Unspoken pain: its assessment in persons with aphasia

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Chapter 1

General introduction

Prologue

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

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

Stroke and its consequences

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

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

Aphasia

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

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

Spoken language

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

Auditory language comprehension

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

Read and write

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

Articulation disorders

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

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

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

Pain and pain after stroke

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

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

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

Pain in aphasia

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

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

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

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

Outline of this thesis

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

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

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

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

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

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

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

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

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

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

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

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

  This part answers the question:

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

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

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

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