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RESEARCH ARTICLE

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Translation, cultural adaptation and recommendations for clinical implementation of the Abbey Pain Scale to a Swedish dementia care context

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Abstract

Aim: To translate and culturally adapt the APS for people with end-stage dementia in various care settings in Sweden and to investigate factors important for clinical implementation.

Design: Qualitative study design with interviews with care staff.

Methods: After an initial discussion of concepts, the Abbey Pain Scale was translated into Swedish and back into English to check for accuracy. The resulting Swedish version was then revised and culturally adapted through a series of interviews with nursing assistants, nurses and physicians ($n = 11$) to develop the final Swedish version.

Results: A Swedish version of the Abbey Pain Scale was developed. The instrument was considered straightforward and easy to use, but needed adjustments to make it more comprehensible to staff with less education in health care or with other first languages than Swedish. It was found important to carefully introduce new staff members to the instrument, to ensure they understand all the words and items.

KEYWORDS
Abbey Pain Scale, cognitive dysfunction, cross-culture comparison, dementia, development, implementation, pain, pain measurement

1 | INTRODUCTION

Pain is a profoundly personal experience that is most accurately and reliably described when self-reported by the patient. The most commonly used scales for self-reported pain are the visual analogue scale (VAS), the numeric rating scale (NRS) and the verbal rating/descriptor scale (VRS/VDS). In general, the NRS is preferred by the cognitively intact, while VRS/VDS is favoured by elder persons and those with mild to moderate cognitive impairment (Hjermstad et al., 2011; Karcioglu et al., 2018).

When patients can no longer communicate verbally, as when they develop late-stage dementia, the focus shifts from self-reports to observations of expressions of pain. The need for observational scales is evident, since dementia is the seventh most common cause of death worldwide (World Health Organization [WHO], 2020) and the prevalence of pain reported among people with dementia or cognitive impairment ranges from 15% to 78% (Atee et al., 2021; Feast et al., 2018; Tan et al., 2015).

Several observational scales for patients with dementia, cognitive impairment or nonverbal patients are available in English (Lichtner et al., 2014; Tapp et al., 2019). The white paper on dementia from the European Association for Palliative Care (EAPC), does not specify which of these observational scales should be used (van der Steen et al., 2014). In Sweden, three different pain

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assessment tools, one of which is the Abbey Pain Scale (APS), are recommended by the Swedish National Clinical Practice Guideline for Palliative Care (Regional Cancer Centre, 2021). The APS was developed to assess pain in people with late- or end-stage dementia in residential aged care facilities in Australia (Abbey et al., 2004). The scale uses six indicators: vocalization, facial expression, change in body language, behavioural change, physiological change and physical change. Each indicator includes examples such as "vocalization, e.g. whimpering, groaning, crying." The person's total pain is assessed by adding up the indicator scores. For example, 0–2 indicates no pain and 14–18 is considered severe pain. The pain is then classified as chronic, acute or acute on chronic (Abbey et al., 2004).

The APS is the most widely used pain assessment tool for people with end-stage dementia in residential care facilities in Australia (Abbey, 2007). In Sweden, it is estimated that up to 75% of all patients in residential aged care facilities live with dementia (Swedish National Board of Health and Welfare, 2014). In comparison, a study comparing quality in end-of-life care in six different European countries estimated that the prevalence of people with dementia in nursing homes ranged from 60% to 83% (Pivodic et al., 2018). However, people with end-stage dementia are also treated for pain in other care settings. The proportion of people who die from dementia-related causes in hospitals differs substantially among countries, ranging from just under 2% in the Netherlands to over 70% in South Korea (Cross et al., 2020; Reyniers et al., 2015). In Sweden, approximately 5% of all who die from dementia die in acute hospital wards (Martinsson et al., 2020).

Psychometric testing of the APS in the original study showed a Cronbach's alpha of 0.74 and a significant correlation between the APS and the nurses' holistic pain assessment. The inter-rater reliability was tested in only a few patients and was considered modest (Abbey et al., 2004). The APS has since then been translated and tested for validity in Japan (Takai et al., 2010), Denmark (Gregersen et al., 2016), Italy (Storti, 2009) and Spain (Chamorro & Puche, 2013), and various versions have been available in Sweden since the year 2011. The most commonly used version in Sweden is distributed by Swedish Register of Palliative Care [SRPC] (2011), whose purpose is to improve the quality of end-of-life care regardless of diagnosis and care setting (Lundström et al., 2012). The APS is widely used in various care contexts in Sweden, and the SRPC has distributed it to almost 650 healthcare facilities throughout Sweden (M. Andersson, register manager of the SRPC, personal communication, September 24, 2020).

