Challenges When Translating and Culturally Adapting a Measurement Instrument: The Suitability and Comprehensibility of Materials (SAM+CAM)

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Abstract

There is evidence that low suitability and comprehensibility of printed education materials (PEMs) affects patients' and relatives' ability to read and comprehend information. However, few instruments measure the suitability of written information, and none exist in the Swedish language. The aim was to describe the translation and adaptation of the Suitability and Comprehensibility of Materials (SAM+CAM) instrument into the Swedish language and health care context and to explore challenges related to this process. The SAM+CAM instrument was translated and culturally adapted in five steps: forward translation, synthesis, back translation, expert review, and pretests. Differences were found when translating and culturally adapting the SAM+CAM instrument in the areas of semantic, idiomatic, and experiences. Participants revealed several clarity inconsistencies between items. They also identified linguistic differences and unfamiliar wording; they found that the instrument was perplexing to use and lacked knowledge regarding the specific health care areas in the examined PEMs. The cultural perspective is a significant factor that influences the usability of PEMs. Therefore, expert groups of participants are useful when adapting instruments to different cultures. The Swedish SAM+CAM instrument requires experienced and highly qualified raters.

Introduction

In general, printed education materials (PEMs) reduce anxiety, improve self-efficacy, and increase satisfaction among patients and relatives (Arnold, Goodacre, Bath, & Price, 2009; Eames, Hoffmann, Worrall, Read, & Wong, 2013). However, PEMs may be challenging to read and comprehend because of flaws in their design characteristics (Eames, Hoffmann, Worrall, & Read, 2010; Sadowski, 2011). The suitability of PEMs indicates how well the text fits the reader and it can be enhanced by paying attention to accurate content, language, organization, layout, illustration, and learning strategies (Hoffmann & Worrall, 2004). Studies have revealed weaknesses of existing PEMs in several areas (Taylor-Clarke et al., 2012; Yin et al., 2013).

Instruments designed to measure the suitability of PEMs can reveal how demanding the material is to a reader and provide the developers of PEMs with information about areas that need to be improved (Eames et al., 2010). However, few existing instruments measure suitability in PEMs (Finnie, Felder, Linder, & Mullen, 2010). One is the Suitability of Material (SAM) instrument developed by Doak, Doak, and Root (1996). This instrument has the capacity to identify deficiencies that reduce suitability (Hoffmann & Ladner, 2012; Wolff et al., 2016). However, SAM has

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Table 1. Overview of Factors and Items of the Instrument (SAM+CAM).

Factors	Items and Their Number
Content	1. Purpose
	2. Summary/review
	3. Desired reader behavior
	4. Credibility
Literacy demand	5. Writing style
	6. Vocabulary helpers
	7. Confusion reducers
	8. Context
	9. Scope and length
Numeracy	10. Numeric presentation
	11. Calculation
Graphic material	12. Document clarity
	13. Illustrations
Layout and typography	14. Layout and organization
	15. Typography
	16. Subheading or advance organizers
Learning stimulation and motivation	17. Motivators to attend to text
	18. Inclusion
	19. Reader interaction
	20. Theoretical application
	22. Tone
	23. Persuasion techniques

Note. Response options: superior (2 points), adequate (1 point) and not suitable (0 point). SAM+CAM = Suitability and Comprehensibility of Materials.

been criticized for not reporting how to calculate the reading grade level and for the lack of items to measure understanding (Clayton, 2009; Weintraub, Maliski, Fink, Choe, & Litwin, 2004). When, Helitzer, Hollis, Cotner, and Oestreicher (2009) recognized important concepts were missing, they added items to assess reading, calculating, and solving problems and named the new instrument Suitability and Comprehensibility of Materials (SAM+CAM).

The SAM+CAM instrument consists of 22 items in six categories: Content (four items), Literacy demand (five items), Numeracy (two items), Graphic material (two items), Layout/typography (three items), and Learning stimulation and motivation (six items; see Table 1). The professional users rate their appraisal of suitability by selecting one of the following three response options: superior (2 points), adequate (1 point), and not suitable (0 point). Items not applicable are excluded from the maximum score. Total scores are transformed into percentages and 70% to 100 % is interpreted as superior, 40% to 69 % as adequate while 0% to 39% is deemed not suitable. The validity of SAM+CAM has been examined using 69 PEMs used in cervix cancer care. The interrater reliability, measured by Cohen's kappa (κ), has revealed a value of κ = .77 (Helitzer et al., 2009).

Guidelines for translating and culturally adapting questionnaire-based measurement instruments generally focus on describing the results (Maneesriwongul & Dixon, 2004;

Yu, Lee, & Woo, 2004). However, the process of translation and cultural adaptation of a questionnaire is often not explicit but it provides important insight into how future researchers may limit the risk that respondents are not able to follow instructions or fail to answer items (Drennan, 2003). In the process, there are challenges such as linguistic errors in terms of idiomatic, semantic, and experiential expressions (Chang, Chen, Gau, & Tzeng, 2014; Epstein, Santo, & Guillemin, 2015; Yu et al., 2004). These errors may change the original intent of the instrument and influence its validity and reliability (Beaton, Bombardier, Guillemin, & Ferraz, 2000).

