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Unspoken pain: its assessment in persons with aphasia

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Citation

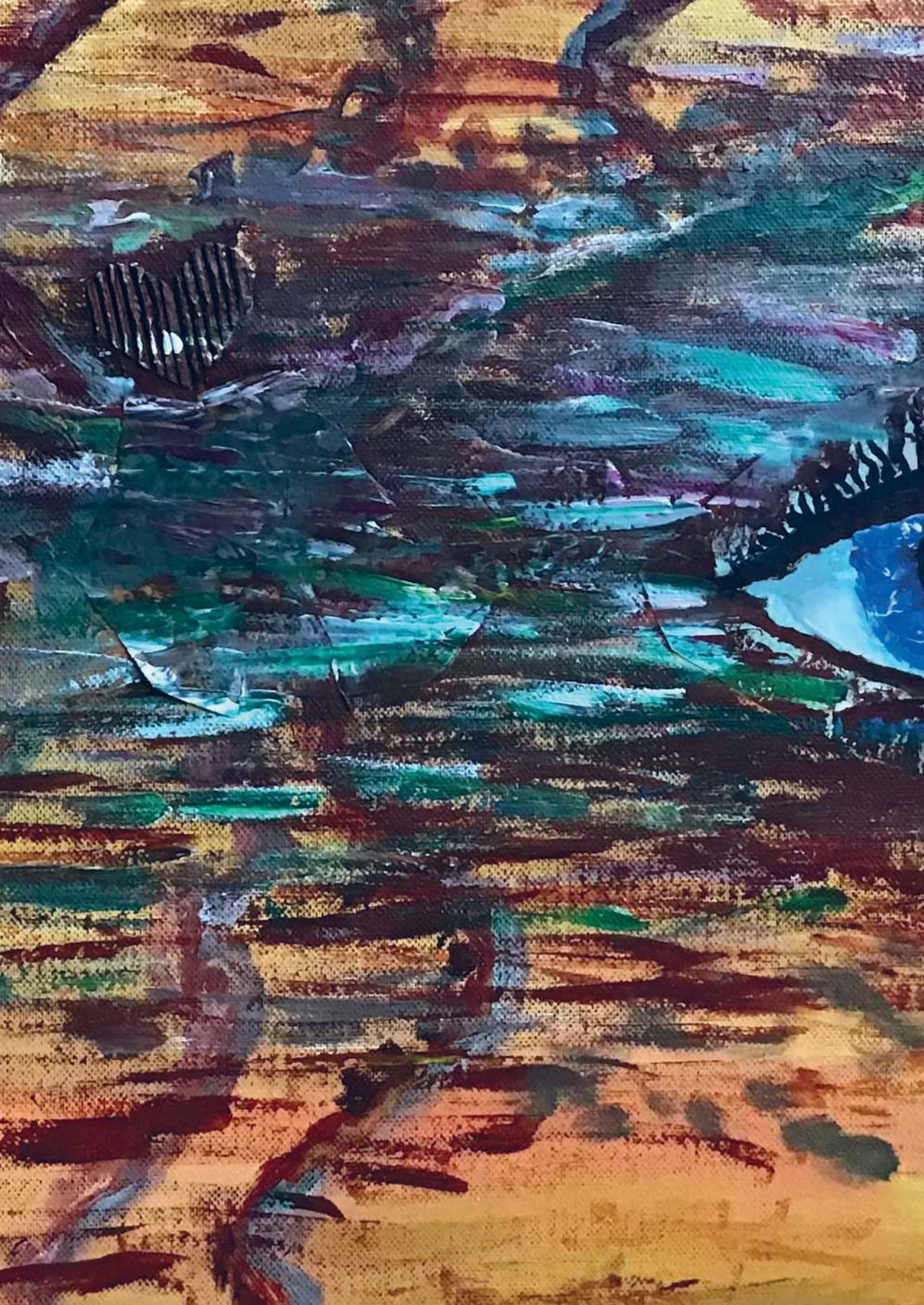
Vries, N. J. de. (2025, October 10). *Unspoken pain: its assessment in persons with aphasia*. Retrieved from <https://hdl.handle.net/1887/4262784>

Version: Publisher's Version

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Note: To cite this publication please use the final published version (if applicable).





