

## Cultural adaptation of Quality Of Care Through The Patient's Eyes -QUOTE-HIV

*Adaptação cultural do Quality Of Care Through The Patient's Eyes -QUOTE-HIV*  
*Adaptación cultural de Quality Of Care Through The Patient's Eyes - QUOTE-HIV*

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### ABSTRACT

**Objective:** to translate and adapt Quality of Care Through the Patient's Eyes - HIV (QUOTE-HIV) for the Brazilian population living with HIV/AIDS. **Method:** a methodological study, which followed the stages of translation, synthesis, back-translation, evaluation by the committee of experts and pre-test for cultural adaptation of the instrument. **Results:** the process of translation and cultural adaptation was considered adequate. Evaluation by the expert committee resulted in semantic, structural and grammatical adequacy of the evaluated items. 30 subjects considered the instrument to be easy to understand and suggested minor adjustments in some items. **Conclusion:** the Brazilian version of QUOTE-HIV has been adapted and validated in relation to its content. However, this is a study that precedes the process of evaluating the psychometric properties of the instrument, the results of which will be presented in a later publication.

**Descriptors:** Translation; Validation Studies; HIV; Acquired Immunodeficiency Syndrome; Nursing.

### RESUMO

**Objetivo:** traduzir e adaptar o Quality of Care Through the Patient's Eyes - HIV (QUOTE-HIV) para população brasileira que vive com HIV/aids. **Método:** estudo do tipo metodológico, que seguiu as etapas de tradução, síntese, retrotradução, avaliação pelo comitê de especialistas e pré-teste para adaptação cultural do instrumento. **Resultados:** o processo de tradução e adaptação cultural foi considerado adequado. A avaliação pelo comitê de especialistas resultou em adequações semânticas, estruturais e gramaticais dos itens avaliados. Participaram do pré-teste 30 sujeitos que consideraram o instrumento de fácil compreensão e sugeriram pequenas adequações em alguns de seus itens. **Conclusão:** a versão brasileira do QUOTE-HIV encontra-se adaptada e validada em relação ao seu conteúdo. Contudo, este é um estudo que antecede o processo de avaliação das propriedades psicométricas do instrumento, cujos resultados serão apresentados em publicação posterior.

**Descritores:** Tradução; Estudos de Validação; HIV; Síndrome de Imunodeficiência Adquirida; Enfermagem.

### RESUMEN

**Objetivo:** traducir y adaptar el Quality of Care Through the Patient's Eyes - HIV (QUOTE-HIV) para población brasileña que vive con HIV/sida. **Método:** estudio del tipo metodológico, que siguió las etapas de traducción, síntesis, retro traducción, evaluación por comité de especialistas y pre test para adaptación cultural del instrumento. **Resultados:** el proceso de traducción y adaptación cultural fue considerado adecuado. La evaluación por comité de especialistas resultó en adecuaciones semánticas, estructurales y gramaticales de los ítems evaluados. Participaron del pre test 30 sujetos que consideraron el instrumento de fácil comprensión y sugirieron pequeñas adecuaciones en algunos de sus ítems. **Conclusión:** la versión brasileña del QUOTE-HIV se encuentra adaptada y validada con relación a su contenido. Sin embargo, este es un estudio que antecede el proceso de evaluación de las propiedades psicométricas del instrumento, cuyos resultados serán presentados en publicaciones posterior.

**Descriptores:** Traducción; Estudios de Validación; HIV; Síndrome de Inmunodeficiencia Adquirida; Enfermería.

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## INTRODUCTION

Acquired Immunodeficiency Syndrome (AIDS), caused by the Human Immunodeficiency Virus (HIV), stands out among infectious diseases due to the great magnitude and extent of harm it causes<sup>(1)</sup>.

According to data from the Joint United Nations Program on HIV/AIDS (UNAIDS), in 2014 there were a total of 36.9 million people living with HIV in the world. That same year, two million people were infected with the virus and 1.2 million died from HIV/AIDS-related illnesses. In Brazil, from the first cases identified up until June 2015, a total of 798,366 HIV/AIDS cases have been reported. In the last five years, the country has registered an average of 40,600 new cases of the disease per year<sup>(2-3)</sup>.

From the beginning of the epidemic to the present day, the disease has progressed in a complex, chronic and controllable way. The quality of life of people infected with the virus has improved considerably, thanks to the set of procedures available for their treatment (highly effective antiretroviral therapy, medicines for prophylaxis of opportunistic diseases, routine immunizations, periodic medical examinations and consultations, and health programs)<sup>(4-5)</sup>. However, maintaining the quality of care provided and guaranteeing patients' adherence to care programs will continue to be a challenge for health professionals. Thus, systematically evaluating the quality of care provided for people living with HIV/AIDS (PLWHA) is essential for the development of good practices and the maintenance of satisfactory results that have already been achieved<sup>(6-7)</sup>.