As neither of the above instruments has been written in or translated into the Swedish language, translation and cultural adaptation are necessary (Beaton et al., 2000). A further challenge during the cultural adaption is managing different interpretations of the meaning of specific words or sentences (Epstein et al., 2015). A specific challenge from a Swedish perspective is that the American English language has more words than the Swedish language, 350,000 words (Oxford Dictionary, 2014) versus 126,000 Swedish words (Swedish Academy, 2015). Thus, finding a Swedish word that has the exact meaning as the corresponding American English word could be difficult. For example, in the American English version of the SF-36 instrument, which is a patient-reported survey of patient health, one of the items on physical function refers to *bowling or playing golf* as examples of regular physical activities. However, the corresponding examples in the Swedish version of the SF-36 refer to *walking in the forest or gardening* (Wagner et al., 1998). This indicates a need to identify similar concepts rather than exactly replicate the words in the source instrument. Despite these challenges, the benefits of using a translated and culturally adapted instrument are that it is less time consuming than developing a new instrument; it helps professionals, organizations, and researchers identify shortages and create a plan to correct those shortages; and it facilitates cross-cultural comparisons involving different languages (Epstein et al., 2015).

Patients and relatives ask for PEMs, and there is a need for an instrument to assess the suitability of PEMs in Swedish. To our knowledge, SAM+CAM has not been translated and culturally adapted into any other language, and therefore, there is limited knowledge about the challenges ahead in the process. The aim of this study was to describe the translation and adaption of the SAM+CAM instrument into the Swedish language and health care context and explore challenges related to this process.

Method

This article translated and culturally adapted the SAM+CAM instrument by using forward translation (FT), synthesis, back translation (BT), expert committee review,
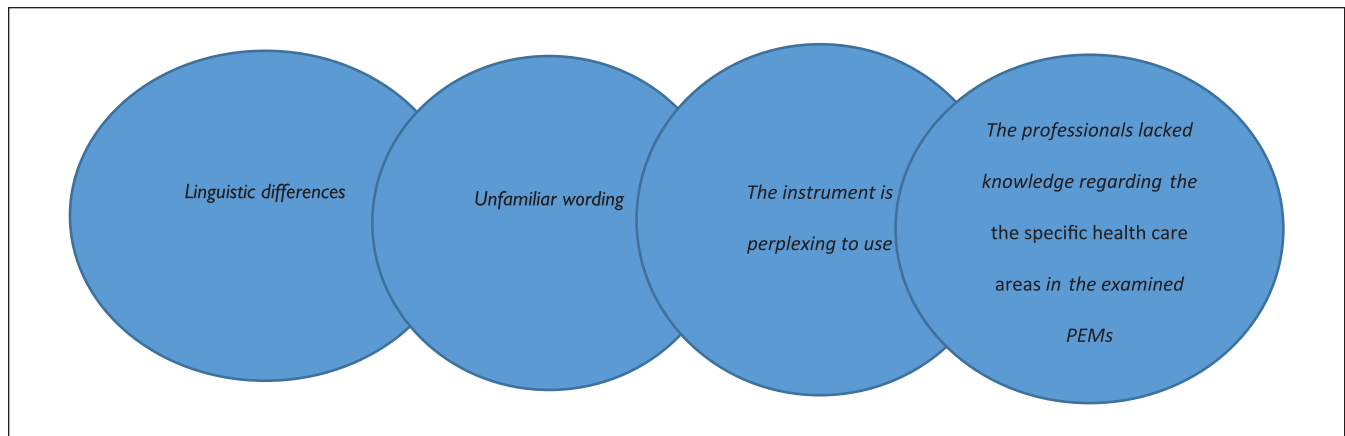
Figure 1. Identified challenges during the process of translation and adaption of SAM+CAM instrument.
Note. SAM+CAM = Suitability and Comprehensibility of Materials; PEM = printed education materials.

and pretesting (Beaton et al., 2000; Guillemin, Bombardier, & Beaton, 1993).

Setting and Sample

Participants were recruited by snowball sampling, with the goal of obtaining a sample of participants with different professional backgrounds from one region in Sweden. Participants in the expert committee were selected for their knowledge and skills in the area (Polit & Beck, 2012). Participants in the expert groups were recruited from different settings, such as university, hospitals, primary care, outpatient care, and municipality services through the researchers' networks. Inclusion criteria were at least 2 years of clinical experience and fluency in Swedish (Beaton et al., 2000; Guillemin et al., 1993). Of the 21 participants who were invited to join the Expert Group A, eight withdrew their participation (lack of time/interest or considered the instrument complicated to use), and 13 formed the Expert Group A (Table 1). Six new participants were invited and formed Expert Group B (Table 1).

FT/Adaption and Synthesis

This study used bilingual translators with varying profiles (professional translators, PhD in nursing) and consensus to conduct a synthesis of the FTs and adaption (Beaton et al., 2000; Guillemin et al., 1993). Accordingly, an FT/adaption was performed by two translators, one professional translator, and one researcher (first author, C.W.), with Swedish as mother tongue and English as a second language (Table 2). Each translator independently translated and adapted the SAM+CAM instrument and its scoring sheet into Swedish (FT 1 and FT 2, Figure 1), and then the two versions were synthesized. The clarity and wholeness of the two translations/adaptions were independently assessed by the expert committee, which consisted of two of the researchers and two clinical nurse specialists with expertise in evaluating

PEMs (Table 2). They were instructed to individually read and mark uncommon or uncomfortable words from a Swedish perspective: (a) semantic (vocabulary, syntax, and synonyms), (b) idiomatic (unfamiliar expression or slang), and (c) experience (daily life perspective). Thereafter, comparison and discussion regarding differences in the translations/adaptions (FT 1 and FT 2) were conducted by the expert committee. After discussion, changes were made in nine items (3–6, 15, 19, 20–22). This process (comparison and discussion regarding differences in the translation/adaptions) was repeated three times until consensus was reached.