Although different Swedish versions exist, to the best of our knowledge, no peer-reviewed culturally adapted translation of the APS to Swedish is available. Appropriate instruments and tools are needed to maintain and improve healthcare quality and research. This study aimed to translate and culturally adapt the APS for people with end-stage dementia in various care settings in Sweden and to investigate factors important for clinical implementation.

TABLE 1 Translation and cultural adaptation of the Swedish version of Abbey Pain Scale, the APS-SE

Step 1. Planning and conceptual phase
Literature review of pain assessment tools, guidelines on translation, and guidelines on palliative care in Sweden (ST, PF, LM)
Informal group discussion on concepts of the APS items with healthcare staff: ST, LM, a senior lecturer in nursing, three nurses in palliative care and a manager of a palliative care unit
Step 2. Forward translation
Forward translation separately by two native Swedish speakers: a professional translator without medical education and a specialist in palliative medicine
Consensus of the versions mediated by the second author (PF)
Step 3. Backward translation
Blinded[a] backward translation separately by two native English speakers: a professional translator without medical education and a nurse working in a palliative care setting. Consensus of the versions mediated by the second author (PF)
Step 4. Expert review
Expert group discussion (ST, PF, LM and all translators) on the translations of items
Consensus on all items except two
Step 5. Conceptual phase 2
Literature review, consultation with colleagues and experts on the two remaining items (ST, LM)
Proposals of new alternatives and getting consensus on the two remaining items from the expert group (ST, PF, LM and all translators)
Agreement on the initial Swedish APS version for testing
Step 6. Interviews, analysis and adjustments
Pilot interview to test the semi-structured interview guide
Interviews of staff working with people with dementia
Alterations of the Swedish version of APS when needed according to the interviews
Repeated interviews and alterations until no new essential information was revealed in the interviews
Final version of the Swedish APS: the APS-SE

[a]Blinded translation: to minimize any bias, translators had no previous knowledge of the original APS.

2 | METHOD

Based on guidelines for translation and cross-cultural adaptation (Antunes et al., 2012; Beaton et al., 2000), the Swedish version of APS (APS-SE) was generated as follows in Table 1.

For APS-SE, see Appendix S1.

2.1 | Participants and data collection

Interviews with physicians, nurses and nursing assistants were conducted to expose any problems with the initial APS-SE and to investigate factors important for clinical implementation. Purposeful sampling was used to achieve variation in gender, age, occupation (nurse, nursing assistant or physician), workplace and Swedish versus other first languages. To be included, interviewees had to be adult healthcare staff working in a geriatric department, nursing

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home, palliative care facility or emergency department and provide oral and written consent. The participants were approached by face-to-face, email or phone and all accepted the invitation to participate. All the interviews were conducted at the participants' workplace without anyone else present besides the participants and researchers. With the exception of two colleagues, there was no relationship established prior to study commencement between the interviewer and the participants. Thus, prior to the start of the interview, the interviewer(s) presented herself/themselves and the reason for conducting the research.

At the beginning of the interview, all participants were asked to visualize a patient whom they had cared for and to think out loud with that patient in mind while completing the newly translated APS-SE. A semi-structured interview guide developed by the authors was used during the interviews, with example items such as "What do you think of question 1?" A pilot interview was conducted to test the interview guide. All participants were interviewed once and field notes were made after the interviews. All interviews were audio-recorded and transcribed. The transcripts were not returned to the participants for comments and the participants have not been provided with feedback on the findings.

2.2 | Analysis

After listening to each interview and reading the transcripts, two authors (ST and LM) individually identified ambiguous items. Those items were then altered when needed through consensus by ST, and the revised version of the APS-SE was used for the next interview. This process was repeated until nothing essentially new was uncovered during the interviews. The analysis of the interviews was inspired by theoretical thematic analysis (Braun & Clarke, 2006). The result was reported using the COREQ checklist (Tong et al., 2007).

2.3 | Ethics

This study was approved by the Regional Ethical Review Board in Umeå, Sweden, [registration number 2017/504-31].

3 | RESULTS

3.1 | Demographics

A total of 11 interviews were conducted. The interviews lasted 18 to 64 min (median: 32 min). For interviewee demographics, see Table 2. All but the four interviewees working in the emergency department had previously used other Swedish versions of the APS in clinical practice.

