Original Article

Content validation of an instrument to characterize people over 50 years of age living with Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome*

Validação do conteúdo de instrumento para caracterizar pessoas maiores de 50 anos portadoras do Vírus da Imunodeficiência Humana/Síndrome da Imunodeficiência Adquirida

Validación del contenido de un instrumento para caracterizar a personas mayores de 50 años portadoras del Virus de la Inmunodeficiencia Humana/Síndrome de la Inmunodeficiencia Adquirida

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ABSTRACT

Objective: To present the development and validation of an instrument for characterizing people, aged 50 or over, who are carriers of the Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome. **Methods:** The content of the instrument, which was developed based on consulted literature and the professional experience of the researchers, was validated by seven experts. The validation was performed in two stages of evaluation, using the Kendall coefficient of concordance to evaluate, the first time, concordance among experts with regard to relevance, clarity, and completeness of content, and secondly, the adequacy and comprehensiveness. The Cochran test was used to evaluate the concordance regarding clarity, in the second evaluation. **Results:** There was disagreement among the experts in the first evaluation, and after reformulation of the instrument, concordance was obtained in the second evaluation. **Conclusion:** The instrument for characterizing this population was validated against the content being used by researchers, and is now made available for use.

Keywords: HIV; Acquired immunodeficiency syndrome; Adult; Validation studies.

RESUMO

Objetivo: Apresentar o desenvolvimento e a validação de um instrumento para caracterização de pessoas, com 50 anos ou mais, portadoras do Vírus da Imunodeficiência Humana/Síndrome da Imunodeficiência Adquirida. **Métodos:** O conteúdo do instrumento, elaborado com base na literatura consultada e experiência profissional dos pesquisadores, foi validado por sete peritos. A validação foi feita em dois momentos de avaliação, utilizando-se o coeficiente de concordância de Kendall para avaliar no primeiro momento a concordância entre os juízes quanto à pertinência, clareza e abrangência do conteúdo e, no segundo, a pertinência e abrangência. O teste de Cochran foi utilizado para avaliar a concordância quanto à clareza, na segunda avaliação. **Resultados:** Observou-se discordância entre os peritos na primeira avaliação e após a reformulação do instrumento, obteve-se concordância na segunda avaliação. **Conclusão:** O instrumento para caracterização dessa população foi validado em relação ao conteúdo, sendo aplicado pelos pesquisadores e encontra-se disponível para utilização.

Descritores: HIV; Síndrome de imunodeficiência adquirida; Adulto; Estudos de validação.

RESÚMEN

Objetivo: Presentar el desarrollo y la validación de un instrumento para la caracterización de personas, con 50 años o más, portadoras del Virus de la Inmunodeficiencia Humana/Síndrome de la Inmunodeficiencia Adquirida. **Métodos:** El contenido del instrumento, elaborado con base en la literatura consultada y experiencia profesional de los investigadores, fue validado por siete peritos. La validación fue realizada en dos momentos de evaluación, utilizándose el coeficiente de concordancia de Kendall para evaluar en el primer momento la concordancia entre los jueces en cuanto a la pertinencia, claridad y alcance del contenido y, en segundo, la pertinencia y alcance. El test de Cochran fue utilizado para evaluar la concordancia en relación a la claridad, en la segunda evaluación. **Resultados:** Se observó discordancia entre los peritos en la primera evaluación y después de la reformulación del instrumento, se obtuvo concordancia en la segunda evaluación. **Conclusión:** El instrumento para la caracterización de esa población fue validado en relación al contenido, siendo aplicado por los investigadores encontrándose disponible para su utilización.

Descriptores: VIH; Síndrome de inmunodeficiencia adquirida; Adulto; Estudios de validación.

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INTRODUCTION

The epidemic caused by the human immunodeficiency virus (HIV) represents a dynamic and unstable global phenomenon, the form of occurrence depending on other determinants, such as individual and collective human behavior, in different regions of the world. The Acquired Immunodeficiency Syndrome (Aids) stands out among the emerging infectious diseases, because of the great magnitude and extent of damage to populations [1].

