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## Unspoken pain: its assessment in persons with aphasia

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## Chapter 3

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

**Keywords:**

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

**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 <sup>1</sup>. Joint pain is equally common in patients with or without post-stroke pain <sup>2</sup>. 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 <sup>3,4</sup>. 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 <sup>5</sup>. It is unclear if this leads to under identification and under treatment of pain in PWA <sup>6</sup>. 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) <sup>7</sup> 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) <sup>8</sup> and the Faces Pain Scale (FPS) <sup>9</sup>. 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.

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## 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 <sup>10</sup>. 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) <sup>11</sup>
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) <sup>7</sup>
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) <sup>11</sup>
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”. <i>NB. Additional FPS tools are available with less or more than 7 faces or smileys</i>	Wong and Baker (1988) <sup>9</sup>
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) <sup>11</sup>
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. <i>NB. Additional VRS tools are available with less or more points to rate the patient’s pain</i>	Seymour (1982) <sup>12</sup>

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  $\geq 18$  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 Conswensus-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<sup>13</sup>. 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 <sup>14, 15</sup>. 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. <sup>16</sup> and De Vet et al. <sup>17</sup>. 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  $\geq 0.70$  or Pearson's  $r \geq 0.80$  <sup>16</sup>.
- 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 <sup>16</sup>.
- A positive criterion validity indicates a correlation between the results of both the pain scale used and the gold standard pain measurement instrument <sup>16</sup>.
- Responsiveness corresponds with a correlation with an instrument measuring the same construct  $\geq 0.50$  or at least 75% of the results are in accordance with the hypotheses or area under the curve  $\geq 0.70$ , and correlation with related constructs is higher than with unrelated constructs <sup>16, 17</sup>.