Quality in health can be defined as the degree of compliance with quality standards established according to norms and protocols that organize actions and practices, as well as current technical and scientific knowledge, respecting culturally accepted values and considering, also, the attendance to health needs perceived expectations of users and their families, as well as the response to technically defined needs<sup>(8)</sup>.

Patients' perspectives on health services include their needs, opinions, perceptions and individual experiences that require responses from these services to users. Thus, the quality of health care, from the perspective of the patient, can be defined as the degree to which health services meet the needs of their users, considering the multi-dimensionality that guarantee such quality, namely courtesy, information, autonomy, competence, continuity of care, costs and accessibility to services<sup>(9)</sup>.

The importance of incorporating the perspective of patients in the elaboration, evaluation and adequacy of health programs has been discussed extensively<sup>(10-13)</sup>. Nevertheless, it has been observed in practice that there is a lack of instruments that contemplate such concern, especially when one considers the quality of care provided by health professionals to specific groups of individuals, such as PLWHA or have specificities related to their health condition that need to be addressed. In 2003, a group of studies from the University of Amsterdam, Department of General Practice of the Clinical Methods & Public Health Division proposed an instrument<sup>(11)</sup> to evaluate the quality of care provided to PLWHA from their perspectives: "Quality of Care Through the Patient's Eyes – HIV" (QUOTE-HIV).

This is a questionnaire published in the English language, which is self-reported and consists of three independent instruments that evaluate the specialist doctor in HIV/AIDS, the general practitioner and the nurse, the latter of these being chosen for the development of the present study.

The instrument that evaluates the care provided by nurses consists of 23 items answered in two stages. In the first, the user is asked about the importance he or she attaches to each item, and in the second, their evaluation of how the actions specified in each item are being performed by the health professionals. These items are distributed in three domains, and the data evaluation can consider each item individually or the score obtained in each domain through specific formulas<sup>(14)</sup>.

Inter-item Correlation Analysis, Reliability Testing and Factor Analysis were used to test the internal consistency and reliability of the instrument, which demonstrated good validity and reliability with an internal consistency  $\geq 0.80$  (Cronbach's Alpha).

Although there is no knowledge of a translation and cultural adaptation of QUOTE-HIV into other languages and cultures, it is a relevant tool for evaluating the care provided to PLWHA, and is a reference for the elaboration of studies on the theme<sup>(15-18)</sup>.

Considering the inexistence of instruments with this purpose in the country and the importance of systematically evaluating the care provided to Brazilian PLWHA, it was decided to translate and adapt the QUOTE-HIV to Brazilian Portuguese.

## OBJECTIVE

To translate and culturally adapt the Quality of Care Through the Patient's Eyes - HIV (QUOTE-HIV) instrument for use in Brazil.

## METHOD

### Ethical aspects

Authorization to carry out the research was requested and obtained from the author of QUOTE – HIV, Dr. Christine F Hekkinck, and the Ethics in Research Committee of the Faculty of Medical Sciences of the State University of Campinas. The HIV/AIDS patients were invited to participate in the study and, after clarifying its objectives, they expressed their consent and signed the Informed Consent Term.

### Design, place of study and period

A methodological type study was performed, characterized by processes of development and evaluation of data collection instruments<sup>(19)</sup>.

In order to guarantee quality in the process and equivalence between the translated and adapted version with the original version of the instrument, the stages of translation, synthesis, back-translation, evaluation by the expert committee and pre-test were followed, as recommended in the literature<sup>(20-21)</sup> for the process of cultural adaptation of QUOTE-HIV.

The pre-test was applied at a reference center for HIV/AIDS located in a teaching hospital in the interior of the state of São Paulo, in May and June, 2015.

### Sample and inclusion criteria

Thirty patients diagnosed with HIV/AIDS undergoing outpatient care for at least one year participated in the pre-test at the HIV/AIDS reference center. The sample size followed recommendations in the literature<sup>(21)</sup> for cultural adaptation studies.

Inclusion criteria for this stage were: a) to be a carrier of the HIV virus; b) under specialized HIV/AIDS outpatient care for at least one year; c) age 18 years or over; d) present conditions to understand and respond to the instrument.

### Study Protocol

In the first stage, the instrument was translated from English into Brazilian Portuguese by two independent translators, one of which a bilingual health professional, whose mother tongue is Brazilian Portuguese. Only one of the translators was informed of the objectives of the instrument and related concepts. From this stage, two independent versions of the instrument, T1 and T2, resulted, which was then analyzed by a third translator from the health area, who, together with the authors, prepared the synthesis-version of the translations (T12), which constituted the second stage in the cultural adaptation process for the instrument.

In the third stage, two independent translators, both fluent in Portuguese and having the same mother tongue as the instrument's native language, performed the translation of the synthesis version into English again, generating two back-translated versions of the instrument, BT1 and BT2. These translators were not informed of the objectives and concepts related to the instrument.