The increase in the number of Aids cases among older adults has been reported worldwide [2]. In Brazil, between 1996 and 2006, the incidence rate per 100 thousand inhabitants aged 50-59 years, increased from 17.9 to 29.3 among men, and from 6.0 to 17.3 among women. In the same period, there was an increase in the incidence rate among individuals over 60 years. Among men, the rate per 100 thousand inhabitants increased from 5.9 to 8.8 and in women, from 1.7 to 5.1 [3]. In this context it is important to recognize that Aids in the elderly is characterized as a social phenomenon of large proportions, impacting moral, religious and ethical principles, procedures for public health and private behavior, questions related to sexuality, drug use and conjugal morality that require critical professionals, open to new values, trained in the complexity of the virus and disease caused by it, and with knowledge of health policies [4].

Thus, to properly direct their work with this group of patients, nurses should be directed to recognize the characteristics of this "new generation" of older people with HIV / Aids. This information should subsidize educational activities that can contribute to improving the care provided to elderly people with HIV / Aids and, above all, take a preventive form with this population, to avoid contagion. To design these interventions, however, it is essential to accurately characterize this group of subjects. Given the paucity of related studies, we found the need to develop an instrument that would allow such exploration.

In developing an instrument for data collection, the researcher should be aware that the phenomena of interest must be translated into concepts that can be measured, observed or recorded. The task of selecting or developing methods for collecting data is among the most challenging in the research process. Without adequate methods for data collection, the validity of the research conclusions is easily questioned [5]. Thus, some important points should be considered throughout the process of developing an instrument for data collection: extensive review of literature and all forms of tests and measurements that address the theme, the experience of the researcher in the area to be studied, the care and monitoring of the formulation of each question regarding clarity, consistency, relevance and impartiality, and, the evaluation of the instrument by experts in the field of knowledge and testing to verify that the instrument was formulated with clarity, without bias, and that it is useful for the generation of the desired information [5 - 7]. The validation of an instrument can be understood as a methodological procedure by which the quality is evaluated, and which can be defined as the capacity of an instrument to accurately measure that which it is intended to measure, i.e., the phenomenon of concern. There are three main types of validity, namely: content, construct and criterion-related [5 – 8].

This study aimed to develop an instrument, and to analyze its content validity, for the characterization of people aged 50 or over, living with HIV/Aids, considering their sociodemographic and clinical characteristics, their health behaviors, and their beliefs and attitudes towards ongoing treatment.

METHODS

Development of the instrument

The instrument was designed after an extensive literature review [9 -13], also considering the clinical experience of the researchers. The first version was composed of 58 questions divided into four major sections, described below:

Sociodemographic characteristics: gender; marital status; religion; age; children; education; profession; how respondent occupied his time; number of people residing with the respondent; responsibility for the upkeep of the home; income; and, support in times of difficulty.

Clinical characteristics: viral load; T CD4+ cell count; disease classification; opportunistic diseases treated; current opportunistic diseases; use of antiretroviral medications; presence of other nonopportunistic diseases.

Health behaviors: habits (smoking, alcoholism or drug addiction); sexual relationships; monogomy / stable partner; current and past use of protection during sexual relations; reason for use / non-use of protection; sexual relationship with more than one person before diagnosis of HIV / Aids; and, use of medication to aid sexual performance.

Beliefs and attitudes about the disease and treatment: time and form of knowledge about contamination / disease; beliefs as to how the disease was acquired; present and past complications related to HIV / Aids reported by the patient; treatment time; treatment adherence; and, reasons for abandonment of the treatment.

Pilot test

The first version of the instrument was administered to four people more than 50 years of age who were

seropositive for HIV / Aids, and afterward the tool was redesigned in accordance with identified needs, with the collaboration of a nursing professor who had experience in developing tools for data collection.