## 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).

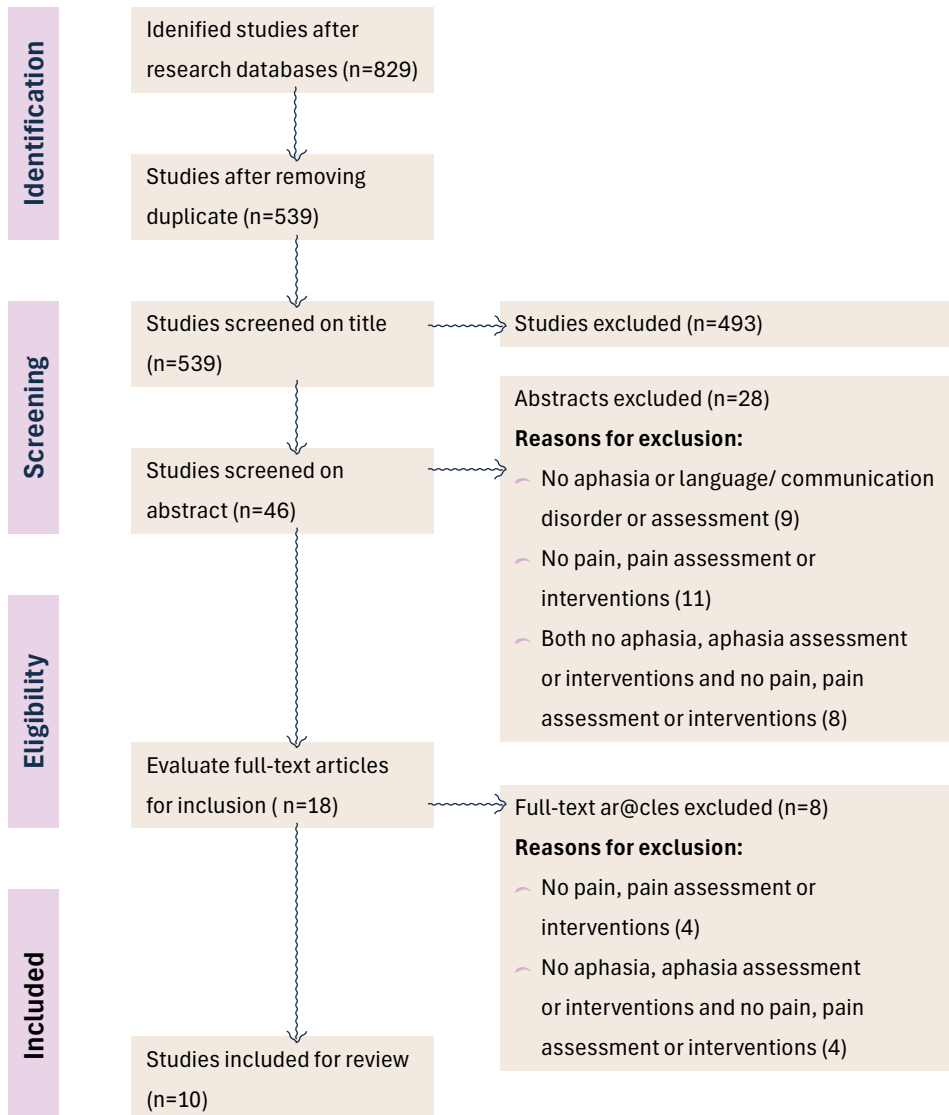


Figure 1: PRISMA flow chart of study selection

### — *Study characteristics*

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

Data from three studies were collected at a community setting<sup>19, 24</sup>. Most of the included studies used a prospective cohort design; of the ten articles, three described a retrospective cohort study<sup>6, 19, 21</sup>. The studies including PWA consisted of sample sizes of 33–388 participants<sup>5, 24</sup>. 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<sup>6, 20, 24</sup>. 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<sup>18-20, 25</sup>. Mean age ranges from 43 to 84 years, where the youngest patient is 36 and the oldest 92 years<sup>6, 21, 23</sup>.

**Table 2: Characteristics of included articles.**

Author (year of publication)	Country	Design	Setting	Sample (size)
1. Pomeroy <i>et al.</i> , (2000)	United Kingdom	Prospective cohort study	Community	<i>n</i> = 33 Groups: 1: Without aphasia and neglect (12) 2: Receptive aphasia (8) 3: Neglect (8) 4 4: Receptive aphasia + neglect (5)
2. Benaim <i>et al.</i> , (2007)	France	Prospective cohort study (2001-2006)	Rehabilitation unit	<i>n</i> = 127 Groups: 1: 21 Controls 2: LHSP (63) 3: RHSP (64) 82% (104) ischemia, 18% (23) haemorrhage
3. Korner-Bitensky <i>et al.</i> , (2006)	Canada	Prospective cohort study	University hospital	<i>n</i> = 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 <i>et al.</i> , (1999)	United Kingdom	Prospective cohort study	General hospital	<i>n</i> = 96 + 48 controls
5. Kehayia and Korner-Bitensky (1997)	Canada	Retrospective cohort study (1988-1993)	Rehabilitation hospital	<i>n</i> = 207 Groups: 1: Without aphasia (69) 2: Mild-moderate aphasia (69) 3: Severe aphasia (69)
6. Cruice <i>et al.</i> (2010)	Australia	Prospective cohort study (1999-2001)	Community	<i>n</i> = 105 aphasic <i>n</i> = 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 cognitive 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 <i>et al.</i> , (2005)	Australia	Retrospective cohort study	Community	Aphasic $n = 30 + 30$ proxies
8. Mazzocato <i>et al.</i> (2010)	Switzerland	Retrospective cohort study (2000-2005)	Hospital	$n = 42$
9. Jackson <i>et al.</i> , (2006)	United Kingdom	Case study	Rehabilitation centre	$n = 1$
10. Smith <i>et al.</i> , (2013)	United States of America	Prospective cohort study (2008-2012)	Hospital	$n = 388$ inpatients and outpatients Groups: 1. 85% (331) infarction 2. 15% (57) haemorrhage

LHSP: left hemisphere stroke patient;

RHSP: right hemisphere stroke patient;

BDAE: Boston Diagnostic Aphasia Examination <sup>26</sup>.