The fourth stage in the methodological procedure consisted in the evaluation of the instrument by an expert committee which aimed to consolidate all versions of translation and to obtain a consensus between the translated version to Brazilian Portuguese and the original version in addition to evaluating the validity of content. A professional with experience in methodological research, a linguist and three health professionals participated in this committee, one with experience in direct assistance to PLWHA and two teachers from public universities with teaching, research experience and that has worked with PLWHA. For this evaluation, each member of the expert committee received all the translated versions, the synthesis, the original instrument and specific instructions for analysis of the semantic, idiomatic, cultural and conceptual equivalences. This resulted in the pre-final version of QUOTE-HIV, used in the final stage of the process of cultural adaptation, i.e. the pre-test.

This stage aimed at evaluating the comprehension, clarity of the items and the response time. The participants answered the questionnaire and then were asked about possible issues during its completion and degree of difficulty to understand the items. The instrument response time was measured by recording the start time and the completion time. The data were collected individually, in a reserved place and in the presence of the researcher.

### Analysis of the results

The results were analyzed by the expert committee in two stages: one quantitative and the other qualitative in nature<sup>(22)</sup>.

In the quantitative analysis, the individual evaluation of each item by the committee members was tabulated, and the Content Validity Index (CVI)<sup>(22-23)</sup> was used to calculate the

degree of agreement between the evaluations. An agreement rate of 100% for the items in the instrument was considered to be satisfactory. Lower values would imply mandatory adjustments to the item under consideration.

Regarding the qualitative analysis, during the consensus meeting, committee members suggested modifications to ensure equivalence with the original instrument. This required two meetings, lasting approximately three hours each, to obtain the pre-final version of the QUOTE-HIV used in the pre-test.

The results from the pre-test are presented in a descriptive way.

## RESULTS

All stages proposed by the literature for cultural adaptation of instruments were satisfactorily completed: translation, synthesis, back-translation, expert committee analysis and pre-test.

In the quantitative evaluation of the content validity performed by the committee, semantic, idiomatic, cultural and conceptual equivalence between the original instrument and the translations and back-translations were observed. Chart 1 presents the CVI values found for the items of the instrument at each stage of its application.

Although most of the items received a score of CVI = 1, suggesting the questions should remain unchanged, the consensus meeting with the committee members found there was a need, on all items, for grammatical changes, inversion of word order in the sentences, replacement of some terms by synonyms and change of certain terms such as "Specialized nurse in HIV/AIDS" for "Nursing Team". These modifications aimed to facilitate the understanding of items by the population to be studied. The changes made are shown in Chart 2.

The introductory text of the instrument, as well as its layout, was also modified by the committee during the consensus meeting, in order to facilitate its understanding by the respondents. After changes, the pre-final version of the instrument was pre-tested. Thirty patients participated in this stage, with a diagnosis of HIV/AIDS in outpatient follow-up for at least one year in a reference center for HIV/AIDS. The mean age of respondents was 42 years, of which 19 (63%) were male and 11 (37%) were female. There was an educational level of on average 9 full years of study.

**Chart 1 –** Content Validity Index for the items in the Brazilian version of QUOTE-HIV

Stage 1 - Importance	CVI*
Items (1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 13, 14, 15, 16, 17, 19, 20, 22)	1
Items (8, 18, 21, 23)	0.80
Stage 2 - Performance	
Items (1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 19, 20, 22, 23)	1
Items (6, 21)	0.80
Items (18)	0.60

