasia during transfer (median 3; IQR 2-6) than during rest (median 1; IQR 1-3); z = -4.15, p < .05.

Observations with the PAIC15 during rest showed more pain in persons with aphasia using pain medication (median 1.5; IQR 1-3.75) versus persons who use no pain medication (median 1; IQR 0-2). However, this difference was not significant, U ($N_{\text{using pain medication}}$ = 44, $N_{\text{using no pain medication}}$ = 26,) = 463, z = -1.36, p = .175. Similar results were found during transfer (with pain medication: median 3; IQR 2-6.75; without pain medication: median 3; IQR 2-5.5); U ($N_{\text{using pain medication}}$ = 44, $N_{\text{using no pain medication}}$ = 25,) = 487, z = -.80, p = .423. Our hypothesis was rejected.

During rest, less pain was observed in persons with joint diseases such as osteoarthritis or rheumatism (median 1; IQR 1-2.5) versus persons without these diseases (median 1; IQR 1-3). However, the difference was not significant; U ($N_{\text{osteoarthritis/rheumatism}}$ = 9, $N_{\text{no osteoarthritis/rheumatism}}$ = 55) = 238, z = -.19, p = .851. Similar results were found during transfer (with joint disease: median 2; IQR 1.5-6; without joint disease: median 3; IQR 2-6.25); U ($N_{\text{osteoarthritis/rheumatis}}$m= 9, $N_{\text{no osteoarthritis/rheumatism}}$ = 54) = 190, z = -1.05, p = .293. Our hypothesis was rejected.

Reliability

Internal consistency

The internal consistency of the PAIC15 was acceptable, varying between α= 0.73 and 0.93 during rest and between α= 0.82 and 0.85 during transfer. These values were assessed using the combined PAIC15 scores of observers A and B, during measurement 1, measurement 2 and measurement 1 and 2 together.

Intraobserver and interobserver agreement

Table 5 presents the intraobserver and interobserver agreement of the PAIC15 scores with the 4-point scale in persons with aphasia during rest and transfer. See Table 5 with percentages of ≥ 70% shaded- in green. Of the items in the domain facial expressions, all except 'opening mouth' showed high intraobserver agreement (≥70%) during rest. During transfer, agreement was high only on the items 'narrowing eyes' and 'raising upper lip'. Interobserver agreement was also high (≥70%) during rest. During transfer, only the items 'narrowing eyes' and 'raising upper lip' achieved high agreement (≥70%), as did intraobserver agreement. Of all items in the domains body movements and vocalizations, intra- and interobserver agreement was >70% during rest and transfer. Percentage agreement was also assessed after dichotomization of the PAIC15 scores, indicating that pain related behaviours were either present (score 1-3) or absent (score 0). Intra- and interobserver agreement of the PAIC15 dichotomized scores are also presented in Table 6. This resulted in higher agreement percentages than when using the 4-point scale (Table 6). All dichotomized scores of the 15 items showed good reliability with percentages of 70 or higher for both intra- and interobserver agreement during rest and transfer.

Table 6: Intra- and interobserver agreement of the PAIC15[a] scores (in percentages) during rest and transfer in 71 patients with aphasia, both with 4-point and dichotomized sore.

	PAIC15 scores on the 4-point scale				PAIC15 dichotomized scores			
PAIC15 item	**Intraobserver agreement** Percentage agreement		**Interobserver agreement** Percentage agreement		**Intraobserver agreement** Percentage agreement		**Interobserver agreement** Percentage agreement	
	Rest	**Transfer**	**Rest**	**Transfer**	**Rest**	**Transfer**	**Rest**	**Transfer**
Facial expressions								
1 Frowning	72	65	84	66	74	77	84	78
2 Narrowing eyes	91	82	96	80	92	86	96	84
3 Raising upper lip	94	79	96	72	94	82	96	76
4 Opening mouth	63	58	84	63	70	72	85	77
5 Looking tense	74	57	84	61	76	73	86	71
Body movements								
6 Freezing	95	82	98	76	96	85	99	78
7 Guarding	94	85	98	84	97	90	99	88
8 Resisting care	89	90	95	88	91	90	95	88
9 Rubbling	93	93	98	95	94	94	98	96
10 Restlessness	89	91	94	91	91	92	96	92
Vocalizations								
11 Using pain-related-words	97	80	99	90	97	82	99	94
12 Shouting	95	99	97	97	95	99	98	98
13 Groaning	93	71	95	76	94	78	96	82
14 Mumbling	93	84	93	86	91	85	94	88
15 Complaining	93	88	96	90	93	88	97	91

Discussion

This study aimed to examine the validity and reliability of the pain observation instrument PAIC15 in persons with aphasia and is therefore of clinical value for professionals to optimize pain assessment in persons with aphasia. Descriptive statistics of PAIC15 show that self-reporting pain was not possible in one third of participants (24/71). The prevalence of individual items of the PAIC15 observed in persons with aphasia was low for most items. Higher prevalence was observed in the domain facial expressions. This is in accordance with findings of a PAIC15 study in

a long-term care setting in patients with dementia [35]. The items of the domains body movements and vocalizations showed the lowest prevalence. This result was expected, because of the minimal movement of the musculoskeletal system during rest. Regarding results during transfer, the overall prevalence of the individual items of PAIC15 was higher compared to the results during rest, which was expected.

Validity

The results of the current study indicate fair criterion validity because of largely fair positive correlations between PAIC15 and the self-report pain scales that could be completed by persons with aphasia. This study utilized consensus scores of PAIC15 after discussing the scores recorded by observer A and B following independent observations during rest and transfer on measurement 1. These consensus scores were needed to assess the correlations between the PAIC15 and self-report pain scales. If we compare the consensus scores to the scores of the independent observations, a few of the consensus scores were higher. However, discussion of the combined independent observations by observers A and B still yielded a higher score. An implication of this study is that using two observers improves the PAIC15 scores, because two observers see more than one observer during rest and transfer.

Another important finding, in terms of construct validity and assessed with hypothesis 1: significantly more pain was observed with the PAIC15 during transfer compared to during rest. However, hypothesis 2 (more pain observed when treated with pain medication compared to no-pain medication) was rejected. Contrary to studies of pain and pain medication in persons with dementia [27, 28], we did not find more pain in persons with aphasia when pain medication was used compared to when not treated with pain medication. Many studies have stressed that pain after stroke was under-recognized and persons received inadequate pain management [1, 37]. When pain is under-recognized and undertreated, while treatment would be effective, this hypothesis may not be suitable. Hypothesis 3 was also rejected because there was no difference in observed pain in persons with aphasia with and without joint disease. Joint disease is one of the most frequent general causes of pain, yet indeed, joint disease is not specific to stroke patients. Stroke patients experience significant pain after stroke, especially headache, shoulder pain, pain from increased muscle stiffness, and central post-stroke pain which are not related to joint disease and are uncommon in this study sample [38, 39]. Therefore, this hypothesis may not work well in this population and further research on causes of pain in stroke patients is warranted.

Reliability

Acceptable internal consistency of PAIC15 in persons with aphasia was examined. We found that intra- and interobserver agreement for the items of the PAIC15 domains body movements and vocalizations are both good (≥70%). Results on the domain facial expressions show good intraobserver agreement for almost all items and good interobserver for all items during rest. This is contrary to the findings during transfer with a high percentage only on both

intra- and interobserver agreement for the items 'narrowing eyes' and 'raising upper lip'. These results resemble those of Van Dalen-Kok et al. [36] who also found that fewer items in the domain facial expressions had good intraobserver- and interobserver agreement during both rest and transfer. Lower intra- and interobserver agreement for the facial expression items suggest that these items are more difficult to observe in a clinical setting. Research of Oosterman et al. [40] reported that recognizing and observing facial expressions for pain assessment in dementia requires specific training and education [40]. Assessing pain based on the observation of facial expressions in persons with dementia can be compared to persons with aphasia, because of their impaired cognition and communications problems. Percentages of 70 or higher for both intra- and interobserver agreement indicate good reliability of PAIC15 with dichotomized scores. This implies that assessing the presence of a pain-related item using PAIC15 is more reliable than assessing the degree/intensity of the pain-related items of PAIC15 with the 4-point scale in persons with aphasia.

Strength and limitations

Our study is the first to explore alternative methods for the long-standing and distressing situation of poor assessment and management of pain in persons with aphasia. Other strengths include the use of clinical situations and providing elaborate training for the research assistants. Also, no other pain research in persons with aphasia has used several self-report pain scales and a combined self-report scale. A limitation is that we did not check the competency of the different raters after training. However, we used a standardized training, and each first observation of an observer was carried out with the researcher for instructions and practice in using PAIC15 independently. The prevalence of individual items observed in persons with aphasia was low for most items. The scores 2 and 3 of the PAIC15 were rarely rated, due to the fact that the observed persons with aphasia showed few items and the observers struggled to differentiate between score 2 or 3. Deciding between a 2 or 3 could be difficult, when is someone frowning with a 'moderate' or 'great degree'? The rating of these scores has recently been revised and adjusted in the online PAIC15 e-learning.

It is also possible that the low scores are due to failure to observe behavior described in the PAIC15 items in persons with aphasia after stroke. This could lead to the question whether reporting items 'not at all' means that these persons do not experience any pain? This raises questions about the applicability of the PAIC15 in this population. However, literature reported that persons with aphasia can also experience pain, especially if they have communication problems. If this is the case and a self-report pain scale cannot be completed, pain may not be detected. The PAIC15 can meet this need by observing possible behaviors that indicate possible pain.

Another limitation might be that the time between the observations of measurements 1 and 2 varied from 1 to 7 days, and the use of self-report pain scales was not checked again after 7 days.

Depending on the recovery of the stroke, it is recommended to check if self-reporting of pain is possible a week later. Within rehabilitation, spontaneous recovery can certainly occur within 7 days or the situation changes, e.g., re-admission to hospital or discharge home. These changes could affect the intraobserver agreement more strongly if the interval is 7 instead of 2 days.

Results may have been influenced because of current study was conducted during the COVID-19 pandemic. Which means that participants were observed during a period with restrictive rules to reduce the spread of COVID-19. These circumstances may potentially have influenced the observed behaviors of the participants using PAIC15, Future studies are recommended to determine if the results are valid in the post-COVID era.

Conclusions

Results show fair criterion validity, and significantly more pain was observed during transfer compared to rest using PAIC15 regarding construct validity. Regarding reliability, we found an acceptable internal consistency of PAIC15 and good intra- and interobserver agreement for most PAIC15 items, particularly for the domains body movements and vocalizations in persons with aphasia. This study shows that PAIC15 can be used to assess pain in persons with aphasia. Further research in the daily practice setting should clarify whether combining PAIC15 with self-report and other clinical leads will deliver results that can be confidently used in practice.

Abbreviations

PAIC15	Pain Assessment in Impaired Cognition
NRS	Numerical Rating Scale
VAS	Visual Analog Scale
FPS	Faces Pain Scale
EU-COST	European Cooperation in Science and Technology
UNC-ZH	Network for the Care sector – South Holland
COSMIN	COnsensus based Standards for the selection of health Measurement INstruments
COVID-19	coronavirus caused by severe acute respiratory syndrome -coronavirus -2
WMO	Medical Research Involving Human Subjects Act

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

Supplementary Material 4.

136

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Authors' contributions

All authors have had substantial contributions to the design of the study. NJdV collected the data. NJdV, WA and HJAS analyzed and interpreted the data. NJdV, HJAS and WA drafted the manuscript. HJAS, JTvdS and WA reviewed the manuscript critically. All authors gave final approval of the manuscript to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Availability of data and materials

The datasets are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study protocol (P18.230) was reviewed by the Medical Ethics Review Committee Leiden-The Hague-Delft, and declared exempt from the Medical Research Involving Human Subjects Act (WMO). The study was conducted according to the guidelines of the Declaration of Helsinki. Informed consent was obtained using aphasia-friendly informed consent forms. When there was doubt about the ability to provide informed consent, informed consent was obtained from the legal representative.

Consent for publication

Informed consent for publication collected data was obtained from persons with aphasia using aphasia-friendly informed consent forms or from the legal representative.

Competing interests

The authors declare no competing interests.

References

1. Harrison, R.A. and T.S. Field, *Post stroke pain: identification, assessment, and therapy.* Cerebrovasc Dis, 2015. **39**(3-4): p. 190-201.
2. Hjermstad, M.J., et al., *Studies Comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for Assessment of Pain Intensity in Adults: A Systematic Literature Review.* J Pain Sym Man, 2011. **41**(6): p. 1073-1093.
3. Heller, G.Z., M. Manuguerra, and R. Chow, *How to analyze the Visual Analogue Scale: Myths, truths and clinical relevance.* Scand J Pain, 2016. **13**: p. 67-75.
4. Kim, E.J. and M.T. Buschmann, *Reliability and validity of the Faces Pain Scale with older adults.* Int J Nurs Stud, 2006. **43**(4): p. 447-56.
5. de Vries, N.J., P.H. Sloot, and W.P. Achterberg, *Pain and pain assessment in stroke patients with aphasia: a systematic review.* Aphasiology, 2017. **31**(6): p. 703-719.
6. Benaim, C., et al., *Use of the Faces Pain Scale by left and right hemispheric stroke patients.* Pain, 2007. **128**(1-2): p. 52-58.
7. de Vries, N.J., P.H. Sloot, and W.P. Achterberg, *Pain and pain assessment in stroke patients with aphasia: a systematic review.* Aphasiology, 2016. **31**(6): p. 703-719.
8. Smith, J.H., et al., *Inability to self-report pain after a stroke: a population-based study.* Pain, 2013. **154**(8): p. 1281-6.
9. Mandysova, P., et al., *Assessment instruments used for self-report of pain in hospitalized stroke patients with communication problems: a scoping review.* Jbi Evidence Synthesis, 2022. **20**(6): p. 1511-1536.
10. Price, C.I.M., R.H. Curless, and H. Rodgers, *Can stroke patients use visual analogue scales?* Stroke, 1999. **30**(7): p. 1357-1361.
11. Husebo, B.S., W. Achterberg, and E. Flo, *Identifying and Managing Pain in People with Alzheimer's Disease and Other Types of Dementia: A Systematic Review.* CNS Drugs, 2016. **30**(6): p. 481-97.
12. de Vries, N.J., et al., *Measuring Pain in Aphasia: Validity and Reliability of the PACSLAC-D.* Pain Manag Nurs, 2023. **24**(4): p. e68-e74.
13. Herr, K., et al., *Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations.* Pain Manag Nurs, 2011. **12**(4): p. 230-50.
14. Lautenbacher, S., A.L. Walz, and M. Kunz, *Using observational facial descriptors to infer pain in persons with and without dementia.* BMC Geriatr, 2018. **18**.
15. Kunz, M., et al., *The Pain Assessment in Impaired Cognition scale (PAIC15): A multidisciplinary and international approach to develop and test a meta-tool for pain assessment in impaired cognition, especially dementia.* Eur J Pain, 2020. **24**(1): p. 192-208.
16. van Dalen-Kok, A.H., et al., *Pain Assessment in Impaired Cognition (PAIC): content validity of the Dutch version of a new and universal tool to measure pain in dementia.* Clin Interv Aging, 2018. **13**: p. 25-34.
17. El Hachioui, H., et al., *The ScreeLing: occurrence of linguistic deficits in acute aphasia post-stroke.* J Rehabil Med, 2012. **44**(5): p. 429-35.
18. Doesborgh, S.J., et al., *Linguistic deficits in the acute phase of stroke.* J Neurol, 2003. **250**(8): p. 977-82.

19. de Waal, M.W.M., et al., *Observational pain assessment in older persons with dementia in four countries: Observer agreement of items and factor structure of the Pain Assessment in Impaired Cognition.* Eur J Pain, 2020. **24**(2): p. 279-296.

20. van der Steen, J.T., et al., *Probable Pain on the Pain Assessment in Impaired Cognition (PAIC15) Instrument: Assessing Sensitivity and Specificity of Cut-Offs against Three Standards.* Brain Science, 2021. **11**(7).

21. De Vet, H., Terwee, C.B., Mokkink, L.B., Knol, D.L., *Measurement in Medicine. A Practical Guide.*, ed. P.g.t.B.a. Epidemiology. 2011, Cambridge: Cambridge University Press.

22. Chan, Y.H., Biostatistics 104: *Correlational Analysis.* Singapore Medical Journal, 2003. **44**(12): 614-619.

23. Mokkink, L.B., et al., *The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes.* J Clin Epidemiol, 2010. **63**(7): p. 737-45.

24. Hadjistavropoulos, T., et al., *Pain assessment in elderly adults with dementia.* Lancet Neurol, 2014. **13**(12): p. 1216-1227.

25. Lints-Martindale, A.C., et al., *A Comparative Investigation of Observational Pain Assessment Tools for Older Adults With Dementia.* Clinical Journal of Pain, 2012. **28**(3): p. 226-237.

26. Zwakhalen, S.M., et al., *Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools.* BMC Geriatr, 2006. **6**: p. 3.

27. Rajkumar, A.P., et al., *Epidemiology of Pain in People With Dementia Living in Care Homes: Longitudinal Course, Prevalence, and Treatment Implications.* J Am Med Dir Assoc, 2017. **18**(5): p. 453.e1-453.e6.

28. van Dam, P.H., et al., *Quality of Life and Pain Medication Use in Persons With Advanced Dementia Living in Long-Term Care Facilities.* J Am Med Dir Assoc, 2019. **20**(11): p. 1432-1437.

29. Boltz, M., Resnick, B., Kuzmik, A., Mogle, J., Jones, J. R., Arendacs, R., BeLue, R., Cacchione, P., & Galvin, J. E. (2021). *Pain Incidence, Treatment, and Associated Symptoms in Hospitalized Persons with Dementia.* Pain Management Nursing, **22**(2), 158-163.

30. Arendt-Nielsen, L., *Joint pain: more to it than just structural damage?* Pain, 2017. **158 Suppl 1**: p. S66-S73.

31. Breivik, H., et al., *Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment.* Eur J Pain, 2006. **10**(4): p. 287-333.

32. Ebell, M.H., *Osteoarthritis: Rapid Evidence Review.* Am Fam Physician, 2018. **97**(8): p. 523-526.

33. Bland, H.M. and D.G. Altman, *Cronbach's Alpha.* British Medical Journal, 1997. **314**(7080): p. 572.

34. de Vet, H.C., et al., *When to use agreement versus reliability measures.* J Clin Epidemiol, 2006. **59**(10): p. 1033-9.

35. de Vet, H.C., et al., *Clinicians are right not to like Cohen's kappa.* BMJ, 2013. **346**: p. f2125.

36. van Dalen-Kok, A.H., et al., *Pain assessment in impaired cognition: observer agreement in a long-term care setting in patients with dementia.* Pain Manag, 2019. **9**(5): p. 461-473.

37. Widar, M., et al., *Long-term pain conditions after a stroke.* J Rehabil Med, 2002. **34**(4): p. 165-70.

38. Trouvin, A.P. and S. Perrot, *Pain in osteoarthritis. Implications for optimal management.* Joint Bone Spine, 2018.

85(4): p. 429-434.
39. Liampas, A., et al., *Prevalence and Management Challenges in Central Post-Stroke Neuropathic Pain: A Systematic Review and Meta-analysis.* Advances in Therapy, 2020. **37**(7): p. 3278-3291.
40. Oosterman, J.M., et al., *The use of facial expressions for pain assessment purposes in dementia: a narrative review.* Neurodegener Dis Manag, 2016. **6**(2): p. 119-31.

Additional file 1: Questionnaire 1

Questionnaire for informal caregiver/ legal representative

ID-number:

Instruction

Thank you for your participation in the study "Measuring pain in aphasia".
We would like to get some background information on your spouse, family member / fellow creator.

Can you please complete this questionnaire and return it via the enclosed return envelope to the Department of Public Health and Primary Care of the LUMC? We would like to receive your completed questionnaire before _____ / _____ / 2020.

Completing this questionnaire will take approximately 10 minutes.

142

For each question, please tick the answer that best describes your family member / the person with aphasia. When multiple answers can be given, this will be mentioned in the question. Try to answer all questions as possible.

Thank you for your contribution!

Do you still have questions after reading this?
Contact: Carolien de Vries, executive researcher via E: n.j.de_vries@lumc.nl or T: +316-...

1. **Today's date (dd/mm/yyyy): _____ / _____ / _____**

2. **What is your relationship with the person with aphasia?**
   - ○ husband/ wife/ partner
   - ○ sister/ brother/ sister-in-law/ brother-in-law
   - ○ daughter/ son/ daughter-in-law/ son-in-law.
   - ○ legal representative
   - ○ other, namely:

3. What is the cultural background of the person with aphasia?

○ my family member / legal representative has a Dutch nationality or cultural background

○ my family member / legal representative has a Western migration background
(This means that the country of origin is in Europe (excluding Turkey), North America, New Zealand, New Guinea, Australia, Indonesia, and Japan.)

○ my family member / legal representative has a non-Western migration background
(This means that the country of origin is in Africa, Latin America and Asia (including Turkey))

4. What is the mother tongue of the person with aphasia?

○ Dutch

○ Other, namely:

5. What is the education level of the person with aphasia?

○ Primary education (LO)/ Home school (HH)

○ Lower Vocational Education (LBO)

○ Lower General Vocational Education (MULO; MAVO)

○ Higher General Vocational Education (HAVO); Secondary Vocational Education (MBO)

○ Secondary Scientific Education (VWO); Higher Professional Education (HBO)

○ Scientific Education (WO)

6. With which hand did the person with aphasia write?

○ Right

○ Left

○ Ambidextrous

○ Unknown

7. How long will the person with aphasia stay in the nursing home?

Length of residence in years and months: _____ **years +** _____ **months.**

Thank you for completing and returning this questionnaire!

Please send this form via the enclosed return envelope to:

LUMC; Dept. PHEG
attn. Mrs. N.J. (Carolien) de Vries
Hippocratespad 21
2333 ZD LEIDEN
Postal zone V0-P

Additional file 2: Questionnaire 2

Questionnaire for healthcare professionals

ID-number:

Instruction

This questionnaire aims to collect data for the study "Measuring pain in aphasia: self-report or observation?"
As a healthcare professional involved with the person with aphasia who participates in this study, you have been asked to complete this form using the participant's data from the electronic client file.

Please select one answer per question unless otherwise indicated. If there is an option to check more than one answer, select the answer that applies to the participant.
Completing the questionnaire will take approximately 10 minutes.

We would like to receive your completed questionnaire before _____ / _____ / 2020.

Please send the completed questionnaire in the enclosed return envelope to the Public Health and Primary Care Department of the LUMC.
Do you still have questions after reading this? Contact: Carolien de Vries, executive researcher via E: n.j.de_vries@lumc.nl or T: +316-.....

General data:

1. **Today's date (dd/mm/yyyy): _____ / _____ / _____**

2. **Participant's month and year of birth (mm/yyyy): _____ / _____**

3. **Gender of participant:**
   ○ Female
   ○ Male

Medical data:

1. **Date of onset of aphasia (dd/mm/yyyy):** _____ / _____ / _____

2. **Research aphasia:**

   Enter the total scores of the aphasia examinations and the date of administration in the table below. If multiple examinations have been conducted, enter the details of the last examination. When possible, enter the scores of various examinations.