BT/Adaptions and Expert Committee Review

The Swedish SAM+CAM instrument was sent to two bilingual, independent, and professional translators (Beaton et al., 2000; Guillemin et al., 1993) (Table 1) whose mother tongue is English and who have Swedish as a second language. The translators individually back-translated the Swedish SAM+CAM instrument. Then, the back-translated instruments were reviewed by the expert committee, which examined the compatibility between the BTs/adaptions (BTI and BT2 instruments) with the SAM+CAM instrument relating to the same issues as in the FT/adaption: (a) semantic, (b) idiomatic, and (c) experience. The comparison between the SAM+CAM instrument and the BT/adaptations also revealed some differences (Table 3). Identified differences were discussed, and consensus was made after two iterations.

Pretests of Swedish SAM+CAM Instrument

The pretest for group A consisted of three tasks: to rate two PEMs with the Swedish SAM+CAM instrument, to rate the clarity of each items in the instrument, and to answer questions regarding personal reflections when using the instrument. Data were collected via mailed questionnaires asking participants in Expert Group A to provide demographic

Table 2. Demographic Variables and Experiences of the Included Participants ($N = 27$).

	Translators (From English to Swedish)	Translators (From Swedish to English)	Expert Committee	Expert Group A	Expert Group B
Professions, *n*					
Translator	1	2	0	0	0
Researcher	1	0	2	0	0
Nurse	0	0	2	12	6
Physiotherapist	0	0	0	1	0
Gender, *n*					
Male	0	1	0	2	3
Female	2	1	4	11	3
Age, mean	Not relevant	Not relevant	44	43	33
Years in profession, mean	Not relevant	Not relevant	21	16	8
Education	Not relevant	Not relevant			
Bachelor			0	4	4
Master			2	5	2
PhD			2	4	0
Place of work, *n*	Not relevant	Not relevant			
Hospital care			2	6	5
Primary care			0	3	0
Municipality care			0	1	0
University			2	3	0
Outpatient care			0	0	1
Transfer PEM to patients, *n*	Not relevant	Not relevant			
Yes, often			2	5	2
Yes, sometimes			0	5	3
Yes, but rarely			0	2	1
No			2	1	0
Experience in assessing PEM, *n*	Not relevant	Not relevant			
Yes			4	3	1
No			0	10	5
Number of assessed PEMs			125	80	15
Experience in developing PEM?	Not relevant	Not relevant			
Yes			4	6	3
No			0	7	3
Number of developed PEMs			15	51	13

Note. PEM = printed education materials.

information and to rate all the items in the Swedish SAM+CAM instrument in relation to two PEMs. The participants rated PEMs with the Swedish SAM+CAM instrument, as we wanted to make the rating more realistic. The first PEM was "Support for information and discussion." Investigation in connection of disease of the colon and rectum (Smith, Wallengren, & Öhlén, 2017) and the second PEM was "Your road to recovery after colon surgery" (Smith et al., 2014). To assess the content validity, the participants were asked to rate the clarity of each item on a four-point scale, classified from 1 = *item is unclear*, 2 = *item needs major revisions to be clear*, 3 = *item needs minor revisions to be clear*, and 4 = *item is clear* (Chang et al., 2014). Finally, the participants were asked to individually answer the following three questions regarding their reflections on using the instrument (Willis, 2006): (a) According to you, are there words/sentences/phrases that you experience hard to understand? If yes,

indicate which words/sentences and in what way these are hard to understand (b) According to you, are there items that are unnecessary? and (c) Additional comments?

Participants in Expert Group B were invited to a focus group interview (Willis, 2006). About 4 weeks before the focus group interview, participants received the same materials as Expert Group A. An introduction and review of the pre-mailed information sheet opened the focus group interview, and an "ice-breaker" exercise was used to promote a friendly atmosphere in the group. Then, the participants individually reviewed a PEM for 15 min. During the rating process (audio recorded), the participants were encouraged to discuss their reflections about using the Swedish SAM+CAM instrument by verbal probing questions (Willis, 2006) such as "Tell me what you're thinking about item X and its meaning" or "Tell me more about what you think of any terms you do not understand." Thereafter, two key questions were asked: "What

Table 3. Examples of Identified Differences Between the SAM+CAM Instrument and Swedish SAM+CAM Instrument.