Content Validation

The redesigned instrument was initially submitted for evaluation by seven experts who were recognized for their expertise in the area of study, or who had experience in validation of measurement instruments for the evaluation of conceptual adequacy, relevance, comprehensiveness, and clarity of the items. The panel of experts consisted of: a doctorally prepared nurse with experience in care and teaching in the area of infectious/contagious disease; a doctorally prepared nurse with experience in validation of instruments; a doctorally prepared nurse with experience in care and teaching in the area of infectious/contagious disease; a master's-prepared nurse, with experience in management of health services in the area of infectious/contagious disease, with an emphasis on management of a Day Hospital unit for HIV/Aids; a doctorally-prepared physician with experience in teaching and research in the area of infectious/contagious disease, in particular, with patients seropositive for HIV/Aids; a doctorally-prepared physician, with experience in teaching and research in the clinical area of medical/geriatrics/ gerontology; and, a doctorally-prepared linguist and university professor. The inclusion of a linguist was to verify the objective and development of adequacy of the components that made up the questions.

The experts were sent a letter, specifying the evaluation criteria and the request for review, along with a copy of the proposed instrument for data collection, and an evaluation form for each item. The material was presented personally to six experts, and mailed to one of them. Evaluations were returned to the researchers after, approximately, 25 days. The items were evaluated for clarity and relevance, not only to evaluate the comprehensiveness of the questionnaire as a whole.

After analyzing the data, the instrument was redesigned in accordance with the guidelines and suggestions from the experts, and was then returned to four out of the seven experts who worked in the area of infectious diseases and geriatrics/gerontology for a second evaluation. Revaluations were returned after approximately 30 days.

Data Analysis

The agreement among the experts for the evaluation criteria of relevance and clarity of the questionnaire was verified using the Kendall (W) coefficient of concordance which ranges from 0 to 1. High W-values ($W \geq 0.66$) [14] can be interpreted as indicating that the experts applied the same standards of evaluation. Low W-values suggest disagreement among the experts.

To incorporate the suggestions of the experts on the evaluated items of the instrument, after the first evaluation, we considered the percentage of agreement obtained in each item. Items with less than 80% agreement for any one of these evaluated criteria (relevance, clarity), were deleted or changed. We established for acceptance criteria of the items, those with discriminating power - Favorable or Unfavorable – with agreement among the experts of equal to or greater than 80%, conforming to what was encountered within the literature [10, 12, 15]. After re-structuring the instrument and the second evaluation by experts, we tested the agreement between the experts for the criteria of relevance and comprehensiveness of the items, using the Kendall (W) coefficient of concordance and the Cochran Q-test, which has the property of verifying if the opinion of the experts differed significantly, to analyze the criterion of clarity. The significance level adopted was 5%.

Ethical aspects

The research project was approved by the Committee on Ethics in Research of the Faculty of Medical Sciences, UNICAMP, in Opinion No. 275/2007 and the experts participating in the study signed a Term of Free and Informed Consent**.**

RESULTS

The first version of the instrument consisted of four main sections, namely: sociodemographic characteristics, clinical characteristics, health behaviors, and, beliefs and attitudes about the disease and the treatment they were receiving. Each section had subitems, adding up to a total of 58 questions.

In the section on *sociodemographic and clinical characteristics*, regarding the first evaluation of the instrument by the experts, the value of the Kendall coefficient was 0.231 (p-value = 0.026) for relevance and 0.114 (p-value = 0.751) for clarity. In the *health behaviors* section, the value of the Kendall coefficient was 0.143 (p-value = 0.457) for relevance and 0.102 (p-value = 0.806) for clarity. In the section on *beliefs and attitudes about illness and treatment*, the value of the Kendall coefficient was 0.241 (p-value = 0.070) for relevance and 0.251 (p-value = 0.056) for clarity. These values denote disagreement among the experts as to the clarity and relevance in the sections that comprised the first version of the instrument. This fact highlighted the need to make modifications to the instrument, according to the suggestions and comments made by experts. To proceed with the corrections, we

considered the acceptance criteria for each item, with discriminative power - favorable or unfavorable – equal to or greater than 80% agreement among the experts.

