Unspoken pain: its assessment in persons with aphasia

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Chapter 8

General discussion

This thesis describes the method, results, and implications 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 persons with aphasia, and to develop a practice guideline for pain measurement specifically for persons with aphasia.

8.1 Main research findings

- *Which assessment instruments are used for self-report of pain in stroke patients with communication problems?*

A scoping review to identify assessment instruments used for self-report pain by hospitalized patients who have had a stroke and have communication problems, reported a range of both unidimensional and multidimensional self-report pain instruments (**Chapter 2).** The most common communication problem in these patients was aphasia. The eleven identified assessment instruments focused on assessing pain presence and pain intensity. The most frequently used unidimensional pain intensity instrument was the Numeric Rating Scale (NRS). Four instruments were multidimensional, two of which assessed health-related quality of life, including pain. The most comprehensive pain assessment instrument was the ShoulderQ [1], which includes 10 verbal questions and three visual vertical graphic rating scales that focus on the assessment of stroke-related shoulder pain. This review study concluded that the challenges of measuring pain in persons with moderate to severe communication problems or severe aphasia after stroke remain understudied. As a result, it is unknown how pain is and should be assessed and managed in persons who are unable to complete self-report pain scales after stroke.

- *What is known in the literature about pain and pain assessment in persons with aphasia?*

The prevalence of pain in persons with post-stroke aphasia was reported in two studies and ranged from 43.8–87.5%. The self-report pain scales used included the Vertical, Mechanical and Horizontal Visual Analogue Scale, the Faces Pain Scale, the Verbal Rating Scale, and the Numeric Rating Scale. Interestingly, studies described pain assessment in post-stroke aphasia patients with mild-to-moderate aphasia, while patients with severe aphasia were excluded. Various pain assessment instruments were used, but their feasibility, validity and reliability were of low methodological quality **(Chapter 3)**. These findings underline the difficulty of identifying pain in persons with severe aphasia after stroke. This review also found that there is no information on how pain is or should be assessed and managed in persons with severe communication problems due to aphasia. Therefore, these two reviews **(Chapters 2 and 3)** report a gap in knowledge; persons with aphasia who are not able to complete self-report pain scales are at risk of their pain not being noticed. An alternative way of assessing pain in persons with aphasia could be a pain observation instrument.

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

Previous research has examined the psychometric quality of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version (PACSLAC-D). PACSLAC-D is a pain observation instrument that consists of 24 items divided into three categories: facial expressions (10 items), resistance/ defensive behavior (6 items), and social/ emotional items (8 items). The PACSLAC-D is widely used in Dutch nursing homes, and this study was conducted to explore whether the PACSLAC-D has added value for pain observation in persons with aphasia [2, 3]. 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 4**). **Chapter 5** describes the use of the Pain Assessment in Impaired Cognition (PAIC15) instrument in persons with aphasia, because PAIC15 has shown satisfactory psychometric properties in persons with impaired cognition. PAIC15 is a pain observation instrument that assists healthcare professionals in recognizing pain in persons with cognitive impairments, by assessing 15 items with described behaviors divided into facial expressions, body movements, and vocalizations, with 5 items each.
In **Chapter 5**, the results of observations during rest and transfer of the PAIC15 reported fair positive correlations between PAIC15 and all self-report pain scales in persons with aphasia. Significantly more pain was observed in persons with aphasia during transfer than during rest, confirming validity. 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 who do not. These results called the validity into question However, the test-retest reliability and inter-reliability of the PAIC15 were high in persons with aphasia during both rest and transfer.

The studies in **Chapters 4 and 5** conclude that PACSLAC-D and PAIC15 capture pain during activity in persons with aphasia who are unable to self-report, but may be less accurate during rest. The user-friendliness study of PAIC15 for persons with aphasia (**Chapter 6)** reported that the PAIC15 was considered by all observers to be user-friendly for persons with aphasia. The results of this study indicated that observers assess the PAIC15 as a helpful instrument to aid clinical judgment and to screen for the presence of pain in persons with aphasia.
The PAIC15 items were clear and not difficult to score, prompted observers to pay attention to nonverbal signals in persons unable to express themselves, and facilitated clinical judgement (**Chapter 6**). Most observers preferred to use the combined self-report pain scale for persons with aphasia, because it was thought that the amount of information provided best facilitates self-report in persons with aphasia (**Chapter 6**).