Identified Differences		Number of Items	SAM+CAM Instrument	First Translator	Second Translator	Actions
Forward Translation	Semantic					
	Vocabulary	8	Context	Kontext	Sammanhang	Substituted with situation
		4	Credibility	Tillförlitlighet	Trovärdighet	Substituted with believable
	Syntax	3	Desired reader actions/ behavior(s) clearly described	Önskvärda handlingar/ beteenden är tydligt beskrivna	Önskade handlingar/önskat beteende från läsaren beskrivs tydligt	Substituted with desired actions/behaviors from the reader is clearly described
	Synonyms	1–22	Adequate	Lämpligt	Adekvat	Substituted with sufficiently
	Idiomatic					
	Meaning of word (slang)	12	Material with a document (chart, table) must be assessed with PMOSE/ IKIRSCH*	Material som har (diagram, tabell) måste bedömas med PMOSE / IKIRSCH.	Material med ett dokument (diagram, tabell), måste bedömas med PMOSE/ IKIRSCH	Substituted with materials that contains graphs/tables must be assessed with quantitative methodology
		19	Quiz	Frågesport	Quiz	Substituted with question
		16	"chunk"	"stycken"	"textsjok"	Substituted with "Paragraphs of texts"
		18	Second opinion	Second opinion	Andra utlåtande	Was not substituted
		20	Cues to action	Ledtrådar till handling	"cues to action"	Was deleted from the instrument
	Experiential					
	Experiences of daily life	11	You must pay 20% of the charges"	Du måste betala 20% av avgifterna	Du måste betala 20% av kostnaderna	Substituted with you must pay the patient charge.
Back Translation	Identified differences	Number of items	SAM+CAM instrument	First translator	Second translator	Actions
	Semantic					
	Syntax	1	No purpose clearly stated, either explicitly or implicitly.	No clear purpose is stated, either explicitly or implicitly.	No clear purpose stated, either explicitly or implicitly.	No changes of the target instrument.
		3	One (1) of the above factors present and/ or behavior addressed but not as clearly as specific as above.	One (1) of the above factors is present and/ or activities behavior are addressed but not as clearly or specifically as above.	One (1) of the above factors is present and/ or activities/behavior is raised, but not as clearly or specifically as above.	The word activity was deleted from the target instrument.
	Deleting words	1	Helps the reader to easily understand the intended purpose of the material.	Makes it easy for the reader to understand the purpose of the material.	Facilitates the reader's understanding of the purpose of the text.	The word intended was included in the target instrument.
	Abbreviation	11	When the text includes #s, %s, or probabilities and/or discussion of risks, either or both of the following is present:	When the text contains figures, percentages, probabilities, and/ or addresses risks, one or both of the following are present:	When the text contains figures, percentages, or probabilities. One or both of the following are the case:	No changes of the target instrument.
	Meaning of words (slang)	16	Information is grouped under descriptive subheadings or "chunks."	Information is grouped under descriptive subheadings or blocks of text.	Information is grouped under descriptive subheadings or paragraphs.	No changes of the target instrument.
	Experiential					
	Experiences of daily life	11	You must pay 20% of the charges.	You must pay the patient charge.	You should pay a patient fee.	No changes of the target instrument.

Note. SAM+CAM = Suitability and Comprehensibility of Materials.
*A readability formula to consider and rate structure, density, and dependency of printed materials in list format or in graphic display.

challenges did you experience when using the instrument to assess the PEM?" and "Is there anything that has not been said about the instrument's usability?." The participants in Expert Group B also individually assessed the two above described PEMs (Smith et al., 2014; Smith et al., 2017) and answered the written questions (Wagner et al., 1998) relating to the clarity of the instrument and their reflections on using it.

Ethical Research Considerations

Ethical approval and permission for the study were obtained from one regional ethical review board (diary number 545–10 [T364–14]). Respect for the participants was a main concern during the study. All participants were informed that participation was voluntary; they had the right to withdraw at

any time, and their answers would be kept confidential. All consented to participate in the study ethical guidelines for human and social research were followed throughout the study (Codex, 2017).

Data Analysis

FT/adaption, synthesis, BT/adaptions, and expert committee review. The FT and synthesis were analyzed for semantic, idiomatic, and experience equivalence between SAM+CAM and the Swedish SAM+CAM instrument. Thereafter, the expert committee compared and discussed similarities and differences in the translations/adaptions. The BTs were subsequently reviewed by the expert committee and analyzed for equivalence between the Swedish and the English versions (Beaton et al., 2000; Guillemin et al., 1993).

Pretests (Expert Groups A and B) of the Swedish SAM+CAM instrument. Means, frequencies, and percentages were used to describe the samples (Expert Groups A and B) and their responses on the clarity of the SAM+CAM items (Polit & Beck, 2012). Responses to the questions in the focus group interview and written answers were analyzed using content analysis (Elo & Kyngäs, 2008). Elo and Kyngäs (2008) method includes three phases: preparation, organization, and reporting. First, the focus group interview and written answers were read repeatedly to obtain a sense of the whole. Then, when reading the unit of analysis again, words and sentences referring to the research question (what are the challenges when using the target instrument) was identified and marked by using open coding. Totally 19 codes were identified and then sorted into a code map. The developed code map from Expert Group A, guided the coding process in the analysis of the Expert Group B material (focus group interview and written answers). Thereafter, the research question was again posed to the whole unit of the analysis and similar codes were further abstracted, grouped together, and sorted into four categories (see Figure 1).

Trustworthiness

Elo and Kyngäs (2008) emphasize the necessity of continually taking action that strengthens the validity and reliability of the research. To increase the validity in previous study, first and second authors (C.W. and K.R.) were involved in all three phases and any points of disagreements were discussed until consensus was reached. C.W. and K.R. examined categories. Participants, data collection and analyzing processes were described as detailed as possible to increase the reliability.