Examination	Date of collection: (dd/mm/yyyy)	Score:	Comments:
ScreeLing	___ / ____ / _____	Total score:	
Token Test or Token Test Shortened*	___ / ____ / _____		
Other, namely:	___ / ____ / _____		

* = delete the test that is not applicable

3. **Cause of aphasia:**

   ○ Stroke / CVA (= cerebrovascular accident)

   ○ Brain tumor (go to question 7)

   ○ Trauma / accident (go to question 7)

   ○ Infection (go to question 7)

4. **Localization and type of stroke:**

   ○ Right hemisphere infarction

   ○ Left hemisphere infarction

   ○ Hemorrhage. If yes, localization: _____

   ○ Other, namely: _____

5. **First Stroke / CVA:**

   ○ Yes (go to question 7)

   ○ No, this is number: _____

6. Dates of previous stroke/CVA:

Enter the date and localization of any previous stroke(s)/ CVA(s) in the table below.

Date previous stroke/CVA:	Type: Infarction or hemorrhage	Localization: Left hemisphere, right hemisphere, brainstem, cerebellum, thalamus, frontal, parietal, etc.	Comments:
___ / ____ / _____			
___ / ____ / _____			
___ / ____ / _____			
___ / ____ / _____			

7. Which pain treatment is the participant currently receiving?

Check what applies. You can select multiple options.

○ **non-pharmacological methods:**

- ○ physiotherapy
- ○ occupational therapy
- ○ exercise therapy
- ○ posture advice
- ○ transcutaneous electrical neurostimulation (TENS)
- ○ massage
- ○ distraction
- ○ other, namely:
- ○ none of the above

○ **pain medication**

8. Start date of pain medication (dd/mm/yyyy): _____ / _____ / _____

9. Dosage of pain medication:

_____

_____

_____

_____

10. Possible other causes of pain (comorbidity):

Check the current diseases and conditions of the patient. Multiple answers are possible

- ○ stroke, cerebral hemorrhage, cerebral infarction or TIA
- ○ heart failure
- ○ ischemic heart disease
- ○ arrhythmias
- ○ hypertension
- ○ peripheral vascular disease
- ○ a form of cancer (malignant condition)
- ○ cardiovascular disease other than the above, namely: _____
- ○ diabetes
- ○ asthma, chronic bronchitis, emphysema or CARA / COPD
- ○ urinary incontinence
- ○ joint wear (arthrosis, wear and tear rheumatism) of the hips or knees
- ○ bone decalcification (osteoporosis)
- ○ broken hip
- ○ fractures other than a broken hip
- ○ dizziness with falls
- ○ prostate complaints due to benign prostate enlargement
- ○ depression
- ○ anxiety / panic disorder
- ○ hearing problems
- ○ problems with vision
- ○ convulsions / epilepsy
- ○ anemia
- ○ vitamin B12 deficiency
- ○ thyroid abnormalities
- ○ chronic renal insufficiency
- ○ duodenal ulcer / ventriculi / oesophagitis
- ○ other endocrine/metabolic disorder, namely: _____
- ○ other important psychiatric diagnosis, namely: _____
- ○ other serious lung or respiratory disease, namely: _____
- ○ another condition, namely: _____

11. Other comments:

_____

_____

_____

_____

Thank you for completing this questionnaire!

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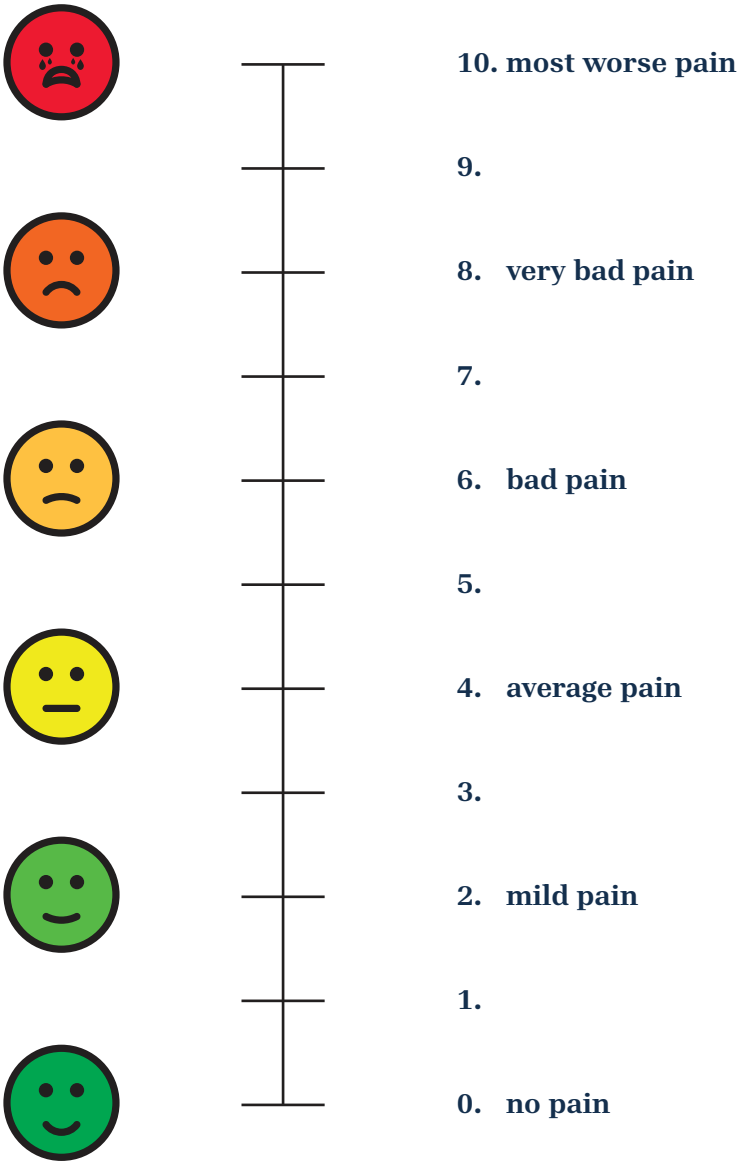
Additional file 3: Self-report combined pain scale

Combined scale, a combination of Numerical Rating, Verbal Rating, Visual Analogue Scale and Faces Pain Scale



Additional file 4: Descriptive statistics of the PAIC15a of observer A and B and the self-report pain scalesb in persons with aphasia during rest and transfer at assessments 1 and 2.

	Assessment 1			Assessment 2		
Instrument	**N**	**Median (IQR)**	**Observed Range**	**N**	**Median (IQR)**	**Observed Range**
During rest						
PAIC15 total score A	71	1 (0-2)	0-20	69	1 (0-2)	0-11
PAIC15 total score B	71	1 (0-3)	0-29	62	1 (0-2)	0-11
Self-report pain scales						
FPS	46	2 (0-4)	0-10	44	2 (0-4)	0-8
NRS	46	2 (0-4)	0-10	44	1.5 (0-3)	0-9
VAS	45	1 (0-4)	0-8	42	1 (0-4)	0-9
Combined scale	46	2 (0-4)	0-10	44	2 (0-4)	0-8
During transfer						
PAIC15 total score A	67	2 (1-5)	0-17	59	2 (1-5)	0-19
PAIC15 total score B	67	3 (1-7)	0-14	55	2 (1-5)	0-25
Self-report pain scales						
FPS	43	2 (0-4)	0-10	37	2 (0-4)	0-10
NRS	43	2 (0-4)	0-9	37	2 (0-5)	0-9
VAS	42	1 (0-4)	0-9	36	1.5 (0-5)	0-10
Combined scale	43	2 (0-4)	0-9	37	2 (0-4)	0-9
Days between assessment 1 and 2	62	3 (2-5)	1-7			

a = Pain Assessment in Impaired Cognition with 15 items, subdomain ranges of 0-15 and a total range of 0-45.

b = the range of self-report pain scales is: 0-10.

IQR = Interquartile Range;

FPS = Faces Pain Scale;

NRS = Numeric Rating Scale;

VAS = Visual Analogue Scale.

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and W.P. Achterberg

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Chapter 6

User-friendliness of the Pain Assessment in Impaired Cognition (PAIC15) in persons with aphasia: a pilot study

Keywords:

- pain;
- pain observation;
- aphasia;
- user-friendliness;
- PAIC15;
- user-friendliness

Abstract

Background: Persons with aphasia have difficulties communicating pain symptoms.

Methods: Thirteen observers performed multiple observations using the Pain Assessment in Impaired Cognition (PAIC15) scale for persons with aphasia during rest and transfer in persons with aphasia. This pilot study examined the user-friendliness of PAIC15 and preference for type of self-report pain scales with a questionnaire.

Results: The PAIC15 was considered user-friendly for persons with aphasia: items were clear and not difficult to score. When self-report is possible, the combined scale with verbal, visual, and numerical elements is preferred for persons with aphasia.

Conclusion: PAIC15 is a helpful instrument to aid clinical judgement and to screen for the presence of pain in persons with aphasia. There were mixed opinions, but most observers preferred to use the combined self-report scale for persons with aphasia.

Plain language summary

The Pain Assessment in Impaired Cognition (PAIC15) is an observation instrument that can be used to screen for pain in persons who are not able to express themselves. The pilot study investigated if the PAIC15 is user-friendly when applied to persons with aphasia (i.e., a language disorder caused by brain damage). A questionnaire about the user-friendliness was filled in by 13 persons who used the PAIC15 to observe persons with aphasia during rest and during transfer. The PAIC15 was considered user-friendly for persons with aphasia by all observers. The items of the PAIC15 were clear and not difficult to score, prompted observers to pay attention to non-verbal signals in persons unable to express themselves, and facilitated clinical judgement. Compared to self-report pain scales which cannot be completed due to aphasia, the PAIC15 observation instrument is easy to use to screen for the presence of pain in persons with aphasia.

Article Highlights

- PAIC15 was considered user-friendly when used to observe persons with aphasia.
- PAIC15 prompted observers to pay attention to non-verbal signals in persons unable to express themselves.
- PAIC15 facilitated clinical judgement of healthcare professionals when screening for pain in persons with aphasia.
- Observers preferred the use of a combined self-report pain scale for persons with aphasia who were still able to self-report pain.

Introduction

Self-report pain scales are the golden standard to assess pain in persons with aphasia. Examples are the Faces Pain Scale (FPS) [1], Numerical Rating Scale (NRS) [2] and Visual Analog Scale (VAS) [3]. However, it is not clear which self-report scale is preferred for use in persons with aphasia [4]. Also, for patients with severe aphasia, self-report is often not possible [5]. Cognitive and communication impairments complicate identifying and treating pain in persons with aphasia, resulting in suboptimal pain management and therefore a negative impact on quality of life and care [6, 7]. As an alternative for self-reporting, an observational instrument could be used to screen for the presence of pain.

The psychometric properties of the pain observation instruments Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version (PACSLAC-D) [8] and the Pain Assessment in Impaired Cognition (PAIC15) have been examined in persons with cognitive impairment, indicating their potential usefulness for clinical practice [9, 10]. The PAIC15 was developed by selecting items from existing observational scales and critically re-assessing their suitability to detect pain in patients with impaired cognition, especially dementia, using the combined the expertise of clinicians and researchers [11, 12]. The PAIC15 has shown satisfactory psychometric qualities in several types of diseases with impaired cognition, such as Huntington's or Korsakov's disease [12-14].

The PAIC15 comprises three categories with 5 items each. The categories are facial expressions (frowning, narrowing eyes, raising upper lip, opening mouth, and looking tense), body movements (freezing, guarding, resisting care, rubbing, and restlessness) and vocalizations (using pain-related words, shouting, groaning, mumbling, and complaining). The presence of the fifteen items is scored from 0 (not at all) to 3 (great degree) or as 'not scorable'. A sum-score can be calculated, ranging from 0 to 45, with higher scores indicating a greater degree of observed pain. For screening in practice, scores of ≥3 are indicative of pain [15].

Essentially, the observational instrument also needs to be user-friendly to ensure its application in clinical practice. So far, the user-friendliness of the PAIC15 has not been examined. The aim of this pilot study is to assess the user-friendliness of the PAIC15 to observe persons with aphasia. User-friendliness refers to the ease with which the PAIC15 can be used by healthcare professionals to achieve the intended goal of pain assessment in persons with aphasia. A secondary aim is to examine which of the four used self-report pain scales (i.e., VAS, NRS, FPS, and combined scale) the observers thought most user-friendly for persons with aphasia who are able to self-report.

Methods

This pilot study used a questionnaire among observers who used the PAIC15 in a study examining the reliability and validity of the PAIC15 in patients with aphasia [16]. Comparison with self-report pain scales was chosen to assess whether the results of the PAIC15 and the measured construct match. The observations for the psychometric study were performed between

April 2019 and September 2021. The data of the current study were collected between March and September 2021.

The convenience sample of observers consisted of members recruited from the 19 participating care organizations via their speech and language therapist, and master-students (psychology and medicine) [16]. Observers received information about the study and were asked to contact researchers if they were willing to participate. The observers must have performed observations with the PAIC15 in long-term care with persons with aphasia.

The current pilot study was assessed by the Medical Ethics Review Committee Leiden-The Hague-Delft (protocol number: P18.230, March 7, 2019) and declared exempt from the Medical Research Involving Human Subjects Act. The observers received a small gift for conducting the observations for the PAIC15 study.

Instruments

The questionnaire to assess user-friendliness consisted of three parts. In the first part, observers were asked to provide demographic characteristics (i.e., age, gender, profession, years of experience with patients with aphasia). In the second part, observers were asked to rank the self-report pain scales Faces Pain Scale (FPS) [1], Numerical Rating Scale (NRS) [2] and Visual Analog Scale (VAS) [3], and combined scale from most to least useable for persons with aphasia. They clarified and discussed their ranking in an open-ended item.

The VAS offers a 10-centimetre line with 'no pain' at one end and 'unbearable pain' at the other end. The NRS consists of a line with numbers from 0 'no pain' to 10 'worst pain imaginable'. The FPS shows six coloured vertically placed cartoon-faces ranging from no pain (dark green smiling face) to worst pain (dark red sad face). The combined scale combines these three self-report pain scales into one scale using the numbers zero to ten, coloured smileys, and written expressions of pain displayed along a vertical line. This combined self-report pain scale ensures a reinforced information display for clarification and support communication with persons with language problems [17]. For each self-report scale, the person was asked to indicate the intensity of experienced pain on the line.

In the last part of the questionnaire, observers were asked about their experience with and the user-friendliness of the PAIC15 in persons with aphasia using nine items. The items about user-friendliness were 'Do you find the PAIC15 useful for persons with aphasia?'(yes/no), 'In general, could all items of the PAIC15 of the category facial expressions / body movements / vocalizations be scored?' (yes/no/variable), 'What is your general experience of observing persons with aphasia with the PAIC15?' (0-10, with 0=very bad – 10=very good), 'To what extent was the PAIC15 difficult or easy to use in persons with aphasia?'(4-point Likert scale from 'Not difficult at all, almost no item was difficult' [1] to 'Very difficult, almost all items were difficult' [4]), and 'To what extent do you consider the PAIC15 suitable for use in clinical practice for screening pain in persons with aphasia'(0-10, with 0=very unsuitable – 10=very suitable). After each item, observers had the opportunity to clarify their answer in an open text field.

Procedure

All observers completed the PAIC15 eLearning (www.paic15.com/) and a 1-hour training provided by the primary researcher and trained and experienced speech and language therapist (NJdV) about the aim and procedure of the psychometric study, including practical tips and recommendations for conducting observations. Before conducting the observations, observers first checked whether persons with aphasia were able to self-report [16]. If their language comprehension was deemed sufficient, the persons with aphasia were asked to complete the self-report pain scales. Next, the persons with aphasia were observed using the PAIC15 for a minimum of five minutes and a maximum of ten minutes during rest (e.g., participant could be lying in bed or sitting in a chair or wheelchair) and transfer (e.g., physical moves from bed to chair or wheelchair, repositioning in bed, a short walk, or receiving physiotherapy). Afterwards, if possible, the participant completed the four self-report pain scales. The order of the first three self-report pain scales was randomized, while the final self-report scale was always the combined scale. The observers did not know the persons they observed. After completing the observations for the psychometric study, observers received the user-friendliness questionnaire on paper. After two weeks, a reminder was sent to complete the questionnaire. The completed paper questionnaires were entered into Castor Electronic Data Capture (EDC), Castor Academy, version 2022.2.1.

Analysis

Descriptive statistics were used to assess user-friendliness. All analyses were carried out with SPSS, IBM SPSS Statistics 25.0 for Windows, 2017 (SPSS, Chicago, IL, USA).

Results

All 13 observers were female with a mean age of 34 years (SD 13, range 22 – 53, median 28, IQR 24 – 51). Their experience with persons with aphasia ranged from 0 to 28 years (median 5, IQR 0 - 15). The observers were speech and language therapists (n=5), nurses (n=2) and master-students (n=6). Six observers used the PAIC15 between 0-5 times, three between 5-10 times, and three more than 10 times for persons with aphasia during this study (data of one observer missing).

User-friendliness

The general experience with the PAIC15 for persons with aphasia was rated 8.0 out 10 (SD=0.7, range 7 – 9, median 8.0, IQR 8 – 8). The PAIC15 was considered user-friendly for persons with aphasia by all observers (100% Yes; n=12, 1 missing); "*For the self-report pain scales, some communication was necessary to explain how it worked. When observing persons with communication problems, it was possible to see differences between persons. A person possibly experiencing pain could not indicate this on the self-report scales, but it could be clearly observed with the PAIC15*." – Student ID18. Other elaborations on user-friendliness included the items

being clear and not difficult to score, they prompted observers to pay attention to non-verbal signals in persons unable to express themselves and facilitated clinical judgement. "*It ensures that you do not fill in the blanks for persons but keep looking objectively.*" – Speech and language therapist ID5.

The PAIC15 was assessed as not being difficult to use for persons with aphasia by 4 of the 13 observers (31%), while the other 9 observers (69%) considered it just a little difficult. None found the PAIC15 somewhat or very difficult to use for persons with aphasia. The numbers of items to observe in combination with quick changes that may occur in facial expressions, vocalizations and body movements in persons, made observations challenging at times. Table 1 provides an overview of all items the observers could score under facial expressions, body movements, and vocalizations, including the explanations that were reported. One observer indicated that more experience with the PAIC15 made it easier to distinguish the vocalization items. Some observers mentioned that a few items did not occur during their observations, especially during rest (for example 'resisting care' as no care was then given, or no staff were present).

Table 1: Observed items of the PAIC15 for facial expressions, body movements, and vocalizations in persons with aphasia

Could all items of the PAIC15 of the following category be completed:	Yes (n)	No (n)	Explanation by observers when selected 'No' or 'Variable' (n)
Facial expressions	8	0	‘Opening mouth’ can also be part of aging or other complaints (2/5) Did not always see the face clearly or difficult to score due to (hemi-)facial paralysis (1/5) Easy to miss certain facial expression when expressions change quickly (1/5) ‘Raising upper lip’ difficult to score in combination with ‘opening mouth’ (1/5)
Body movements	7	3	‘Resisting care’ was not observed during rest (5/6) Some persons hold onto a body part, because they have learned to do so [by staff] to improve ADL[a] care, making it difficult to distinguish it from ‘guarding’ (1/6)
Vocalizations	9	0	Some persons were not able to or it was unclear whether they could make vocalizations, so this section could then not be scored (2/4) Difficult to differentiate between the items (1/4) ‘Shouting’ and ‘using pain-related words’ did not occur during observations (1/4)

a = ADL= Activities of Daily Living

The PAIC15 useability for persons with aphasia in clinical practice was rated 8.1 out of 10 by the observers (SD=0.9, range 6 – 10, median 8.0, IQR 8 – 8). They regarded the PAIC15 as user-friendly, a helpful addition to clinical judgement, and a valuable tool to screen for the presence of pain in persons with aphasia: "*The PAIC15 is easy to use and can be filled in quickly. A brief moment of observation can give an indication of whether pain may be present, so that it can be further investigated and treated more quickly. Pain complaints that the person with aphasia has but is unable to express can still be noticed this way.*" – Student ID13.

Two observers mentioned that successful application in practice would depend on the quality of the implementation and the support base within the organization. "*A manual must be made available before implementation. Especially because physicians may prescribe additional or less medication.*" – Speech and language therapist ID5. Another observer mentioned that: "*The tricky part is that you have to observe consciously because otherwise you miss things, and this takes more time than the self-report scales. I think in busy clinical practice, the nurses can easily forget to really think about this and not take their time, and they may fill the PAIC15 based on what they noticed during daily care. They may, for example, not pay specific attention to facial expressions, and I think the PAIC15 then becomes less reliable.*" – Student ID19.

Preference of self-report pain scale

Table 2 presents the observers' ranking of the four self-report pain scales for persons with aphasia who can self-report pain from most to least user-friendly for this population. Most (8 of 13) observers preferred to use the combined scale for persons with aphasia, as it was thought that the amount of information provided best facilitates self-report in persons with aphasia. "*Usually, I start with the combined scale, but sometimes I observe that the information seems to be too much and then I switch to the FPS. I use the VAS least with severe aphasia, I find it the most difficult to explain.*" – Speech and language therapist ID7. The VAS was preferred least (5 out of 13): "*The VAS is the vaguest and can be interpreted differently by everyone*" – Student ID13.

Table 2 Ranking of four self-report pain scales from most to least useful for persons with aphasia

Self-report scale	1st preference (n)	2nd preference (n)*	3rd preference (n)*	4th preference (n)
VAS	2	2	4	5
NRS	0	6	4	3
FPS	3	6	2	2
Combined scale	8	0	2	3

N=13 * one observer had no preference for NRS or FPS, giving them both the score '2nd preference' and had no '3rd preference'. VAS= Visual Analog Scale, FPS= Faces Pain Scale, NRS= Numerical Rating Scale.

However, those who least preferred the combined scale mentioned that the scale was confusing due to all the information; "[combined scale] *too much noise*" – Speech and language therapist ID5. Interestingly, speech and language therapists either preferred the combined scale most or least for persons with aphasia. One speech and language therapist (ID4) suggested: "*Combined scale most useful [....] Depending on the language skills of the person, you can also cover parts if it is too confusing*."

Discussion

This study examined the user-friendliness of the PAIC15 and observers' preference for self-report scales for use in persons with aphasia. All observers found the PAIC15 user-friendly in persons with aphasia. Most observers preferred to use – when the person with aphasia was able to self-report pain – the combined self-report scale, although there were some mixed opinions in preferences.

Using the PAIC15 to assess pain in persons with aphasia forced observers to pay attention to non-verbal signals in persons who are not able to communicate their pain and facilitated clinical judgement about the presence of pain. Comparison of this finding with other studies on pain in persons with cognitive impairment confirms the recommendations of using an observational pain scale in persons who cannot complete a self-report pain scale [18, 19]. Kaasalainen et al. [20] concluded that items of facial expression were observed more frequently among persons who were not able to verbally report their pain compared to persons who were. This suggests that observing facial expression and using an observational pain assessment instrument is paramount when assessing pain in persons with communication problems [10, 21]. Nurses or healthcare professionals can miss facial or other behavioural items when they simultaneously support the person with aphasia during a transfer or activity. This was mentioned by the observers that made the PAIC15 a little difficult to use at times. To prevent this, it is recommended that someone else observes while the nurse or healthcare professional provides care or support during a transfer or activity [10].