Based on the evaluation and suggestions of the experts, some items were excluded: city of residence; address; living conditions; completion of a course; condition in which the individual was in relation to work; occupation; free time activities; personal income; receipt of any financial assistance; smoking history; history of alcoholism; blank space for any final message by the respondent. Other items that had less than 80% agreement in the expert evaluation were modified, according to the suggestions made, thus obtaining the second version of the instrument which consisted of the same sections, with a total of 43 questions. In the second evaluation, using the redesigned instrument, we obtained absolute agreement among the experts for the relevant criteria in all sections of the instrument (Kendall coefficient = 1.00, p = 0.001).

With regard to the criterion of clarity, we used the Cochran Q-test (Table 1), in which a score of 1 signified that the option is *clear* and a score of -1 signified that the option was *not clear*; the items in the data collection instrument were evaluated by the experts. There was a statistically significant agreement among the experts for clarity in the sections of *health behaviors,* and *beliefs and attitudes about illness and treatment* (p = 0.392, Cochran Q-test). In the *sociodemographic characteristics* and *clinical characterstics* sections, there were differences among the experts for the evaluation criteria of clarity (p = 0.0001, Cochran Q-test). Thus, we needed an adaptation of these sections of this instrument with regard to the clarity of the questions. We incorporated the new suggestions of experts before drafting the final version to be distributed to the study population.

Both the first and second evaluation obtained agreement among the experts in regard to the comprehensiveness of the instrument (Table 2), with the Kendall coefficient of 1.00 (p = 0.001). The final instrument (Appendix 1) was distributed to a target population and formed the basis of the master's thesis prepared by the first author [16].

DISCUSSION

Data from this study reinforced the importance of using rigorous methods for the development of instruments validated by experts. Specifically in the context of this study, it highlighted the importance of the developed instrument .

The increase in the number of older people living with HIV/Aids has been reported in Brazil, as in other parts of the world. In this study, we considered the age group of 50 years or older, because the majority of studies involving people with HIV/Aids involve those up through 49 years of age. The number of people aged 50 to 60 years who are infected by the disease is considerable, which presents peculiarities regarding the manifestation of their needs, functional capabilities and cultural values [17-18]. However, we observed a lack of appropriate instruments that consider the particular and individual characteristics for these individuals. This fact was noted by the authors at the completion of the primary literature review. We did not encounter any instrument that had been constructed specifically to study this segment of the population.

Several factors guided and supported the construction and validation of the contents of the instrument, such as: the increase in the number of sexually active older people using unsafe sexual practices [19]; the use of alcohol and drugs [20]; lack of knowledge about the risks for infection with HIV/Aids and the need for prevention [21];

Table 1. Expert agreement regarding the criteria of *clarity* of the data collection instrument for patients aged 50 or older, living with HIV/Aids. Campinas, 2008.

Experts	Sociodemographic and clinical characteristics		Health behaviors		Beliefs and attitudes about the disease and its treatment	
	Not clear	Clear	Not clear	Clear	Not clear	Clear
Rjuiz1	2	17	0	13	1	10
Rjuiz2	0	19	0	13	0	11
Rjuiz3	0	19	1	12	0	11
Rjuiz4	9	10	1	12	0	11

Table 2. Expert agreement regarding the criteria of *comprehensiveness* of the data collection instrument for patients aged 50 or older, living with HIV/Aids Campinas, 2008.

Evaluated Items	Comprehensiveness - n (%)					
	Yes		No		Without Opinion	
Sociodemographic and clinical characteristics	6	(86)	1	(14)	0	(0)
Health behaviors	6	(86)	1	(14)	0	(0)
Beliefs and attitudes about the disease and its treatment	6	(86)	1	(14)	0	(0)

lack of preparation of health professionals to identify the elderly as sexually active, thereby losing an opportunity to provide necessary information for disease prevention [22]; and, prejudice and stigma (on the part of relatives and friends) towards this population, with regard to sexuality and the presence of sexually transmitted disease [19].