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

A practice pain guideline for persons with aphasia was developed based on evidence about pain, pain assessments (studies presented in **Chapters 2 and 3**) and observational studies of pain in persons with aphasia (studies presented in **Chapters 4, 5 and 6**), as well as the experiences of persons with aphasia and their family caregivers and the experiences of experts (**Chapter 7**). Both the content and design of the practice pain guideline were co-created with professionals, patients, and family caregivers. This practice pain guideline supports professionals in personalizing the recognition and assessment of pain in aphasia (**Chapter 7**).

8.2 Critical reflection on main findings

- *Self-report pain instruments in stroke patients with communication problems*

Self-report is considered the gold standard for routine assessment of symptoms: however, this is challenging in post-stroke patients [7-9]. Assessing pain becomes challenging in the post-stroke population due to deficits such as aphasia and neglect [10]. Pain assessment in similar cognitively and communicatively impaired populations, such as those with intellectual disabilities or dementia, presents similar challenges regarding the use of self-report instruments, resulting in underreport and undertreatment of pain [7-9]. The difference between these populations and persons with aphasia is that persons with aphasia may recover after stroke. Both the severity of aphasia and the severity of cognitive problems may change [11]. Cognitive problems after a stroke may include a delayed rate of information processing, attention problems, difficulty solving problems and planning/organizing. Persons with dementia often have difficulty processing information, but cognitive functions may also be impaired, which can manifest as, for example, forgetfulness, getting lost or being unable to solve problems. The varying and sometimes changing post-stroke cognitive problems make persons with stroke a distinct group that deserves a specific approach and research. Individuals with communication problems are vulnerable to incomplete self-report regarding pain assessment and inadequate pain management. It is recommended that self-report scales be used as the first and preferred method for as long as possible [10, 12]. However, when self-report of pain becomes challenging due to deficits such as aphasia, pain observation is an acceptable and preferred additional or alternative assessment.

- *Pain in aphasia*

Pain after stroke is an under-recognized and under-assessed phenomenon, and it is usually assumed that communication difficulties in stroke patients are a major contributing factor [13-15]. The rationale behind the studies in this thesis was that pain in persons with aphasia is a challenge, and certainly there is little attention for this problem in literature. A German study in a stroke unit confirmed that pain in persons with aphasia is not systematically assessed and therefore not adequately treated [16]. This thesis confirms the hypothesis that persons with aphasia who cannot express pain due to communication problems are excluded from pain assessments (**Chapters 2 and 3**). In contrast to persons with dementia, who also experience communication and cognitive problems, research on pain measurement in persons with aphasia is limited. The current research project is about pain in a target group that has not been studied before, pain in persons with aphasia.

Pain assessment in aphasia

Persons with aphasia have more difficulty expressing their needs or requests for help and accessing care than persons without aphasia. Various studies have described different methods that can support and aid spontaneous language production or expression of unmet needs, such as photographs or pictures of the human body [4, 17-19]. A developmental study of a pictorial scale of pain intensity (SPIN) for persons with communication problems performed well in comparison with two well-validated pain intensity scales, and quantified the severity of pain as well as the preferred Numeric Rating Scale [20]. However, this study included persons who were able to report their pain symptoms.

Studies in persons who are able to complete self-report instruments have shown moderate validity and reliability of the self-report pain scales Faces Pain Scale (FPS), Numeric Rating Scale (NRS), and Visual Analogue Scale (VAS) [21, 22]. The study by Smith et al. [10] describes the inability to self-report pain after a stroke as being less common than previously thought. Nevertheless, 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 informal caregiver. The use of a structured approach to pain assessment in nonverbal post-stroke patients will improve quality of care [13, 14].

Pain observation in persons with aphasia

As the use of a pain observation instrument has been shown to be feasible in persons with dementia [23, 24], it may also be an alternative for persons with aphasia. Whether a pain observation instrument is also valid and reliable in persons with aphasia was investigated in the quantitative studies on these psychometric properties of the PACSLAC-D and the PAIC15 in **Chapters 4 and 5**.