Additionally, the current study assessed which of the four used self-report pain scales (i.e., VAS, NRS, FPS, and combined scale) the observers thought most user-friendly for persons with aphasia who can self-report their pain. Although there were some differences in the ranking, most observers preferred to use the combined self-report pain scale for persons with aphasia, because the amount of information in this scale best facilitates self-reporting of pain in persons with aphasia. In line with our study, research on the use of self-report pain scales in persons with dementia found a significantly better comprehension of the Verbal Rating Scale [22] and FPS, which provide more written and visual information than VAS [23]. A self-report pain scale with more information may improve the likelihood that the person comprehends the request and can provide an answer. We recommend selecting a self-report scale that provides more information, both verbal and non-verbal, to use for persons with aphasia who are still able to self-report.

The observers followed the PAIC15 e-learning and received a training and instructions, before completing the observations for the psychometric study, to score only what they observe without interpretations. However, scoring of the PAIC15 items with the scores slight degree (1), moderate degree (2) or great degree (3) varied and resulted in discussion during consensus meetings [24]. The recurring question was when to score the item 1, 2 or 3. This became more apparent as the observers gained more experience with PAIC15. In addition to the training, it is recommended to check and practice observations using the PAIC15 in persons with aphasia. Recently, the e-learning of PAIC15 has been updated with specific instructions regarding the assessment of the 15 items and the differentiation of the 3 proposed scoring options, based on the current as well as other recent studies. Not all items of PAIC15 could be observed during rest. Therefore, observing persons with aphasia using PAIC15 is most appropriate during a transfer or activity to observe pain caused by mobility. However, repetition of e-learning or practice sessions are recommended to increase the competencies and skills of nurses and healthcare professionals and the quality of pain observation assessment using PAIC15.

Although the small all female sample size limits generalizability, the results are still relevant as this is the first pilot study to examine the user-friendliness of self-report scales and an observation pain scale in persons with aphasia. The strength of this research lies in the deployment of various observers, the application of an extensive pain panel using four self-report pain scales and the use of pain observation instrument PAIC15. Future studies should also collect information on the preference of the persons with aphasia regarding the self-report pain scales. More research on the user-friendliness of PAIC15 using a larger and more diverse sample is needed to replicate the findings. In addition, it is recommended to conduct further research in an international context.

Conclusion

The PAIC15 can be regarded as user-friendly, a helpful addition to facilitate clinical judgement, and a valuable tool to screen for the presence of pain in persons with aphasia. Most observers preferred to use the combined self-report scale for persons with aphasia because of the information this scale provides to facilitate self-report in persons with aphasia. The use of the PAIC15 can be recommended as an alternative to improve pain assessment and management in persons with aphasia who are not able to communicate their pain.

Acknowledgements

The authors thank Ahmad Abduljabar for assisting in the quantitative data analysis.

Ethical disclosure

The study was declared exempt from the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee Leiden-The Hague-Delft (protocol number: P18.230, March 7, 2019).

Authors' contributions

All authors have had substantial contributions to the design of the study. NJdV collected the data. NJdV and HJAS analyzed and interpreted the data and drafted the manuscript. JTvdS and WA reviewed the manuscript critically. All authors gave final approval of the manuscript to be published.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

Data are available from the corresponding author upon request up to 5 years after publication.

References annotations

Papers of special note have been highlighted as either of interest (*) or of considerable interest (**) to readers.

* de Vries, N. J., Sloot, P. H., & Achterberg, W. P. (2016). Pain and pain assessment in stroke patients with aphasia: a systematic review. *Aphasiology*, *31*(6), 703-719.

This study reports the prevalence and incidence of pain in persons with aphasia after stroke, presents an overview of which pain assessment instruments are used, and examines whether they are feasible, valid and reliable.

* van Dalen-Kok, A. H., Achterberg, W. P., Rijkmans, W. E., Tukker-van Vuuren, S. A., Delwel, S., de Vet, H. C., Lobbezoo, F., & de Waal, M. W. (2018). Pain Assessment in Impaired Cognition (PAIC): content validity of the Dutch version of a new and universal tool to measure pain in dementia. *Clin Interv Aging*, *13*, 25-34.

This article describes the translation of the PAIC into Dutch and, determines whether the PAIC items are indicative of pain and whether items are specific for pain or other disorders, and quantifies content validity.

** de Vries, N. J., Smaling, H. J. A., van der Steen, J. T., & Achterberg, W. P. (2024). Validity and reliability of the Pain Assessment in Impaired Cognition 15 (PAIC15) observation scale in persons with aphasia. *BMC Neurol*.

This validity and reliability study of PAIC15 shows mixed but promising validity results and good reliability indicating presence of pain related behaviours. Also, authors concluded PAIC15 can be of additional value in the assessment of pain in persons with aphasia when self-report is not possible.

** Hadjistavropoulos, T., Herr, K., Turk, D. C., Fine, P. G., Dworkin, R. H., Helme, R., Jackson, K., Parmelee, P. A., Rudy, T. E., Lynn Beattie, B., Chibnall, J. T., Craig, K. D., Ferrell, B., Ferrell, B., Fillingim, R. B., Gagliese, L., Gallagher, R., Gibson, S. J., Harrison, E. L., Williams, J. (2007). An interdisciplinary expert consensus statement on assessment of pain in older persons. *Clinical Journal of Pain*, *23*(1 Suppl), S1-43.

This paper represents an expert-based consensus statement on pain assessment among older adults. It is intended to provide recommendations that will be useful for both researchers and clinicians.

** Kaasalainen, S., Akhtar-Danesh, N., Hadjistavropoulos, T., Zwakhalen, S., & Verreault, R. (2013). A Comparison Between Behavioral and Verbal Report Pain Assessment Tools for Use with Residents in Long Term Care. *Pain Management Nursing*, *14*(4), E106-E114.

This study evaluates four pain assessment tools for use with long-term care residents who were able to verbally report their pain and those who were not, and to assess whether pain behaviours displayed vary as a function of ability to self-report pain.

References

1. Kim, E.J. and M.T. Buschmann, *Reliability and validity of the Faces Pain Scale with older adults.* Int J Nurs Stud, 2006. **43**(4): p. 447-56.
2. Hjermstad, M.J., et al., *Studies comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for assessment of pain intensity in adults: a systematic literature review.* J Pain Symptom Manage, 2011. **41**(6): p. 1073-93.
3. Heller, G.Z., M. Manuguerra, and R. Chow, *How to analyze the Visual Analogue Scale: Myths, truths and clinical relevance.* Scand J Pain, 2016. **13**: p. 67-75.
4. de Vries, N.J., P.H. Sloot, and W.P. Achterberg, *Pain and pain assessment in stroke patients with aphasia: a systematic review.* Aphasiology, 2016. **31**(6): p. 703-719.
5. Smith, J.H., et al., *Inability to self-report pain after a stroke: a population-based study.* Pain, 2013. **154**(8): p. 1281-6.
6. Davies, E., et al., *Pain assessment and cognitive impairment: part 2.* Nurs Stand, 2004. **19**(13): p. 33-40.
7. Reynolds, K.S., et al., *Disparities in pain management between cognitively intact and cognitively impaired nursing home residents.* Journal of Pain and Symptom Management, 2008. **35**(4): p. 388-396.
8. de Vries, N.J., et al., *Measuring Pain in Aphasia: Validity and Reliability of the PACSLAC-D.* Pain Manag Nurs, 2023. **24**(4): p. e68-e74.
9. de Waal, M.W.M., et al., *Observational pain assessment in older persons with dementia in four countries: Observer agreement of items and factor structure of the Pain Assessment in Impaired Cognition.* Eur J Pain, 2020. **24**(2): p. 279-296.
10. van Dalen-Kok, A.H., et al., *Pain Assessment in Impaired Cognition (PAIC): content validity of the Dutch version of a new and universal tool to measure pain in dementia.* Clin Interv Aging, 2018. **13**: p. 25-34.
11. Corbett, A., et al., *An international road map to improve pain assessment in people with impaired cognition: the development of the Pain Assessment in Impaired Cognition (PAIC) meta-tool.* BMC Neurol, 2014. **14**: p. 229.
12. Kunz, M., et al., *The Pain Assessment in Impaired Cognition scale (PAIC15): A multidisciplinary and international approach to develop and test a meta-tool for pain assessment in impaired cognition, especially dementia.* Eur J Pain, 2020. **24**(1): p. 192-208.
13. Oudman, E., et al., *Self-Reported Pain and Pain Observations in People with Korsakoff's Syndrome: A Pilot Study.* J Clin Med, 2023. **12**(14).
14. van Dalen-Kok, A.H., et al., *Pain assessment in impaired cognition: observer agreement in a long-term care setting in patients with dementia.* Pain Manag, 2019. **9**(5): p. 461-473.
15. van der Steen, J.T., et al., *Probable Pain on the Pain Assessment in Impaired Cognition (PAIC15) Instrument: Assessing Sensitivity and Specificity of Cut-Offs against Three Standards.* Brain Sci, 2021. **11**(7).
16. de Vries, N.J., et al., *Validity and reliability of the Pain Assessment in Impaired Cognition 15 (PAIC15) observation scale in persons with aphasia.* BMC Neurol, 2024. 24(1): 319.
17. Beukelman, D.R., et al., *Using Visual Scene Displays as Communication Support Options for People with Chronic, Severe Aphasia: A Summary of AAC Research and Future Research Directions.* Augment Altern Commun, 2015. **31**(3): p. 234-45.

18. Corbett, A., et al., *Assessment and treatment of pain in people with dementia.* Nat Rev Neurol, 2012. **8**(5): p. 264-74.

19. Hadjistavropoulos, T., et al., *An interdisciplinary expert consensus statement on assessment of pain in older persons.* Clin J Pain, 2007. **23**(1 Suppl): p. S1-43.

20. Kaasalainen, S., et al., *A Comparison Between Behavioral and Verbal Report Pain Assessment Tools for Use with Residents in Long Term Care.* Pain Manag Nurs, 2013. **14**(4): p. E106-E114.

21. Lautenbacher, S., A.L. Walz, and M. Kunz, *Using observational facial descriptors to infer pain in persons with and without dementia.* BMC Geriatr, 2018. **18**(1): p. 88.

22. Boureau, F., M. Luu, and J.F. Doubrere, *Comparative study of the validity of four French McGill Pain Questionnaire (MPQ) versions.* Pain, 1992. **50**(1): p. 59-65.

23. Pautex, S., et al., *Feasibility and reliability of four pain self-assessment scales and correlation with an observational rating scale in hospitalized elderly demented patients.* J Gerontol A Biol Sci Med Sci, 2005. **60**(4): p. 524-9.

24. de Vries, N.J., et al., *Validity and reliability of the Pain Assessment in Impaired Cognition 15 (PAIC15) observation scale in persons with aphasia.* BMC Neurol, 2024. **24**(1): p. 319.

PART 3

A practice pain guideline for persons with aphasia

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Submitted

Chapter 7

Development of a practice guideline for persons with aphasia in co-creation with persons with aphasia, family, and professional caregivers

Keywords:

- *pain;*
- *aphasia;*
- *self-report pain;*
- *pain observation;*
- *practice pain guideline*

Abstract

Background: Persons with moderate to severe aphasia experience great difficulty or are unable to communicate their pain verbally. Self-report pain scales cannot always be used due to the cognitive, physical and communication problems associated with aphasia, but a multidisciplinary guideline to assess and treat pain in persons with aphasia is still lacking.

Aims: This study describes the development of a practice guideline based on the needs, wishes and ideas of persons with aphasia, their family and professional caregivers for pain in persons with aphasia that should be clinically useful in nursing homes, rehabilitation centers and other clinical settings.

Methods & procedure: This study used a stepwise qualitative research approach with inductive content analysis. In semi-structured interviews and focus groups, we identified needs, wishes, preferences and ideas of four persons with aphasia, one family caregiver, and five professional caregivers regarding pain measurement and pain management for persons with aphasia (phases three and four). These results, together with previous results of a literature review (phase 1) and observational studies (phase two) of pain in person with aphasia, formed the input for the development of the practice guideline. The research team drafted three preliminary practice guideline versions based on the outcomes of phases one to three. During three expert meetings, seven clinical experts established the preferred draft version and discussed and refined the final practice pain guideline (phase five).

Outcomes & results: The pain guideline consisted of the following seven steps: STEP 1: Mapping/ actions + report; examined and reported are the person with aphasia's way of communication and how the person previously communicated pain. STEP 2: Recognizing situations. STEP 3: Check; check if basic needs are met and check possible causes of pain. STEP 4: Research; possible causes of pain are investigated by means of a physical examination by a physician. STEP 5: Treatment; start treating the cause of pain and/or start non-pharmacological intervention(s) and/or start with pain medication.

STEP 6: Monitoring plan; multidisciplinary discussion of the situation, the frequency and manner of monitoring the pain. STEP 7: Evaluation plan; multidisciplinary discussion of the pain and pain treatment, the frequency and how to evaluate the pain. The final, co-created practice pain guideline was presented on two pamphlets, one containing a round flow chart with practical steps. The second pamphlet contains descriptions and explanations of each step.

Conclusions: We co-created a practical pain guideline for persons with aphasia in nursing homes. This provides guideline to improve pain assessment with the aim to establish better pain treatment, pain management and quality of life of persons with aphasia. Further research is recommended to implement the practice guideline, test, and examine the impact of the practice guideline for persons with aphasia internationally and in different settings.

Introduction

Aphasia is a very disabling symptom after brain injury, affecting one-third of patients surviving an acute stroke [1]. Persons with moderate to severe aphasia experience great difficulty or are unable to communicate verbally and non-verbally [2, 3]. They depend for a large part on the interpretation of family caregivers and healthcare professionals to express themselves.

Pain is common in stroke-survivors with aphasia [4-6]. However, after a stroke, patients with aphasia receive significantly less pain medication than stroke patients without aphasia [7]. A systematic review of pain and pain measurement in stroke patients with aphasia shows that stroke patients with mild to moderately severe aphasia experience pain just as often as stroke patients without aphasia (e.g., due to shoulder pain and central pain), but also that it is difficult to recognize this pain in clinical practice. Persons with moderately severe to very severe aphasia are often excluded from pain studies because they are unable to complete self-reported pain scales, which in turn also leads to pain in aphasia not being addressed in guidelines. This all contributes to underdiagnosis and suboptimal treatment of pain in persons with aphasia [7].

Self-report pain scales are considered the gold standard for the assessment of pain, also in persons with aphasia [8, 9]. However, these self-report pain scales cannot always be used due to the cognitive, physical, and communication problems associated with aphasia [8, 10, 11]. Using a pain observation instrument could be a possible alternative for persons with aphasia [12-14]. This has also been found to be feasible in persons with dementia [15, 16].

The Pain Assessment in Impaired Cognition (PAIC15) [17] is a pain observation scale that has been developed in a European consortium as a meta-tool, a tool that includes promising items from earlier developed pain observation scales based on its psychometric qualities [12] and user-friendliness [18], it may also provide an adequate alternative for persons with aphasia.

Currently, there no multidisciplinary guideline exists for the assessment and treatment of pain in persons with aphasia comparable to the guideline for the recognition and treatment of pain in frail older people [19-21]. To improve the recognition of pain in persons with aphasia, the next step is the development of a standardized method of identifying pain in this target group and to evaluate its treatment. The aim of this study was to develop a pain guideline for persons with aphasia that can be used in clinical practice. We stated that such a clinically useful practice guideline should meets the needs, wishes and ideas of the most important stakeholders: persons with aphasia, their family caregivers, and healthcare professionals.

Methods

Design

The development of the practice pain guideline for persons with aphasia comprised five phases, as presented in Table 1. Prior to the development of the practice pain guideline (phases three, four and five), phases one (literature study) [7] and phase two (observational studies) [12, 13] were performed. The current study describes phases three, four and five, in which we use the input from the most important stakeholders [22, 23]. In this qualitative study we use a stepwise

iterative approach. Phase three consisted of four semi-structured interviews with persons with aphasia and family caregivers or legal representatives. In phase four, we conducted two focus groups with professional caregivers. We aimed to continue to sample until data saturation [24]. The aim of phases three and four was to identify needs, wishes, preferences and ideas of persons with aphasia, family caregivers, and professional caregivers regarding pain measurement and pain management for persons with aphasia. The results from phases one to four were used to prepare for phase five, in which the research team compiled a total of three draft versions of a pain guideline for persons with aphasia. These three draft versions were used as inspiration and the starting point for the next step, in which three meetings with clinical experts took place. First, the most preferred draft version in terms of user design was chosen. This version was then discussed and refined in terms of content to reach consensus about the definitive practice pain guideline.

Medical ethics review

The study was deemed exempt from the Medical Research Involving Human Subjects Act after review by the Medical Ethics Review Committee Leiden-The Hague-Delft (protocol number: P18.230, March 7, 2019). The study was conducted according to the guidelines of the Declaration of Helsinki [25]. Persons with aphasia received an aphasia-friendly informed consent form and were asked to give informed consent. In case of doubt about their ability to provide informed consent due to the severity of language comprehension problems, informed consent was requested from the family caregiver by the speech and language therapist.

Setting, study sample, and recruitment

Phase three

In phase three, persons with aphasia and their family caregivers were recruited via speech and language therapists who work at long-term care organizations that participate in the University Network for the Care Sector-South Holland (UNC-ZH) in the Netherlands. The persons with aphasia and their family caregiver or legal representative received a written information letter about the study, including a consent form and a one-page flyer from the speech and language therapists. Persons with aphasia who met the following selection criteria were invited: 18 years or older, stay at a unit of a long-term care organization for residents with physical disability, and diagnosed with aphasia. The diagnosis of aphasia was established by a score of ≤ 68 on the ScreeLing [26] or a score of ≥ 7 on the TokenTest [27] or the speech and language therapist's judgment. Special inclusion criteria for participation in an interview are: 1) The person has "average language comprehension" and has given consent to participate. 2) The person can express themselves, with help or supporting communication tools and/or with a well-instructed conversation partner/aphasia buddy. 3) Sufficient capacity to participate an interview of 1 to 1.5 hours. In consultation with the participant, the interview can also be conducted in two parts.

Table 1: Characteristics of phases 1 – 5 of the development of a pain guideline for persons with aphasia

Phase	Study method	Period
Phase 1 **Literature study** De Vries et. al., 2016	Systematic review	June 2015
Phase 2 **Observational Studies** De Vries et al., 2023 De Vries et al., 2024	Observational study with PACSLAC-D Observational study with PAIC15 User-friendliness study	July 2014- December 2018 May 2019- July 2021 March- September 2021
Phase 3-5 are described in current article.		
Phase 3 **Development pain guideline**	Semi-structured interviews with four persons with aphasia and their family caregivers / legal representatives	January - February 2023

VAS = Visual Analogue Scale;
FPS = Faces Pain Scale;
VRS = Verbal Rating Scale;
NRS = Numeric Rating Scale;
PAIC15 = Pain Assessment in Impaired Cognition 15

Outcomes of phase and how this phase informed the next phase

Outcomes:
- Prevalence of pain in aphasia ranging from 43.8 – 87.5%.
- Self-report pain scales VAS (vertical) and FPS reported best results in terms of methodological quality.
- Patients with left hemisphere stroke prefer to use FPS instead of VAS and VRS.
- Most studies describe assessment of persons with mild to moderate aphasia, while persons with severe aphasia are excluded.
- Individuals with aphasia receive less pain medication than prescribed and receive less pain medication than individuals without aphasia.
- There is no feasible, reliable, and valid instrument for persons with aphasia after stroke.

Informed next phase:
The above led to the design and setting up of observational follow-up studies using a pain observation instrument.

Outcomes:
- PACSLAC-D captures pain in persons with aphasia who are unable to self-report during ADL and physiotherapy but is less accurate during rest.
- PAIC15 is useful for observation of pain in persons with aphasia, more during transfer versus rest.
- PAIC15 has moderate to good values on test-retest and inter-rater reliability in persons with aphasia.
- PAIC15 has insufficient internal consistency.
- PAIC15 is a useful instrument to aid clinical judgment and to screen for the presence of pain in persons with aphasia. The use of PAIC15 forces the observer to pick up nonverbal pain signals from persons with aphasia.

Informed next phase:
A pain observation instrument is of added value in the assessment of pain in persons with aphasia. Especially when a self-report pain scale cannot be completed. Observers prefer the following order of self-report pain scales in persons with aphasia: 1. Combination self-report pain scale, 2. FPS, 3. NRS, or 4. VAS if individuals do not understand numbers.

Outcomes:
- Persons with aphasia ‘want to be known’: to know who the person with aphasia is by having some idea of what someone was like, what someone did and found and now finds important.
- Signs of pain: becoming quieter, turning more introspective, not being able to take/tolerate much, or changes in behavior.
- Persons with aphasia want to be asked about pain daily and weekly and have pain and pain treatment evaluated by a physician.
- If possible, use standard severity rating scales of 0-10 or a self-report pain scale, 3 times a day.
- Involve family and ask: how did the person with aphasia express pain in the past and has this changed after the stroke?

Informed next phase:
The points above are input for the content of the pain guideline to be developed.

(Continued)

Phase	Study method	Period
Phase 4 **Development pain guideline**	Two focus groups with professional caregivers	February - March 2023
Phase 5 **Development pain guideline**	Brainstorming session research team	March 2023
	Three expert meetings with clinical experts	April - May 2023

VAS = Visual Analogue Scale;
FPS = Faces Pain Scale;
VRS = Verbal Rating Scale;
NRS = Numeric Rating Scale;
PAIC15 = Pain Assessment in Impaired Cognition 15

Family caregivers or legal representatives who met the following selection criteria were invited: he or she is a family member or family caregiver of a person with aphasia who is staying at a somatic department of a participating nursing home organization.

Phases four and five

Similarly, in phases four and five, professional caregivers and clinical experts were recruited via speech and language therapists via practice-based linking-pins working at the same long term care institution that is part of the academic network UNC-ZH. A practice-based linking-pin is a healthcare professional employed by a long-term care organization whose role is to connect science and practice within the regional elderly care network [28]. Both professional caregivers and clinical experts who met the following selection criteria were invited: they collaborate with

Outcomes of phase and how this phase informed the next phase

Outcomes:
- Get to know the person with aphasia.
- Take plenty of time, check continuously and do not just accept what is made clear.
- Ask about pain using the communication aid used by the person with aphasia.
- Learn to use/interpret a pain observation instrument in daily care.
- Do not rely only on what family caregivers say about pain in the person with aphasia, but also on what the person with aphasia indicates and on your own judgment.
- Non-verbal observations if persons with aphasia can no longer indicate pain verbally.
- Focus on facial expressions when interacting with a person, as this also provides much information.
- Self-report pain score is sometimes difficult because patient score does not always match what nurses see in non-verbal cues.
- Continue multidisciplinary discussion of pain: also discuss physiotherapy or homeopathy or other forms of therapy that may be helpful.

Informed next phase:
The points above provide input for the content of the practice pain guideline to be developed.

Outcomes:
- Based on the results of phases one through four, three preliminary draft versions of a guideline for persons with aphasia were compiled.
- See Fig. 1 for the three designs of the pain guideline.

Outcomes:
- Content of the practice pain guideline was discussed and for each step it was decided: does this fit into the guideline yes or no, is the step complete and who performs the step?
- Reaching consensus on the content of pain guideline.
- The practice pain guideline consisted of seven steps. For a description of these steps see manuscript and the guideline included as Supplemental material.
- Reaching consensus on pain guideline lay-out.

persons with aphasia, work within a clinical setting such as geriatric rehabilitation, medical specialist rehabilitation or long-term care/somatic department. Clinical experts are also required to have experience in identifying pain in persons with aphasia and to practice one of the following disciplines: elderly care physician (a physician who specializes in long-term *care* for frail *older* people and chronic patients with complex health problems), other physicians, nurse practitioner, physiotherapist, psychologist, occupational therapist, speech and language therapist or nurse.