Results

Throughout the FT and BT/adaption process revealed several differences between the English and the Swedish

versions of the SAM+CAM instrument that needed to be resolved (Table 3). In addition, the participants' (Expert Groups A and B) responses when using the items from the Swedish SAM+CAM revealed several unclear items (Table 4). Expert Group A highlighted 13 items (2, 5, 7–11, 15, 18–22) that were unclear and 18 items (1–4, 6–9, 12, 14–22) that needed major revision for clarity. Expert Group B noted five unclear items (6, 11, 17, 20, 22) and 13 items (2, 6–8, 10, 11, 14, 15, 18–22) that needed major revision for clarity.

The results revealed the following four challenges: linguistic differences, unfamiliar wording, the instrument is perplexing to use, and the professionals' lack of knowledge regarding the specific health care areas in the examined PEMs.

Linguistic Differences

The results revealed differences in the semantic, idiomatic, and experience aspects, but particularly in the idiomatic area (Table 3). For example, in item 7, the metaphor *Cervical cancer as a bad kernel in an ear of corn* is an unfamiliar expression for cancer in Swedish; therefore, as one member in the expert committee reported "We need a Swedish metaphor for cancer" (Participant 1 in the expert committee).

To reach idiomatic equivalence between the SAM+CAM and Swedish SAM+CAM items, the expert committee discussed, negotiated, and reached consensus on using the following metaphor:

> Show that genes increase cell division. This can be compared to an accelerator pedal. If the pedal becomes stuck in the depressed position, the car will run away. Other genes suppress cell division and can be compared to a brake. If the brake does not work, the car continues to move forward and is out of control. If the mechanic is ill, the damage cannot be repaired and more faults arise.

To clarify items in Swedish, the expert committee needed to adjust 15 of the 22 items (68%). For example, several examples were added in the Items 3, 4, 5 to 8, 11, 15, 17 to 19; "We need to change the examples that don't fit the Swedish context" (Participant 3 in expert committee).

When the expert committee checked the equivalence between SAM+CAM and the back-translated instrument, most differences were found in the semantic area. The expert committee reached consensus and agreed on adding, changing, or deleting words or sentences in the Swedish SAM+CAM instrument. For example, in Item 21, the sentence *Adequate: 1 of the superior factors is present* had been added with the sentence *Few to no solutions are present; the tone is neutral.* To reach equivalence with the item in the SAM+CAM instrument, the last sentence was deleted from the Swedish SAM+CAM instrument. In Item 20, the word *Severity* had been deleted in the Swedish SAM+CAM instrument. The expert committee needed to adjust 7 of the 22 items (32%), Table 3.

Table 4. Number of Participants' Answers Regarding the Clarity of the Items.

	Expert Group A					Expert Group B				
Questions	Items is Not Clear, n (%)	Items Need Major Revision to be Clear, n (%)	Items Need Minor Revision to be Clear, n (%)	Item is Clear, n (%)	Total, n	Items is Not Clear, n (%)	Items Need Major Revision to be Clear, n (%)	Items Need Minor Revision to be clear, n (%)	Item is Clear, n (%)	Total, n
1	0	1 (8)	1 (8)	11 (84)	13	0	0	0	6 (100)	6
2	0	1 (8)	2 (15)	10 (77)	13	0	1 (17)	1 (17)	4 (66)	6
3	2 (15)	4 (31)	1 (8)	6 (46)	13	0	0	4 (66)	2 (34)	6
4	0	2 (18)	2 (18)	7 (64)	11	0	0	3 (50)	3 (50)	6
5	2 (15)	0	4 (31)	7 (54)	13	0	0	2 (34)	4 (66)	6
6	0	1 (8)	4 (33)	7 (59)	12	1 (17)	1 (17)	0	4 (66)	6
7	1 (8)	2 (15)	6 (46)	4 (31)	13	0	3 (50)	1 (16)	2 (34)	6
8	1 (8)	2 (17)	2 (17)	7 (58)	12	0	1 (16)	2 (34)	3 (50)	6
9	1 (8)	1 (8)	1 (8)	9 (76)	12	0	0	3 (50)	3 (50)	6
10	2 (18)	0	2 (18)	7 (64)	11	0	1 (16)	2 (34)	3 (50)	6
11	1 (10)	0	2 (20)	7 (70)	10	2 (34)	1 (16)	2 (34)	1 (34)	6
12	0	2 (15)	2 (15)	9 (70)	13	0	0	1 (17)	5 (83)	6
13	0	0	6 (46)	7 (54)	13	0	0	1 (17)	5 (83)	6
14	0	1 (8)	3 (23)	9 (69)	13	0	1 (17)	0	5 (83)	6
15	1 (8)	2 (15)	2 (15)	8 (62)	13	0	1 (16)	3 (50)	2 (34)	6
16	0	2 (15)	2 (15)	9 (70)	13	0	0	1 (17)	5 (83)	6
17	0	2 (15)	5 (39)	6 (46)	13	1 (17)	0	0	5 (83)	6
18	3 (23)	2 (15)	1 (8)	7 (54)	13	0	2 (34)	1 (16)	3 (50)	6
19	1 (8)	2 (15)	2 (15)	8 (62)	13	0	1 (17)	0	5 (83)	6
20	3 (25)	3 (25)	2 (17)	4 (33)	12	2 (34)	1 (16)	1 (36)	2 (34)	6
21	1 (8)	1 (8)	2 (15)	9 (69)	13	0	1 (16)	2 (34)	3 (50)	6
22	2 (15)	4 (31)	3 (23)	4 (31)	13	1 (16)	2 (34)	2 (34)	1 (16)	6

Unfamiliar Wording

Expert Group A emphasized the need to increase the clarity of Items 2, 6, 19, and 20 and recommended several synonyms and examples that could be included in the Swedish SAM+CAM instrument. For example, in Item 2, to increase the unclearness in the superior criteria, it was complemented by the words "patients' own summaries." Items 3 and 20 were unnecessary from a Swedish perspective and were deleted; "Item 20 is difficult to understand. Is it (theory) relevant or not? I don't know . . . It is difficult to understand what a theory is. Is it a philosophy? Is it the theory behind Enhanced Recovery After Surgery (ERAS)?" (Participant 1 in Expert Group A).