The PACSLAC-D captures pain in persons with aphasia who are unable to self-report, during ADL and physiotherapy, but may be less accurate during rest (**Chapter 4**). Disadvantages of using the PACSLAC-D are that this instrument consists of up to 24 items, not all of which are clearly defined, reliable or valid. The same applies to many other pain observation instruments and an EU initiative (EU-COST TD1005) therefore developed the PAIC15 as a meta-tool, with 15 structured and comprehensible items divided into three domains: facial expressions, body movements and, vocalizations [25].

A study of the PAIC15 used in persons with dementia showed that there are differences in the perception of pain characteristics between nurses and physicians working in nursing homes [26]. In addition, it is also possible that information provided by nurses is not taken seriously by physicians, due to an inability to properly describe the problem or desired action [27]. This can have negative consequences for the person with communication problems - and pain - who is dependent on the nurse being attentive to any symptoms.

A recent systematic review and meta-analysis by Sabater-Garriz and colleagues [9] found that the predominant method of pain assessment in adults with communication disorders (including post-stroke aphasia) is the use of observation scales, with some scales showing promising psychometric properties for specific populations. However, the existing diversity of assessment tools and study designs prevents the selection of a universally suitable scale for evaluating pain across all adults with communication disorders. The current thesis is consistent with the consensus that pain observation instruments such as the PACSLAC-D and PAIC15 can be used to assess pain in persons with aphasia when self-report pain scales cannot be used. Furthermore, when self-report is possible, it is the gold standard for measuring pain.

Proxy report

It is common for healthcare professionals to ask family caregivers if the person with aphasia is in pain when the person cannot verbally express their pain themselves. However, research on proxy report indicates that family caregivers of persons with aphasia rate their loved ones significantly lower on global quality of life, physical functioning, general or overall health, pain, and vitality [28]. Nevertheless, their systematic patterns in proxy ratings could be useful for clinicians and researchers as their aphasic partners' scores can be easily and confidently predicted [28]. This is also in line with a recent study that concluded that family caregivers can make valuable contributions to the observation, assessment, and management of pain in cancer patients receiving palliative care [29]. Research on assessment of pain by proxy compared with self-report of pain in persons with dementia showed mixed results. Proxies of community-dwelling older adults with dementia reported slightly higher rates of pain than self-reporters, but differences were statistically significant only for activity-limiting pain [30]. Pain assessed by proxy, both by family members and healthcare professionals, in patients with and without cognitive impairment, reports differences between self-reported pain and proxy ratings [28, 31]. Researchers and clinicians should be aware of these biases when using proxy reports.

Communication support for persons with aphasia

Persons with aphasia, regardless of the severity of the aphasia, need the support and assistance of a speech language therapist or trained conversation partner to have an adequate conversation about pain [4, 5]. In addition, there are all kinds of supportive communication aids that can be used to facilitate a conversation. For example, communication apps, photographs or images are used to support the language production or understanding of a message [4-6]. The 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 (**Chapter 7**). 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.

8.3 Critical reflection on methodology

Design of the study

The applied mixed-methods approach, in which an extensive set of quantitative and qualitative data was collected, resulted in an in-depth understanding of pain in aphasia and pain measurement instruments for persons with aphasia. The combination of data from the literature reviews (**Chapters 2 and 3**) and the studies on the psychometric properties of PACSLAC-D and PAIC15 in persons with aphasia (**Chapters 4 and 5**), together with the user-friendliness of the PAIC15 (**Chapter 6**) provided the input for the development of the pain guideline for persons with aphasia (**Chapter 7**). Its development was a co-creation process with a qualitative design and a stepwise approach. This approach provided relevant information about the needs, wishes and ideas of the most important stakeholders, persons with aphasia, their informal caregivers, and healthcare professionals. Therefore, the developed practice pain guideline could provide a clinically useful tool to improve the recognition of pain in persons with aphasia. The different types of research required substantial expertise and knowledge on the part of the researcher, which may not always have been optimal. In addition, the researcher of this project is a speech and language therapist and was instrumental in inviting a few participants with aphasia. She also conducted a few observations using the PACSLAC-D and PAIC15 when it was not possible to have other observers do this. Her expertise and perspective on individuals with aphasia, combined with her role as a researcher, may have led to biased results.