Potential participants received an information letter, consent form and one-page flyer. Participation was on a voluntary basis. All participants of phases three to five received a gift voucher for their participation in the study and any incurred travel expenses were reimbursed.

Procedure

Phase three

The semi-structured interviews took place at the participants' home. The interview was conducted with the person with aphasia together with the family caregiver, or separately. The interviews were conducted by NJdeV (female speech and language therapist).

The following questions were used during the semi-structured interviews to start the conversation: A) Are you (or: Is your loved one) currently experiencing pain? Can you tell me more about that?; B) What is (or: are) your experience(s) with the pain care provided by the professional caregiver, nurse, or doctor?; C) What is your experience with mapping pain?; D) What is your experience with the treatment of pain by the nurse or doctor?; E) What are your thoughts on your partner's/family caregiver's possible contribution to the treatment of pain in aphasia?; F) How can you or do you, as a family member, want to be involved in the roadmap for pain in aphasia?

The interviews were audio-recorded and transcribed verbatim.

Phase four

Two focus groups were conducted with four to eight healthcare professionals from different professions with the aim to improve the internal validity of the collected data (Poppleton, 2020). The focus group lasted a maximum of 1.5 hours and took place at the healthcare organization of the participating healthcare professionals. The focus group was led by NJdeV, assisted by HJAS [female psychologist] or AA [male research assistant with a background in Health Sciences]).

The focus groups were structured as follows: (1) Brief introduction explaining the study and the goals of the focus group; (2) Discussion about what is going well and what needs improvement in the current assessment and treatment of pain in persons with aphasia. To facilitate the discussion, participants were first invited to think of answers for themselves and write them down on post-it notes, which were collected and clustered, after which their input was discussed in the group; (3) Discussion of best practices and what to change in current pain assessment and treatment to optimize pain assessment and treatment in people with aphasia. The projective technique [29] was used: "If you could change 3 things about identifying pain in persons with aphasia, what would they be? What do you want to keep?"; (4) Debriefing and reflection on the focus group.

After the focus groups and expert meetings, the participants received a synopsis of the focus groups and expert meetings for a member check. This member check was conducted to check whether the participants felt that the collected results of the meetings accurately reflected what they meant to say and their perceptions [30].

Phase five

Based on the results of phases one to four, NJdeV prepared a presentation for the research team about the main findings regarding identifying and treating pain in persons with aphasia. The research team consisted of a speech and language therapist (NJdeV), a psychologist (HJAS),

an elderly care physician (WPA), and an epidemiologist (JvdS). All participants have extensive (research) experience with assessing pain in persons with communication and cognitive impairments. The team was supported by AA (a research assistant with a background in Health Sciences). During a three-hour brainstorming session, the research team produced three preliminary draft versions of a pain guideline in which the collected outcomes of phases one to four were incorporated. During the next step, which consisted of three expert meetings, clinical experts chose the most preferred draft version in terms of design. To reach consensus about a definitive practice guideline, the content of this preferred version was discussed and refined. The expert meetings were attended by five to seven clinical experts from different disciplines. The expert meeting lasted 1.5 hours and the first two were hybrid in-person and online sessions at healthcare organizations participating in the academic network, while the third meeting was in person.

Data collection

Demographic data of the participants of phases three to five were collected using a brief questionnaire that could be filled in online via the CASTOR Electronic Data Capture tool (Castor Academy, version 2022.2.1) (2024) or on paper at the start of the meeting. Information was gathered about age, gender, education level, and ethnicity. Regarding the persons with aphasia, additional information was collected about years of aphasia, pain, and pain medication. Furthermore, the family caregiver was asked to indicate their relationship to the person with aphasia, the length of their relationship with the person with aphasia, and type of work (paid; unpaid; retired; unable to work; unemployed). Professional caregivers were asked about their profession, work setting (specialist medical rehabilitation; geriatric rehabilitation; somatic unit of long-term care organization or other), and years of experience with persons with aphasia.

Data processing and analysis

Phase three and phase four

An inductive approach and qualitative content analysis were used to analyze the interview and focus group data collected in phase three and four. Qualitative content analysis involves a process designed to condense raw data into themes or categories based on valid inference and interpretation [31]. All transcripts were analyzed. During the first step, text fragments relevant for answering the research questions (i.e., units of analysis) were independently selected from the transcripts of the first two interviews (phase three) and first focus group (phase four) by two researchers (NJdeV, AA). The unit of analysis refers to the basic unit of text to be classified during content analysis. In this step, the units were reviewed for possible topics by NJdeV and AA and discussed based on the questions: 'What is the fragment about?' and 'What does this fragment mean?'. Each unit of analysis was assigned to a category (topic) by the two researchers independently. In the second step, the two researchers developed a coding scheme using the categories derived from the transcripts. The third step was coding the data; this entailed assigning

categories and codes (labels) to all fragments [32]. During the process of steps two and three, questions raised by the researchers were discussed with HJAS. The data analysis was supported by the software program ATLAS.ti. Descriptive statistics to describe the samples were analyzed using IBM SPSS Statistics version 25 for Windows, 2017 (SPSS, Chicago, IL, USA).

Results

Table 2 presents the characteristics of phases one to five of the development of a pain guideline for persons with aphasia. Table 2 presents the demographic characteristics of participants of phases three, four and five.

Phase three and phase four

Different categories were identified in the data and coded as input for the practice guideline to be developed. Table 3 presents an overview of the categories and codes with most relevant input and suggestions of the participants of phase three and for developing the pain guideline. The three main codes include what does and what does not work regarding recognizing and treating pain in persons with aphasia, and suggestions for the to-be-developed practice pain guideline.

The interviewed person with aphasia in the quote below has had back pain for some time. He has been undergoing physiotherapy for this pain for a long time. Subsequently, on referral from the general practitioner, the pain clinic of the hospital started a medical examination into the pain complaints. When the person with aphasia and their family caregiver were asked if they would like to be asked more often about pain, the family caregiver said yes. When asked if, for example, a pain scale with faces was also used, the answer was no.

180

Interviewer:	[Don't you fill out those (those rating scales*) anymore?]
Person with aphasia:	[No.]
Family caregiver:	[Yes, then we really had to keep track of 'what did the pain relief do?' And then we got one of those little electrode thingies and then after so many weeks something is done somewhere and then it should become less. Well, it didn't, not really. So, it was nice for me to see like, it was measured and monitored so well. They did a good job. And can see: does it have an effect? Yes, this was through the pain clinic.]
Interviewer:	[Yes evaluated well, they keep track.]
Family caregiver:	[So, they do this for everybody, but for him and for me it's a godsend really.]
Interviewer:	[Do they ever consider pain?]
Family caregiver:	[Never.]

* rating scale = a list showing morning, afternoon, and evening to record the pain severity (rating 0-10)

In general, family, and professional caregivers agreed and complemented each other on codes that worked or did not work in terms of recognizing and treating pain in persons with aphasia. Regarding recognizing pain, persons with aphasia mentioned that becoming quieter and more inwardly focused or other changes in behavior, are indicative of being in pain. Persons with aphasia indicated that they want to be 'known' by the caregivers.

Person with aphasia: [When I'm in pain, the people around me can tell.]
Interviewer: [So, we do have to - the people around you need to keep an eye on you?]
Person with aphasia: [Yes, yes, yes]
Interviewer: [How could you say that she was in pain? What do you look for?]
Family caregiver: [Well, you get a little quieter. Yes, quieter, a little withdrawn. And then and professional caregivers don't know you. So, they think, I don't hear anything. She's okay.]

Involving family caregivers may help in identifying pain. Persons with aphasia wanted professional caregivers to ask and evaluate their pain using self-report, for example with a Numeric Rating Scale, three times a day.

To obtain relevant input from professionals caring for persons with aphasia and co-create a practice guideline, the following key principles were collected. First, know the person with aphasia. Second, take enough time, check several times what the person with aphasia is trying to convey. Third, do not immediately assume that you have understood the person with aphasia correctly. Fourth, a self-report pain score, supported by, for example, a self-report pain Visual Analogue Scale, may be difficult to interpret if the person's score does not match the professional caregiver's observations of nonverbal behavior. In principle, the indication of pain by the person with aphasia themselves is most important.

Interviewer: [You said you shouldn't always accept it at face value, what do you mean by that?]
Professional caregiver: [When you see a person grimace with pain and you ask: 'how are you experiencing the pain now, can you give it a score between 1 and 10'. Then sometimes they say 4, and I think: that can't be quite right. Either they don't understand the question, or they have a very high pain threshold. I find that a little difficult sometimes.]

Table 2: Demographic characteristics of participants of phase three, four and five

Phase 3				
Persons with aphasia (n= 4)		**Mean [SD] range, or % (n)**		
Age		70.8 [14.3] 52-85		
Sex	Female Male	50 (2) 50 (2)		
Years with aphasia		3.7 [2.9] 2-8		
Level of education	Lower Medium High	- 75 (3) 25 (1)		
Family member or legal representative (n= 1)				
Age category		50-60		
Sex	Female	100 (1)		
Level of education	Medium	100 (1)		
Phase 4				
Healthcare professionals (n= 5)				
Age		57.4 [7.9] 47-65		
Sex	Female Male	60 (3) 40 (2)		
Level of education[a]	Low Medium High	- 40 (2) 60 (3)		
Phase 5				
Clinical experts (n= 7)				
Age		40.9 [9.0] 29-54		
Sex	Female Male	86 (6) 14 (1)		
Level of education	Low Medium High	- - 100 (7)		
Work setting	Geriatric rehabilitation Long-term care/ somatic department	71 (2) 29 (5)		
Years working with aphasia		13.4 [7.5] 4-24		
Used a pain observation instrument – yes		28.6 (2)		
Frequency used		**monthly:**	**every six months:**	**daily:**
	PAINAD[b] PACSLAC-D[c] REPOS[d] PAIC15[e]	- 1 - -	- - 1 1	- - - 1

a = International Standard Classification of Education (ISCED): Lower= 8 years of primary and special primary education; prevocational secondary education; lower secondary vocational training and assistant's training. Medium= upper secondary education, (basic) vocational training, middle management, and specialist education. Higher= higher education, 4-year education at universities of applied sciences and research universities; doctoral degree programs at research universities (UNESCO, 2012).
b = Pain Assessment IN Advanced Dementia [33]
c = Pain Assessment Checklist for Seniors with Limited Ability to Communicate- Dutch version [34]
d = Rotterdam Elderly Pain Observation Scale [35]
e = The Pain Assessment in Impaired Cognition [17]

In addition, professional caregivers indicated that you should not only rely on what family members say about pain. What the person with aphasia says themselves is most important. Moreover, professional caregivers indicated that they also rely on their own observation and judgment. Therefore, they recommended using nonverbal observations when persons with aphasia who could no longer verbally express their pain and focusing on facial expressions when interacting with someone. Also, they recommended continuing multidisciplinary discussion of pain multidisciplinary and to discuss other forms of therapy such as physiotherapy, homeopathy, relaxation, or distraction.

Professional caregiver: [You get to know someone; you have all this information provided by the family. You work with someone every day, then sometimes half a word is enough, literally, and it can be the same with people with aphasia too, of course. Family often also recognizes pain, but even then, you don't want to automatically rely on family. You also want to check with the person if "your husband is right when he says that you are in pain". That is really good about our work in daily care work.]

Other codes that were discussed were pain medication, the transfer report from the hospital where the person with aphasia was admitted. Also discussed were the guideline and treatment given by a hospital pain clinic, speech and language therapy or aphasia center, and the use of a supportive communication instrument by the person with aphasia. One professional caregiver indicated that it is also important to use the supporting communication tool (for example the TouchToTell-app or TouchToTalk-app for persons with aphasia) used by the person with aphasia when examining pain [36, 37]. Table 3 presents an overview of the categories and codes that were discussed for the development of the practice guideline for pain in persons with aphasia.

Table 3: Overview of themes and codes for the development of the pain guideline

Themes:	Codes:
	Input from person with aphasia and family caregiver:
What works well [recognizing and treating pain]	**Experiences with expressing pain:** ⁀ Indicate or point at location of the pain. ⁀ If the person uses a supportive communication tool, for example a notepad and pen to rate the pain, use this. ⁀ Signs of pain may include stop going to appointments, staying at home, and going quiet. ⁀ Facial expressions, can't laugh anymore. **Task of professional caregiver according to family caregiver:** ⁀ Professional caregivers should take more time to communicate about pain. ⁀ Professional caregivers should carefully write down everything related to pain of the person with aphasia and share this with other professional caregivers. ⁀ The physician should inquire about pain repeatedly. **Use of pain measurement instruments:** ⁀ If possible, rate their pain with a number 0-10. ⁀ If possible, use self-report pain scales: like Faces Pain Scale. ⁀ Use icons or visual support to communicate about pain. **Contribution of family caregiver:** ⁀ Family members can ask about pain regularly. ⁀ Those around person with aphasia will notice; family and friends must pay attention to any pain in the person with aphasia.
What does not work well [recognizing and treating pain]	**Experiences with expressing pain:** ⁀ When person with aphasia uses a supportive communication app that does not cover pain. ⁀ It may be difficult to figure out where the pain is coming from due limited communication because of aphasia. ⁀ When a person with aphasia is tough and does not immediately report be in pain. So, if this person starts moaning, this may indicate that the complaint is already in a more advanced stage, and something is wrong.
Suggestions for developing pain guideline	**Experiences with expressing pain:** ⁀ Persons with aphasia indicate that they need family or professional caregivers who help with communication about pain through stimulation and help with using a notepad and pen or communication tool and who give extra thought to this. **Task of professional caregiver:** ⁀ Continue to assess pain several time a day. ⁀ Ask more frequently and pay more attention to pain. ⁀ Know who the person with aphasia is by forming an idea of what someone was like, what someone did and found and now finds important. ⁀ Involve family and ask them how person with aphasia expressed/ ⁀ showed pain in the past. Ask family if this has changed after the stroke. ⁀ Daily assessment of pain by nursing staff and weekly evaluation of pain and discussion of pain treatment with physician.

Codes:

Input from professional caregiver:

Experiences with expressing pain:
- They show if they are in pain through their facial expression.
- When they turn inwards and/or go silent.
- If a person refuses their pain medication because this may also indicate whether they are in pain or not.

Task of professional caregiver:
- Pay attention to facial expressions and body language.
- Frequently ask about pain using a pain score, a VAS score.
- Ask 'How is the pain?' with a pain score a few times a day during care or toileting moments and when you distribute (pain) medications.
- Evaluate pain and pain medication weekly with a physician.
- Check the medical file to see if there has been any change in the past few days or if the person with aphasia was unable to go to therapy or an appointment.
- When in doubt or if you cannot ask the person with aphasia if they are in pain, you should assume that they are in pain.
- Question the family caregiver of the person with aphasia.
- Get to know the person with aphasia and use information provided by family.

Use of pain measurement instruments:
- Use a pain score 0-10, self-report pain scales like Faces Pain Scale, Numeric Rating Scale.
- If person with aphasia is unable to complete a self-report pain scale, use a pain observation tool or describe what you see.

Experiences with expressing pain:
- The physician and professional caregiver may not notice signals from persons aphasia that they are in pain.
- Family caregiver takes over from person with aphasia when staff ask about their pain.

Task of professional caregiver:
- A physician does not always communicate correctly with a person with aphasia – it is something they must learn.

Contribution of family caregiver according to professional caregiver:
- Family often also recognizes pain, but as a professional caregiver you cannot automatically assume that it is accurate.

Use of pain measurement instruments:
- Professional caregivers wonder and have doubts about whether persons with aphasia understand the self-report pain scale.

Task of professional caregiver:
- Provide information about pain guideline to family caregivers.
- Involve family caregivers.
- Ask about pain daily, using severity score 0-10.
- Use a pain observation scale if self-report pain scales can't be completed.
- Use a pain observation instrument more often.
- Use a standard form with background information about the person with aphasia, including pain.
- Use of a pain observation instrument during daily care or transfers.
- Ask family how person with aphasia expresses pain (currently and in past).
- Weekly evaluation of pain medication during physician visits.
- Attention to non-drug pain interventions.

Phase five

The scientific insights from the literature review (phase one) and the conclusions of the observational studies (phase two) form the content of the guideline to be developed. Together with the input gathered from persons with aphasia, their family caregiver, and professional caregivers (phases three and four) they were considered in drafting the content of the pain guideline to be developed. The research team discussed all the input collected in the previous phases to determine which guideline should be strongly recommended in the practice guideline for pain in persons with aphasia and what should be suggested in the guideline. This resulted in three preliminary draft versions, which differed mainly in form and layout. These three draft versions were used for inspiration and to decide which design was preferred and most useful according to the clinical experts during the first expert meeting. Fig. 1 presents the lay-out of the three draft versions. All three draft versions consisted of seven steps:

STEP 0: Mapping/ actions + reporting. Examined and reported are the person with aphasia's manner of communication and how the person previously communicated pain. The method and preference for assessing pain is recorded: severity rate (A), self-report pain scale/scales (B) or pain observation instrument (C).

STEP 1: Recognizing situations. Spontaneous change in behavior, signs of pain during rest, transfer or activity and signals from family are noticed. Supplement with information about pain of the person with aphasia using A, B or C.

STEP 2: Check. Check if basic needs are provided and check possible causes of pain. Check whether there is pain due to use A, B or C when signals are noticed during situations Step 1.

STEP 3: Investigate. Possible causes of pain are investigated by means of a physical examination by a physician.

STEP 4: Treatment. Start treating the cause of pain and/or start non-pharmacological intervention(s) and/or start with pain medication.

STEP 5: Monitoring plan. Multidisciplinary discussion of the situation, the frequency and manner of monitoring the pain. The plan includes frequency of Step 2, the situation in which pain is noticed and the use of A, B or C. Reassessment of the use of A, B or C is optional.

STEP 6: Evaluation plan. Multidisciplinary discussion of the situation, the frequency and how to evaluate the pain. The plan includes frequency of evaluation, who is present, treatment of pain, A, B or C. If necessary, repeat Research (Step 3) and evaluation of Treatment (Step 4) with outcomes A, B or C from Monitor plan (Step 5).

The clinical experts attending the first meeting were an elderly care physician, a nurse, and two speech and language therapists. They agreed that the practice guideline should be a mix of guideline draft versions 1 and 2, because of the logical flow from top to bottom (draft version 1) but should also include a loop (draft version 2) to ensure continuous monitoring and improvement of pain management and treatment. Guideline version 2 was considered

unclear with too many shapes and colors. Guideline version 3 was deemed unsuitable for use in practice, because the steps do not represent a continuous evaluation of the care. The clinical experts also felt that using a step 0 in the practice guideline made it unclear. The guideline must start with step 1, and this must be clearly visible.

The seven steps are described below, including the most important adjustments that were made with the experts:

STEP 1: Mapping/ Actions + Reporting. The ability and way of communication (language comprehension and spontaneous language production) of the person with aphasia must be clear and must be reported in the patient file. This is a task best done by a speech and language therapist. If there is no speech and language therapist, it was suggested this can also be done by a physician or nurse. The preferred method of pain assessment should also be documented: A= pain severity score 0-10, B= the use of a self-report pain scale (including which one is preferred), C= the use of a pain observation instrument.

STEP 2: Recognizing situations. This step should also include aggression and agitation (such as attacking). The fact that persons with aphasia express pain differently must also be considered. This step can be done by anyone.

STEP 3: Check. The pain severity rating must be checked, and this must be done according to the needs of the person with aphasia up to three times a day. The basic needs (e.g., hungry, thirsty, tired) must be described more clearly. This step can be done by a nurse. Step 3 was regarded as very important, because meeting the basic needs of persons with aphasia is essential and requires extra attention because these are persons with decreased communication capabilities.

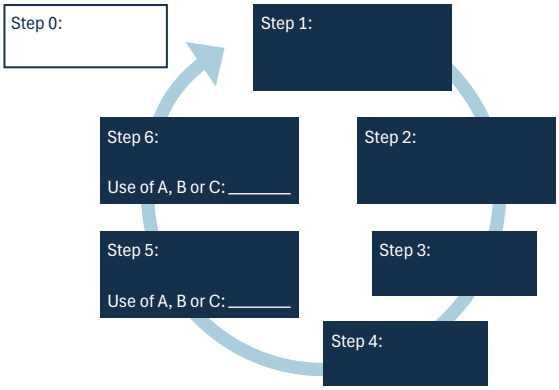
STEP 4: Investigate. This should be done once a week if pain persists. The physical examination or research can be performed by a physician or another member of the medical team.

STEP 5: Treatment. A few examples of treatment should be given. This step is done by someone from the medical team and in a multidisciplinary manner.

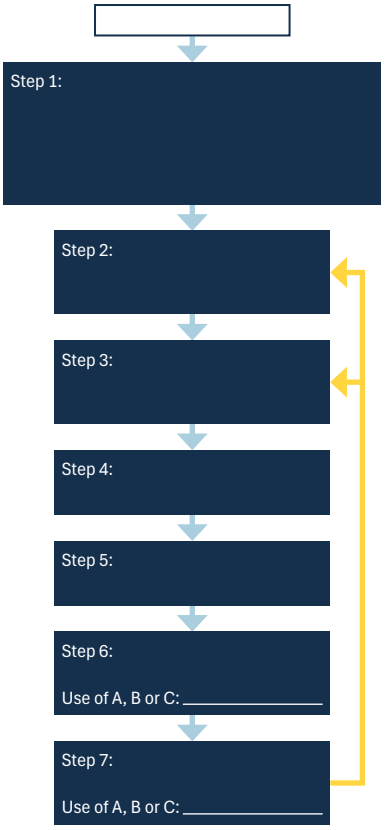
STEP 6: Monitoring plan. Action needs to be better described; give examples of the activities. Describe the use of pain observation instruments and/or self-report pain scales. These instruments must be available. Write down in the plan how this will be monitored. It is recommended to use one pain observation instrument per institution. For self-report more self-report scales can be used.

STEP 7: Evaluation plan. Evaluate the monitoring plan in multidisciplinary team meetings. Nurses must have knowledge of pain in the person with aphasia and the changes related to pain treatment. If needed, new information is collected with STEP 3.

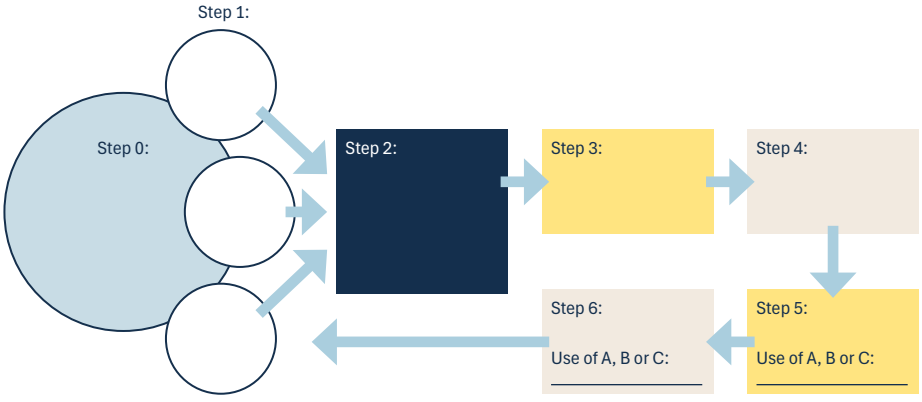
The input from the first clinical expert meeting results in an adjusted draft of the practice guideline. This version was discussed and refined by clinical experts in the second and third meetings. The second meeting included an elderly care physician, a nurse, three speech and



Draft version 1



Draft version 3



Draft version 2

Figure 1: Lay-out draft versions of the pain guideline

language therapists and a physiotherapist. During this meeting, the participants went through the draft version step by step and provided feedback and comments.
In addition to some minor textual adjustments, the following changes were recommended:

- **Step 2:** Add rest.
- **Step 3:** Add who can perform this step, which may vary per healthcare organization and depends on the composition of the care team.
- **Step 6:** Change the terminology for round/ visit, as this may be varied per organization; change it to physician's visit/round.