Note: \* CVI - content validity index

**Chart 2** – Description of changes made to items of the instrument after evaluation by the expert committee

Stage 1 of the Instrument – Importance				
Items	Original version	Synthesis of translations	Back-translation	Version after evaluation and suggestions by the committee
1	The Aids Nursing Consultant should always explain the advantages and disadvantages of any treatment.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve sempre explicar as vantagens e desvantagens de qualquer tratamento.	1. The HIV/AIDS nursing consultant should always explain the advantages and disadvantages of any treatment. 2. The specialist nurse in HIV/AIDS should always inform me about the pros and cons of a treatment.	O quanto é importante que a equipe de enfermagem sempre explique as vantagens e desvantagens de qualquer tratamento.
2	The Aids Nursing Consultant should work efficiently.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve trabalhar com eficiência.	1. The HIV/AIDS nursing consultant should work efficiently. 2. The specialist nurse in HIV/AIDS should work efficiently.	O quanto é importante que a equipe de enfermagem trabalhe com eficiência.
3	The Aids Nursing Consultant should have specific expertise in the field of HIV.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve ter conhecimento específico na área de HIV.	1. The HIV/AIDS nursing consultant should have specific knowledge in the field of HIV. 2. The specialist nurse in HIV/AIDS should have special knowledge of HIV.	O quanto é importante que a equipe de enfermagem tenha conhecimento específico sobre HIV.
4	The Aids Nursing Consultant should keep me as fit as possible, using preventive methods.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve me manter tão saudável quanto possível, utilizando métodos preventivos.	1. The HIV/AIDS nursing consultant should keep me as healthy as possible, using preventive method. 2. The specialist nurse in HIV/AIDS should keep me healthy with preventive methods.	O quanto é importante que a equipe de enfermagem me mantenha tão saudável quanto possível, utilizando métodos preventivos.
5	The Aids Nursing Consultant should be open to a discussion about euthanasia.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve estar aberta para discutir sobre eutanásia.	1. The HIV/AIDS nursing consultant should be open to discuss euthanasia. 2. The specialist nurse in HIV/AIDS should have an open ear for a conversation about euthanasia.	O quanto é importante que a equipe de enfermagem esteja aberta para falar a respeito de eutanásia.
6	The Aids Nursing Consultant should always tell me what the possible side-effects of a medicine are.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve sempre me informar quais são os possíveis efeitos colaterais de um medicamento.	1. The HIV/AIDS nursing consultant should always inform me about the possible side effects of a drug. 2. The specialist nurse in HIV/AIDS should always give information about possible side effects of drugs.	O quanto é importante que a equipe de enfermagem sempre me informe quais são os possíveis efeitos colaterais dos medicamentos.
7	The Aids Nursing Consultant should provide information about how I should take the prescribed HIV medication.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve me orientar sobre como eu devo tomar o medicamento prescrito para o HIV.	1. The HIV/AIDS nursing consultant should guide me about how I should take the prescribed drug for HIV. 2. The specialist nurse in HIV/AIDS should give information about the use of my prescribed HIV medication.	O quanto é importante que a equipe de enfermagem me explique sobre como eu devo tomar os medicamentos prescritos para o HIV.
8	The Aids Nursing Consultant should always provide an explanation, in language I can understand, concerning prescribed medicines.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve sempre me explicar, em uma linguagem que eu possa entender, sobre os medicamentos prescritos.	1. The HIV/AIDS nursing consultant should always explain, in a language I can understand, about the prescribed drugs. 2. The specialist nurse in HIV/AIDS should always explain my medication clearly.	O quanto é importante que a equipe de enfermagem sempre me explique, em uma linguagem que eu possa entender, sobre os medicamentos prescritos.
9	The Aids Nursing Consultant should always take me seriously.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve sempre levar-me a sério.	1. The HIV/AIDS nursing consultant should always take me seriously. 2. The specialist nurse in HIV/AIDS should always take me seriously.	O quanto é importante que a equipe de enfermagem sempre valorize o que eu falo.
10	The Aids Nursing Consultant should give 'bad' news carefully.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve me dar as "más" notícias de forma cuidadosa.	1. The HIV/AIDS nursing consultant should break the news carefully. 2. The specialist nurse in HIV/AIDS should break news gently.	O quanto é importante que a equipe de enfermagem tenha cautela ao me dar "más" notícias.
11	The Aids Nursing Consultant should always take sufficient time to talk to me.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve sempre ter tempo suficiente para conversar comigo.	1. The HIV/AIDS nursing consultant should always have enough time to talk to me. 2. The specialist nurse in HIV/AIDS should always take enough time to talk with me.	O quanto é importante que a equipe de enfermagem sempre disponibilize tempo suficiente para conversar comigo.