There was a discussion about what types of theories (Item 20) could be found in written materials. The participants agreed that a theory in written material could be, for example, the Sense of Coherence by Antonovsky (1979). All participants (Expert Group B) agreed that this question is demanding; "We as raters must have a broad theoretical base so we feel comfortable to assess written materials" (Participant 14 in Expert Group B).

The participants (Expert Group A) revealed a need to read every item repeatedly to understand its wording. Translations of words and phrases such as desired reading behavior (Item 3), *sentences are written in active direct style* (Item 5), *serif, font* (Item 15), *tone* (Item 21), and *testimonial* (Item 22) were described as strange. Participants wrote that some of the words/sentences/phrases needed to be clarified, as they were unsure of their meanings. Specifically, the word theory in Item 20 was described as hard to understand.

Another ambiguous term was *Persuasion Techniques* in Item 22. Several participants pondered the intended meaning of persuasion techniques: is it about behavior? Method? Attitude? Changes?; "From a Swedish perspective, the role of the professional is not to persuade the patient" (Participant 3 in Expert Group A).

Expert Group B noticed that the Swedish SAM+CAM instrument contained many words/sentences/phrases that needed to be more clearly understood before they could use it. For example, what are *credible sources* (Item 4)? The participants agreed that credible sources are not Wikipedia, blogs, or text produced by individuals who write without support from institutions or research.

Other words/phrases that were viewed as unfamiliar include *prophylaxis materials* (Item 3), *accepted dating of written materials, active direct style* (Item 4), *cueing devices* (Item 13), *cartoons* (Item 17), *and clear symbols* (Item 22).

Participants (Expert Group B) identified the following words/sentences/phrases that were still unclear: *active, direct style* (Item 5), *most of the time* (Item 8), and *inclusion* (Item 18). Some of the participants also recommended deleting Items 11, 20, and 22 with the same motivation that Expert Group A expressed. Their argument was that Swedish patients do not need to calculate the cost of fees or their risk factors, as most Swedish health care is publicly funded.

The Instrument is Perplexing to Use

The participants (Expert Group A) communicated that future users of the Swedish instrument SAM+CAM must have in-depth knowledge regarding the items in the instrument. Others (Expert Group B) described that the columns in the instrument was illogical and suggested therefore a new order. The participants also reported that rating with the Swedish SAM+CAM instrument took much longer than described in the instructions; "The instrument is too comprehensive. No nurse will have time to use this to assess the quality of written information. The assessment took considerably longer than 1.5 hours per material" (Participant 18 in Expert Group B).

Furthermore, the participants in Expert Group B recommended more practice with the Swedish SAM+CAM instrument for future users. They observed the need to be familiar with the instrument, as it is complex and challenging. Some said that the layout of the instrument was difficult to navigate; "It would be interesting to see if the instrument would be easier to follow if its layout was trimmed" (Participant 16 in Expert Group B).

The Professionals Lacked Knowledge Regarding the Specific Health Care Areas in the Examined PEMs

The participants in Expert Group A emphasized that it was impossible to know whether the topics in the PEM were correct and whether reliable sources were used (Item 4, *credibility*). They questioned whether they were responsible for assessing the credibility of the content; "How do I know that the content is correct? Further, is the idea that the person who reviews the written material should check if the facts are correct?" (Participant 11 in Expert Group A).

Moreover, a participant in Expert Group B stated that the users of the instrument need to be familiar with content and evidence to assess the credibility of the written text; "You have to be an expert to know if the content is correct" (Participant 17 in Expert Group B).

Discussion

This study describes the translation and adaption of the SAM+CAM instrument into the Swedish language and health care context and explores challenges related to the process. During this process, differences were identified in the semantic, idiomatic, and experience areas. Moreover, there were inconsistencies among raters regarding the clarity of the items. Identified challenges were linguistic differences, unfamiliar wording, instrument is perplexing to use, and the professionals' lack of knowledge regarding the specific health care areas in the examined PEMs.

The expert committee examined, compared, and synthesized four versions of the translations/adaptions by performing FT and BT. They identified linguistic differences in semantic, idiomatic, and experience areas that are similar to findings from studies on translations from English into Portuguese (Carvalho, Garcia, Silva, & Ribeiro, 2016), into Chinese (Chang et al., 2014; Yu et al., 2004), into French (Epstein et al., 2015), and into Swedish (Nordin, Elf, McKee, & Wijk, 2015). For example, the expert committee analysis of the BT revealed that words/sentences/phrases used in the SAM+CAM instrument had been added or deleted in the Swedish SAM+CAM instrument. These types of errors are called Types 1 and 2 (Capitulo, Cornelio, & Lenz, 2001) and are common errors found when translating instruments (Chang et al., 2014). One way of avoiding these errors is performing a cultural adaptation (Ljungberg, Fossum, Fürst, & Hagelin, 2015; O'sullivan, Öhlén, Alvariza, & Håkanson, 2017).