During the third meeting, all seven clinical experts from meeting 1 and meeting 2 reviewed the practice guideline and the explanation of each step. This resulted in a few minor additions to the steps of the guideline and their explanations, making them more concrete and clearer for the user of the pain guideline.

The final pain guideline for persons with aphasia is presented on two pamphlets and is included as supplemental material. The first pamphlet contains a circular low chart showing steps 2 through 7. See Box 1 for the steps of the practice pain guideline for persons with aphasia.

Box 1 Steps of the practice pain guideline for persons with aphasia:

STEP 1:	Mapping / Actions + Reporting - The person with aphasia's manner of communication is examined and reported, as is how the person previously communicated pain.
STEP 2:	Recognizing situations - Changes in behaviour; Signals during rest, care moment, move or activity; Signals from family/healthcare professionals.
STEP 3:	Check - Check if basic needs are provided and check possible causes of pain.
STEP 4:	Investigate - Possible causes of pain are investigated by means of a physical examination by a physician.
STEP 5:	Treatment - Start treating the cause of pain and/or start non-pharmacological intervention(s) and/or start with pain medication.
STEP 6:	Monitoring plan - Multidisciplinary discussion of the situation, the frequency and manner how to monitor the pain.
STEP 7:	Evaluation plan - Multidisciplinary discussion of the situation, the frequency and how to monitor the pain.

Step 1 is described at the top and contains the substantive steps that must be completed for each person with aphasia and that must be recorded in the electronic file. The second pamphlet contains descriptions and explanations of each step. This includes a QR code for additional background information on the practice pain guideline for persons with aphasia and on self-report pain scales and recommended pain observation instruments.

Discussion

This study describes the five-stage process for the composition and development of a pain guideline for use in clinical practice to identify, assess, and treat pain in persons with aphasia. The development was based on triangulation, which consisted of a literature study about pain and pain assessment in aphasia (phase one) [7], and studies on the psychometric properties of pain observation tools used in persons with aphasia (phase two) [12, 13]. In addition, the current study, using a stepwise qualitative research approach with semi-structured interviews, focus groups and expert meetings, developed a pain guideline for persons with aphasia in co-creation (phase three to five).

This practice pain guideline is developed in co-creation with the stakeholders, so it includes the needs, wishes, preferences and ideas of persons with aphasia, their family caregivers, and professional caregivers. Through input of the persons with aphasia themselves, the practice pain guideline starts with step 1. This step comprises the assessment of the ability and mode of communication of the person with aphasia and the preferred method of pain assessment to be used. This first step contributes to the personal wishes of the person with aphasia to be acknowledged and 'known' by the professional caregivers. Several guidelines have described the different phases in the development of quality interventions and emphasize that they should be produced in collaboration with key stakeholders [38, 39]. Phases three to five in our development study are like the phased approaches in which working with key stakeholders and patient involvement are applied [40].

Family caregivers play an important role in recognizing signs of pain in persons with aphasia. This is consistent with the study by [41] who concluded that proxy respondents are reliable informants in other related areas, such as feelings, daily activities, and well-being, as well as overall quality of life. This is also in line with a recent study that concluded that family caregivers can make valuable contributions to the observation, assessment, and management of pain in cancer patients receiving palliative care [42]. This knowledge ensures that through family involvement, the person with aphasia become more familiar to the professional caregivers, which is appropriate to the wishes and needs of persons with aphasia.

Strengths and limitations

This study has several strengths. By using a co-creation process, the wishes, needs and ideas of the key stakeholders, i.e., persons with aphasia, their family caregivers, and professional caregivers from different disciplines with experience with persons with aphasia were considered, ensuring that the pain guideline matches the needs of clinical practice. Persons with aphasia living at home, in geriatric rehabilitation and long-term care settings were interviewed. Other strengths include the use of triangulation of data for the development of the practice pain guideline and different research methods, including thorough preliminary literature research, observational cohort studies, and a qualitative study with a stepwise approach.

One limitation is the small number of participants in phases three to five, all of whom were from the elderly care setting. Another limitation is that the pain guideline has not been (pilot) tested in clinical practice. The next step is to implement, test, and evaluate the guideline in clinical practice to see if further refinements are needed and to examine whether the guideline improves the recognition and treatment of pain in persons with aphasia. Also, a process evaluation of the implementation is recommended.

Conclusion

We have co-created a practice pain guideline for persons with aphasia in clinical settings with the aim of improving pain assessment and management. Further research is needed to examine the feasibility of implementation and the impact of the pain guideline on persons with aphasia.

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Declaration of interest statement:

The authors report there are no competing interests to declare.

Data availability statement

Data of this study are available from the corresponding author NJdV on request. Data are available up to 15 years after collecting data.

References

1. Wu, C., et al., *Prevalence and Impact of Aphasia among Patients Admitted with Acute Ischemic Stroke.* Journal of Stroke & Cerebrovascular Diseases, 2020. **29**(5).
2. Code, C. and B. Petheram, *Delivering for aphasia.* Int J Speech Lang Pathol, 2011. **13**(1): p. 3-10.
3. Lazar, R.M. and A.K. Boehme, *Aphasia As a Predictor of Stroke Outcome.* Curr Neurol Neurosci Rep, 2017. **17**(11): p. 83.
4. Harrison, R.A. and T.S. Field, *Post stroke pain: identification, assessment, and therapy.* Cerebrovasc Dis, 2015. **39**(3-4): p. 190-201.
5. Haslam, B.S., D.S. Butler, and L.M. Carey, *Novel insights into stroke pain beliefs and perceptions.* Top Stroke Rehabil, 2019: p. 1-10.
6. Liampas, A., et al., *Prevalence and Management Challenges in Central Post-Stroke Neuropathic Pain: A Systematic Review and Meta-analysis.* Adv Ther, 2020. **37**(7): p. 3278-3291.
7. de Vries, N.J., P.H. Sloot, and W.P. Achterberg, *Pain and pain assessment in stroke patients with aphasia: a systematic review.* Aphasiology, 2016. **31**(6): p. 703-719.
8. Benaim, C., et al., *Use of the Faces Pain Scale by left and right hemispheric stroke patients.* Pain, 2007. **128**(1-2): p. 52-8.
9. Hadjistavropoulos, T., et al., *Pain assessment in elderly adults with dementia.* Lancet Neurology, 2014. **13**(12): p. 1216-1227.
10. Closs, S.J., et al., *A comparison of five pain assessment scales for nursing home residents with varying degrees of cognitive impairment.* J Pain Symptom Manage, 2004. **27**(3): p. 196-205.
11. Smith, J.H., et al., *Inability to self-report pain after a stroke: a population-based study.* Pain, 2013. **154**(8): p. 1281-6.
12. de Vries, N.J., et al., *Validity and reliability of the Pain Assessment in Impaired Cognition 15 (PAIC15) observation scale in persons with aphasia.* BMC Neurol, 2024. **24**(1): p. 319.
13. de Vries, N.J., et al., *Measuring Pain in Aphasia: Validity and Reliability of the PACSLAC-D.* Pain Manag Nurs, 2023. **24**(4): p. e68-e74.
14. Soares, C.D., et al., *Experimental pain assessment in patients with poststroke aphasia.* Neurology, 2018. **91**(9): p. e793-e799.
15. Lautenbacher, S., A.L. Walz, and M. Kunz, *Using observational facial descriptors to infer pain in persons with and without dementia.* BMC Geriatr, 2018. **18**(1): p. 88.
16. Lukas, A., et al., *Pain assessment in advanced dementia. Validity of the German PAINAD-a prospective double-blind randomised placebo-controlled trial.* Pain, 2019. **160**(3): p. 742-753.
17. Corbett, A., et al., *An international road map to improve pain assessment in people with impaired cognition: the development of the Pain Assessment in Impaired Cognition (PAIC) meta-tool.* BMC Neurol, 2014. **14**: p. 229.
18. de Vries, N.J., et al., *User-friendliness of the pain assessment in impaired cognition (PAIC15) in persons with aphasia: a pilot study.* Future Sci OA, 2025. **11**(1): p. 2456440.
19. Abdulla, A., et al., *Guidance on the management of pain in older people.* Age Ageing, 2013. **42**: p. I1-I57.
20. Achterberg, W.P., et al., *[Multidisciplinary guideline 'Recognition and treatment of chronic pain in vulnerable elderly people'].* Ned Tijdschr Geneeskd, 2012. **155**(35): p. A4606.

21. Sabater-Garriz, A., et al., *Pain assessment tools in adults with communication disorders: systematic review and meta-analysis.* BMC Neurol, 2024. **24**(1): p. 66.

22. Koskinas, E., M. Gilfoyle, and J. Salsberg, *Exploring how patients, carers and members of the public are recruited to advisory boards, groups and panels as partners in public and patient involved health research: a scoping review protocol.* BMJ Open, 2022. **12**(4): p. e059048.

23. Pearce, T., et al., *What Is the Co-Creation of New Knowledge? A Content Analysis and Proposed Definition for Health Interventions.* Int J Environ Res Public Health, 2020. **17**(7).

24. Poppleton, A., *Books: Researching Health: Qualitative, Quantitative and Mixed Methods. Third edition.: Filling in Your Research Knowledge Gaps.* Br J Gen Pract, 2020. **70**(692): p. 134.

25. World Medical, A., *World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects.* JAMA, 2013. **310**(20): p. 2191-4.

26. E.G. Visch-Brink, M.v.d.S.-K., H. El Hachioui, *Screeling*. 2010, Houten: Bohn Stafleu van Loghum.

27. De Renzi, E. and L.A. Vignolo, *The token test: A sensitive test to detect receptive disturbances in aphasics.* Brain, 1962. **85**: p. 665-78.

28. Verbeek, H., et al., *The Living Lab In Ageing and Long-Term Care: A Sustainable Model for Translational Research Improving Quality of Life, Quality of Care and Quality of Work.* J Nutr Health Aging, 2020. **24**(1): p. 43-47.

29. Tu, P., et al., *Patients' Characterization of Medication, Emotions, and Incongruent Perceptions around Adherence.* J Pers Med, 2021. **11**(10).

30. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.* Int J Qual Health Care, 2007. **19**(6): p. 349-57.

31. Vaismoradi, M., H. Turunen, and T. Bondas, *Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study.* Nurs Health Sci, 2013. **15**(3): p. 398-405.

32. Crowe, M., M. Inder, and R. Porter, *Conducting qualitative research in mental health: Thematic and content analyses.* Aust N Z J Psychiatry, 2015. **49**(7): p. 616-23.

33. Zwakhalen, S.M., et al., *Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools.* BMC Geriatr, 2006. **6**: p. 3.

34. Zwakhalen, S.M., J.P. Hamers, and M.P. Berger, *Improving the clinical usefulness of a behavioural pain scale for older people with dementia.* J Adv Nurs, 2007. **58**(5): p. 493-502.

35. van Herk, R., et al., *Pain management in Dutch nursing homes leaves much to be desired.* Pain Manag Nurs, 2009. **10**(1): p. 32-9.

36. Beukelman, D.R., et al., *Using Visual Scene Displays as Communication Support Options for People with Chronic, Severe Aphasia: A Summary of AAC Research and Future Research Directions.* Augment Altern Commun, 2015. **31**(3): p. 234-45.

37. van de Sandt-Koenderman, M., J. Wiegers, and P. Hardy, *A computerised communication aid for people with aphasia.* Disabil Rehabil, 2005. **27**(9): p. 529-33.

38. O'Cathain, A., et al., *Guidance on how to develop complex interventions to improve health and healthcare.* BMJ Open, 2019. **9**(8): p. e029954.

39. Skivington, K., et al., *A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance.* BMJ, 2021. **374**: p. n2061.

40. Lawless, A., et al., *Developing a Framework for a Program Theory-Based Approach to Evaluating Policy Processes and Outcomes: Health in All Policies in South Australia.* Int J Health Policy Manag, 2018. **7**(6): p. 510-521.

41. Cruice, M., et al., *Measuring quality of life: Comparing family members' and friends' ratings with those of their aphasic partners.* Aphasiology, 2005. **19**(2): p. 111-129.

42. Chi, N.C., et al., *Family Caregivers' Challenges in Cancer Pain Management for Patients Receiving Palliative Care.* Am J Hosp Palliat Care, 2023. **40**(1): p. 43-51.

Chapter 8

General discussion

This thesis describes the method, results, and implications of the research project **'Pain in aphasia: an unspoken problem'**. The overall aim of the 'Pain in Aphasia' project was to describe the current scientific status on pain and pain measurement in persons with aphasia, and to develop a practice guideline for pain measurement specifically for persons with aphasia.

8.1 Main research findings

- *Which assessment instruments are used for self-report of pain in stroke patients with communication problems?*

A scoping review to identify assessment instruments used for self-report pain by hospitalized patients who have had a stroke and have communication problems, reported a range of both unidimensional and multidimensional self-report pain instruments (**Chapter 2).** The most common communication problem in these patients was aphasia. The eleven identified assessment instruments focused on assessing pain presence and pain intensity. The most frequently used unidimensional pain intensity instrument was the Numeric Rating Scale (NRS). Four instruments were multidimensional, two of which assessed health-related quality of life, including pain. The most comprehensive pain assessment instrument was the ShoulderQ [1], which includes 10 verbal questions and three visual vertical graphic rating scales that focus on the assessment of stroke-related shoulder pain. This review study concluded that the challenges of measuring pain in persons with moderate to severe communication problems or severe aphasia after stroke remain understudied. As a result, it is unknown how pain is and should be assessed and managed in persons who are unable to complete self-report pain scales after stroke.

- *What is known in the literature about pain and pain assessment in persons with aphasia?*

The prevalence of pain in persons with post-stroke aphasia was reported in two studies and ranged from 43.8–87.5%. The self-report pain scales used included the Vertical, Mechanical and Horizontal Visual Analogue Scale, the Faces Pain Scale, the Verbal Rating Scale, and the Numeric Rating Scale. Interestingly, studies described pain assessment in post-stroke aphasia patients with mild-to-moderate aphasia, while patients with severe aphasia were excluded. Various pain assessment instruments were used, but their feasibility, validity and reliability were of low methodological quality **(Chapter 3)**. These findings underline the difficulty of identifying pain in persons with severe aphasia after stroke. This review also found that there is no information on how pain is or should be assessed and managed in persons with severe communication problems due to aphasia. Therefore, these two reviews **(Chapters 2 and 3)** report a gap in knowledge; persons with aphasia who are not able to complete self-report pain scales are at risk of their pain not being noticed. An alternative way of assessing pain in persons with aphasia could be a pain observation instrument.

- *Are pain observation instruments that were developed for persons with dementia also valid, reliable and feasible for assessing pain in persons with aphasia?*

Previous research has examined the psychometric quality of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version (PACSLAC-D). PACSLAC-D is a pain observation instrument that consists of 24 items divided into three categories: facial expressions (10 items), resistance/ defensive behavior (6 items), and social/ emotional items (8 items). The PACSLAC-D is widely used in Dutch nursing homes, and this study was conducted to explore whether the PACSLAC-D has added value for pain observation in persons with aphasia [2, 3]. The validity of the PACSLAC-D in persons with aphasia was adequate during Activities of Daily Living (ADL) or physiotherapy, but not during rest. Reliability was also situation dependent: reliability was adequate during activities of daily living (ADL) or physiotherapy, but not during rest (**Chapter 4**). **Chapter 5** describes the use of the Pain Assessment in Impaired Cognition (PAIC15) instrument in persons with aphasia, because PAIC15 has shown satisfactory psychometric properties in persons with impaired cognition. PAIC15 is a pain observation instrument that assists healthcare professionals in recognizing pain in persons with cognitive impairments, by assessing 15 items with described behaviors divided into facial expressions, body movements, and vocalizations, with 5 items each.
In **Chapter 5**, the results of observations during rest and transfer of the PAIC15 reported fair positive correlations between PAIC15 and all self-report pain scales in persons with aphasia. Significantly more pain was observed in persons with aphasia during transfer than during rest, confirming validity. No differences in observed pain were found between persons with aphasia who use pain medication and those who do not, or between those who have joint diseases compared to those who do not. These results called the validity into question However, the test-retest reliability and inter-reliability of the PAIC15 were high in persons with aphasia during both rest and transfer.

The studies in **Chapters 4 and 5** conclude that PACSLAC-D and PAIC15 capture pain during activity in persons with aphasia who are unable to self-report, but may be less accurate during rest. The user-friendliness study of PAIC15 for persons with aphasia (**Chapter 6)** reported that the PAIC15 was considered by all observers to be user-friendly for persons with aphasia. The results of this study indicated that observers assess the PAIC15 as a helpful instrument to aid clinical judgment and to screen for the presence of pain in persons with aphasia.
The PAIC15 items were clear and not difficult to score, prompted observers to pay attention to nonverbal signals in persons unable to express themselves, and facilitated clinical judgement (**Chapter 6**). Most observers preferred to use the combined self-report pain scale for persons with aphasia, because it was thought that the amount of information provided best facilitates self-report in persons with aphasia (**Chapter 6**).

What should a clinically applicable pain guideline for recognizing pain in persons with aphasia look like - both in terms of content and design?

A practice pain guideline for persons with aphasia was developed based on evidence about pain, pain assessments (studies presented in **Chapters 2 and 3**) and observational studies of pain in persons with aphasia (studies presented in **Chapters 4, 5 and 6**), as well as the experiences of persons with aphasia and their family caregivers and the experiences of experts (**Chapter 7**). Both the content and design of the practice pain guideline were co-created with professionals, patients, and family caregivers. This practice pain guideline supports professionals in personalizing the recognition and assessment of pain in aphasia (**Chapter 7**).

8.2 Critical reflection on main findings

Self-report pain instruments in stroke patients with communication problems

Self-report is considered the gold standard for routine assessment of symptoms: however, this is challenging in post-stroke patients [7-9]. Assessing pain becomes challenging in the post-stroke population due to deficits such as aphasia and neglect [10]. Pain assessment in similar cognitively and communicatively impaired populations, such as those with intellectual disabilities or dementia, presents similar challenges regarding the use of self-report instruments, resulting in underreport and undertreatment of pain [7-9]. The difference between these populations and persons with aphasia is that persons with aphasia may recover after stroke. Both the severity of aphasia and the severity of cognitive problems may change [11]. Cognitive problems after a stroke may include a delayed rate of information processing, attention problems, difficulty solving problems and planning/organizing. Persons with dementia often have difficulty processing information, but cognitive functions may also be impaired, which can manifest as, for example, forgetfulness, getting lost or being unable to solve problems. The varying and sometimes changing post-stroke cognitive problems make persons with stroke a distinct group that deserves a specific approach and research. Individuals with communication problems are vulnerable to incomplete self-report regarding pain assessment and inadequate pain management. It is recommended that self-report scales be used as the first and preferred method for as long as possible [10, 12]. However, when self-report of pain becomes challenging due to deficits such as aphasia, pain observation is an acceptable and preferred additional or alternative assessment.

Pain in aphasia

Pain after stroke is an under-recognized and under-assessed phenomenon, and it is usually assumed that communication difficulties in stroke patients are a major contributing factor [13-15]. The rationale behind the studies in this thesis was that pain in persons with aphasia is a challenge, and certainly there is little attention for this problem in literature. A German study in a stroke unit confirmed that pain in persons with aphasia is not systematically assessed

and therefore not adequately treated [16]. This thesis confirms the hypothesis that persons with aphasia who cannot express pain due to communication problems are excluded from pain assessments (**Chapters 2 and 3**). In contrast to persons with dementia, who also experience communication and cognitive problems, research on pain measurement in persons with aphasia is limited. The current research project is about pain in a target group that has not been studied before, pain in persons with aphasia.

Pain assessment in aphasia

Persons with aphasia have more difficulty expressing their needs or requests for help and accessing care than persons without aphasia. Various studies have described different methods that can support and aid spontaneous language production or expression of unmet needs, such as photographs or pictures of the human body [4, 17-19]. A developmental study of a pictorial scale of pain intensity (SPIN) for persons with communication problems performed well in comparison with two well-validated pain intensity scales, and quantified the severity of pain as well as the preferred Numeric Rating Scale [20]. However, this study included persons who were able to report their pain symptoms.

Studies in persons who are able to complete self-report instruments have shown moderate validity and reliability of the self-report pain scales Faces Pain Scale (FPS), Numeric Rating Scale (NRS), and Visual Analogue Scale (VAS) [21, 22]. The study by Smith et al. [10] describes the inability to self-report pain after a stroke as being less common than previously thought. Nevertheless, individuals who may have difficulty reporting their pain with a self-report pain scale are dependent on a different pain measurement instrument or the assessment of a healthcare professional or informal caregiver. The use of a structured approach to pain assessment in nonverbal post-stroke patients will improve quality of care [13, 14].

Pain observation in persons with aphasia

As the use of a pain observation instrument has been shown to be feasible in persons with dementia [23, 24], it may also be an alternative for persons with aphasia. Whether a pain observation instrument is also valid and reliable in persons with aphasia was investigated in the quantitative studies on these psychometric properties of the PACSLAC-D and the PAIC15 in **Chapters 4 and 5**.

The PACSLAC-D captures pain in persons with aphasia who are unable to self-report, during ADL and physiotherapy, but may be less accurate during rest (**Chapter 4**). Disadvantages of using the PACSLAC-D are that this instrument consists of up to 24 items, not all of which are clearly defined, reliable or valid. The same applies to many other pain observation instruments and an EU initiative (EU-COST TD1005) therefore developed the PAIC15 as a meta-tool, with 15 structured and comprehensible items divided into three domains: facial expressions, body movements and, vocalizations [25].

A study of the PAIC15 used in persons with dementia showed that there are differences in the perception of pain characteristics between nurses and physicians working in nursing homes [26]. In addition, it is also possible that information provided by nurses is not taken seriously by physicians, due to an inability to properly describe the problem or desired action [27]. This can have negative consequences for the person with communication problems - and pain - who is dependent on the nurse being attentive to any symptoms.

A recent systematic review and meta-analysis by Sabater-Garriz and colleagues [9] found that the predominant method of pain assessment in adults with communication disorders (including post-stroke aphasia) is the use of observation scales, with some scales showing promising psychometric properties for specific populations. However, the existing diversity of assessment tools and study designs prevents the selection of a universally suitable scale for evaluating pain across all adults with communication disorders. The current thesis is consistent with the consensus that pain observation instruments such as the PACSLAC-D and PAIC15 can be used to assess pain in persons with aphasia when self-report pain scales cannot be used. Furthermore, when self-report is possible, it is the gold standard for measuring pain.