TABLE 2 Interviewee demographics, $n = 11$

Occupation, *n* (%)	
Nursing assistant	2 (18)
Nurse	3 (27)
Physician	6 (55)
Age, range (years)	
Female	33–65
Male	20–54
Gender, *n* (%)	
Female	6 (55)
Male	5 (45)
Working with people with dementia, range (years)	
Nursing assistant	1–8
Nurse	2–19
Physician	5–25
Workplace, *n* (%)	
Residential aged care facility	4 (36)
Specialized palliative home care unit	1 (9)
Geriatric department	2 (18)
Emergency department	4 (36)
Swedish as first language, *n* (%)	
Yes	7 (64)
No	4 (36)

3.2 | Steps 1–6

Based on guidelines for translation and cross-cultural adaptation (Antunes et al., 2012; Beaton et al., 2000), the APS-SE was developed in a series of six steps.

3.2.1 | Step 1. Conceptual phase 1

During the informal group discussion among medical professionals, most key concepts in the APS concerning health care in Sweden were found easily understandable. The term "resident" was used in the original version of the APS. In Sweden, several different institutions care for people with dementia: hospitals, residential aged care facilities, in-home care services and hospices. Since all these institutions use different terms (e.g. "patient," "resident" or "guest") we settled on the neutral designator "person."

The concept "acute on chronic pain" was not fully understood and lacked a definition (Abbey et al., 2004). Consulting the literature revealed that "acute on chronic pain" does not exist as a diagnosis in the International Classification of Diseases-11(ICD-11), developed by the World Health Organization (WHO) for clinical and research purposes (WHO, 2021). After consulting with several colleagues, the authors finally decided to use "chronic and acute" pain.

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3.2.2 | Step 2. Forward translation

The two forward translations were similar in general, but two terms, "fidgeting" (Q3) and "skin tears" (Q6), needed further discussion. Neither translator could offer a single Swedish word for "fidgeting." The Swedish phrase meaning to "moving anxiously" was proposed instead. For Q6, the translator without medical training translated "skin tears" differently to the medical meaning of the term. After discussion between the two translators and the mediator, the Swedish word meaning "laceration" was suggested and accepted.

3.2.3 | Step 3 Backward translation

The two backward translations uncovered no major differences.

3.2.4 | Step 4 Expert review

The expert group compared the backward translation with the original APS, and agreed with all the translations except "fidgeting" and "skin tears." The semantics in the backward translation of these terms were considered too far apart from the semantics in the original APS to be acceptable. The expert group concluded that an additional conceptual phase was needed for "fidgeting" and "skin tears," and a second conceptual phase was added in step 5.

3.2.5 | Step 5 Conceptual phase 2

In this second conceptual phase, we made a purposeful search of the literature and consulted colleagues and experts for the terms "fidgeting" and "skin tears." New translations for these terms were found after consultations with several healthcare professionals. "Fidgeting" was translated as "moving restlessly," which was perceived as a more accurate description. Our search for an equivalent Swedish term for "skin tears" identified a study from 2018 that translated the International Skin Tear Advisory Panel's classification system for skin tears into Swedish and then validated the translated system. After a survey of wound care specialists in Sweden, the study established *hudfliksskada* as the best Swedish translation of the term "skin tears" (Källman et al., 2019). The alterations of the two terms were accordingly proposed to the expert group and accepted, resulting in the initial Swedish version of the APS.

3.2.6 | Step 6. Analysis

During the analysis of the interviews, three themes were identified: comprehension, usefulness and implementation.

Comprehension

Several adjustments were made based on participants' comprehension of the items.

The first Swedish translation of "whimpering" (Q1) was not well recognized by some staff whose first language was not Swedish. One of the nurses who had regularly introduced a previously used version of the APS to staff with other first languages, suggested a new synonym, which was understood by all interviewees regardless of linguistic background.

The translation of "fidgeting" (Q3) required several alterations. Interviewees proposed a multitude of suggestions, some of which were well understood by native Swedish speakers, but not so clear to those with other first languages. The understanding of the word increased only after the addition of a few explanatory examples, that is "move restlessly (e.g. to fiddle or shake one's leg)."

Interviewees with more extensive education had a better understanding of medical terminology and fewer linguistic difficulties regardless of their first language. Although the term "contractures" (Q6) was well recognized by nurses and physicians, it was not understood by nursing assistants, so an additional explanation, "cannot bend or straighten a joint (contractures)" seemed necessary. The Swedish validated word for "skin tears" (Q6) was also better understood by staff with longer education.