Furthermore, face validity of the Swedish SAM+CAM instrument was checked by using a probing technique during pretests and focus group interview. The probing technique has the ability to identify participants' interpretations and understanding of a specific phenomenon such as instruments (Willis, 2006). Referring to Conrad and Blair's (1996) taxonomy of possible problems in translating instruments, this study identified Lexical problems (unfamiliar wording), Logic problems (perplexing to use), and Computational problems (the professionals' lack of knowledge). Identification of these problems may help future translators and/or users of the SAM+CAM instrument to know how to refine the translation and adaption process, recruit, pretest and support professionals' familiarity with the instrument. Furthermore, future translators of the SAM+CAM instrument should be prepared to manage lexical and computational problems. This is in line with the conclusions that details about the process of translation and cultural adaption need to be provided in research reports, as this may help future translators to avoid or manage already known challenges (Maneesriwongul & Dixon, 2004). This further supports the need to run pretests when translating and adapting an instrument. The pretests and the use of a probing technique reveal important weaknesses and challenges in the Swedish SAM+CAM instrument, even though multiple translators and an expert committee had translated and culturally adapted the instrument.

When researchers developed and tested the SAM+CAM instrument (Helitzer et al., 2009), they used experienced raters, and none of them indicated that the instrument was perplexing to use, while the participants included in this study described the opposite. One explanation for why the

participants in this study found the instrument perplexing to use may be that 15 of the 19 participants (Expert Groups A and B) lacked experience in assessing written information. This indicates that the Swedish SAM+CAM instrument should be used by experienced raters.

Finally, the process of translating and adapting is classified in a hierarchy, from requiring minimum effort (Category 1—only FT) to substantial effort (Category 6—BT, monolingual, and bilingual tests) (Maneesriwongul & Dixon, 2004). Considering this study's methods of translation and cultural adaption, it is classified in Category 4. The interpretation is that this study has required a moderate effort in the process of translation and adaption.

Limitations

This study has limitations. It is recommended to use 30 to 40 participants in the pretest (Guillemin et al., 1993), and this study included 19, which may limit the amount of reflection. However, a focus group interview was added to compensate for the number of participants. There is also a risk that participants read the instrument more methodically because the researchers were present during the focus group interview (Drennan, 2003). The Swedish SAM+CAM instrument was not tested for validity and reliability, as the focus was on the process of translation and adaptation. Therefore, a validation and reliability analysis of the Swedish SAM+CAM instrument needs to be undertaken in future research.

Conclusion

When translating and adapting existing instruments, the cultural perspective is a significant factor that influences the usability of an instrument for assessing PEMs, such as SAM+CAM. Assessment of the suitability of PEMs using the Swedish SAM+CAM requires experienced and highly qualified raters.

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References

Antonovsky, A. (1979). *Health, stress, and coping*. San Francisco, CA: Jossey-Bass.

Arnold, J., Goodacre, S., Bath, P., & Price, J. (2009). Information sheets for patients with acute chest pain: Randomised controlled trial. *British Medical Journal*, *338*, Article b541.

Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, *25*, 3186–3191.

Capitulo, K. L., Cornelio, M. A., & Lenz, E. R. (2001). Translating the short version of the Perinatal Grief Scale: Process and challenges. *Applied Nursing Research*, *14*, 165–170.

Carvalho, A. B., Garcia, J. B. S., Silva, T. K. M., & Ribeiro, J. V. F. (2016). Translation and transcultural adaptation of Pain Quality Assessment Scale (PQAS) to Brazilian version. *Brazilian Journal of Anesthesiology*, *66*, 94–104.

Chang, M. C., Chen, Y. C., Gau, B. S., & Tzeng, Y. F. (2014). Translation and validation of an instrument for measuring the suitability of health educational materials in taiwan: Suitability assessment of materials. *Journal of Nursing Research*, *22*, 61–68.

Clayton, L. H. (2009). TEMPtEd: Development and psychometric properties of a tool to evaluate material used in patient education. *Journal of Advanced Nursing*, *65*, 2229–2238.

Codex. (2017). *The humanities and social sciences*. Rules & guidelines for research. Retrieved from http://www.codex.vr.se/en/forskninghumsam.shtml

Conrad, F., & Blair, J. (1996, August). From impressions to data: Increasing the objectivity of cognitive interviews. In *Proceedings of the section on survey research methods, annual meetings of the American Statistical Association* (pp. 1–10). Washington, DC: American Statistical Association.

Doak, C. C., Doak, L. G., & Root, J. H. (1996). *Teaching patients with low literacy skills*. Philadelphia, PA: Lippincott. Retrieved from http://www.hsph.harvard.edu/healthliteracy/resources/

Drennan, J. (2003). Cognitive interviewing: Verbal data in the design and pretesting of questionnaires. *Journal of Advanced Nursing*, *42*, 57–63.

Eames, S., Hoffmann, T., Worrall, L., & Read, S. (2010). Stroke patients' and carers' perception of barriers to accessing stroke information. *Topics in Stroke Rehabilitation*, *17*, 69–78.