Proxy report

It is common for healthcare professionals to ask family caregivers if the person with aphasia is in pain when the person cannot verbally express their pain themselves. However, research on proxy report indicates that family caregivers of persons with aphasia rate their loved ones significantly lower on global quality of life, physical functioning, general or overall health, pain, and vitality [28]. Nevertheless, their systematic patterns in proxy ratings could be useful for clinicians and researchers as their aphasic partners' scores can be easily and confidently predicted [28]. This is also in line with a recent study that concluded that family caregivers can make valuable contributions to the observation, assessment, and management of pain in cancer patients receiving palliative care [29]. Research on assessment of pain by proxy compared with self-report of pain in persons with dementia showed mixed results. Proxies of community-dwelling older adults with dementia reported slightly higher rates of pain than self-reporters, but differences were statistically significant only for activity-limiting pain [30]. Pain assessed by proxy, both by family members and healthcare professionals, in patients with and without cognitive impairment, reports differences between self-reported pain and proxy ratings [28, 31]. Researchers and clinicians should be aware of these biases when using proxy reports.

Communication support for persons with aphasia

Persons with aphasia, regardless of the severity of the aphasia, need the support and assistance of a speech language therapist or trained conversation partner to have an adequate conversation about pain [4, 5]. In addition, there are all kinds of supportive communication aids that can be used to facilitate a conversation. For example, communication apps, photographs

or images are used to support the language production or understanding of a message [4-6].
The results of developing the practice pain guideline in co-creation with persons with aphasia and their family caregivers show that they want others to know in what ways the person with aphasia can communicate and how to best support them (**Chapter 7**). This is an important task for speech and language therapists, other healthcare professionals and family caregivers of the person with aphasia and it requires interprofessional collaboration.

8.3 Critical reflection on methodology

Design of the study

The applied mixed-methods approach, in which an extensive set of quantitative and qualitative data was collected, resulted in an in-depth understanding of pain in aphasia and pain measurement instruments for persons with aphasia. The combination of data from the literature reviews (**Chapters 2 and 3**) and the studies on the psychometric properties of PACSLAC-D and PAIC15 in persons with aphasia (**Chapters 4 and 5**), together with the user-friendliness of the PAIC15 (**Chapter 6**) provided the input for the development of the pain guideline for persons with aphasia (**Chapter 7**). Its development was a co-creation process with a qualitative design and a stepwise approach. This approach provided relevant information about the needs, wishes and ideas of the most important stakeholders, persons with aphasia, their informal caregivers, and healthcare professionals. Therefore, the developed practice pain guideline could provide a clinically useful tool to improve the recognition of pain in persons with aphasia. The different types of research required substantial expertise and knowledge on the part of the researcher, which may not always have been optimal. In addition, the researcher of this project is a speech and language therapist and was instrumental in inviting a few participants with aphasia. She also conducted a few observations using the PACSLAC-D and PAIC15 when it was not possible to have other observers do this. Her expertise and perspective on individuals with aphasia, combined with her role as a researcher, may have led to biased results.

Setting

Data were primarily collected in long-term care and geriatric rehabilitation organizations. The literature review includes studies with hospitalized patients, while the observational studies include participants in geriatric rehabilitation or somatic departments of nursing homes. Relevant stakeholders were involved in the development of the practice pain guideline. Participants in phases three to five (**Chapter 7**) were from nursing homes, but phase two also included input from persons with aphasia and their relatives living in the home situation.
This thesis and the development of the practice guideline therefore did not include a balanced sample of all settings in which persons with aphasia live, but focused heavily on more long-term and rehabilitation settings for older persons with aphasia. This makes the application of the results in these settings more feasible, but the external validity for other settings is uncertain.

Sample sizes

The number of articles included in the systematic review was small (n=10), confirming that pain in aphasia is an understudied problem. Regarding the quantitative studies, 60 and 75 persons with aphasia were observed using PACSLAC-D and PAIC15, respectively. A sample size with a minimum of 50 persons is recommended for validation and reliability analysis [32]. The qualitative study to collect data for the development of a pain guideline for persons with aphasia included a small number (N=17) of stakeholder participants. However, data saturation was achieved in the individual phases of this qualitative study.

Psychometric properties of pain observation instruments

Regarding the examination of the psychometric properties of the PACSLAC-D and PAIC15 in the quantitative studies conducted in persons with aphasia, the following 4 types of validity were tested: content, construct, face validity and criterion validity. The validity scores of the pain observation instruments which are used were adequate during ADL, transfer, or physiotherapy, but insufficient during rest. The qualitative studies in this thesis reported acceptable internal consistency and test-retest reliability of the PACSLAC-D in persons with aphasia during ADL and physiotherapy, which is consistent with studies using the PACSLAC-D in patients with dementia or other older persons with communication problems [33,34]. Especially during movement, a higher prevalence of facial expression items was found compared to items in the other two domains (body movements and vocalizations) of the PAIC15. This is consistent with findings from a PAIC15 study in a long-term care setting in patients with dementia [35]. The prevalence of individual PAIC15 items observed in persons with aphasia was low for most items. It is possible that low scores on PAIC15 items are due to a failure to observe the behaviors described in the PAIC15 items in persons with aphasia after stroke. Another possible explanation is that pain can be experienced differently in this population.

Lower intra- and interobserver agreement for the facial expression items suggests that these items are more difficult to observe in a clinical setting. This is interesting, because Kaasalainen et al. concluded that facial expression items were observed more frequently in clinical practice in people who were unable to verbally report their pain than in persons who were able to report [36]. Lautenbacher et al. also showed that in experimental settings, people with dementia show more facial expressions after a painful stimulus compared to non-dementia controls. This provides evidence that observing facial expressions and using an observational pain assessment instrument is paramount when assessing pain in persons with communication problems [23,26]. However, it may be that healthcare professionals are less used or less trained to pay special attention to the face and its expressions.

8.4 Implications of this research project

Implications for clinical practice

The research described in this thesis has resulted in a clinical practice guideline for the assessment of pain in persons with aphasia, an area that has received very little attention so far. If this newly developed practice pain guideline is properly implemented in nursing homes or other settings where persons with aphasia reside, there will be more attention for how the person with aphasia communicates, how they expressed pain before and how it is now expressed differently. Use of this practice pain guideline may lead to increased attention to the assessment of pain in persons with aphasia. One of the key components of this guideline is to record knowledge about who the person was and both the current way of communicating and expressing pain with aphasia and the way of communicating and expressing pain before the aphasia. Examples of tools for getting to know the person include the use of hetero-anamnesis, notebooks with personal information, photo albums, and a doodle board [5, 17, 37]. It is essential to continue to see persons with aphasia as individuals with unique needs and talents. Person-centered care contributes to this by putting the person at the center and adapting communication to his or her abilities, thereby increasing self-confidence and participation. It also requires practitioners to develop mutually respectful relationships with residents (including persons with aphasia), and family caregivers who are important to them, and to seek to understand the residents' values and preferences [38]. It requires good cooperation between different disciplines, such as speech and language therapists and healthcare providers, because effective communication in aphasia is complex and needs a collaborative approach. The practice pain guideline for persons with aphasia contributes to person-centered care.

The standard use of pain observation instruments in persons with aphasia who are unable to complete self-reports is still lacking in the daily care of persons with aphasia. The standard use of a pain observation instrument when self-report is not possible is another key component of the practice pain guideline for persons with aphasia. It is recommended that pain should preferably be observed not only during rest, but especially during daily activities (e.g., washing and getting up), because little has been observed with pain observation instruments PACSLAC-D and PAIC15 during rest. Also, new instructions have recently been added to the e-learning of PAIC15 to improve the assessment of pain: if you have observed a pain signal, select score 2: "medium degree" by default. The options score 1: "low degree" and score 3: "high degree" should only be selected for very weak or strong responses. These new instructions were initiated because the PAIC15 scores 2: "medium degree" and 3: "high degree" were rarely scored, possibly because observers had difficulty distinguishing between scores 2 and 3 (**Chapter 5**). In addition, a follow-up study on user-friendliness for persons with aphasia with a larger and more diverse study sample in an international context is recommended.

Technology and pain assessment

Pain in people living with cognitive or communicative impairment and in those with both may be treated sub-optimally. Communication challenges lead to suboptimal assessment of pain. When pain is not adequate assessed, its management will invariably be suboptimal [39]. Pain is, among other things, one of the main indicators of discomfort. It is possible that digital support could be helpful in the assessment and treatment of pain in persons with aphasia. Digital phenotyping deals with observable features in digital form, such as those of sensor-supporting devices, and may provide new and more informative data than existing clinical approaches regarding how pain manifests and how treatment strategies affect pain [40]. Today, non-invasive monitoring technologies to identify discomfort and distressing symptoms in persons with limited communication are available [41]. These monitoring technologies and possible other technological developments will help to improve the assessment of pain in persons with aphasia and/or cognitive problems in the future.

A recent study of an augmentative and alternative communication (AAC) pain description system for persons with communication problems used symbols to express pain. This is challenging because designing a series of comprehensible symbols to represent personal experiences such as pain is not straightforward [42]. Augmentative and alternative communication (AAC) describes multiple ways of communicating that can complement of compensate for the impairment and disability patterns of individuals with severe expressive communication problems. Pain expression symbols derived from Chinese pain-related similes and metaphors were used for a mobile AAC application developed specifically for this study. Results show that the use of the app was effective in reporting pain and that people required less time to report a pain event. The results also indicate that the pain diary app was better received by younger individuals than by their older counterparts [42]. The potential value of adding this type of AAC in the practice pain guideline is something to further explore.

Implications for health care policy and education

Aphasia experts, such as speech and language therapists, aphasia therapists, and policy makers in healthcare organizations where persons with aphasia reside will need to be aware of the existence of the practice pain guideline for persons with aphasia. They should prioritize the implementation of this pain guideline because aphasia is a condition that has a significant negative impact on health-related quality of life [43] with a high risk of depression and a lower probability of returning to pre-aphasia levels of functioning [44]. The combination of the inability to communicate pain due to aphasia, and the high prevalence of pain after stroke suggests a need for improved pain assessment in this vulnerable population.

From an educational perspective, it is important that training courses for nurses, physicians, elderly care physicians, speech and language therapists, and other experts who work with persons with communication and cognitive problems include competencies in

pain and pain assessment. Especially for this vulnerable population, who may have difficulty expressing their distress and symptoms, it is important that professional caregivers learn that observing may be more important than listening. Thorough training and education in the use of self-report pain scales, pain observation scales, and the practice pain guideline is important for proper implementation. Differences in the perception of pain characteristics between nurses and physicians in nursing homes, as mentioned earlier, demonstrate the need for more interdisciplinary interprofessional education about pain in persons with communication and cognitive problems [26]. Research indicates that nurses do not always use observational pain instruments to assess pain, even when they are available and their use is encouraged. They often prefer to rely on their intuition and feelings [45]. However, non-use of a pain observation instrument is a barrier to adequate pain management in persons with dementia [26]. This highlights the need for awareness of the usefulness of pain observation instruments. This may require a culture change in the way nurses and physicians collaborate.

Recommendations for future research

Research on the performance of self-report pain compared to observational scales in persons with dementia shows that self-report, the highest standard of pain measurement, can be reliably administered in a large proportion of older people with severe dementia [46, 47].

Encouraging the use of self-report pain scales as much as possible in persons with aphasia is recommended. By implementing the pain protocol for persons with aphasia, the use of self-report pain scales will be systematically applied and evaluated.

As in persons with Down syndrome and impaired cognition, further research could provide insight into the role of cognitive processes in self-report, involving aspects such as acquiescence and repeated measurements to evaluate whether neuropsychological examination could contribute to pain assessment in persons with aphasia [7]. Studies of the role of cognitive processes in persons with aphasia are lacking but should be encouraged.

Further research is also needed to investigate the feasibility of the developed practice pain guideline for persons with aphasia, as the practice pain guideline has not yet been (pilot) assessed in clinical practice. Also, the added value of complementary use of the pictorial scale of pain intensity (SPIN) for persons with communication problems in addition to the self-report pain scales to quantify the severity of pain should be investigated [20]. Plus, the addition of technology/digital phenotyping is worth exploring.

A next step for further research is to implement, test, and evaluate the developed pain guideline in clinical practice to see if refinements are needed and to investigate whether the guideline improves the recognition and treatment of pain in persons with aphasia.

A study of the effects of implementing an intervention for mapping and treating pain in people with dementia (STA OP!) found clinically relevant reductions in pain in the intervention group compared with the control group [48]. This study shows that individuals in the intervention

group who received the stepwise multidisciplinary intervention were significantly more likely to receive opioids in addition to other pain medication. A cluster randomized controlled trial is recommended to assess the effects of the developed pain guideline with structural pain assessment in individuals with aphasia. It should include previously started or new pain treatment (pharmacological or non-pharmacological). Side effects of (pharmacological) treatment may influence mood, physical functioning or participation in interactions, which may affect the quality of life of the person with aphasia. Therefore, it is important to include effects on the quality of life of persons with aphasia in the outcome measures. These effects can be elicited using an instrument validated for persons with aphasia, such as the Stroke and Aphasia Quality of Life Scale (SAQOL-39) [49]. In addition, a process evaluation of the implementation of the pain practice guideline is recommended. This process evaluation will clarify the facilitators and barriers that may be encountered when implementing and using the practice pain guideline for persons with aphasia.

Thanks to technological developments, the steps of the practice pain guideline can be entered into an application. The steps could also have a place in the electronic health record of persons with aphasia. It may be possible to use reminders in the electronic patient record to support implementation of the steps. In addition, various supporting communication systems or applications are being developed and increasingly used in clinical practice by speech and language therapists to help compensate for communication problems. Also, persons with aphasia themselves increasingly have mobile communication applications on various devices [50]. If caregivers want to get to know the person with aphasia, they need to know how to use these applications properly. Mobile applications with symbols to express pain, derived from pain-related simulations and metaphors, are the future. They can provide a solution for persons with aphasia who have difficulty expressing their pain themselves.

Improving healthcare for persons with aphasia requires knowing that looking at the person can be more important than listening. A pain observation instrument is a tool to make the caregiver's 'sense' that the person with aphasia may be in pain explicit.

Epilogue

Music of the future

The case of Mrs. S. with an implemented pain guideline for persons with aphasia

Mrs. S. is 85 years old and has severe aphasia. Every nurse and healthcare professional calls her Inge, because this is her wish and it is noted in her medical record. Inge was once trained as a pediatric nurse herself and worked in a hospital for years caring for children. Inge loved piano music very much. It was also noted that Inge wants to be approached by care staff as an equal and is happy to give her opinion and input on her daily care and circumstances.

After a few weeks of practising language comprehension and production, Inge produces short sentences in everyday situations. These are characterized by word finding problems. Every morning and evening, Inge can rate her abdominal symptoms and pain on a scale of 0-10. In consultation with Inge, if the score is 7 or higher, she is given pain medication. With this policy, the previous resistance to nurses is no longer observed. If her pain cannot be assessed with a rating of 0-10 or self-report scale, the nurse will complete a PAIC15 during morning care. During each multidisciplinary consultation, any pain and treatment is monitored and evaluated. In this way, the pain of the person with aphasia is always on the agenda, and during daily care moments, piano music in the background creates a pleasant atmosphere.

References

1. Turner-Stokes, L. and S. Rusconi, *Screening for ability to complete a questionnaire: a preliminary evaluation of the AbilityQ and ShoulderQ for assessing shoulder pain in stroke patients.* Clin Rehabil, 2003. **17**(2): p. 150-7.
2. Qi NG, S., Brammer, J.D., Creedy, D.K., *The psychometric properties, feasibility and utility of behaviouralobservation methods in pain assessment of cognitively impaired elderly people in acute and long-term care: A systematic review.* JBI Libr Syst Rev, 2012. **10**(17): p. 977-1085.
3. Zwakhalen, S.M., J.P. Hamers, and M.P. Berger, *Improving the clinical usefulness of a behavioural pain scale for older people with dementia.* J Adv Nurs, 2007. **58**(5): p. 493-502.
4. Hinckley, J. and M. Jayes, *Person-centered care for people with aphasia: tools for shared decision-making.* Front Rehabil Sci, 2023. **4**: p. 1236534.
5. Stipinovich, A.M., K. Tonsing, and S. Dada, *Communication strategies to support decision-making by persons with aphasia: A scoping review.* Int J Lang Commun Disord, 2023. **58**(6): p. 1955-1976.
6. Dietz, A., S.E. Wallace, and K. Weissling, *Revisiting the Role of Augmentative and Alternative Communication in Aphasia Rehabilitation.* Am J Speech Lang Pathol, 2020. **29**(2): p. 909-913.
7. de Knegt, N.C., et al., *Pain and Cognitive Functioning in Adults with Down Syndrome.* Pain Med, 2017. **18**(7): p. 1264-1277.
8. Oudman, E., et al., *Self-Reported Pain and Pain Observations in People with Korsakoff's Syndrome: A Pilot Study.* J Clin Med, 2023. **12**(14).
9. Sabater-Garriz, A., et al., *Pain assessment tools in adults with communication disorders: systematic review and meta-analysis.* BMC Neurol, 2024. **24**(1): p. 66.
10. Smith, J.H., et al., *Inability to self-report pain after a stroke: a population-based study.* Pain, 2013. **154**(8): p. 1281-6.
11. Code, C. and B. Petheram, *Delivering for aphasia.* Int J Speech Lang Pathol, 2011. **13**(1): p. 3-10.
12. Lukas, A., et al., *Pain and dementia A diagnostic challenge.* Zeitschrift Fur Gerontologie Und Geriatrie, 2012. **45**(1): p. 45-49.
13. Harrison, R.A. and T.S. Field, *Post stroke pain: identification, assessment, and therapy.* Cerebrovasc Dis, 2015. **39**(3-4): p. 190-201.
14. Nesbitt, J., et al., *Improving pain assessment and managment in stroke patients.* BMJ Qual Improv Rep, 2015. **4**(1).
15. Westerlind, E., et al., *Experienced pain after stroke: a cross-sectional 5-year follow-up study.* Bmc Neurology, 2020. **20**(1).
16. Schuster, J., et al., *Use of analgesics in acute stroke patients with inability to self-report pain: a retrospective cohort study.* Bmc Neurology, 2020. **20**(1).
17. Beukelman, D.R., et al., *Using Visual Scene Displays as Communication Support Options for People with Chronic, Severe Aphasia: A Summary of AAC Research and Future Research Directions.* Augment Altern Commun, 2015. **31**(3): p. 234-45.
18. Doedens, W.J. and L. Meteyard, *What is Functional Communication? A Theoretical Framework for Real-World Communication Applied to Aphasia Rehabilitation.* Neuropsychol Rev, 2022. **32**(4): p. 937-973.
19. Van de Sandt-Koenderman, W.M., et al., *A computerised communication aid in severe aphasia: an exploratory study.* Disabil Rehabil, 2007. **29**(22): p. 1701-9.

20. Jackson, D., et al., *Development of a pictorial scale of pain intensity for patients with communication impairments: initial validation in a general population.* Clin Med (Lond), 2006. **6**(6): p. 580-5.

21. Chow, S., et al., *Pain assessment tools for older adults with dementia in long-term care facilities: a systematic review.* Neurodegener Dis Manag, 2016. **6**(6): p. 525-538.

22. Kang, Y. and G. Demiris, *Self-report pain assessment tools for cognitively intact older adults: Integrative review.* Int J Older People Nurs, 2018. **13**(2): p. e12170.

23. Lautenbacher, S., A.L. Walz, and M. Kunz, *Using observational facial descriptors to infer pain in persons with and without dementia.* BMC Geriatr, 2018. **18**(1): p. 88.

24. Lukas, A., et al., *Pain assessment in advanced dementia. Validity of the German PAINAD-a prospective double-blind randomised placebo-controlled trial.* Pain, 2019. **160**(3): p. 742-753.

25. Corbett, A., et al., *An international road map to improve pain assessment in people with impaired cognition: the development of the Pain Assessment in Impaired Cognition (PAIC) meta-tool.* BMC Neurol, 2014. **14**: p. 229.

26. van Dalen-Kok, A.H., et al., *Pain Assessment in Impaired Cognition (PAIC): content validity of the Dutch version of a new and universal tool to measure pain in dementia.* Clin Interv Aging, 2018. **13**: p. 25-34.

27. van der Steen, J.T., et al., *Nurse-Physician Communication Around Identifying Palliative Care Needs in Nursing Home Residents.* J Am Med Dir Assoc, 2022. **23**(5): p. 893-894.

28. Cruice, M., et al., *Measuring quality of life: Comparing family members' and friends' ratings with those of their aphasic partners.* Aphasiology, 2005. **19**(2): p. 111-129.

29. Chi, N.C., et al., *Family Caregivers' Challenges in Cancer Pain Management for Patients Receiving Palliative Care.* Am J Hosp Palliat Care, 2023. **40**(1): p. 43-51.

30. Hunt, L.J., et al., *Pain in Community-Dwelling Older Adults with Dementia: Results from the National Health and Aging Trends Study.* J Am Geriatr Soc, 2015. **63**(8): p. 1503-11.

31. Lukas, A., et al., *Self- and proxy report for the assessment of pain in patients with and without cognitive impairment: experiences gained in a geriatric hospital.* Z Gerontol Geriatr, 2013. **46**(3): p. 214-21.

32. De Vet, H., Terwee, C.B., Mokkink, L.B., Knol, D.L., *Measurement in Medicine. A Practical Guide.*, ed. P.g.t.B.a. Epidemiology. 2011, Cambridge: Cambridge University Press.

33. Haghi, M., Fadayevatan, R., Alizadeh-Khoei, M., Kaboudi, B., Foroughan, M., Mahdavi. B. (2020). *Validation of Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II (PACSLAC-II) in Iranian older adults with dementia living in nursing homes*. **20**, 278-287.

34. Thé, K. B., Gazoni, F. M., Cherpak, G. L., Lorenzet, I. C., Santos, L. A., Nardes, E. M., & Santos, F. C. (2016). *Pain assessment in elderly with dementia: Brazilian validation of the PACSLAC scale*. Einstein (São Paulo), **14**(2), 152-157.

35. van Dalen-Kok, A. H., Achterberg, W. P., Rijkmans, W. E., de Vet, H. C., & de Waal, M. W. (2019). *Pain assessment in impaired cognition: observer agreement in a long-term care setting in patients with dementia.* Pain Manag, **9**(5), 461-473.

36. Kaasalainen, S., Akhtar-Danesh, N., Hadjistavropoulos, T., Zwakhalen, S., & Verreault, R. (2013). *A Comparison Between Behavioral and Verbal Report Pain Assessment Tools for Use with Residents in Long Term Care*. Pain Management Nursing, **14**(4), E106-E114.

37. Christensen, C., et al., *Doodle Health: A Crowdsourcing Game for the Co-design and Testing of Pictographs to Reduce Disparities in Healthcare Communication*. AMIA Annu Symp Proc, 2017. **2017**: p. 585-594.

38. Hakansson Eklund, J., et al., *"Same same or different?" A review of reviews of person-centered and patient-centered care*. Patient Educ Couns, 2019. **102**(1): p. 3-11.

39. Collins, J.T., et al., *Chronic pain in people living with dementia: challenges to recognising and managing pain, and personalising intervention by phenotype*. Age Ageing, 2023. **52**(1).

40. Collins, J.T., et al., *The Difficulties of Managing Pain in People Living with Frailty: The Potential for Digital Phenotyping*. Drugs Aging, 2024. **41**(3): p. 199-208.

41. Xu, J., et al., *Noninvasive monitoring technologies to identify discomfort and distressing symptoms in persons with limited communication at the end of life: a scoping review*. BMC Palliat Care, 2024. **23**(1): p. 78.

42. Kuo, C.L., et al., *The usability of an AAC pain description system for patients with acquired expressive communication disorders*. Augment Altern Commun, 2023. **39**(2): p. 61-72.

