Unspoken pain: its assessment in persons with aphasia

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Chapter 9

Summary

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

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

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

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

Main findings

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

Part 1

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

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

Part 2

The first two chapters of part 2 (**Chapters 4 and 5**) describe the psychometric properties of two pain observation instruments, Pain Assessment Checklist for Seniors with Limited Ability to Communicate - Dutch version (PACSLAC-D) and Pain Assessment in Impaired Cognition (PAIC15), respectively, for assessing pain in persons with aphasia who are unable to self-report. PACSLAC-D (**Chapter 4**) is a widely used pain observation instrument in Dutch nursing homes and consists of 24 items across: facial expressions (10 items), resistance/ defensive behavior (6 items), and social/ emotional items (8 items). The validity of the PACSLAC-D in persons with aphasia was adequate during Activities of Daily Living (ADL) or physiotherapy, but not during rest. Reliability was also situation dependent: reliability was adequate during activities of daily living (ADL) or physiotherapy, but not during rest.

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

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

Part 3

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

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

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

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

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

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

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

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

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

Key aspects of the guideline are: 1) record past and current communication and pain expression of the person with aphasia; 2) emphasizes person-centered care, adapting communication to each person with aphasia's abilities, boosting confidence, and encouraging participation of the person with aphasia; 3) the use of pain observations instruments like PACSLAC-D or PAIC15; and 4) collaboration between healthcare professionals, such as speech and language therapists and other caregivers, is paramount for more effective communication.

General discussion

A recommendation is to use self-report scales as the first and preferred method for as long as possible for assessing pain. The use of self-report pain scales becomes challenging in the post-stroke population due to deficits such as aphasia, cognitive problems, and neglect, but also because the severity of aphasia and the severity of cognitive problems may change. Individuals who may have difficulty reporting their pain with a self-report pain scale are dependent on a different pain measurement instrument or the assessment of a healthcare professional or family caregiver.

Proxy reports of family caregivers can be useful but should be use cautiously alongside professional assessments, because family caregivers' pain assessments of the person with aphasia can be biased, typically underestimating pain intensity. Researchers and clinicians should be aware of these biases when using proxy reports. Family caregivers and healthcare professionals play a key role in ensuring effective communication strategies.

Persons with aphasia, need the support and assistance of a speech language therapist or trained conversation partner to have an adequate conversation about pain. There are all kinds of supportive communication aids (for example: communication apps, photographs, or images) that can used to support a conversation.

Reflection on methodology

The applied mixed-methods approach, in which an extensive set of quantitative and qualitative data was collect, resulted in an in-depth understanding of pain in aphasia and pain measurement instruments for persons with aphasia. The diverse types of research required substantial expertise and knowledge on the part of the researcher. In addition, the researcher of this project is a speech and language therapist, combined with her role as a researcher, may have led to biased results. This thesis and the development of the practice guideline therefore did not include a balanced sample of all settings in which persons with aphasia live but focused particularly on long-term and rehabilitation settings for older persons with aphasia.

Recognition of pain in persons aphasia using the PAIC15 showed mixed yet promising results. During rest, only the items “opening the mouth”, “frowning” and “looking tense” were rated with score 1 (mild degree). During transfer, these 3 items were more often assessed with both score 1 (slight degree) and score 2 (moderate degree). Also, during transfer, the items “freezing” and “moaning” were scored with a score 1 or 2. The prevalence of individual PAIC15 items observed in persons with aphasia was low for remaining items, maybe due to a failure to observe the behaviors described in the PAIC15 items in persons with aphasia after stroke. Lower agreement between different observations with PAIC15 by one observer and by two observers, observed separately, for the items facial expression of the PAIC15 suggests that these items are more difficult to observe or were assessed differently in a clinical setting. It may be that healthcare professionals are less used or less trained to pay special attention to the face and its expressions.

Implications and recommendations

Results of developing the practice pain guideline in co-creation with persons with aphasia and their family caregivers show that they want others to know in what ways the person with aphasia can communicate and how to best support them. This is an important task for speech and language therapists, other healthcare professionals and family caregivers of the person with aphasia and it requires interprofessional collaboration.

Prioritizing the guideline, training needs, and interdisciplinary collaborations are recommendations are made for clinical practice. Healthcare professionals are encouraged to know and start using this guideline to improve the quality of life for persons with aphasia, who often face depression and a decline in self-reliance and participation. Education for nurses, physicians, and caregivers must emphasize pain assessment competencies, as observation may be more effective than verbal communication. Differences in pain perception between nurses and physicians highlight the need for more interprofessional education to ensure consistent pain management. Most nurses rely on intuition instead of structured observation instruments, creating barriers to pain management. It is important to raise awareness of the added value of observation instruments. Using pain observation instruments at the right time requires incorporating them into work processes. This sometimes requires a change of culture in the workplace.

Future research will need to focus on encouraging self-report pain scales, investigating cognitive processes, feasibility studies a real-world testing, technology integration, exploring medication effects and evaluation of quality of life of persons with aphasia. Since self-report is the gold standard for pain assessment, efforts should made to help individuals with aphasia use these tools where possible. The newly developed pain guideline should be piloted in clinical settings to refine its implementation. The guideline must be evaluated through implementation trials to evaluate its effectiveness in pain recognition and treatment. Pharmacological treatments for pain may influence mood, physical health, and social participation, requiring further investigation. Using validated tools to measure quality-of-life of persons with aphasia (like SAQOL-39), researchers can measure whether the guideline improves the overall well-being of individuals with aphasia. This research highlights the urgent need for better pain assessment practices, education, and technology-driven solutions to support persons with aphasia.

Conclusion

A structured approach like the developed pain guideline for persons with aphasia is crucial wfor accurate identification, diagnosis, and treatment of pain in persons with aphasia. Self-report should be used whenever possible, with pain observation and proxy reporting as supportive methods. When self-report pain is not possible, the use of a pain observation instrument, such as PACSDLAC-D and PAIC15, is recommended. In doing so, this research contributes to improving the quality of healthcare and quality of life for persons with aphasia. To improve healthcare for persons with aphasia, it is important to know that looking at the person is as important as listening, or in some cases may be more important than listening. A pain observation instrument is a tool for the caregiver to make explicit the “feeling” that the person with aphasia may have pain.