To be continued



Chart 2

Stage 1 of the Instrument – Importance				
Items	Original version	Synthesis of translations	Back-translation	Version after evaluation and suggestions by the committee
12	The Aids Nursing Consultant should be aware of my current situation at home and at work/school.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve conhecer minha situação atual em casa e no trabalho/escola.	1. The HIV/AIDS nursing consultant should be aware of my current situation at home and at work/school. 2. The specialist nurse in HIV/AIDS should be aware of my current situation at home and at work / at school.	O quanto é importante que a equipe de enfermagem conheça minha situação atual em casa e no trabalho/escola.
13	I want always to be treated by my own Aids Nursing Consultant.	Eu quero sempre ser tratado por minha própria Enfermeira(o) Especializada(o) em HIV/AIDS.	1. I always want to be treated by my own HIV/AIDS nursing consultant. 2. I always want to be treated by the same specialist nurse in HIV/AIDS.	O quanto é importante que eu seja atendido sempre pela mesma equipe de enfermagem.
14	The Aids Nursing Consultant should work in close cooperation with other care-givers.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve trabalhar em estreita cooperação com outros cuidadores.	1. The HIV/AIDS nursing consultant should work closely with other caregivers. 2. The specialist nurse in HIV/AIDS should work in close cooperation with other carers.	O quanto é importante que a equipe de enfermagem trabalhe em colaboração com outros profissionais.
15	The Aids Nursing Consultant should be easily accessible by telephone.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve ser facilmente contatada por telefone.	1. The HIV/AIDS nursing consultant should be easily contacted by telephone. 2. The specialist nurse in HIV/AIDS should easily be reached by telephone.	O quanto é importante que a equipe de enfermagem esteja facilmente acessível via telefone.
16	The Aids Nursing Consultant should not keep me waiting more than 15 minutes in the waiting-room.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS não deve deixar-me esperando por mais de 15 minutos na sala de espera.	1. The HIV/AIDS nursing consultant should not keep me waiting in the waiting room more than 15 minutes. 2. The specialist nurse in HIV/AIDS should never keep me waiting in the waiting room longer than 15 minutes.	O quanto é importante que a equipe de enfermagem não me deixe esperando por mais de 15 minutos na sala de espera.
17	The Aids Nursing Consultant should keep strictly to the appointments and/or agreements that have been made.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve respeitar rigorosamente os compromissos e acordos feitos.	1. The HIV/AIDS nursing consultant should strictly keep the appointments and agreements closed. 2. The specialist nurse in HIV/AIDS must keep his / her appointments and agreements made.	O quanto é importante que a equipe de enfermagem respeite rigorosamente os compromissos assumidos.
18	The Aids Nursing Consultant should ensure that, whenever necessary, I can always come to the surgery quickly (within 24 hours).	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve assegurar que, quando for preciso, eu possa sempre ter acesso rapidamente a cirurgia (dentro de 24 horas).	1. The HIV/AIDS nursing consultant should make sure that, if necessary, I can always get a surgical appointment fast (within 24 hours). 2. The specialist nurse in HIV/AIDS should make sure that I always get the care I need for emergency surgery (within 24 hours).	O quanto é importante que a equipe de enfermagem assegure que, quando necessário, eu possa sempre ser rapidamente atendido em uma consulta (dentro de 24 horas).
19	The Aids Nursing Consultant should ensure that we are not disturbed during a consultation.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve assegurar que não seremos perturbados durante a consulta.	1. The HIV/AIDS nursing consultant should make sure there are no interruptions during the consult. 2. The specialist nurse in HIV/AIDS should avoid interruptions during a consultation.	O quanto é importante que a equipe de enfermagem assegure que não seremos interrompidos durante a consulta.
20	The Aids Nursing Consultant should tell me that I may ask another doctor for advice ('second opinion').	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve orientar-me que eu posso consultar um outro médico ("segunda opinião").	1. The HIV/AIDS nursing consultant should advise me about the possibility of a second opinion. 2. The specialist nurse in HIV/AIDS should allow me to ask a second opinion.	O quanto é importante que a equipe de enfermagem me oriente de que eu possa consultar outro médico para ouvir uma segunda opinião.
21	The Aids Nursing Consultant should always allow me to look at my medical file if I wish to.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve sempre permitir que eu veja meu arquivo médico caso eu desejar.	1. The HIV/AIDS nursing consultant should always allow me to see my medical file if I want to. 2. The specialist nurse in HIV/AIDS should always allow me to check my personal file if I want to.	O quanto é importante que a equipe de enfermagem sempre permita que eu veja meu prontuário, caso eu deseje.
22	The Aids Nursing Consultant should safeguard my privacy as regards my HIV-status.	A(o) Enfermeira(o) Especializada(o) em HIV/AIDS deve assegurar minha privacidade em relação ao meu diagnóstico de HIV.	1. The HIV/AIDS nursing consultant should keep my HIV diagnosis confidential. 2. The specialist nurse in HIV/AIDS should maintain confidentiality about my HIV status.	O quanto é importante que a equipe de enfermagem assegure minha privacidade em relação ao meu diagnóstico de HIV.