PART 2

Pain observation in persons with aphasia

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Pain Management Nursing. 2023 Aug; 24(4): e68-e74
<https://doi.org/10.1016/j.pmn.2023.03.010>

Chapter 4

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

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

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

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

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

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

Background

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

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

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

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

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

Methods

~ Design and study population

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

unit of a Geriatric Rehabilitation Care center in The Netherlands. Patients with dementia or delirium were not eligible. Patients who were able to communicate gave oral informed consent for participation in this study. If patients were not able to give verbal informed consent or if there were doubts about the patient's communication abilities, the legal representative also provided verbal informed consent. Stroke patients, both with and without aphasia, were included. If aphasia was suspected; aphasia was diagnosed by a speech and language therapist using TokenTest³⁵ or ScreeLing³⁶. A score of ≥ 7 on the TokenTest or a score of ≤ 68 on ScreeLing indicates the presence of aphasia. If tests could not be taken, the clinical judgement of the speech and language therapist was decisive.

A sample size with a minimum of 50 patients is recommended for validation studies and for the analysis of reliability³⁷.

— *Measurement instruments*

To assess the presence of pain, the PACSLAC-D, was used because of good psychometric properties in Dutch persons with dementia³⁴. The 24 items are related to face, resistance/defense, and social emotional/mood. The observer indicated for each item whether it was observed (1) or not (0). The total score ranges from 0 to 24, with a higher score indicating more pain. A score of 4 or higher may indicate the presence of pain³⁸.

Further, two self-report pain scales were used to measure pain. The FPS consists of six vertically placed faces, with face 1 (no pain) at the bottom and face 6 (maximum pain) at the top⁹. These 6 faces are assigned the following scores: 0 (no pain), 2, 4, 6, 8 and 10 (worst imaginable pain). Patients were asked to select the face that represents their experienced pain. The combined vertical NRS and VAS consists of a 10-centimeter vertical line with scores of 0 to 10, anchored by two extremes of pain: no pain (0) and extreme pain (10). Appendix A includes the FPS and the NRS/VAS combined scale.

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

— *Assessment of measurement properties*

Construct validity

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

Convergent validity

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

Discriminative validity

Three a-priori hypotheses were tested to examine discriminative validity: 1) More pain is expected in patients with aphasia during ADL compared with rest. In persons with dementia, more pain is observed during ADL compared to rest^{23, 33, 39}. Second hypothesis: more pain is expected in patients with aphasia using pain medication than in those who use no pain medication. Persons with dementia who used pain medication have more pain than those who did not use pain medication⁴⁰. Also, a study of hospitalized persons with dementia found that 60% (of n=108) of persons who demonstrated pain received pain medication compared to 40% who did not receive pain medication⁴¹. Third hypothesis: more pain is expected in patients with aphasia compared to patients without aphasia. Stroke patients with aphasia received significantly less pain medication compared to patients without aphasia and those with moderate to severe aphasia are often excluded from pain research⁴².

Reliability

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

~ Procedure

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

All patients, not blinded for aphasia, were observed by one observer on one day during rest, activities of living (ADL), and physiotherapy using the PACSLAC-D pain observation instrument for five to ten minutes. The observer was a speech and language therapist with a university education level Master of Arts. Subsequently, the observer asked the patient to indicate the degree of experienced pain using the self-report pain scales FPS⁹, and a combination of the NRS⁷ and VAS⁸. 'Not applicable' was noted if the participant was unable to self-report using (one of) these scales. After the observation during ADL and physiotherapy, the nurse and physiotherapist respectively, with no knowledge of the PACSLAC-D score, were asked to use clinical judgement if the patient had experienced pain. After two weeks, the measurements were repeated.

~ Statistical analysis

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

used: '.00-.19'= very weak; '.20-.39'= weak; '.40-.59'= moderate; '.60-.79'= strong; '.80-1.0'= very strong⁴⁵. Additionally, a 95% confidence interval using bootstrapping (number of samples: 1,000) of the correlations was calculated. To investigate discriminative validity, the three hypotheses were tested. First, a non-parametric Wilcoxon signed-rank test was used to examine whether more pain was observed during rest than ADL (paired test) in patients with aphasia. Second, a Kruskal-Wallis test was used to investigate if patients with aphasia who use pain medication experienced more pain than those without pain medication. Third, to examine whether patients with aphasia had more pain than patients without aphasia, a Mann-Whitney U test was used.

The reliability of the PACSLAC-D was examined using Cronbach's alpha. Cronbach's α -values ranging from 0.70 to 0.95 are generally considered acceptable⁴⁶.

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

— Ethical considerations

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

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Results

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

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

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

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

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

~ Convergent validity

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

Table 1: Patients’ characteristics

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

^a $p < .05$;

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

— Discriminative validity

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

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

During rest, we found no difference in pain in patients with aphasia (median = 0) compared to non-aphasia patients (median = 0); $U = 437$, $z = -0.26$, $p = .792$. Significantly more pain was observed during ADL in patients with aphasia (median 1) compared to patients without aphasia (median = 0); $U = 310$, $z = -2.37$, $p < .05$. During physiotherapy, no difference in pain was observed between patients with aphasia (median = 0) and without aphasia (median = 0); $U = 258$, $z = -0.86$, $p = .388$.