43. Lam, J.M. and W.P. Wodchis, *The relationship of 60 disease diagnoses and 15 conditions to preference-based health-related quality of life in Ontario hospital-based long-term care residents*. Med Care, 2010. **48**(4): p. 380-7.

44. Ali, M., et al., *Aphasia and Dysarthria in Acute Stroke: Recovery and Functional Outcome*. Int J Stroke, 2015. **10**(3): p. 400-406.

45. Manias, E., *Complexities of pain assessment and management in hospitalised older people: a qualitative observation and interview study*. Int J Nurs Stud, 2012. **49**(10): p. 1243-54.

46. Pautex, S., et al., *Pain in Severe Dementia: Self-Assessment or Observational Scales?* Journal of the American Geriatrics Society, 2006. **54**(7): p. 1040-1045.

47. van der Steen, J.T., et al., *Probable Pain on the Pain Assessment in Impaired Cognition (PAIC15) Instrument: Assessing Sensitivity and Specificity of Cut-Offs against Three Standards*. Brain Sci, 2021. **11**(7).

48. Pieper, M.J.C., et al., *Effects on pain of a stepwise multidisciplinary intervention (STA OP!) that targets pain and behavior in advanced dementia: A cluster randomized controlled trial*. Palliat Med, 2018. **32**(3): p. 682-692.

49. Ahmadi, A., et al., *Acceptability, reliability, and validity of the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) across languages: a systematic review*. Clin Rehabil, 2017. **31**(9): p. 1201-1214.

50. Russo, M.J., et al., *High-technology augmentative communication for adults with post-stroke aphasia: a systematic review*. Expert Rev Med Devices, 2017. **14**(5): p. 355-370.

Chapter 9

Summary

Aphasia is an acquired language disorder due to brain damage of which stroke occurs most often. If we include communication problems due to traumatic brain injury, primary progressive aphasia, aphasia, and dementia, the incidence and prevalence of aphasia increase. Depending on the severity and location of the brain injury, persons with aphasia have difficulties communicating. Examples of symptoms are problems with spoken language, the ability to understand spoken language, read and write or problems with speaking fluently. How these symptoms manifest is different for each person and each person with aphasia is different. Nowadays, aphasia diagnosis focuses on individualized patient profiles with a description of clinical symptoms. In general, the more severe the aphasia, the more important it is to include compensatory techniques or supportive communication methods or tools. The extent to which a person with aphasia will be able to independently use supportive communication methods is not only related to the severity of the aphasia but also to the occurrence of impairments in other cognitive functions, such as executive functions.

Pain often occurs after stroke. The most frequently occurring post-stroke pain syndromes are headache, musculoskeletal pain, shoulder pain, complex regional pain syndrome, and central post-stroke pain. Pain in persons with difficulties to communicate, such as in aphasia, is not systematically assessed and therefore not sufficiently treated, because the communication of pain in persons with aphasia is challenging.

Self-report pain scales are considered the gold standard to measure pain in persons with aphasia, which however cannot be applied to all persons with aphasia because of an inability to communicate their pain verbally. In people with advanced dementia, pain observational scales have been used successfully as an alternative to self-report pain. The use of such a pain observation instrument may be also a viable alternative for persons with aphasia. Examples of pain observation instruments are the Dutch version of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC-D) or and Pain Assessment in Impaired Cognition (PAIC15).

Persons with aphasia are dependent on the interpretation of behavior by the healthcare professional, legal representative, family members and friends. This leads to a gap in terms of being able to adequately report or measure pain in persons with aphasia or with valid and reliable appropriate instruments. Therefore, it is important to get more insight into pain, pain measurement instruments, and alternatives to measure pain in persons with aphasia. The overall aim of the project ‘Pain in Aphasia: an unspoken problem’ was to describe the current scientific status on pain and pain measurement in persons with aphasia, and to develop a practice guideline to measure pain specifically for persons with aphasia.

Main findings

to achieve the overall aim above-mentioned, multiple studies were conducted which are in this thesis divided into 3 parts. Part 1 consists of **Chapters 2 and 3** and described which assessment instruments were used for self-report pain in stroke patients with communication

problems and what is known in literature about pain and pain assessment in persons with aphasia.

Part 1

A scoping review (**Chapter 2**) examined self-report pain assessment instruments for hospitalized stroke patients with communication problems, particularly those with aphasia. Eleven instruments were identified, focusing on pain presence and intensity. The Numeric Rating Scale (NRS) was the most frequently used unidimensional tool. Four instruments assessed several aspects, with two assessing health-related quality of life, including pain. The *ShoulderQ* was the most comprehensive pain assessment tool, comprising 10 verbal questions and three visual vertical graphic rating scales tailored to stroke-related shoulder pain. However, the review highlighted a significant gap: pain assessment in individuals with moderate to severe communication issues or severe aphasia remains understudied. Consequently, there is no established method for assessing and managing pain in patients unable to complete self-report scales after a stroke.

A systematic literature review (**Chapter 3**) focused specifically on pain assessment in individuals with aphasia after stroke, distinguishing it from the broader scoping review on stroke patients with communication problems. The study aimed to determine pain prevalence, the instruments used for pain assessment, and their feasibility, validity, and reliability. A systematic search identified 10 relevant studies, which utilized a variety of pain assessment tools, including: Visual Analogue Scales (Vertical, Mechanical, Horizontal), Faces Pain Scale, Verbal Rating Scale, Numeric Rating Scale, Categorical site-of-pain scale, Pictorial pain intensity scale, Short-Form 36 Health Survey, Dartmouth COOP Charts (includes a pain item). Pain prevalence in individuals with aphasia after stroke ranged from 43.8% to 87.5% across two studies. However, most assessments focused on patients with mild-to-moderate aphasia, excluding individuals with severe aphasia. Furthermore, while various pain assessment instruments were used, their feasibility, validity, and reliability were of low methodological quality. The review concludes that a reliable and valid pain assessment instrument for individuals with aphasia after stroke is currently unavailable, leaving a significant gap in effective pain management for this population.

Part 2

The first two chapters of part 2 (**Chapters 4 and 5**) describe the psychometric properties of two pain observation instruments, Pain Assessment Checklist for Seniors with Limited Ability to Communicate - Dutch version (PACSLAC-D) and Pain Assessment in Impaired Cognition (PAIC15), respectively, for assessing pain in persons with aphasia who are unable to self-report. PACSLAC-D (**Chapter 4**) is a widely used pain observation instrument in Dutch nursing homes and consists of 24 items across: facial expressions (10 items), resistance/ defensive behavior (6 items), and social/ emotional items (8 items). The validity of the PACSLAC-D in persons with

aphasia was adequate during Activities of Daily Living (ADL) or physiotherapy, but not during rest. Reliability was also situation dependent: reliability was adequate during activities of daily living (ADL) or physiotherapy, but not during rest.

Chapter 5 describes the use of PAIC15 in persons with aphasia. This pain observation instrument, originally developed for all types of patients with cognitive impairment, assesses pain through 15 items divided into facial expressions, body movements, and vocalizations, with 5 items each. Results reported fair positive correlations between PAIC15 and all self-report pain scales in persons with aphasia. The test-retest reliability and inter-reliability of the PAIC15 were high in persons with aphasia during both rest and transfer. Significantly more pain was observed in persons with aphasia during transfer than during rest, confirming validity. However, no differences in observed pain were found between persons with aphasia who use pain medication and those who do not, or between those who have joint diseases compared to those without joint diseases.

Third chapter of part 2 (**Chapter 6**) contains a pilot study of the user-friendliness of the PAIC15 and presents which self-report pain scale is preferred for persons with aphasia. This study reported PAIC15 was considered by all observers to be user-friendly for persons with aphasia. The PAIC15 items were clear and not difficult to score. This prompted observers to pay attention to nonverbal signals in persons unable to express themselves, and facilitated assessment of any pain that may be present. Most observers preferred to use the self-report pain scale with a combination of numbers, words and faces for persons with aphasia. This scale provides more information that can help assess pain. They then preferred the self-report scale with faces, followed by the scale with numbers. Users found the scale with only a line and 0 and 10 at the ends vague and least preferred in use.

Part 3

Chapter 7 presents the development of a clinically useful pain guideline tailored to persons with aphasia, incorporating insights from patients, family caregivers, and healthcare professionals. The guideline is designed for nursing homes, rehabilitation centers, and clinical settings. A stepwise qualitative approach with inductive content analysis was used. With semi-structured interviews and focus groups, needs, wishes, preferences and ideas of four persons with aphasia, a family caregiver, and five professional caregivers regarding pain measurement and pain management for persons with aphasia where collected. These results, together with previous results of literature reviews (part 1) and observational studies (part 2) of pain in person with aphasia, formed the input for the development of the practice guideline. The research team drafted three preliminary practice guideline versions based on the outcomes of phases one to three. During three expert meetings, seven clinical experts established the preferred draft version and discussed and refined the final practice pain guideline. The final pain guideline consisted of the following seven steps:

STEP 1: Mapping / Actions + Reporting - The person with aphasia's manner of communication is examined and reported, as is how the person previously communicated pain.

STEP 2: Recognizing situations - Changes in behaviour; Signals during rest, care moment, move or activity; Signals from family/healthcare professionals..

STEP 3: Check - Check if basic needs are provided and check possible causes of pain. Changes in behaviour; Signals during rest, care moment, move or activity; Signals from family/healthcare professionals.

STEP 4: Investigate - Possible causes of pain are investigated by means of a physical examination by a physician.

STEP 5: Treatment - Start treating the cause of pain and/or start non-pharmacological intervention(s) and/or start with pain medication.

STEP 6: Monitoring plan - Multidisciplinary discussion of the situation, the frequency and manner how to monitor the pain.

STEP 7: Evaluation plan - Multidisciplinary discussion of the situation, the frequency and how to monitor the pain.

The guideline was prepared by experts with input from persons with aphasia, a family carer and healthcare professionals, and presented on two pages. The first page presents a circular flow chart with practical steps and the second page detailed explanations of each step. This practice pain guideline provides a structured approach for recognizing and managing pain in persons with aphasia. The guideline will help caregivers pay closer attention to how persons with aphasia express pain, both before and after the onset of aphasia. It is known whether the person with aphasia can rate pain with a severity rating 0-10 (A), use a self-report pain scale (B) or whether a pain observation tool (C) is recommended to be used. In the implementation of steps 2, 6 and 7, the way to best assess pain in the person with aphasia is always used.

Key aspects of the guideline are: 1) record past and current communication and pain expression of the person with aphasia; 2) emphasizes person-centered care, adapting communication to each person with aphasia's abilities, boosting confidence, and encouraging participation of the person with aphasia; 3) the use of pain observations instruments like PACSLAC-D or PAIC15; and 4) collaboration between healthcare professionals, such as speech and language therapists and other caregivers, is paramount for more effective communication.

General discussion

A recommendation is to use self-report scales as the first and preferred method for as long as possible for assessing pain. The use of self-report pain scales becomes challenging in the post-stroke population due to deficits such as aphasia, cognitive problems, and neglect,

but also because the severity of aphasia and the severity of cognitive problems may change. Individuals who may have difficulty reporting their pain with a self-report pain scale are dependent on a different pain measurement instrument or the assessment of a healthcare professional or family caregiver.

Proxy reports of family caregivers can be useful but should be use cautiously alongside professional assessments, because family caregivers' pain assessments of the person with aphasia can be biased, typically underestimating pain intensity. Researchers and clinicians should be aware of these biases when using proxy reports. Family caregivers and healthcare professionals play a key role in ensuring effective communication strategies.

Persons with aphasia, need the support and assistance of a speech language therapist or trained conversation partner to have an adequate conversation about pain. There are all kinds of supportive communication aids (for example: communication apps, photographs, or images) that can used to support a conversation.

Reflection on methodology

The applied mixed-methods approach, in which an extensive set of quantitative and qualitative data was collect, resulted in an in-depth understanding of pain in aphasia and pain measurement instruments for persons with aphasia. The diverse types of research required substantial expertise and knowledge on the part of the researcher. In addition, the researcher of this project is a speech and language therapist, combined with her role as a researcher, may have led to biased results. This thesis and the development of the practice guideline therefore did not include a balanced sample of all settings in which persons with aphasia live but focused particularly on long-term and rehabilitation settings for older persons with aphasia.

Recognition of pain in persons aphasia using the PAIC15 showed mixed yet promising results. During rest, only the items "opening the mouth", "frowning" and "looking tense" were rated with score 1 (mild degree). During transfer, these 3 items were more often assessed with both score 1 (slight degree) and score 2 (moderate degree). Also, during transfer, the items "freezing" and "moaning" were scored with a score 1 or 2. The prevalence of individual PAIC15 items observed in persons with aphasia was low for remaining items, maybe due to a failure to observe the behaviors described in the PAIC15 items in persons with aphasia after stroke. Lower agreement between different observations with PAIC15 by one observer and by two observers, observed separately, for the items facial expression of the PAIC15 suggests that these items are more difficult to observe or were assessed differently in a clinical setting. It may be that healthcare professionals are less used or less trained to pay special attention to the face and its expressions.

Implications and recommendations

Results of developing the practice pain guideline in co-creation with persons with aphasia and their family caregivers show that they want others to know in what ways the person with aphasia can communicate and how to best support them. This is an

important task for speech and language therapists, other healthcare professionals and family caregivers of the person with aphasia and it requires interprofessional collaboration.

Prioritizing the guideline, training needs, and interdisciplinary collaborations are recommendations are made for clinical practice. Healthcare professionals are encouraged to know and start using this guideline to improve the quality of life for persons with aphasia, who often face depression and a decline in self-reliance and participation. Education for nurses, physicians, and caregivers must emphasize pain assessment competencies, as observation may be more effective than verbal communication. Differences in pain perception between nurses and physicians highlight the need for more interprofessional education to ensure consistent pain management. Most nurses rely on intuition instead of structured observation instruments, creating barriers to pain management. It is important to raise awareness of the added value of observation instruments. Using pain observation instruments at the right time requires incorporating them into work processes. This sometimes requires a change of culture in the workplace.

Future research will need to focus on encouraging self-report pain scales, investigating cognitive processes, feasibility studies a real-world testing, technology integration, exploring medication effects and evaluation of quality of life of persons with aphasia. Since self-report is the gold standard for pain assessment, efforts should made to help individuals with aphasia use these tools where possible. The newly developed pain guideline should be piloted in clinical settings to refine its implementation. The guideline must be evaluated through implementation trials to evaluate its effectiveness in pain recognition and treatment. Pharmacological treatments for pain may influence mood, physical health, and social participation, requiring further investigation. Using validated tools to measure quality-of-life of persons with aphasia (like SAQOL-39), researchers can measure whether the guideline improves the overall well-being of individuals with aphasia. This research highlights the urgent need for better pain assessment practices, education, and technology-driven solutions to support persons with aphasia.

Conclusion

A structured approach like the developed pain guideline for persons with aphasia is crucial wfor accurate identification, diagnosis, and treatment of pain in persons with aphasia. Self-report should be used whenever possible, with pain observation and proxy reporting as supportive methods. When self-report pain is not possible, the use of a pain observation instrument, such as PACSDLAC-D and PAIC15, is recommended. In doing so, this research contributes to improving the quality of healthcare and quality of life for persons with aphasia. To improve healthcare for persons with aphasia, it is important to know that looking at the person is as important as listening, or in some cases may be more important than listening. A pain observation instrument is a tool for the caregiver to make explicit the “feeling” that the person with aphasia may have pain.

Chapter 10

Nederlandse samenvatting
Dankwoord
About the author
PhD Portfolio
Research Data Management

Nederlandse samenvatting

Afasie is een verworven taalstoornis als gevolg van hersenletsel. In de meeste gevallen is er sprake van een beroerte (hersenbloeding of herseninfarct). Als we communicatieproblemen als gevolg van traumatisch hersenletsel, primaire progressieve afasie en dementie meerekenen, neemt de incidentie en prevalentie van afasie toe. Afhankelijk van de ernst en de plaats van het hersenletsel hebben mensen met afasie moeilijkheden met communiceren. Voorbeelden van symptomen zijn problemen met gesproken taal, het vermogen gesproken taal te begrijpen, lezen en schrijven of problemen met vloeiend spreken. Hoe deze symptomen zich manifesteren is per persoon verschillend en elke persoon met afasie is anders. Tegenwoordig richt de diagnose afasie zich op geïndividualiseerde profielen met een beschrijving van de klinische symptomen. In het algemeen geldt dat hoe ernstiger de afasie is, hoe belangrijker het is om compenserende technieken of ondersteunende communicatiemethoden of -hulpmiddelen te gebruiken. De mate waarin iemand met afasie zelfstandig ondersteunende communicatiemethoden kan gebruiken, hangt niet alleen samen met de ernst van de afasie, maar ook met het optreden van beperkingen in andere cognitieve functies, zoals executieve functies.

Pijn komt vaak voor na een beroerte. De meest voorkomende pijnsyndromen na een beroerte zijn hoofdpijn, pijn aan het bewegingsapparaat, schouderpijn, complex regionaal pijnsyndroom en centrale pijn na een beroerte. Pijn bij mensen met communicatieproblemen, zoals afasie, wordt niet systematisch beoordeeld en daardoor mogelijk niet voldoende behandeld, omdat het communiceren van pijn bij mensen met afasie een uitdaging is.

Zelfrapportage pijnschalen worden beschouwd als de gouden standaard voor het meten van pijn bij mensen met afasie, die echter niet bij alle mensen met afasie kunnen worden gebruikt omdat zij niet in staat zijn om hun pijn verbaal te communiceren. Bij mensen met gevorderde dementie zijn pijnobservatie-instrumenten met succes gebruikt als alternatief voor zelfrapportage van pijn. Het gebruik van pijnobservatie-instrument kan ook een bruikbaar alternatief zijn voor mensen met afasie. Voorbeelden van pijnobservatie-instrumenten zijn de Nederlandse versie van de Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC-D) of en Pain Assessment in Impaired Cognition (PAIC15).

Personen met afasie zijn afhankelijk van de interpretatie van signalen en gedrag door de zorgmedewerkers, familieleden en vrienden. Dit leidt tot een hiaat in het adequaat kunnen rapporteren of meten van pijn bij mensen met afasie of met valide en betrouwbare geschikte instrumenten. Daarom is het belangrijk om meer inzicht te krijgen in pijn, pijnmeetinstrumenten en alternatieven om pijn te beoordelen bij mensen met afasie. Het algemene doel van het project ‘Pijn bij afasie: een onbesproken probleem’ was het beschrijven van de huidige wetenschappelijke status over pijn en pijn meten bij mensen met afasie, en het ontwikkelen van een praktijkrichtlijn om pijn te meten specifiek voor mensen met afasie.

Belangrijkste resultaten

Om het bovengenoemde algemene doel te bereiken, werden meerdere onderzoeken uitgevoerd. Deze zijn in dit proefschrift onderverdeeld in 3 delen. Deel 1 bestaat uit hoofdstuk 2 en 3 en beschrijft welke beoordelingsinstrumenten werden gebruikt voor zelfrapportage van pijn bij patiënten met een beroerte met communicatieproblemen en wat er in de literatuur bekend is over pijn en pijnbeoordeling bij personen met afasie.

Deel 1

Een scoping review (**Hoofdstuk 2**) onderzocht zelfrapportage pijnbeoordelingsinstrumenten voor opgenomen patiënten met een beroerte en communicatieproblemen, met name patiënten met afasie. Elf instrumenten werden geïdentificeerd, gericht op de aanwezigheid en intensiteit van pijn. De Numeric Rating Scale (NRS) was het meest gebruikte instrument dat één aspect meet. Vier instrumenten beoordeelden meerdere aspecten, waarbij twee instrumenten de gezondheid gerelateerde kwaliteit van leven beoordeelden, inclusief pijn. De *ShoulderQ* was het meest uitgebreide pijnbeoordelingsinstrument, bestaande uit 10 vragen en drie visuele verticale grafische beoordelingsschalen op maat voor beroerte gerelateerde schouderpijn. Uit de review kwam echter een belangrijke lacune naar voren: de beoordeling van pijn bij mensen met matige tot ernstige communicatieproblemen of ernstige afasie blijft onderbelicht. Er is geen bestaande methode voor het beoordelen en monitoren van pijn bij patiënten die niet in staat zijn om zelfrapportageschalen in te vullen na een beroerte.

Een systematisch literatuuronderzoek (**Hoofdstuk 3**) richtte zich specifiek op pijnbeoordeling bij mensen met afasie na een beroerte. Deze studie was gericht op het voorkomen van pijn, de pijnbeoordelings-instrumenten die werden gebruikt en hun haalbaarheid, validiteit en betrouwbaarheid. Een systematische zoektocht identificeerde 10 relevante onderzoeken, die gebruik maakten van verschillende pijn beoordelingsinstrumenten, waaronder: Visuele Analoge Schalen (verticaal, mechanisch, horizontaal), Pijngezichtenschaal, Verbale beoordelingsschaal, Numerieke beoordelingsschaal, Categorische pijn-locatie-schaal, Afbeeldingen pijn intensiteitsschaal, Korte 36 gezondheidsenquête en de Dartmouth COOP-grafieken (met een pijn item). Het voorkomen van pijn bij mensen met afasie na een beroerte varieerde in twee onderzoeken van 43,8% tot 87,5%. De meeste beoordelingen waren echter gericht op personen met lichte tot matige afasie, waarbij personen met ernstige afasie werden uitgesloten. Hoewel er verschillende instrumenten voor pijnbeoordeling werden gebruikt, waren de haalbaarheid, validiteit en betrouwbaarheid van deze instrumenten van lage methodologische kwaliteit. De conclusie van de review is dat een betrouwbaar en valide pijnbeoordelingsinstrument voor mensen met afasie na een beroerte momenteel niet beschikbaar is, waardoor mogelijk een effectieve pijnbestrijding voor deze populatie ontbreekt.

Deel 2

De eerste twee hoofdstukken van deel 2 (**Hoofdstuk 4 en 5**) beschrijven de psychometrische eigenschappen van twee pijnobservatie-instrumenten, de Pain Assessment Checklist for Seniors with Limited Ability to Communicate - Dutch version (PACSLAC-D) en Pain Assessment in Impaired Cognition (PAIC15), voor het beoordelen van pijn bij personen met afasie die niet in staat zijn tot zelfrapportage. PACSLAC-D (**Hoofdstuk 4**) is een veelgebruikt pijnobservatie-instrument in Nederlandse verpleeghuizen en bestaat uit 24 items verdeeld over: gelaat (10 items), verzet/afweer (6 items), en sociaal emotioneel/ stemming (8 items). De validiteit van de PACSLAC-D bij personen met afasie was voldoende tijdens activiteiten van het dagelijks leven (ADL) of fysiotherapie, maar niet tijdens rust. Betrouwbaarheid was ook afhankelijk van de situatie: de betrouwbaarheid was voldoende tijdens activiteiten van het dagelijks leven (ADL) of fysiotherapie, maar niet tijdens rust.

