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Culturally Congruent And Linguistically Correct Translations Of Proms As A Basis For Communication In Healthcare

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Abstract: Patient-reported outcome measures (PROMs) are questionnaires used in clinical settings to provide information of a patient's health status. In encounters with ethnic minority patients, translations of these are needed. However, producing linguistically correct and culturally congruent translations of PROMs is complicated. The aim of the study was to investigate the challenges of translating PROMs according to standard translatory rules. The methods were literature research, forward-and-back translations, discussions with those doing the translations, and in-depth interviews with other translators. Thematic analysis. The findings showed that forward-and-back translation was not found to result in meaningful translations for patients. One key issue was poor/incorrect translations; this often occurred due to translators being unfamiliar with biomedical terminology, the exact concepts do not exist as such in the target language, the professional terms are not used in every day/oral language, and/or the patient's level of education made understanding the PROMs difficult. Successful medical treatment depends on PROMs being understood and correctly filled in. Poor/incorrect translations may cause important background information to be missed, which can potentially result in insufficient treatment or even misdiagnosis.

Keywords: Intercultural Communication, Immigrants, Proms, Translation, Healthcare, Culturally Congruent Translations.

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1. Introduction

Patient-reported outcome measures (PROMs) are questionnaires used in clinical settings that involve patients' health, symptoms, quality of life, and daily functioning (ACSQHS, 2022). At outpatient clinics, patients tend to fill in these questionnaires while waiting to be seen by the therapist. The patients' written responses give the therapist an overview of the patient's health problems and current situation; it has the potential to assist in the diagnostic assessment or evaluation of the clinical efficacy of prescribed treatment. It is, therefore, essential that they are filled in correctly, which requires the ability to both read and understand the language the PROMS are written in. The latter is a particular challenge for some immigrants; additionally, cultural differences in manners of expressing health issues may make the PROMs unintelligible to patients as they may have different understandings of disease than biomedically trained health professionals.

In Norway, a country with about 5.4 million inhabitants (Statistic Norway, 2022b), 19% of the population is either an immigrant or has two immigrant parents. The immigrants hail from 245 nations and independent regions (Statistic Norway, 2022a). This means that communication between patients and healthcare professionals may be culturally and linguistically challenging. This has made it necessary to translate PROMs into languages other than English. In this regard, forward-and-back-translation is the so-called translatory "*gold standard*"; forward translation can be described as the "*translation of the original language, also called source, version of the instrument into another language, often called the target language*", while back translation is the "*translation of the new language version back into the original language*" (Wild et al., 2005, p. 97). Even when this method is diligently followed, the translations may not be linguistically correct and/or culturally congruent, resulting in patients being confused when attempting to complete PROMs defined as being translated into their native language. Erroneously filled-in or incomplete PROMs may complicate patient-therapist communication, leading to serious misunderstandings and even inadequate treatment.

1.1 Background

This study was conducted at an outpatient clinic for patients with chronic pain at a large hospital in the Oslo region. Oslo, the capital of Norway, has nearly 700,000 inhabitants, more than

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235,000 of whom are immigrants; of this number, 39.8% hail from Asia, 37.2% from Europe, and 18.1% from Africa (The Municipality of Oslo, 2021). Pain is defined as "*[a]n unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage*" (IASP, 2020). Pain lasting more than three to six months is defined as chronic (Wahl et al., 2009). Chronic pain and musculoskeletal pain are more common among immigrants (NIPH, 2018) and may seriously affect those patients' ability to function and their quality of life. Individuals experience pain differently, making it a personal phenomenon (IASP, 2020) that is further complicated by differences in how pain is expressed both linguistically and culturally (Betancourt, Green, & Carrillo, 2021).

A comprehensive pain assessment is important for diagnosis, the creation of an individualised treatment plan, therapeutic communication, and facilitating optimal treatment outcomes. Prior to their consultation with the interdisciplinary healthcare team, all patients, therefore, complete PROMs related to their pain and quality of life and provide some socio-demographic data. If basic data is found to be missing, insufficient, or, as is often suspected, incorrect, diagnostic work and treatments become difficult.

The PROMS selected here were translated into four languages: Urdu, Somali, Arabic, and Polish. These languages were chosen based on the proportion of immigrants from these countries in the hospital's patient population. Of the six PROMs featured in this paper, one was available in three of the four languages before the project commenced, while the rest were only available in English and Norwegian.