Setting

Data were primarily collected in long-term care and geriatric rehabilitation organizations. The literature review includes studies with hospitalized patients, while the observational studies include participants in geriatric rehabilitation or somatic departments of nursing homes. Relevant stakeholders were involved in the development of the practice pain guideline. Participants in phases three to five (**Chapter 7**) were from nursing homes, but phase two also included input from persons with aphasia and their relatives living in the home situation.
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 heavily on more long-term and rehabilitation settings for older persons with aphasia. This makes the application of the results in these settings more feasible, but the external validity for other settings is uncertain.

Sample sizes

The number of articles included in the systematic review was small (n=10), confirming that pain in aphasia is an understudied problem. Regarding the quantitative studies, 60 and 75 persons with aphasia were observed using PACSLAC-D and PAIC15, respectively. A sample size with a minimum of 50 persons is recommended for validation and reliability analysis [32]. The qualitative study to collect data for the development of a pain guideline for persons with aphasia included a small number (N=17) of stakeholder participants. However, data saturation was achieved in the individual phases of this qualitative study.

Psychometric properties of pain observation instruments

Regarding the examination of the psychometric properties of the PACSLAC-D and PAIC15 in the quantitative studies conducted in persons with aphasia, the following 4 types of validity were tested: content, construct, face validity and criterion validity. The validity scores of the pain observation instruments which are used were adequate during ADL, transfer, or physiotherapy, but insufficient during rest. The qualitative studies in this thesis reported acceptable internal consistency and test-retest reliability of the PACSLAC-D in persons with aphasia during ADL and physiotherapy, which is consistent with studies using the PACSLAC-D in patients with dementia or other older persons with communication problems [33,34]. Especially during movement, a higher prevalence of facial expression items was found compared to items in the other two domains (body movements and vocalizations) of the PAIC15. This is consistent with findings from a PAIC15 study in a long-term care setting in patients with dementia [35]. The prevalence of individual PAIC15 items observed in persons with aphasia was low for most items. It is possible that low scores on PAIC15 items are due to a failure to observe the behaviors described in the PAIC15 items in persons with aphasia after stroke. Another possible explanation is that pain can be experienced differently in this population.

Lower intra- and interobserver agreement for the facial expression items suggests that these items are more difficult to observe in a clinical setting. This is interesting, because Kaasalainen et al. concluded that facial expression items were observed more frequently in clinical practice in people who were unable to verbally report their pain than in persons who were able to report [36]. Lautenbacher et al. also showed that in experimental settings, people with dementia show more facial expressions after a painful stimulus compared to non-dementia controls. This provides evidence that observing facial expressions and using an observational pain assessment instrument is paramount when assessing pain in persons with communication problems [23,26]. However, it may be that healthcare professionals are less used or less trained to pay special attention to the face and its expressions.

8.4 Implications of this research project

Implications for clinical practice

The research described in this thesis has resulted in a clinical practice guideline for the assessment of pain in persons with aphasia, an area that has received very little attention so far. If this newly developed practice pain guideline is properly implemented in nursing homes or other settings where persons with aphasia reside, there will be more attention for how the person with aphasia communicates, how they expressed pain before and how it is now expressed differently. Use of this practice pain guideline may lead to increased attention to the assessment of pain in persons with aphasia. One of the key components of this guideline is to record knowledge about who the person was and both the current way of communicating and expressing pain with aphasia and the way of communicating and expressing pain before the aphasia. Examples of tools for getting to know the person include the use of hetero-anamnesis, notebooks with personal information, photo albums, and a doodle board [5, 17, 37]. It is essential to continue to see persons with aphasia as individuals with unique needs and talents. Person-centered care contributes to this by putting the person at the center and adapting communication to his or her abilities, thereby increasing self-confidence and participation. It also requires practitioners to develop mutually respectful relationships with residents (including persons with aphasia), and family caregivers who are important to them, and to seek to understand the residents' values and preferences [38]. It requires good cooperation between different disciplines, such as speech and language therapists and healthcare providers, because effective communication in aphasia is complex and needs a collaborative approach. The practice pain guideline for persons with aphasia contributes to person-centered care.