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

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

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

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

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

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

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

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

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

* $p < .05$,** $p < 0.01$; PACSLAC-D = Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version,

~ Reliability

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

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

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

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

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

Discussion

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

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

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

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

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

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

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

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

Conclusions

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

– Implications for nursing education, practice and research

More pain was observed in patients who were unable to self-report during potentially painful activities. This means that pain management in patients with aphasia and other communication difficulties may not be optimal, highlighting the fact that alternatives to screen for pain are essential for these patient groups. The PACSLAC-D might be a suitable alternative to screen for the absence and presence of pain in patients with aphasia who are unable to self-report during activities. The use of a pain observation instrument could help healthcare professionals to substantiate their opinion on whether pain is present and to evaluate whether pain interventions were successful. Notwithstanding its limitations, this study supports that a pain observation instrument might be a good alternative when self-reporting pain is not possible because of impaired cognition and/or communication problems¹⁵⁻¹⁷. However, more research is required on how to measure pain in persons with aphasia in a valid and reliable manner, for example by comparing various observation instruments using larger sample sizes.

Acknowledgements

Financial support was provided by Zorgondersteuningsfonds (PROM-6) and TOPAZ.

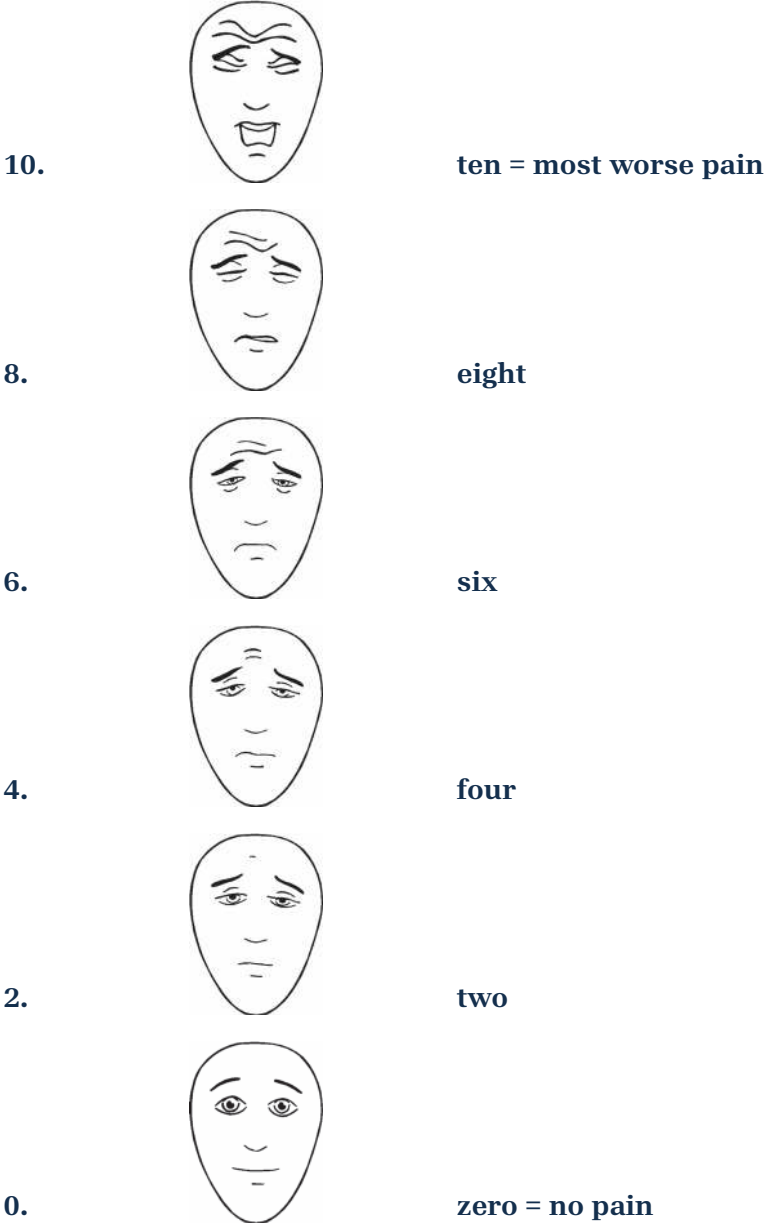
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Appendix A: Faces Pain Scale (FPS)



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