The research questions are as follows: What challenges are involved in the translation of PROMs? What problems need to be solved to ensure understandable translations for various patient groups?

2. Methods

This study used a multi-method design that incorporated translations of PROMs with in-depth interviews with translators/interpreters. The aims of the study were:

i. to investigate challenges concerning the translation of PROMs according to general translatory rules and
ii. to produce linguistically and culturally understandable versions of the pain clinic's PROMs in four different languages (Urdu, Somali, Arabic, and Polish), thereby improving the healthcare provided to intercultural patients.

The PROMs were:

- The Modified Oswestry Disability Index, which maps the patient's pain-related disability
- A body sketch on which patients mark the location of their pain
- Pain characteristics, which define the pain as either continuous, intermittent, or continuous with aggravated episodes
- EQ-5D-5L, which measures the health-related quality of life of a patient and was originally developed by the EuroQol Group in 1991(Brooks, 1996)
- Hopkins symptom checklist-25 (HSCL-25), which tracks anxiety and depression
- Bodily Distress Syndrome, which tracks functional disorders

The content and uses of these PROMs are not the focus for this paper; rather, the goal is to determine what is required to make translations of these PROMS meaningful for the patients who need to fill them in. As the filled-in PROMs serve as guides for provider-patient communication, the consequences of inadequate or inapt translations will also be focused.

The translation of the six PROMs included in this study followed four steps: 1) literature searches, 2) forward-and-back translation (Phongphanngam & Lach, 2019; Wild et al., 2005), 3) discussions with the translators, and 4) interviews with three translators that did not translate the PROMS.

***Step 1*:** The first step involved searching the literature for existing translations into the languages in question. We found the EQ-5D-5L tool in Arabic, Urdu, and Polish, but not in Somali. There were different Arabic versions for different countries (EuroQol Research Foundation, 2020); the Lebanese version was ultimately chosen because it was written in Modern Standard Arabic, which is universally understood by those who read Arabic. A native Arabic-speaking registered nurse/PhD student read this version, which resulted in one change to the user information on the front page. The Polish and Urdu translations were sent to professional translators who compared them to the Norwegian version used at the clinic; no changes were made. The rest of the PROMs were not available in any of the target languages.

***Step 2*:** The second step involved forward-and-back translation. Four translators representing Urdu (T1), Somali (T2), Arabic (T3), and Polish (T4) conducted the forward translation; they translated the PROMs from the original or source language into the target language.

***Step 3*:** The four translators were then asked about their experiences with the translations and challenges they experienced with the work. For instance, they were asked if there were words or concepts that were difficult to translate. The new language versions were then translated back into Norwegian (the source language) by bilingual translators who had not conducted the forward translations (Wild et al., 2005). Phongphanngam and Lach (2019) stated that, ideally, a researcher familiar with the document and its content should compare the back-translated version with the original for similar words and meaning. As such, a pain clinic physician reviewed the

Norwegian back-translations together with the first author. Differences between the original and the back-translated Norwegian versions were discussed with the person who had done the original forward translation to ensure that the meaning of the source version was maintained (Cha, Kim, & Erlen, 2007).

***Step 4*:** The fourth step involved the testing of the new translations on patients at the clinic. The patients' experiences filling in the PROMs translated for this study will be discussed in another paper and are therefore not included here.

3. In-Depth Interviews With "External" Translators

According to Juckett and Unger (2014), professional interpreters are trained to interpret the spoken word, whereas translators work with written words. Although the skill sets of the two professions are somewhat different, there is some overlap, as was the case with the translators/interpreters we interviewed.

To learn more about the challenges involved in the translation of PROMs in general, qualitative interviews were conducted with three professional translators/interpreters, I1–I3, regarding the most important aspects of achieving understandable and trustworthy translations. These three were not a part of the translations of the PROMs used in this study. The interviewees were encouraged to share their thoughts and recount challenging experiences. Follow-up questions and the "*mirroring*" of statements were used to develop, clarify, and verify statements. The interviews were transcribed verbatim.