To be continued

Chart 2

<b>Stage 1 of the Instrument – Importance</b>				
<b>Items</b>	<b>Original version</b>	<b>Synthesis of translations</b>	<b>Back-translation</b>	<b>Version after evaluation and suggestions by the committee</b>
23	The Aids Nursing Consultant should have his/her practice laid-out so that I cannot hear what is discussed at reception and in the consulting room.	A(o)Enfermeira(o) Especializada(o) em HIV/AIDS deve organizar seu atendimento de tal forma que eu não possa escutar o que está sendo discutido na recepção e nas outras salas de consulta.	1. The HIV/AIDS nursing consultant should organize my care in such a way I cannot hear conversations at the desk and in the consulting rooms. 2. The specialist nurse in HIV/AIDS should be organized in such a way I cannot hear conversations at the front desk or in the consulting rooms.	O quanto é importante que a equipe de enfermagem organize seu atendimento de tal forma que eu não escute o que está sendo discutido nos consultórios e ao meu redor.
<b>Stage 2 of the instrument – Performance</b>				
<b>Items</b>	<b>Original Version</b>	<b>Synthesis of the translations</b>	<b>Back-translation</b>	<b>Version after evaluation and suggestions by the committee</b>
1	My Aids Nursing Consultant explains the advantages and disadvantages of any treatment.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS explica as vantagens e desvantagens de qualquer tratamento.	1. My HIV/AIDS nursing consultant explains the advantages and disadvantages of any treatment. 2. My specialist nurse in HIV/AIDS informs me about the pros and cons of a treatment.	A equipe de enfermagem explica as vantagens e desvantagens de qualquer tratamento.
2	My Aids Nursing Consultant works efficiently.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS trabalha eficientemente.	1. My HIV/AIDS nursing consultant works efficiently. 2. My specialist nurse in HIV/AIDS works efficiently.	A equipe de enfermagem trabalha com eficiência.
3	My Aids Nursing Consultant has specific expertise in the field of HIV.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS demonstra conhecimentos específicos na área de HIV.	1. My HIV/AIDS nursing consultant demonstrates specific knowledge in the field of HIV. 2. My specialist nurse in HIV/AIDS has special knowledge of HIV.	A equipe de enfermagem demonstra ter conhecimentos específicos sobre HIV.
4	My Aids Nursing Consultant keeps me as fit as possible, using preventive methods.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS me mantém tão saudável quanto possível, utilizando métodos preventivos.	1. My HIV/AIDS nursing consultant keeps me as healthy as possible, using preventive methods. 2. My specialist nurse in HIV/AIDS keeps me healthy with preventive methods.	A equipe de enfermagem me mantém tão saudável quanto possível, utilizando métodos preventivos.
5	My Aids Nursing Consultant is open to a discussion about euthanasia.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS está aberta para discutir sobre eutanásia.	1. My HIV/AIDS nursing consultant is open to discuss euthanasia. 2. My specialist nurse in HIV/AIDS has an open ear for a conversation about euthanasia.	A equipe de enfermagem está aberta para falar sobre eutanásia.
6	My Aids Nursing Consultant tells me what the possible side-effects of a medicine are.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS me informa quais são os possíveis efeitos colaterais de um medicamento.	1. My HIV/AIDS nursing consultant informs me about the possible side effects of a drug. 2. My specialist nurse in HIV/AIDS gives information about possible side effects of drugs.	A equipe de enfermagem me informa quais são os possíveis efeitos colaterais dos medicamentos.
7	My Aids Nursing Consultant provides information about how I should take the prescribed HIV medication.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS me orienta sobre como eu devo tomar o medicamento prescrito para o HIV.	1. My HIV/AIDS nursing consultant guides me about how I should take the prescribed drug for HIV. 2. My specialist nurse in HIV/AIDS gives information about the use of my prescribed HIV medication.	A equipe de enfermagem me fornece informações sobre como eu devo tomar os medicamentos prescritos para o HIV.
8	My Aids Nursing Consultant provides an explanation, in language I can understand, concerning prescribed medicines.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS me explica, em uma linguagem que eu entendo, sobre os medicamentos prescritos.	1. My HIV/AIDS nursing consultant explains me, in a language I can understand, about the prescribed drug. 2. My specialist nurse in HIV/AIDS explains my medication clearly.	A equipe de enfermagem me fornece explicações, em uma linguagem que eu entendo, sobre os medicamentos prescritos.
9	My Aids Nursing Consultant takes me seriously.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS me leva a sério.	1. My HIV/AIDS nursing consultant takes me seriously. 2. My specialist nurse in HIV/AIDS takes me seriously.	A equipe de enfermagem valoriza o que eu falo.
10	My Aids Nursing Consultant gives 'bad' news carefully.	Minha(me) Enfermeira(o) Especializada(o) em HIV/AIDS me dá as "más" notícias de forma cuidadosa.	1. My HIV/AIDS nursing consultant breaks the news carefully. 2. My specialist nurse in HIV/AIDS breaks news gently.	A equipe de enfermagem dá, com cautela, "más" notícias para mim.