Hoofdstuk 5 beschrijft het gebruik van PAIC15 bij mensen met afasie. Dit pijnobservatie-instrument, oorspronkelijk ontwikkeld voor alle soorten patiënten met cognitieve stoornissen, beoordeelt pijn aan de hand van 15 items verdeeld in gezichtsuitdrukkingen, lichaamsbewegingen en stemmingen, met elk 5 items. De resultaten tonen redelijk positieve correlaties tussen PAIC15 en alle zelfrapportageschalen voor pijn bij mensen met afasie. De test-hertest betrouwbaarheid en betrouwbaarheid tussen verschillende beoordelaars van de PAIC15 waren hoog bij personen met afasie zowel tijdens rust als verplaatsen. Er werd beduidend meer pijn waargenomen bij personen met afasie tijdens verplaatsen dan tijdens rust, wat de validiteit bevestigt. Er werden echter geen verschillen in geobserveerde pijn gevonden tussen mensen met afasie die pijnmedicatie gebruiken en mensen die dat niet doen, of tussen mensen met gewrichtsaandoeningen en mensen zonder deze aandoeningen.

Het derde hoofdstuk van deel 2 (**Hoofdstuk 6**) bevat een pilotstudie naar de gebruiksvriendelijkheid van de PAIC15 en laat zien welke zelfrapportage pijnschaal de voorkeur heeft voor mensen met afasie. Dit onderzoek rapporteerde dat PAIC15 door alle waarnemers als gebruiksvriendelijk werd beschouwd voor mensen met afasie. De PAIC15 items waren duidelijk en niet moeilijk te scoren. Dit zorgde er voor dat gebruikers aandacht besteden aan non-verbale signalen bij personen met communicatieproblemen en vergemakkelijkten de beoordeling van eventuele aanwezige pijn. De meeste gebruikers gaven de voorkeur aan de zelfrapportage pijnschaal met een combinatie van nummers, woorden en gezichtjes voor mensen met afasie. Deze schaal geeft meer informatie dat kan helpen bij het beoordelen van pijn. Daarna gaf men de voorkeur aan de zelfrapportage schaal met gezichtjes, gevolgd door de schaal met nummers. De schaal met alleen een lijn en een 0 en 10 aan de uiteinden vonden de gebruikers vaag en had de minste voorkeur in gebruik.

Deel 3

Hoofdstuk 7 beschrijft de ontwikkeling van een klinisch bruikbaar protocol voor pijn bij mensen met afasie, waarin de inzichten van personen met afasie, een mantelzorger en zorgprofessionals zijn verwerkt. Het protocol is bedoeld voor verpleeghuizen, revalidatiecentra en klinische settingen. Met semigestructureerde interviews en focusgroepen zijn de behoeften, wensen, voorkeuren en ideeën van vier personen met afasie, een mantelzorger en vijf zorgverleners met betrekking tot pijn meten en behandelen bij personen met afasie verzameld. Deze resultaten, samen met eerdere resultaten van literatuuronderzoek (deel 1) en studies naar gebruik van pijn observatie instrumenten bij personen met afasie (deel 2), vormden de input voor de ontwikkeling van het protocol. Het onderzoeksteam stelde drie voorlopige versies van de richtlijn samen gebaseerd op de uitkomsten van deel 1 tot en met 3. Tijdens drie expertmeetings stelden zeven klinisch experts (personen met een medische, paramedische of verpleegkundige achtergrond) de voorkeursversie vast en bespraken en verfijnden de definitieve richtlijn.
De definitieve richtlijn voor pijn bij personen bij afasie bevat de volgende zeven stappen:

STAP 1: In kaart brengen / handelingen + rapportage - De manier van communiceren van de persoon met afasie wordt onderzocht en gerapporteerd, net als de manier waarop de persoon eerder pijn communiceerde.

STAP 2: Situaties herkennen - Veranderingen van gedrag; Signalen tijdens rust, zorgmoment, verplaatsen of activiteit; Signalen van familie/ zorgprofessionals.

STAP 3: Controleren - Controleren of in basisbehoeften wordt voorzien en mogelijke oorzaken van pijn controleren.

STAP 4: Onderzoeken - Mogelijke oorzaken van pijn worden onderzocht door middel van een lichamelijk onderzoek door een arts.

STAP 5: Behandelen - Start de behandeling van de oorzaak van de pijn en/of start met niet-farmacologische interventie(s) en/of start met pijnmedicatie.

STAP 6: Monitoringsplan - Multidisciplinaire bespreking van de situatie, de frequentie en de wijze waarop de pijn moet worden gemonitord.

STAP 7: Evaluatieplan - Multidisciplinaire bespreking van de situatie, de frequentie en de manier waarop de pijn moet worden gemonitord.

Het protocol werd door experts met input van personen met afasie, een mantelzorger en zorgprofessionals opgesteld en gepresenteerd op twee bladzijden. De eerste bladzijde presenteert een rond stroomdiagram met praktische stappen en de tweede bladzijde gedetailleerde uitleg van elke stap. Deze praktische richtlijn biedt een gestructureerde aanpak voor het herkennen en omgaan met pijn bij personen met afasie. De richtlijn helpt zorgverleners beter te letten op de manier waarop mensen met afasie pijn uiten, zowel voor als na het ontstaan van de afasie. Bekend is of de persoon met afasiepijn kan beoordelen met een ernstcijfer 0-10 (A),

gebruik kan maken van een zelfrapportage pijnschaal (B) of dat een pijnobservatie-instrument (C) wordt aangeraden om te gebruiken. In de uitvoering van de stappen 2, 6 en 7 wordt steeds gebruik gemaakt van de manier waarop de pijn bij de persoon met afasie het best kan worden beoordeeld.

De belangrijkste aspecten van de richtlijn zijn: 1) het vastleggen van vroegere en huidige communicatie en pijnexpressie van de persoon met afasie; 2) het benadrukken van persoonsgerichte zorg, het aanpassen van de communicatie aan de mogelijkheden van de persoon met afasie, het stimuleren van zelfvertrouwen en het aanmoedigen van participatie bij de persoon met afasie; 3) het gebruik van pijnobservatie-instrumenten zoals PACSLAC-D of PAIC15; en 4) samenwerking tussen zorgverleners, zoals logopedisten en andere zorgverleners, is van het grootste belang voor effectievere communicatie.

Algemene Discussie

Een aanbeveling is om zo lang mogelijk zelfrapportageschalen te gebruiken als eerste voorkeursoptie voor het beoordelen van pijn. Het gebruik van zelfrapportage pijnschalen is een uitdaging bij mensen met een beroerte wanneer er sprake is van een afasie, cognitieve problemen, maar ook omdat de ernst van afasie en de ernst van cognitieve problemen kunnen veranderen. Personen die moeite hebben met het gebruik van een zelfrapportage pijnschaal zijn afhankelijk van een ander pijnmeetinstrument of de beoordeling van een zorgprofessional of mantelzorger.

Beoordelingen van mantelzorgers kunnen nuttig zijn, maar moeten voorzichtig worden gebruikt naast professionele beoordelingen, omdat de pijnbeoordelingen van mantelzorgers van de persoon met afasie vertekend kunnen zijn en meestal de pijnintensiteit onderschatten. Onderzoekers en zorgmedewerkers moeten zich bewust zijn van deze vertekeningen bij het gebruik van beoordelingen door naasten. Mantelzorgers en zorgverleners spelen een belangrijke rol bij het waarborgen van effectieve communicatiestrategieën.

Mensen met afasie hebben de steun en hulp van een logopedist of een getrainde gesprekspartner nodig om een goed gesprek over pijn te kunnen voeren. Er zijn allerlei ondersteunende communicatiehulpmiddelen (bijvoorbeeld: communicatie-apps, foto's of afbeeldingen) die gebruikt kunnen worden om een gesprek te ondersteunen.

Reflectie op de gebruikte methoden

De toegepaste combinatie van verschillende onderzoeksmethoden, waarbij kwantitatieve en kwalitatieve data werd verzameld, heeft gezorgd voor uitgebreide kennis over pijn bij afasie en pijnmeetinstrumenten voor personen met afasie. De verschillende soorten onderzoek vereisten specifieke expertise en kennis van de onderzoeker. Daarnaast is de onderzoeker van dit project logopedist, wat in combinatie met haar rol als onderzoeker kan hebben geleid tot bevooroordeelde resultaten. Dit proefschrift en de ontwikkeling van de praktische richtlijn omvatte geen evenwichtige steekproef van alle settingen waarin personen met afasie leven,

maar richtte zich met name op langdurige en revalidatie settingen voor oudere personen met afasie.

Het herkennen van pijn bij mensen met afasie met behulp van de PAIC15 liet verschillende maar veelbelovende uitkomsten zien. Tijdens rust werden alleen de items 'openen van de mond', 'fronsen' en 'gespannen kijken' beoordeeld met score 1 (lichte mate). Tijdens verplaatsen werden deze 3 items vaker beoordeeld met zowel score 1 (lichte mate) als met score 2 (gemiddelde mate). Ook werden tijdens verplaatsen de items 'bevriezen' en 'kreunen' gescoord met een score 1 of 2. Tijdens beweging werd hoger gescoord op de items gezichtsuitdrukking van de PAIC15 in vergelijking met items van de andere twee domeinen (lichaamsbewegingen en vocalisaties) van de PAIC15. Het voorkomen van individuele PAIC15-items die werden geobserveerd bij personen met afasie was voor de overige items laag, misschien doordat het in de PAIC15-items beschreven gedrag niet werd waargenomen bij personen met afasie na een beroerte. Een lagere overeenkomst tussen verschillende observaties met PAIC15 door één observator en door twee observatoren, los van elkaar geobserveerd, voor de items gezichtsuitdrukking suggereert dat deze items moeilijker te observeren zijn of verschillend werden beoordeeld in een klinische setting. Het kan zijn dat zorgverleners minder gewend of minder getraind zijn om speciale aandacht te besteden aan het gezicht en zijn uitdrukkingen.

Implicaties en aanbevelingen

Uit de resultaten van het ontwikkelen van de praktische richtlijn in co-creatie met personen met afasie en hun mantelzorgers blijkt dat zij willen dat anderen weten op welke manieren de persoon met afasie kan communiceren en hoe zij daarbij het beste kunnen worden ondersteund. Dit is een belangrijke taak voor logopedisten, andere zorgprofessionals en mantelzorgers van de persoon met afasie en het vereist interprofessionele samenwerking.

Prioritering van de richtlijn, trainingsbehoeften en interdisciplinaire samenwerking zijn aanbevelingen voor de klinische praktijk. Zorgmedewerkers in de gezondheidszorg worden aangemoedigd dit protocol te kennen en te gaan gebruiken om de kwaliteit van leven te verbeteren voor mensen met afasie, die vaak te maken hebben met depressie en een afname van zelfredzaamheid en participatie. Opleidingen voor verpleegkundigen, artsen en verzorgenden moeten de nadruk leggen op pijnbeoordelingsvaardigheden, omdat observatie effectiever kan zijn dan verbale communicatie. Verschillen in pijnperceptie tussen verpleegkundigen en artsen benadrukken de behoefte aan meer interprofessionele educatie om een adequate behandeling van pijn te garanderen. De meeste verpleegkundigen vertrouwen op intuïtie in plaats van gestructureerde observatie-instrumenten, wat barrières kan opwerpen voor zowel de signalering als behandeling van pijn. Het is van belang dat het bewustzijn van de meerwaarde van observatie-instrumenten wordt vergroot. Het gebruiken van pijnobservatie-instrumenten op het juiste moment vraagt om opname er van in werkprocessen. Hier is soms verandering van cultuur op de werkvloer voor nodig.

Toekomstig onderzoek zal zich moeten richten op het stimuleren van zelfrapportage pijnschalen, het onderzoeken van cognitieve processen, haalbaarheidsstudies, integratie van technologie, het onderzoeken van medicatie-effecten en de evaluatie van de kwaliteit van leven van personen met afasie. Aangezien zelfrapportage de gouden standaard is voor pijnbeoordeling, is het van belang te investeren om mensen met afasie waar mogelijk te helpen deze instrumenten te gebruiken. De nieuw ontwikkelde richtlijn moet worden getest in klinische settingen. De richtlijn moet worden geëvalueerd door middel van implementatie trials om de effectiviteit van pijn signalering en behandeling te beoordelen. Digitale en mobiele applicaties kunnen de pijnbeoordeling verbeteren en nieuwe manieren bieden voor mensen met afasie om ongemak te uiten. Farmacologische behandelingen voor pijn kunnen van invloed zijn op de stemming, lichamelijke gezondheid en sociale participatie. Met behulp van gevalideerde instrumenten om de kwaliteit van leven van mensen met afasie te meten (zoals SAQOL-39), kunnen onderzoekers beoordelen of de richtlijn het algehele welzijn van mensen met afasie verbetert.

Conclusie

Een gestructureerde aanpak zoals de ontwikkelde richtlijn voor pijn bij mensen met afasie is cruciaal voor nauwkeurige beoordeling, diagnose en behandeling van pijn bij mensen met afasie. Waar mogelijk moet gebruik worden gemaakt van zelfrapportage, met pijn observatie en beoordeling van naasten als ondersteunende methoden. Als zelfrapportage van pijn niet mogelijk is, wordt het gebruik van een pijnobservatie-instrument zoals PACSDLAC-D en PAIC15 aanbevolen. Hiermee levert dit onderzoek een bijdrage aan het verbeteren van de kwaliteit van de gezondheidszorg en kwaliteit van leven voor personen met afasie. Om de zorg voor mensen met afasie te verbeteren, moet men weten dat naar de persoon kijken even belangrijk is als luisteren, of in sommige gevallen belangrijker kan zijn dan luisteren. Een pijnobservatie-instrument is een hulpmiddel voor de zorgverlener om het ‘gevoel’ dat de persoon met afasie pijn kan hebben expliciet te maken.

Zie hier het ontwikkelde pijnprotocol voor personen met afasie via de QR-code:

Dankwoord

Voor papa, want jij bent het die ooit zei: ‘als je iets doet met je hart en je vindt het leuk, dan gaat het je lukken’ en ‘wat vandaag niet lukt, lukt vast morgen’. Zie hier het resultaat.

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About the author

Carolien (N.J.) de Vries was born on 11 August 1983 in Leiden. Until she was 19, she lived in Valkenburg (South Holland). In 2001, after three years of secondary school, she completed the accelerated training to become a doctor's assistant. Then, after a foundation year in Medical Secretarial Management, she chose to study Speech Therapy at Windesheim University of Applied Sciences in Zwolle, because it meant that, as a paramedic, she wanted to mean something to her fellow man. She received the bachelor's degree for this in 2006. During these studies, while she was living in Deventer, she worked as a doctor's assistant at the Dermatology Department of Leiden University Medical Centre in Leiden and saw several junior doctors receive their PhDs. This is probably where all her interest in doing scientific research was sparked.

In 2006, Carolien started the pre-master Language Science followed by the master Speech and Language Pathology at the University of Groningen, which she completed in 2008 with a Master of Arts. During this study, she started working as a speech therapist at an independent speech and language therapy practice and at specialist rehabilitation centre De Hoogstraat in Utrecht. In 2009, Carolien started working at Topaz in Leiden, where she initially worked with people staying in nursing homes and later chose to work in geriatric rehabilitation. With this, she specialized as a clinical speech therapist within elderly care and geriatric rehabilitation.

For years, she chaired the intercollegiate consultation of speech and language therapists for adults in the Rijnmond region. She also enjoys supervising a speech and language therapist trainee every year and regularly gives guest lectures at the LUMC geriatrics specialist training program.

After working as a speech therapist for several years, Carolien started the research project "Pain in aphasia: an unspoken problem" at Topaz's knowledge centre in collaboration with Leiden University Medical Centre with a literature review. In 2018, the opportunity to do doctoral research at the Department of Public Health and Primary Care at Leiden University Medical Centre followed. This research was funded by Zorgondersteuningsfonds and Topaz. Besides her PhD research, she worked part-time as a clinical speech therapist at the geriatric rehabilitation Topaz Revitel.

Currently, Carolien works as a clinical speech therapist at Revitel and at three Topaz residential locations, and visits people at home through the primary care treatment practice In Leiden-Zuid and Voorschoten. It is especially being able to be of significance to the frail elderly dependent on care and their loved ones that keeps giving her new energy.

Carolien lives in Utrecht with her beloved husband Jaap and their three treasured children: Friso, Vera, and Kasper.

PhD Portfolio

Peer reviewed publications

2025 *User-friendliness of the Pain Assessment in Impaired Cognition (PAIC15) in persons with Aphasia: a pilot study.* N.J. de Vries, H.J.A. Smaling, J.T. van der Steen, W.P. Achterberg. Future Science OA. 2025; 11(1). *doi: 10.1080/20565623.2025.2456440*

2024 *Validity and reliability of the Pain Assessment in Impaired Cognition 15 (PAIC15) observation scale in persons with aphasia.* N.J. de Vries, H.J.A. Smaling, J.T. van der Steen, W.P. Achterberg. BMC Neurology. 2024; 24(1):319. *doi: 10.1186/s12883-024-03824-8*

2023 *Measuring Pain in Aphasia: Validity and Reliability of the PACSLAC-D.* N.J. de Vries, J.T. van der Steen, W.P. Achterberg, H.J.A. Smaling. Pain Management Nursing. 2023; 24(4): 368-e74. *doi: 10.1016/j.pmn.2023.03.010.*

2022 *Pain and neurocognitive disorders: current state of the art and remaining challenges – Pijn en Neurocognitieve Stoornissen: Stand van Zaken en de Weg Nog Te Gaan.* W.P. Achterberg, M.W.M. de Waal, J.M.J.J. Cheuk-A-Lam-Balrak, P. Crutzen-Braaksma, A. van Dalen-Kok, P. van Dam, N.C. de Knegt, J. van Kooten, F. Lobbezoo, H.J.A. Smaling, G.P. Sprenger, J.T. van der Steen, C.N.J. de Vries, S.M.G. Zwakhalen, M. Smalbrugge, J.M. Oosterman. Tijdschrift voor Gerontologie en Geriatrie. 2022; 53(4). *doi: 10.36613/tgg.1875-6832/2022.04.04*

2022 *Assessment instruments used for self-report of pain in hospitalized stroke patients with communication problems: a scoping review.* P. Mandysova, J. Klugarová, I. Matějková, N.J.C. de Vries, M. Klugar. JBI Evidence Synthesis. 2022; 20(6): p1511-1536. *doi: 10.11124/jbies-21-00047*

2020 *Assessment instruments used for the self-report of pain by hospitalized stroke patients with communication problems: a scoping review protocol.* P. Mandysova, M. Klugar, N.J.C. de Vries, I. Matějkova. JBI Evidence Synthesis. 2020; 18 (8):1731–1737. *doi: 10.11124/JBISRIR-D-19-00278*

2019 *Measuring Pain in Aphasia: The Reliability and Validity of the PACSLAC-D Observational Scale (abstract).* H.J.A. Smaling, N.J. de Vries, J.T. van der Steen, W.P. Achterberg. Journal of the American Medical Directors Association. 2019; 20(3), B29. *doi: 10.1016/j.jamda.2019.01.105.*

2016 Pain and pain assessment in stroke patients with aphasia: a systematic review. N.J. de Vries, P.H. Sloot, W.P. Achterberg. Aphasiology. 2016. 31(6), 703-719. *doi: 10.1080/02687038.2016.1254150*

Other publications

2025 *Een pijnprotocol voor personen met afasie. 'Wat zeg je?'* - tijdschrift van de Verenging Afasie in België.

2019 *Nieuwsbrief AfasieNet.* Carolien de Vries over haar onderzoek 'Pijn bij afasie': meer aandacht voor mensen die zich minder goed kunnen uiten.

2017 *Pijn en pijn meten bij CVA-patiënten met afasie: een systematische review.* Neeltje J. (Carolien) de Vries, Petra H. Sloot & Wilco P. Achterberg. Nederlands Tijdschrift voor Pijn en Pijnbestrijding.

Presentations at (inter)national conferences

2025 Pitch inspiratiesessie Zorgondersteuningsfonds: Het pijnprotocol voor personen met afasie – hoe deze te implementeren? (oral presentation)

2024 Het pijnprotocol voor personen met afasie – klaar voor gebruik; UNC-ZH Jaarsymposium 2024, Leiden. (oral presentation)

2023
- Pitch inspiratiemiddag Kwaliteit van Leven UNC-ZH: Pijn bij afasie: een onbesproken probleem. (oral presentation)
- Presentatie Pijnprotocol voor personen met afasie. Afasieconferentie 'State of the Art 2023', Woudschoten. (oral presentation)
- Validity and Reliability of the Pain Observational Scale Pain Assessment in Impaired Cognition 15 (PAIC15) in Patients with Aphasia. 19th EuGMS, Helsinki. (poster presentation: no. 564)
- Development of a Pain Protocol for Patients with Aphasia with input of Patients, Family and Professional Caregivers. 19th EuGMS, Helsinki. (poster presentation: no. 565)
- Presentatie ontwikkelde pijnprotocol voor personen met afasie. UNC-ZH, Saffier locatie Mechropa, Den Haag. (oral presentation)

2022 Pijn bij afasie: een studie naar de validiteit en betrouwbaarheid van de Pain Assessment in Impaired Cognition (PAIC15). SANO Wetenschapsdag, Leiden. (poster presentation)

2021
- Pain in aphasia: a roadmap to the future. Nordic Aphasia Conference 2021. Online Event (poster presentation)
- Presentatie onderzoeksproject afdeling onderzoek binnen Topaz: 'Pijn bij afasie: een onbesproken probleem'.

2020 Flitspresentatie over onderzoeksproject op Afasieconferentie 'State of the Art 2020', Woudschoten. (oral presentation)

Courses

2023
- Scientific Conduct for PhD's
- Effective Communication

2022
- Kwalitatieve Analyse
- Kwalitatief Interviewen

2021 Focusgroepen

2020 Academic Writing

2019
- Clinimetrics (WV-40). EpidM Amsterdam UMC
- Van Case Report Form naar Castor
- Van Database naar Dataset
- eBROK; Basiscursus Regelgeving en Organisatie voor Klinisch Onderzoekers. NFU

2018 Communication in Science

2018
- Basic Methods and Reasoning in Biostatistics
- PhD Introductory Meeting

2012 Epidemiologisch onderzoek (V01). EpidM Amsterdam UMC

Research Data Management

This research followed the applicable laws and ethical guidelines. Research Data Management was conducted according to the FAIR principles. The paragraphs below specify in detail how this was achieved.

Ethics

This thesis is based on the results of human studies, which were conducted in accordance with the principles of the Declaration of Helsinki.
The LUMC Medical Ethics Review Committee has assessed the observational study (Chapters 5 and 6) as a study not subject to the WMO and has not raised any objections to the conduct of this study (P18.230). Research into the development of a pain protocol for persons with aphasia has been assessed by the non-WMO committee of Division 3 of the LUMC, which had no objections to this research (nr: 22-3038). Chapter 2 and 3 was not based on results of human studies.

The studies were conducted within the framework of applicable laws and regulations, such as the Medical Treatment Agreement Act (WGBO) and the General Data Protection Regulation (AVG). The project was funded by a Zorgondersteuningsfonds Grant.

Findable, Accessible

Data of chapters 4, 5, 6 and 7 are digital stored at the project folder Pain and Aphasia on the network drive of the Department Public Health and Primary Care of the LUMC and remain available for at least 15 years after termination of the studies. This project folders is only accessible to members of the researchteam. The data of Chapter 5 and 6 is also stored on Castor EDC (https://data.castoredc.com/studies).

Informed consent was obtained on paper following the procedures of the Department Public Health and Primary Care of the LUMC. The consent forms are separate from the data archived digital for 15 years after termination of the studies.

Privacy

The privacy of the participants in this thesis has been warranted using individual subject codes. A pseudonymization key links this code to personal data. This key was stored on a network drive that only was accessible to members of the project who needed access to it because of their role within the project. The key was stored separately from the research data.