4. Data Analysis

The interviews and discussions with the translators were transcribed by the first author. Bird (2005, p. 227) describes data transcription as "*a key phase of data analysis within the interpretive qualitative methodology*." The interviews and discussions with the translators were analysed together as one dataset; the analysis was thematic in nature. Thematic analysis is "*a method for identifying, analysing, and reporting patterns (themes) within data*" that occurs in six phases (Braun & Clarke, 2006, p. 79). Both authors took part in the analysis, which was directly rooted in the data from the interviews and discussions.

Phase 1: Data familiarisation: This phase involved reading and re-reading the data to develop a deep familiarity with its semantic, obvious meanings (Braun, Clarke, Hayfield, & Terry, 2019). Thoughts and impressions were documented along the way as part of the initial analytic process.

Phase 2*:* Generating initial codes: "*A code captures the essence of what it is about that bit of data that interests you*" (Braun & Clarke, 2013, p. 213). During this phase, we revisited the transcribed texts and worked to produce the initial codes from the data.

Phase 3: Searching for themes: According to Braun and Clarke (2006), a theme "*captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the dataset*" (p. 82). To find this, we identified similar features and relationships "*across a range of different codes*" so that the codes could "*be clustered together into a possible theme*" (Terry, Hayfield, Clarke, & Braun, 2017). In determining what should count as a theme, our main focus was how crucial the theme was to the research questions.

Phase 4: Reviewing themes: This phase involved checking the candidate themes against all of the coded data that was relevant to each theme (Braun & Clarke, 2006). During this phase, we reviewed the themes and discussed whether they accurately reflected the meanings evident in the dataset as a whole.

Phase 5: Defining and naming themes: This phase involved refining the focus and scope of our analysis to determine the exact '*story*' we wanted to tell both for each theme and overall (Braun & Clarke, 2006). The themes and the interviews were, therefore, re-read to identify quotes that were particularly illustrative of the paper's focus. We checked whether the names that we had given to the various themes mirrored the content in a meaningful way and kept returning to the transcripts to ensure that our interpretations were supported by the data.

Phase 6: Writing up thematic analysis/producing the report: In this phase, we finalised the process by writing a paper based on the research questions, the empirical data acquired, and the analysis. The paper itself was developed collaboratively.

5. Credibility, Rigour, And Trustworthiness

Credibility was achieved through both discussions with the translators and interviews with the "*external*" translators about their experiences. Rigour was obtained by following Braun et al.'s (2019) phases of thematic analysis, where the authors conducted phases 4 and 5 collaboratively. Credibility and rigour were also strengthened by being two analysts and by presenting quotations to show the reader that our analysis is based on the interviewees' own descriptions of their thoughts and experiences rather than on potential biases (Polit & Beck, 2021). This also established trustworthiness. Transferability was achieved by presenting thick descriptions to show that the study's findings can be applied to similar contexts, circumstances, and situations.

6. Ethical Considerations

The study was approved by the hospital's Privacy Ombudsman for Research (POR). The interviewees were informed both orally and in writing that their participation was confidential and voluntary and that they were free

to withdraw from the project at any time. Parts of the empirical data collection were done digitally, as the interviews were conducted during the Covid-19 lockdown in southern Norway; this was approved by both the hospital leadership and the POR. All participants also signed an informed consent form.

7. Limitations

As far as we can determine, there are few recent studies on the translations of PROMs. To add some general insight to our study, in addition to the somewhat limited literature, we interviewed three experienced translators. These interviewees have added depth to our discussion.

8. Results

The following themes emerged during the thematic analysis:

- Translators' inadequate knowledge of the target language, culture, and medical terminology.
- Need for expert checking in addition to forward-and-back translations
- Challenges in translating certain concepts
    - Taboos as barriers
- Influence of level of education on communication.

8.1. Inadequate Knowledge Of The Target Language, Culture, And Medical Terminology

The interviewees stated that translating PROMs is more challenging than, for instance, translating literary texts. According to interviewee I1, many immigrant patients neither understand the questions nor the answer options presented in the PROMs, even when they are translated into their native language. According to her, simple questions tended to be adequately translated, while longer and more complicated ones could either be totally unintelligible and/or extremely poorly translated and, therefore, unanswerable. She called them "*Google translate translations*," indicating that they showed an inadequate knowledge of both the target language and culture and medical terminology. This situation created a poor foundation for the development of a treatment plan: "*When one sees such strange questions due to poor translation, no [appropriate] treatment is possible*" (I1). Without correct translations, PROMs do not track symptoms as intended; in other words, "*a small linguistic error leads to much destruction*". I1 maintained that "*the language is the key to everything. The goal cannot be reached if the language is erroneous*".