The standard use of pain observation instruments in persons with aphasia who are unable to complete self-reports is still lacking in the daily care of persons with aphasia. The standard use of a pain observation instrument when self-report is not possible is another key component of the practice pain guideline for persons with aphasia. It is recommended that pain should preferably be observed not only during rest, but especially during daily activities (e.g., washing and getting up), because little has been observed with pain observation instruments PACSLAC-D and PAIC15 during rest. Also, new instructions have recently been added to the e-learning of PAIC15 to improve the assessment of pain: if you have observed a pain signal, select score 2: "medium degree" by default. The options score 1: "low degree" and score 3: "high degree" should only be selected for very weak or strong responses. These new instructions were initiated because the PAIC15 scores 2: "medium degree" and 3: "high degree" were rarely scored, possibly because observers had difficulty distinguishing between scores 2 and 3 (**Chapter 5**). In addition, a follow-up study on user-friendliness for persons with aphasia with a larger and more diverse study sample in an international context is recommended.

Technology and pain assessment

Pain in people living with cognitive or communicative impairment and in those with both may be treated sub-optimally. Communication challenges lead to suboptimal assessment of pain. When pain is not adequate assessed, its management will invariably be suboptimal [39]. Pain is, among other things, one of the main indicators of discomfort. It is possible that digital support could be helpful in the assessment and treatment of pain in persons with aphasia. Digital phenotyping deals with observable features in digital form, such as those of sensor-supporting devices, and may provide new and more informative data than existing clinical approaches regarding how pain manifests and how treatment strategies affect pain [40]. Today, non-invasive monitoring technologies to identify discomfort and distressing symptoms in persons with limited communication are available [41]. These monitoring technologies and possible other technological developments will help to improve the assessment of pain in persons with aphasia and/or cognitive problems in the future.

A recent study of an augmentative and alternative communication (AAC) pain description system for persons with communication problems used symbols to express pain. This is challenging because designing a series of comprehensible symbols to represent personal experiences such as pain is not straightforward [42]. Augmentative and alternative communication (AAC) describes multiple ways of communicating that can complement of compensate for the impairment and disability patterns of individuals with severe expressive communication problems. Pain expression symbols derived from Chinese pain-related similes and metaphors were used for a mobile AAC application developed specifically for this study. Results show that the use of the app was effective in reporting pain and that people required less time to report a pain event. The results also indicate that the pain diary app was better received by younger individuals than by their older counterparts [42]. The potential value of adding this type of AAC in the practice pain guideline is something to further explore.

Implications for health care policy and education

Aphasia experts, such as speech and language therapists, aphasia therapists, and policy makers in healthcare organizations where persons with aphasia reside will need to be aware of the existence of the practice pain guideline for persons with aphasia. They should prioritize the implementation of this pain guideline because aphasia is a condition that has a significant negative impact on health-related quality of life [43] with a high risk of depression and a lower probability of returning to pre-aphasia levels of functioning [44]. The combination of the inability to communicate pain due to aphasia, and the high prevalence of pain after stroke suggests a need for improved pain assessment in this vulnerable population.

From an educational perspective, it is important that training courses for nurses, physicians, elderly care physicians, speech and language therapists, and other experts who work with persons with communication and cognitive problems include competencies in pain and pain assessment. Especially for this vulnerable population, who may have difficulty expressing their distress and symptoms, it is important that professional caregivers learn that observing may be more important than listening. Thorough training and education in the use of self-report pain scales, pain observation scales, and the practice pain guideline is important for proper implementation. Differences in the perception of pain characteristics between nurses and physicians in nursing homes, as mentioned earlier, demonstrate the need for more interdisciplinary interprofessional education about pain in persons with communication and cognitive problems [26]. Research indicates that nurses do not always use observational pain instruments to assess pain, even when they are available and their use is encouraged. They often prefer to rely on their intuition and feelings [45]. However, non-use of a pain observation instrument is a barrier to adequate pain management in persons with dementia [26]. This highlights the need for awareness of the usefulness of pain observation instruments. This may require a culture change in the way nurses and physicians collaborate.

Recommendations for future research

Research on the performance of self-report pain compared to observational scales in persons with dementia shows that self-report, the highest standard of pain measurement, can be reliably administered in a large proportion of older people with severe dementia [46, 47].