To be continued

Chart 2

Stage 2 of the instrument – Performance				
Items	Original Version	Synthesis of the translations	Back-translation	Version after evaluation and suggestions by the committee
11	My Aids Nursing Consultant takes sufficient time to talk to me.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS tem tempo suficiente para conversar comigo.	1. My HIV/AIDS nursing consultant has enough time to talk to me. 2. My specialist nurse in HIV/AIDS takes enough time to talk with me.	A equipe de enfermagem disponibiliza tempo suficiente para conversar comigo.
12	My Aids Nursing Consultant is aware of my current situation at home and at work/school.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS conhece minha situação atual em casa e no trabalho/escola.	1. My HIV/AIDS nursing consultant is aware of my current situation at home and at work/school. 2. My specialist nurse in HIV/AIDS is aware of my current situation at home and at work / at school.	A equipe de enfermagem conhece minha situação atual em casa e no trabalho/escola.
13	I am treated by my own Aids Nursing Consultant.	Eu estou sendo tratado por minha(meu) própria(o) Enfermeira(o) Especializada(o) em HIV/AIDS.	1. I am being treated by my own HIV/AIDS nursing consultant. 2. I have been treated by my specialist nurse in HIV/AIDS.	Eu sou atendido pela mesma equipe de enfermagem.
14	My Aids Nursing Consultant works in close cooperation with other care-givers.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS trabalha em estreita cooperação com outros cuidadores.	1. My HIV/AIDS nursing consultant works closely with other caregivers. 2. My specialist nurse in HIV/AIDS works in close cooperation with other carers.	A equipe de enfermagem trabalha em colaboração com outros profissionais.
15	My Aids Nursing Consultant is easily accessible by telephone.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS é facilmente contatada por telefone.	1. My HIV/AIDS nursing consultant can be easily contacted by telephone. 2. My specialist nurse in HIV/AIDS is easily reached by phone.	A equipe de enfermagem é facilmente acessada via telefone.
16	My Aids Nursing Consultant keeps me waiting more than 15 minutes in the waiting-room.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS me deixa esperando por mais de 15 minutos na sala de espera.	1. My HIV/AIDS nursing consultant keeps me waiting in the waiting room more than 15 minutes. 2. My specialist nurse in HIV/AIDS keeps me waiting in the waiting room longer than 15 minutes.	A equipe de enfermagem não me deixa esperando por mais de 15 minutos na sala de espera.
17	My Aids Nursing Consultant keeps strictly to the appointments and/or agreements that have been made.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS respeita rigorosamente os compromissos e acordos feitos.	1. My HIV/AIDS nursing consultant strictly keeps the appointments and agreements closed. 2. My specialist nurse in HIV/AIDS keeps his / her appointments and agreements made.	A equipe de enfermagem respeita rigorosamente os compromissos assumidos.
18	My Aids Nursing Consultant ensures that, whenever necessary, I can come to the surgery quickly (within 24 hours).	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS assegura que, quando for preciso, eu posso ter acesso rapidamente a cirurgia (dentro de 24 horas).	1. My HIV/AIDS nursing consultant makes sure that, if necessary, I can get a surgical appointment fast (within 24 hours). 2. My specialist nurse in HIV/AIDS makes sure I get the care I need for emergency surgery (within 24 hours).	A equipe de enfermagem assegura que, quando necessário, eu posso ser rapidamente atendido em uma consulta (dentro de 24 horas).
19	During a consultation I am able to talk to my Aids Nursing Consultant undisturbed.	Durante a consulta, eu consigo falar com minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS sem ser perturbado.	1. During the consult, I can talk to my HIV/AIDS nursing consultant without interruptions. 2. During a consultation, I can talk with my specialist nurse in HIV/AIDS with no interruptions.	Durante a consulta, eu posso conversar com a equipe de enfermagem sem ser interrompido.
20	My Aids Nursing Consultant tells me that I may ask another doctor for advice ('second opinion').	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS me orienta que eu posso consultar um outro médico ("segunda opinião").	1. My HIV/AIDS nursing consultant advises me about the possibility of getting a second opinion. 2. My specialist nurse in HIV/AIDS allows me see another doctor ("to ask a second opinion").	A equipe de enfermagem me orienta de que eu posso consultar outro médico para ouvir uma segunda opinião.
21	My Aids Nursing Consultant allows me to look at my medical file if I wish to.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS permite que eu veja meu arquivo médico caso eu desejar.	1. My HIV/AIDS nursing consultant allows me to see my medical file if I want to. 2. My specialist nurse in HIV/AIDS allows me to check my personal file if I want to.	A equipe de enfermagem permite que eu veja meu prontuário, caso eu deseje.
22	My Aids Nursing Consultant safeguards my privacy as regards my HIV-status.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS assegura minha privacidade em relação ao meu diagnóstico de HIV.	1. My HIV/AIDS nursing consultant keeps my HIV diagnosis confidential. 2. My specialist nurse in HIV/AIDS maintains confidentiality about my HIV status.	A equipe de enfermagem assegura minha privacidade em relação ao meu diagnóstico de HIV.

To be continued



Chart 2 (concluded)

Stage 2 of the instrument – Performance				
Items	Original Version	Synthesis of the translations	Back-translation	Version after evaluation and suggestions by the committee
23	My Aids Nursing Consultant has his/her practice laid-out so that I can hear what is discussed at reception and in the consulting room.	Minha(meu) Enfermeira(o) Especializada(o) em HIV/AIDS organiza seu atendimento de tal forma que eu não posso escutar o que está sendo discutido na recepção e nas outras salas de consulta.	1. My HIV/AIDS nursing consultant organizes my care in such a way I cannot hear conversations at the desk and in the consulting rooms. 2. My specialist nurse in HIV/AIDS is organized in such a way I cannot hear conversations at the front desk or in the consulting rooms.	A equipe de enfermagem organiza seu atendimento de tal forma que eu não possa escutar o que está sendo discutido nos consultórios e ao meu redor.

The pre-test occurred in private with the researcher. After applying the instrument, the participants were asked about possible issues during their completion and degree of difficulty to understand the items. The average time for completing the questionnaire was 20 minutes.