The three interviewees all stressed that the focus of a good translation should be on the *meaning* of what is being translated: "*One is to translate meaning, that is, the message, and not [the] words*" (I2). This means that the translation must be culturally adapted via "*the translator [having] one leg in each culture. Translation is a process, not just a linguistic skill*" (I3). The three interviewees also stressed that translators need sufficient knowledge of the professional terminology in question to produce high-quality translations. I1 stated that "*it is the translators' lack of knowledge that leads to poor translations*".

Having experience as a translator does not necessarily mean that one has adequate knowledge of either culture or medical terms. The PROMs' absence of context is an additional challenge when it comes to making questions and statements comprehensible.

8.2. Need For Expert Checking In Addition To Forward-And-Back Translation

The Polish interpreter/translator (I3) opined that back-translations from the target language into the original language are pointless, futile, and may lead to errors. She compared it to "*a game of telephone*", as the original meaning tends to change in the process. A primary issue, she said, is the linguistic and cultural differences between the source and target languages. According to her, the translation should be checked by a professional within the field in question rather than having another professional translator do a back-translation: "*There is too little collaboration and too much procedure. […] Proofreading must be done by healthcare personnel for whom Polish is their native language, not a new translator. A professional within the field and the translator need to prepare the final version together*." She also suggested asking patients whether the translation is understandable.

I2 elaborated on this problem in the context of the differences between Norwegian and Arabic: "*Norwegian is much more succinct than Arabic. In the Arabic language, one uses many more words, while in Norwegian, one goes straight to the point. […] One uses a lot of synonyms in Arabic; words with the same meaning are used one after another; for instance, afraid, distressed, and anxious when one is worried about something, to make the statement stronger*." Translations into Arabic are also challenging because the oral language gives much more freedom than the concise text of a PROM (T3). Moreover, Arabic is a primary language in 22 countries; as such, dialectic differences can occur in addition to the differences between written and oral languages in general.

Contradicting I3, I1 stated that forward-and-back translations are important but that their quality needs to be checked and confirmed by more than one person. I1 presumed that poor translations were the result of the translator's inadequate knowledge of the source language and stated that poor translations were a waste of time and money.

8.3. Challenges in translating certain concepts

When asked if there were words and expressions that were difficult to translate, the translators explained that clarifications were needed along the way to avoid incorrect connotations. An example of this is the term "*hyperventilation*", which is used in the Bodily Distress Syndrome questionnaire. In the initial Somali version, this was translated as simply "*breath*". In discussion with the Somali translator (T2), we agreed that "*quickly/often*" had to be added in parentheses to make the meaning more precise. The Arabic translator (T3) said that angst tends to be understood as worry. He also suggested that some questions would benefit from a footnote or a parenthesis to help patients understand their meaning.

Additionally, the target language may lack a word for the meaning that needs to be translated. Professional medical terms may also not be used in everyday language; Pashto, for instance, lacks an explicit word for the concept of "*anxiety*". The word used, "*estrab*", may also mean being sad or having a feeling of concern (I1). There are often similar problems when translating into Arabic (T3).

8.4. Taboos As Barriers

In settings where patients are to be seen by a psychiatrist or psychologist, they are often asked to fill in PROMs focused on mental problems. I2 pointed out that, as many cultures avoid talking about mental health, words for various mental states are either little known or understood. Having suicidal thoughts, for example, might be considered shameful or taboo, and some cultures could perceive mental health problems as a consequence of not being religious enough. This makes achieving a thorough picture of the symptoms even more difficult. Interviewee I3 also said that psychiatric conditions and depression were both taboo and underestimated among Poles 15 years ago and indicated that this attitude may still be common among older persons.