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 to 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 understand pictures easier 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<sup>20, 22, 24, 25</sup>, the FPS<sup>25</sup>, the NRS<sup>22</sup>, the Verbal Rating Scale (VRS)<sup>22, 25, 27</sup>, a categorical site-of-pain shoulder scale<sup>24</sup> and the Scale Pain Intensity (SPIN) for patients with communication impairments<sup>23</sup>. 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<sup>28</sup> and the Dartmouth COOP Charts<sup>29</sup>. Studies on pain measurement in specific patients with an inability to communicate used the FPS and NRS to measure pain<sup>5, 21</sup>. 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<sup>5, 6, 19, 20, 22, 25</sup>.

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<sup>19, 20, 24, 25</sup>. 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<sup>6</sup>. 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<sup>22</sup>. 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)<sup>25</sup>. One study of excellent methodological quality presented a positive rating result in strong positive evidence for content validity<sup>25</sup>. There was limited positive evidence for criterion validity of the VAS vertical in LHSP and RHSP ( $r = 0.82$  and  $0.72$ , respectively)<sup>25</sup>. An examination of responsiveness across studies showed conflicting findings. Two studies of fair methodological quality confirmed a positive rating<sup>24, 25</sup> and one study of poor quality reported a negative rating<sup>20</sup>. 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<sup>20, 24, 25</sup>.

### **Faces Pain Scale**

The FPS is designed to measure pain and disability<sup>9</sup>. Scores on the FPS were highly correlated with scores on the VAS and VRS in both left and right hemisphere stroke patients<sup>25</sup>. 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<sup>5</sup>. 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 analogue 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 analogue 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 <sup>25</sup>.

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 ( $K = 0.74$ ) <sup>25</sup>. One study of excellent methodological quality reported positive ratings results in strong positive evidence <sup>25</sup>. 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 <sup>25</sup>. 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” <sup>12</sup>. 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  $K = 0.57$ ) <sup>25</sup>. There was strong positive evidence for content validity: one study of excellent methodological quality reported positive results <sup>25</sup>. For responsiveness, there were conflicting findings: two studies of fair methodological quality and one study with poor methodological quality <sup>20, 24, 25</sup>.

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### **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 <sup>24</sup>. 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) <sup>24</sup>.

### **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 <sup>28</sup>. 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 ( $ICC = 0.75$ ) <sup>19</sup>. 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%<sup>19</sup>. 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<sup>18</sup>.

### **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<sup>29</sup>. 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)<sup>19</sup>.

### **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<sup>23</sup>. 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<sup>23</sup>. 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<sup>23</sup>.

### **Prevalence of pain**

Two studies reported prevalence of pain in PWA after stroke, ranging from 43.8% to 87.5%<sup>21, 24</sup>. A prospective study reported higher prevalence of pain in stroke patients without aphasia (83.3–87.5%) compared with PWA after stroke (60–75%)<sup>24</sup>. 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<sup>21</sup>.

## 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<sup>6</sup>. Patients with severe cognitive and/or psychological problems, as indicated in the neuropsychology report (percentage not mentioned), were excluded<sup>6</sup>. A retrospective cohort study including 42 stroke patients reported that 69% of their study population were treated with opioids<sup>21</sup>.

## 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<sup>6, 18, 20, 22, 25</sup>. One article reported a significant difference in prescribed proportions and actually used pain medication in PWA and persons without aphasia after stroke<sup>6</sup>. 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<sup>25</sup>. The VAS vertical showed limited positive evidence for reliability and criterion validity and strong positive evidence for content validity<sup>25</sup>. In contrast to the conflicting findings reported for the responsiveness of the VAS vertical<sup>20, 24, 25</sup>, there is strong positive evidence for content validity of the VRS in contrast to limited negative evidence for reliability and responsiveness<sup>25</sup>. 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<sup>24, 25</sup>, and poor ratings were observed on criterion validity and responsiveness<sup>19, 20, 22</sup>. The study utilizing the FPS in LHSP and RHSP scored excellent rating on content validity and good rating on criterion validity<sup>25</sup>. 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 <sup>30</sup>, 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 <sup>31</sup>. 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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