Encouraging the use of self-report pain scales as much as possible in persons with aphasia is recommended. By implementing the pain protocol for persons with aphasia, the use of self-report pain scales will be systematically applied and evaluated.

As in persons with Down syndrome and impaired cognition, further research could provide insight into the role of cognitive processes in self-report, involving aspects such as acquiescence and repeated measurements to evaluate whether neuropsychological examination could contribute to pain assessment in persons with aphasia [7]. Studies of the role of cognitive processes in persons with aphasia are lacking but should be encouraged.

Further research is also needed to investigate the feasibility of the developed practice pain guideline for persons with aphasia, as the practice pain guideline has not yet been (pilot) assessed in clinical practice. Also, the added value of complementary use of the pictorial scale of pain intensity (SPIN) for persons with communication problems in addition to the self-report pain scales to quantify the severity of pain should be investigated [20]. Plus, the addition of technology/digital phenotyping is worth exploring.

A next step for further research is to implement, test, and evaluate the developed pain guideline in clinical practice to see if refinements are needed and to investigate whether the guideline improves the recognition and treatment of pain in persons with aphasia.

A study of the effects of implementing an intervention for mapping and treating pain in people with dementia (STA OP!) found clinically relevant reductions in pain in the intervention group compared with the control group [48]. This study shows that individuals in the intervention group who received the stepwise multidisciplinary intervention were significantly more likely to receive opioids in addition to other pain medication. A cluster randomized controlled trial is recommended to assess the effects of the developed pain guideline with structural pain assessment in individuals with aphasia. It should include previously started or new pain treatment (pharmacological or non-pharmacological). Side effects of (pharmacological) treatment may influence mood, physical functioning or participation in interactions, which may affect the quality of life of the person with aphasia. Therefore, it is important to include effects on the quality of life of persons with aphasia in the outcome measures. These effects can be elicited using an instrument validated for persons with aphasia, such as the Stroke and Aphasia Quality of Life Scale (SAQOL-39) [49]. In addition, a process evaluation of the implementation of the pain practice guideline is recommended. This process evaluation will clarify the facilitators and barriers that may be encountered when implementing and using the practice pain guideline for persons with aphasia.

Thanks to technological developments, the steps of the practice pain guideline can be entered into an application. The steps could also have a place in the electronic health record of persons with aphasia. It may be possible to use reminders in the electronic patient record to support implementation of the steps. In addition, various supporting communication systems or applications are being developed and increasingly used in clinical practice by speech and language therapists to help compensate for communication problems. Also, persons with aphasia themselves increasingly have mobile communication applications on various devices [50]. If caregivers want to get to know the person with aphasia, they need to know how to use these applications properly. Mobile applications with symbols to express pain, derived from pain-related simulations and metaphors, are the future. They can provide a solution for persons with aphasia who have difficulty expressing their pain themselves.

Improving healthcare for persons with aphasia requires knowing that looking at the person can be more important than listening. A pain observation instrument is a tool to make the caregiver's 'sense' that the person with aphasia may be in pain explicit.

Epilogue

Music of the future

The case of Mrs. S. with an implemented pain guideline for persons with aphasia

Mrs. S. is 85 years old and has severe aphasia. Every nurse and healthcare professional calls her Inge, because this is her wish and it is noted in her medical record. Inge was once trained as a pediatric nurse herself and worked in a hospital for years caring for children. Inge loved piano music very much. It was also noted that Inge wants to be approached by care staff as an equal and is happy to give her opinion and input on her daily care and circumstances.

After a few weeks of practising language comprehension and production, Inge produces short sentences in everyday situations. These are characterized by word finding problems. Every morning and evening, Inge can rate her abdominal symptoms and pain on a scale of 0-10. In consultation with Inge, if the score is 7 or higher, she is given pain medication. With this policy, the previous resistance to nurses is no longer observed. If her pain cannot be assessed with a rating of 0-10 or self-report scale, the nurse will complete a PAIC15 during morning care. During each multidisciplinary consultation, any pain and treatment is monitored and evaluated. In this way, the pain of the person with aphasia is always on the agenda, and during daily care moments, piano music in the background creates a pleasant atmosphere.

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