8.5. Level Of Education Influences Communication

The interviewees stated that the patient's level of education might also influence their understanding of PROMs. The Arabic translator explained that "*there are many words in the written language that are not used in everyday speech. No matter how good the translation is, this could be a problem*". The level of health literacy and understanding of medical expressions vary in any population; this fact, coupled with dialectic variations, may result in particular difficulties for uneducated patients. A dissemination of a language across large geographical areas, and therefore many different cultures, exacerbates these problems even further. The Arabic translator expressed this as follows: "*To understand the written language, you need education. Without education, you have no chance.*" He explained that, even though a patient might be able to read the text, understanding it could still be a challenge if the words are unfamiliar: "*The way you speak and write is almost like two different languages*" (I2). The Polish translator also stated that education might be required to accurately understand certain expressions used in both the PROMs and in general communication with healthcare providers. In such settings, it is important that a bilingual and bicultural interpreter with knowledge of both medical and layman's terms is present to help explain difficult expressions and words while the patient is filling in the PROMs.

9. Discussion

Providing understandable PROMs to the patient is paramount to successful communication and successful medical treatment (Zidan, Awaisu, Hasan, & Kheir, 2016). The goal is to retain the meaning of each part of the PROM throughout the translation process. Success depends on both the bilingual and bicultural acumen of the translators of the PROMs in question.

9.1. Challenges Concerning Forward-And-Back Translations

Our findings indicate that one key translation problem involves the linguistic and cultural differences between the source and target languages. According to Colina, Marrone, & Ingram, (2017), a perfect transition of meaning between languages is impossible, and translatory habits may lead to incorrect meanings at times. For instance, "*amigo*" and "*friend*" do not always hold the same connotation. Moreover, studies on back-translations show that these words may be coloured by the source language such that they do not fully take the expressions and metaphorical and emotional terms used by the target population into account (Cha et al., 2007; Maneesriwongul & Dixon, 2004). Brislin et al. (1973, p. 176) indicated that "*a target language version resulting from poor translation might still retain much of the source language's structure so that it is easy to back-translate correctly despite translation errors. In this case, although back-translation is used, the target language version may not be appropriate for use with the target population.*"

Interviewee I3 implicitly pointed to these problems when she stated that back-translations from the target language into the original language are pointless and futile as the original meaning tends to change in the process, as when playing "*telephone*". The resulting differences may be quite substantial as there may be differences between a language's written and spoken forms. Oral and dialectic differences may also create problems. This may be particularly challenging for uneducated patients. Among immigrants in Norway, Somalis, Afghans, Pakistanis, and Iraqis tend to have a lower level of education than other groups of immigrants (Statistic Norway,

2020), and undocumented immigrants may be affected by a lack of ability to achieve educational attainment (Chang, 2019). Getting a clear picture of levels of education is therefore important.

9.2. Beyond The "Gold Standard"

A pain clinic physician and the first author reviewed the Norwegian back-translations. The ideal would have been a professional who actually uses the PROMs in question and is well-versed in both cultures and languages, reading the target language translations to ensure that their meaning was maintained. This is in line with both I3's suggestion and the WHO's (WHO, 2021) recommendation that "*a health professional, familiar with the terminology of the area covered by the instrument,*" should conduct the translation and that "*his/her mother tongue should be the primary language of the target culture*" (p. 1). Unfortunately, this is a requirement that few professionals can fill as most healthcare professionals are not also professional translators.

In contrast to I3, interviewee I2 stated that forward-and-back translations are important but that the quality of the translations needs to be confirmed by more than one person. A key benefit of conducting a back-translation is that it makes a comparison between the original and the translated versions possible. That is, it adds an extra step of quality control to the translation process. It is important that different translators are used for the forward-and-back translations. As illustrated in our study, this not only requires bilingual native speakers but translators with good knowledge of medical terminology, as the PROMs must be both lexically correct and understandable to those who need to fill them in. Otherwise, communication regarding a particular patient's healthcare needs may be seriously affected.

9.3. The Need For Trustworthy Translations

The way in which the translation of PROMs is handled and tested is an important part of the methodical approach in both intercultural research and an intercultural healthcare context. In a review of 47 articles on research methods, Maneesriwongul and Dixon (2004) found that the description provided about the processes of instrument translation in cross-cultural nursing research, and probably other forms of healthcare research, tended to be inadequate. The authors claimed that "*[t]his information is needed even when the study uses an instrument already translated by other researchers, especially when this information has not been previously published in an accessible source*" (p. 181).