Eames, S., Hoffmann, T., Worrall, L., Read, S., & Wong, A. (2013). Randomised controlled trial of an education and support package for stroke patients and their carers. *BMJ Open*, *3*(5), e002538.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*, 107–115.

Epstein, J., Santo, R. M., & Guillemin, F. (2015). A review of guidelines for cross-cultural adaptation of questionnaires could not bring out a consensus. *Journal of Clinical Epidemiology*, *68*, 435–441.

Finnie, R. K., Felder, T. M., Linder, S. K., & Mullen, P. D. (2010). Beyond reading level: A systematic review of the suitability of cancer education print and web-based materials. *Journal of Cancer Education*, *25*, 497–505.

Guillemin, F., Bombardier, C., & Beaton, D. (1993). Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. *Journal of Clinical Epidemiology*, *46*, 1417–1432.

Helitzer, D., Hollis, C., Cotner, J., & Oestreicher, N. (2009). Health literacy demands of written health information materials: An assessment of cervical cancer prevention materials. *Cancer Control*, *16*, 70–78.

Hoffmann, T., & Ladner, Y. (2012). Assessing the suitability of written stroke materials: An evaluation of the interrater reliability of the Suitability Assessment of Materials (SAM) checklist. *Topics in Stroke Rehabilitation*, *19*, 417–422.

Hoffmann, T., & Worrall, L. (2004). Designing effective written health education materials: Considerations for health professionals. *Disability and Rehabilitation*, *26*, 1166–1173.

Ljungberg, A. K., Fossum, B., Fürst, C. J., & Hagelin, C. L. (2015). Translation and cultural adaptation of research instruments— Guidelines and challenges: An example in FAMCARE-2 for use in Sweden. *Informatics for Health and Social Care*, *40*, 67–78.

Maneesriwongul, W., & Dixon, J. K. (2004). Instrument translation process: A methods review. *Journal of Advanced Nursing*, *48*, 175–186.

Nordin, S., Elf, M., McKee, K., & Wijk, H. (2015). Assessing the physical environment of older people's residential care facilities: Development of the Swedish version of the Sheffield Care Environment Assessment Matrix (S-SCEAM). *BMC Geriatrics*, *15*(1), Article 3.

O'sullivan, A., Öhlén, J., Alvariza, A., & Håkanson, C. (2017). Adaptation and Validation of the VOICES (SF) Questionnaire—For evaluation of end-of-life care in Sweden. *Scandinavian Journal of Caring Sciences*, *32*, 1254–1260. doi:10.1111/scs.12542

Oxford Dictionaries. (2014). *Oxford dictionaries*. Oxford, UK: Oxford University Press. Available from https://www.oxforddictionaries.com/

Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice*. Philadelphia: Lippincott Williams & Wilkins.

Sadowski, C. A. (2011). Providing health information to older adults. *Reviews in Clinical Gerontology*, *21*, 55–66.

Smith, F., Carlsson, E., Kokkinakis, D., Forsberg, M., Kodeda, K., Sawatzky, R., . . . Öhlén, J. (2014). Readability, suitability and comprehensibility in patient education materials for Swedish patients with colorectal cancer undergoing elective surgery: A mixed method design. *Patient Education and Counseling*, *94*, 202–209.

Smith, F., Wallengren, C., & Öhlén, J. (2017). Participatory design in education materials in a health care context. *Action Research*, *15*, 310–336.

Swedish Academy Dictionary. (2015). *Swedish academy dictionary*. Lund: Author. Available from https://www.saob.se/

Taylor-Clarke, K., Henry-Okafor, Q., Murphy, C., Keyes, M., Rothman, R., Churchwell, A., . . . Sampson, U. K. (2012). Assessment of commonly available education materials in heart failure clinics. *Journal of Cardiovascular Nursing*, *27*, 485–494.

Wagner, A. K., Gandek, B., Aaronson, N. K., Acquadro, C., Alonso, J., Apolone, G., . . . Ware, J. E. (1998). Cross-cultural comparisons of the content of SF-36 translations across 10 countries: Results from the IQOLA project. *Journal of Clinical Epidemiology*, *51*, 925–932.

Weintraub, D., Maliski, S. L., Fink, A., Choe, S., & Litwin, M. S. (2004). Suitability of prostate cancer education materials: Applying a standardized assessment tool to currently available materials. *Patient Education and Counseling*, *55*, 275–280.

Willis, G. (2006). Cognitive interviewing as a tool for improving the informed consent process. *Journal of Empirical Research on Human Research Ethics*, *1*, 9–23.

Wolff, K., Chambers, L., Bumol, S., White, R. O., Gregory, B. P., Davis, D., & Rothman, R. L. (2016). The PRIDE (Partnership to Improve Diabetes Education) Toolkit: Development and evaluation of novel literacy and culturally sensitive diabetes education materials. *The Diabetes Educator*, *42*, 23–33.

Yin, H. S., Gupta, R. S., Tomopoulos, S., Wolf, M. S., Mendelsohn, A. L., Antler, L., . . . Dreyer, B. P. (2013). Readability, suitability, and characteristics of asthma action plans: Examination of factors that may impair understanding. *Pediatrics*, *131*(1), e116–e126.

Yu, D. S., Lee, D. T., & Woo, J. (2004). Issues and challenges of instrument translation. *Western Journal of Nursing Research*, *26*, 307–320.

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