Interviewees interpreted "withdrawn" (Q3) in both physical and mental terms. As in English, the word has a dual meaning in Swedish. Both interpretations were found acceptable since both types of change had been registered by the interviewees. This was also confirmed in discussions with experienced specialists in geriatrics.

The term "refusal to eat" (Q4) was perceived to have a negative connotation. The interviewees associated it with the behaviour of toddlers rather than adults. The new translation "does not want to eat" was received as neutral. After these changes, none of the items was considered inappropriate.

Usefulness

The APS-SE was considered straightforward and easy to use. The items concerning vocalization, facial expression, change in body language and behavioural change were considered the easiest to use. The item about physical changes reminded the interviewees to consider the person's previous diseases and injuries during the pain assessment.

Although interviewees considered the instrument useful, they stressed that its utility depended on prior knowledge of the person by the physician, accompanying staff or relatives. This was especially important for Q3 to Q6, as the assessment is supposed to be based on "a change in" the various items. This was especially troublesome for the interviewees working in the emergency department, who usually did not have any prior familiarity with the patient ahead of their assessment.

In Q5, the translations of the terms "flushing" and "pallor" were accepted and understood by nursing assistants as well as nurses and physicians. However, staff considered these items difficult to use in people with darker skin tones due to their lack of knowledge

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and experience on assessing darker skin. "Pallor" was perceived as particularly difficult to assess, while "flushing" was sometimes associated with elevated skin temperature and consequently easier to detect. Only one interviewee trained in Africa, with experience judging normal skin tones in different African countries, described having more confidence in distinguishing pallor in people with dark skin tones.

Implementation

Several interviewees discussed the value of thoroughly introducing the tool to all new staff members. The nurses interviewed were often in charge of a large number of patients in residential care facilities and depended on the nurse assistants to assess and report patients' pain. Therefore, the implementation of a well-functioning pain assessment tool is of the utmost importance. The introduction of the APS was considered especially important for new staff with gaps in their healthcare education and/or a non-Swedish first language. Some interviewees expressed concern that not all staff were fluent enough in Swedish to understand the pain assessment tool. One nurse introduced the scale to new staff members by reading every question out loud while also demonstrating various noises and facial expressions associated with some of the included signs of pain. To ensure that a new staff member could fully utilize the instrument, it was necessary to make sure that the staff understood *all* the words.

4 | DISCUSSION

In this study, we describe the process of developing a Swedish version of APS, the APS-SE, for use in Sweden in people with end-stage dementia by using a forward and backward translation technique and interviews with the targeted staff. During the analysis of the interviews, we identified three themes: comprehension, usefulness and implementation.

Previous studies have shown that although valid and reliable pain assessment tools are available for critically ill people who cannot communicate, they are not always used (Hamdan, 2019; Rose et al., 2012). The likelihood of using such tools is probably even lower if staff's comprehension of its items is poor. The Swedish National Board of Health and Welfare invested roughly 85 million euros from 2011 to 2014 to enhance education among nursing assistants, whose educational backgrounds vary (Swedish National Board of Health and Welfare, 2015). Today, almost 40% of nursing assistants in residential aged care facilities still lack an acceptable standard of education according to the Swedish National Board of Health and Welfare (2018). Considering the disparity in education among staff, it is even more important to avoid unnecessarily complicated medical terms to ensure the comprehension of assessment tools.

The APS-SE was considered generally easy to use in people with dementia except in some situations. Interviewees from all three staff categories expressed the importance of having prior knowledge of the people with dementia to assess some items. This dilemma has been addressed in previous studies using the original APS with nurses in emergency departments, who valued help from relatives and other carers in assessing the pain of people with cognitive impairment (Fry et al., 2015; Fry et al., 2017). The need for familiarity with the person under care also made the nurses consider the instrument more suitable for use in care homes, in-home care or palliative care than in the emergency department (Fry et al., 2017).

Some of the items, such as pallor or flush in people with dark skin tone, were especially difficult to judge without any prior familiarity with the person. Many skin-care guidelines apply mainly to people with fair skin. Natural or halogen lighting is recommended when assessing people with dark skin since other types of lighting can produce a misleading bluish tint (Sommers, 2011). Using the recommended types of lighting could increase the clinical usefulness of both the APS-SE and the original APS. Furthermore, assessing pallor and flush in people with different skin tones could be better incorporated into the education of nurses and physicians.

