Unspoken pain: its assessment in persons with aphasia

Vries, N.J. de

PART 1

Pain and pain assessment in aphasia

Petra Mandysova, Jitka Klugarová, Iryna Matějková,
Neeltje J. (Carolien) de Vries and Miloslav Klugar

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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].

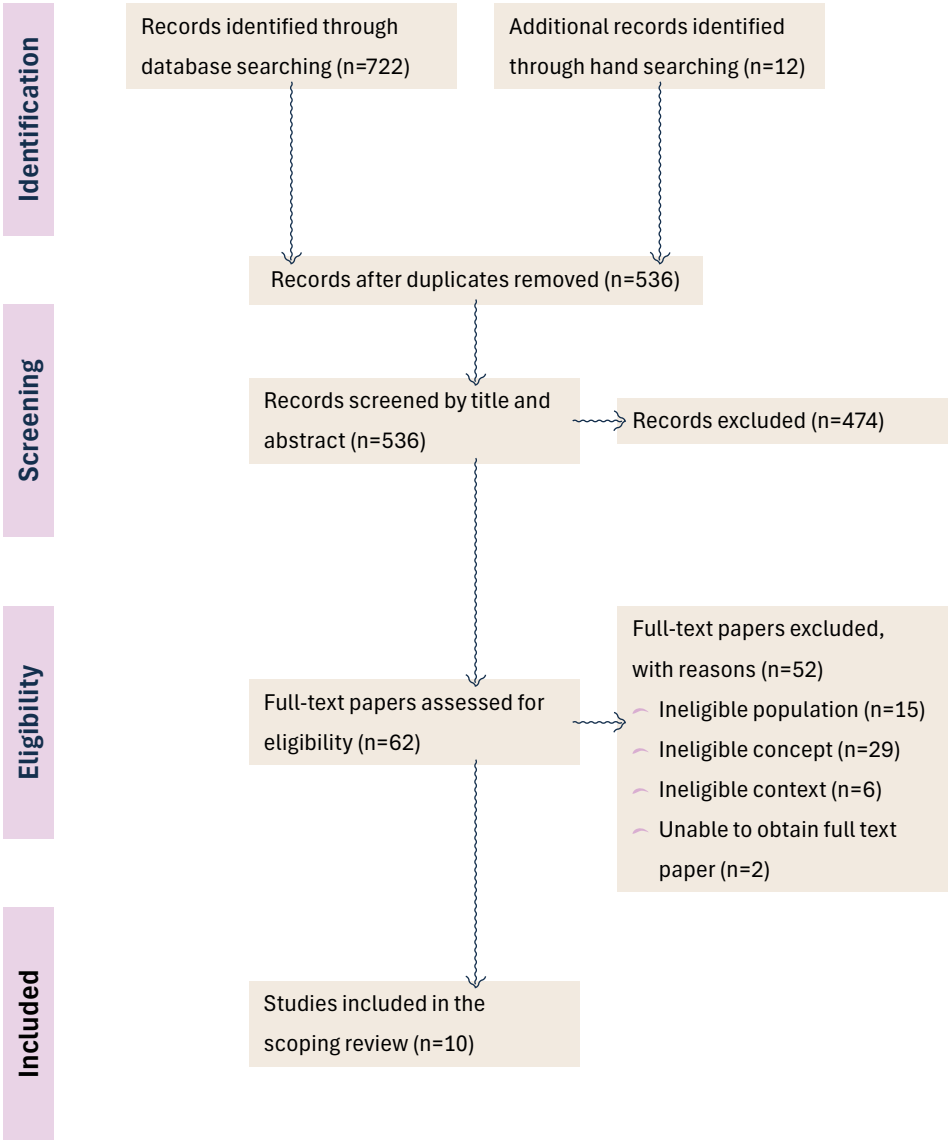

Figure 1: Search results and study selection and inclusion process [18]

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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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

Open Access Theses and Dissertations

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.