In addition to lexical translations, a "*cultural interpretation*" may be required to make the content of the PROMs understandable. Hence, the translator "*must have knowledge of western biomedicine and its vocabulary as well as of the patient's understanding of the situation*" (Hanssen & Alpers, 2010). Many immigrants have a very different understanding of disease than western biomedicine. Interviewee I2 exemplified this by saying that mental health problems may be understood to be caused by inadequate religious faith. Some cultures, for example, believe mental illness to be a product of bodily imbalance, religious-based punishment, possession by evil spirits, and/or loss of soul. In this context, a PROM based on biomedical terminology is even more difficult to comprehend, meaning that providers also need to know what medical system the patient is familiar with. Although this is not part of the PROMs, it is information that somehow needs to be communicated to the healthcare team. It is important to note that the fact that a translator is fluent in a patient's language does not necessarily mean that they have "*one leg in each culture,*" as I3 put it, and know medical systems other than biomedicine. According to Sperber (2004), "*[s]ome clinicians are unaware that a problem exists. Even those who are aware of the problem find the solution daunting. The process of translating and adapting a PROM for a different cultural group can be arduous ... However, unless this process is successfully implemented, the validity of the research results [or, as in our case, the clinical data collection] may be [either] suspect,*" (p. S12 4) or simply incorrect.

9.4. Consequences Of Erroneous Translations

A translator's lack of familiarity with the terminology used in the PROMs in question may lead to erroneous translations. Lack of familiarity with medical concepts will also create problems, even if interpreters are used to helping patients understand the terminology. In a study on the collaboration between professional interpreters and nurses, "*[t]he interpreters claimed to have the necessary knowledge of western biomedicine to do a good job. They also found it difficult when health professionals used medical terminology. These statements are rather conflicting. The latter statement is supported by many health professionals who claim that some professional interpreters lack the necessary understanding of medical terminology etc., to enable skilled interpretation*" (Hanssen & Alpers, 2010).

This seems to be a problem for translators as well. Our interviewees had often seen instruments or PROMs that were translated so poorly that many questions were unintelligible for both the patients and the interpreters themselves, although the text was supposedly in the patient's native language. If the questions and answer options are incomprehensible to the patient, then important health information will be missing. This creates a risk of non–treatment, insufficient treatment, or even erroneous diagnosis and treatment (Flores, 2005) as the incorrectly translated PROMs do not track the symptoms they are supposed to; this jeopardises both provider-patient collaboration and the creation of a tailored treatment plan.

This is a major issue; being an experienced translator does not necessarily mean that one has adequate knowledge of medical terms. In many countries, there are trained medical translators/interpreters (Bird, 2005) who "*are essential healthcare workers and an integral part of the patient care team*" (CCHI, 2021). In Norway, no such specialisation is available. Translators and interpreters are supposed to be "*all-around*" and be able to take on translations within technology, law, police interrogation, medicine, and so on. However, very few people are linguistically proficient within such a wide range of areas, even in their mother tongue.

The interviewees gave examples of medical terms that were either incorrectly translated or did not exist in the target language. Such problems may cause the patient to give answers that do not correspond with the questions and/or cause an incorrect diagnosis, which negatively influences the treatment. Unless one highlights these issues, the validity and reliability of the data are at risk (Khalaila, 2013). Consequently, conceptual and linguistic issues that may influence either the results or information must be identified and fixed to ensure either the accuracy of a given study or the information on which healthcare providers are to base their treatment (Djuve, Sandbæk, & Lunde, 2011). Thus, accurate linguistic translations are the key to ensuring that all patients receive equally good healthcare regardless of linguistic and cultural background.

10. Conclusion

Translation of health-related PROMs is complicated, and errors may have grave consequences. A good translation is not simply a literal translation, as this may be culturally incomprehensible or misunderstood. Many immigrant patients have issues filling in PROMs or questionnaires, even when they are translated into their native language by professional translators. Our study showed that even a rigorous forward-and-back translation does not guarantee a fully linguistic and culturally congruent and conceptually trustworthy translation. At times, misunderstandings need to be resolved, and certain expressions and terminology must be orally explained. This is particularly important when working with fairly uneducated immigrant patients. Collaboration between healthcare personnel and translators may be useful in alleviating this problem. In sum, if the intention is to provide individually tailored and equal care to all patients, neither culture nor language can be ignored.

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