Respondents reported ease in understanding the items in the questionnaire and did not indicate a need to modify them, except item 5 of the instrument. Item 5 refers to the question, "How important is it that the nursing team is open to discuss euthanasia", for which three subjects stated they did not understand the meaning of the word "euthanasia" and four considered this question unnecessary because they were interested in talking about "life" and not "death".

At this point, the experts were consulted again and, in consensus, it was decided to maintain the item as it was written, since it was not possible to suggest any word or term that could replace the word euthanasia without changing its semantic and conceptual structure. The experts suggested waiting for the evaluation of the psychometric properties of the questionnaire to decide on the maintenance or exclusion of this item.

## DISCUSSION

The process of translation and cultural adaptation of QUOTE-HIV for use in Brazil was carried out in a systematized manner and followed all the stages recommended for cultural adaptation of measurement instruments. The use of an internationally standardized method for the cultural adaptation process of the instrument allows its use in diverse populations in the country and the reproducibility of results<sup>(24)</sup>.

In the search for equivalence between the original version of the instrument and the Brazilian version, the semantic, idiomatic, cultural and conceptual equivalences were evaluated through a committee composed of five specialists. In order for the concordance rate among the members of this committee to be considered acceptable, the CVI should be higher than 0.80<sup>(23)</sup>. In both stages for applying the questionnaire, Importance and Performance, a concordance rate of over 80% was obtained for most items.

However, at the consensus meeting among experts, it was found that all items of the instrument were modified to ensure consistency and cohesion of the issues and enable better understanding on the part of the respondents. It should be noted that two face-to-face meetings were necessary with the committee members to finalize the pre-test version of the questionnaire, which can be justified by the number of items

evaluated and the complexity of the discussions in the quest for consensus in the final formulation of the questions.

The presence of a professional linguist and a methodologist in the committee of judges allowed a refinement of the items regarding the semantic and idiomatic aspects of the sentences. The participation of professionals with assistance and research experience with PLWHA also proved to be fundamental to ensure the cultural and conceptual adequacy of the items. Thus, grammatical changes were made together with inversion of word order in the sentence, substitution of some terms for synonyms and the term "Nursing Specialist in HIV/AIDS" was replaced by "Nursing Team". The latter change took into account the context of nursing care in health services in Brazil and the Netherlands, which differs substantially. In the Netherlands, those who provide nursing care to people living with HIV/AIDS are nurses specialized in HIV/AIDS, while in Brazil the nursing care is performed by teams usually composed of nurses and nursing technicians, both providing direct care to the users.

For a successful translation, cultural equivalence is important so that the terms used in the instrument are consistent with the reality experienced by the target population in its cultural context. If a term is outside the context or the experience of that population, then it must be modified<sup>(21)</sup>.

In the pre-test of the instrument, performed with 30 patients, there was good acceptance and easy comprehension by the respondents, except for item 5 of the questionnaire, which inquired about euthanasia, since the term was not understood by the subjects, while others considered it an irrelevant and unnecessary question. It should be noted that, from the Brazilian cultural perspective, questions regarding euthanasia are not yet part of discussions involving health professionals and patients, nor the nursing team<sup>(25)</sup>, in addition the legal implications are not well defined. Although authorized in a number of countries, such as the Netherlands, where the instrument was developed and validated, euthanasia in Brazil is criminalized by the Penal Code, and although there are discussions and varied opinions on the subject, many conceive such a prohibition as a violation of the right to choose over life and death.

When consulted regarding this item, the committee of experts suggested waiting for the evaluation of the psychometric properties of the instrument to decide for its maintenance or exclusion.

The results demonstrate that the Brazilian version of QUOTE-HIV presented good understanding and comprehension among respondents. The evaluation of its psychometric



properties is underway and, after this process, the instrument will be available for use in Brazil.

### Limitations of the study

A limitation that should be considered is that the validity of a measuring instrument is not a fixed property and therefore may vary according to the circumstances, population and purpose of the research. Thus, an instrument that is valid for one set of situations may not have the same validity in different circumstances; therefore, its psychometric characteristics must always be tested.

### Contributions to Nursing

The availability of HIV-QUOTE in Brazil may allow the evaluation of nursing care provided to PLWHA, considering the importance that the individual attributes to each action of care and the performance of the professional in its execution. This

evaluation, from the perspective of the patient, makes it possible to obtain important information for the planning of Nursing care, in order to meet the needs of these subjects, while providing for active participation of the patient in their care.

### CONCLUSION

The procedures for culturally adapting and validating content of QUOTE-HIV have been successfully completed, as recommended in the literature. After evaluation by the committee of experts, the semantic, idiomatic, cultural and conceptual equivalences between the translated version and the original version of the instrument were achieved. However, this is a study that precedes the process of evaluation of the psychometric properties of the questionnaire, the results of which are currently being investigated and will be presented later in order to enable its use in Brazil.

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