Pain monitoring is one of the most frequent nurse activities in the institutional care of end-of-life patients (Kisvetrová et al., 2017). Worldwide, nurses' heavy workloads are a major barrier to proper pain management (Mędrzycka-Dąbrowska et al., 2015). The common opinion that it takes longer in people with dementia than in other people to assess pain (Mędrzycka-Dąbrowka et al., 2017) could be a contributing obstacle to pain management in this population. Implementation of an earlier Swedish version of the APS in residential aged care facilities in 2012 was perceived by staff to take time, but to improve their ability to detect and assess pain. When interviewed a year after the implementation, staff stressed the need for further education and training and recommended required routines for pain assessment (Ludvigsson et al., 2020). To ensure better care for elderly people in Sweden, the Swedish National Board of Health and Welfare will invest roughly 100 million euros from 2022 to 2023 to increase the number of nurses working in residential care facilities (Swedish National Board of Health and Welfare, 2022). Nevertheless, when nurses are short-staffed, the task of pain assessment is often assigned to nursing assistants with little or no education in health care.

4.1 | Relevance to clinical practise

The APS can be useful in people with dementia. However, ample time is needed to ensure its successful implementation, especially if new staff members have problems with comprehension due to linguistic difficulties or gaps in their education. This study highlights the importance of carefully introducing new staff members to the instrument to ensure they understand all the words and items.

To enhance usefulness, we also recommend the APS be used only in care settings that allow continuity and long-term contact between the patient and staff. The scale can only be fully utilized in a care context where staff have prior knowledge of the patient. Clear and consistent routines regarding the frequency of assessment and

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its reporting, follow-up and documentation are also crucial when working with the APS.

The APS may be less applicable for assessing pain in people with darker skin tones, which is a limitation of the instrument itself.

4.2 | Strengths and limitations

A strength of this study is the repeated interviews to test comprehension of the newly translated APS-SE in a variety of care settings, not only residential care facilities. Identifying the significance of education and the interviewee's first language early in the interviews, we also actively recruited to obtain interviewees with diverse educational and linguistic backgrounds. This approach exposed some comprehension problems that may not have been evident in interviews only with those who had Swedish as their first language.

The interviews continued until no new essential information emerged during three consecutive interviews. We surmised that no additional important information would arise in any forthcoming interviews after a total of 11 interviews were conducted. This is consistent with a study from 2006 that showed saturation occurring within the first 12 interviews (Guest et al., 2006). Nevertheless, since there is a multitude of different first languages among healthcare staff in Sweden, problems with comprehension due to linguistic difficulties may still linger.

All participants were asked to visualize a patient whom they had cared for while completing the APS-SE. An alternative, as described in an article by van Dalen-Kok et al., would have been to ask the participants to complete the instrument while observing video recordings of persons with dementia (van Dalen-Kok et al., 2018). The latter would have regulated which patients the participants assessed, but we wanted to ensure that they could visualize a person they typically met in their own workplace while completing the tool.

During the first conceptual phase in Step 1, we discussed concepts with medical professionals working mainly within specialized palliative care. A limitation of the study may be that these professionals did not work exclusively with people with dementia. We chose these professionals, however, because they were well accustomed to daily use of another Swedish version of the APS.

During this conversation, the medical professionals did not identify the term "skin tears" as problematic. This problem became evident only when the term was introduced to the professional translator without medical knowledge during the forward translations. Therefore, we had not searched the literature for a specific translation of the term and initially missed identifying the validated Swedish term for "skin tears." We believe that the outcome of this discussion would have been no different had it included only professionals working in a purely geriatric setting.

5 | CONCLUSION

The scientific translation and cultural adaptation of the original Australian APS resulted in a Swedish version, the APS-SE, for use on patients with end-stage dementia. The APS-SE can be used for clinical pain assessment in various Swedish care contexts as well as for research purposes.

Further research is needed to psychometrically evaluate and validate the APS-SE.

AUTHOR CONTRIBUTIONS

ST, PF and LM planned the study. PF participated as a mediator during the forward and backward translation. ST and LM interviewed the first five interviewees together, and ST the last six. ST and LM read each transcript and through consensus revised each version of the APS-SE. ST wrote the first manuscript draft and LM and PF made critical revisions. All authors approved the final version.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

DATA AVAILABILITY STATEMENT

National legislation and ethics boards in Sweden do not permit the authors to share raw data.

CONSENT FOR PUBLICATION

Each interviewee gave oral and written consent to participate and for the data to be published. The developer of the APS, Dr Jennifer Abbey, provided her permission for us to translate and culturally adapt the APS to Swedish.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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