This study presents strong points for obeying the elements considered to be key in developing a reliable and valid instrument that is based on evidence of the problem to be assessed/measured [22]: clear definition of the target population; accurate determination of what should be measured and the purpose of each measure; determination of those items that could be measured using only one question, or requiring more than one, to meet the proposed objectives; determination of an appropriate response format for the target population; evaluation of the sequence of questons presented, conforming to the intended goals; and involvement of experts in the process of evaluating the instrument. However, it is important to note that, at this point, only the content validity evaluation is presented. In future studies, it would be interesting to assess other properties of the measurement instrument, for example, reliability using the criterion of reproducibility, i.e., the verification of proportion of agreement among the responses, when the instrument is applied to the same individual by different professionals.

This is a novel instrument within the nation. Its application will allow us to obtain important information to guide the priorities of care for patients over 50 years of age with HIV/Aids. The use of the instrument in different cultural environments will allow the comparison and identification of similar points that may become the target of collective actions aimed at improving the quality of health care and its outcomes with this group of patients, which has been, in reality, underestimated.

CONCLUSION

The instrument developed for the characterization of people aged 50 or over living with HIV/Aids was validated with respect to content, after careful revision of its items. After it was redesigned, the items were considered relevant and comprehensive by the experts (both with agreement by Kendall = 1.0; p = 0.001), which pernits it to be available for use in further studies.

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Appendix - Instrument. Characterization of individuals aged 50 or over living with HIV / Aids

1. SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS

1.1. IDENTIFICATION

1.1.1) Gender: (1) masculine (2) feminine

1.1.2) What is your marital status? (1) married (2) single (3) separated / divorced (4) widowed (5) living together (6) other. What? _____

1.1.3) What is your religion? (1) Catholic (2) Evangelical (3) Protestant (4) Jehovah's Witness (5) Do not have a religion (6) other. What? _____

1.1.4) How old are you? _____ years. **(Date of birth: ____ / ____ / _____)**

1.1.5) Do you have children? (1) no (2) yes. **1.1.5.1) How many?** _____ children

1.1.6) Have you attended school? (1) no (2) yes.
1.1.6.1) To what grade? _____ grade (____ years of study completed)

1.1.7) What is your profession? _____

1.1.8) How do you spend most of your time?_____

1.2. INCOME

1.2.1) How many people live with you? (1) living alone (2) 1 to 3 people (3) 4 to 6 people (4) more than 6 people

1.2.2) Are you primarily responsible for the upkeep of the house? (1) no (2) yes

1.2.3) **What is your household income, per month?** R$ _____ (___ minimum wages) (1) did not know (2) did not respond

1.2.4) **In times of trouble, does someone help you?** (1) no (2) yes
1.2.4.1) Who? (1) friends (2) partner (3) family (4) other _____

1.3. CLINICAL DATA

The interviewer will get the data from the patient's medical record:

1.3.1) Last result for the patient's viral load: _____ Date: _____

1.3.2) Last result for the patient's T CD4+: _____ Date: _____

1.3.3) Current rating of the disease (HIV/Aids): _____ Date: _____

1.3.4) Has had any opportunistic disease related to HIV/Aids?: (1) No (2) Yes (3) not in the record (s).
1.3.4.1) If so, what? _____

1.3.5) Currently has some opportunistic disease(s) related to HIV/Aids?: (1) No (2) Yes (3) not in the record (s).
1.3.5.1) If so, what? _____

1.3.6) Uses antiretroviral drugs?: (1) No (2) Yes (3) not in the record (s).
1.3.6.1) If so, what? _____

1.3.7) Currently presents with other nonopportunistic diseases?: (1) No (2) Yes (3) not in the record (s).
1.3.7.1) If so, what? _____

1.3.8) **Currently uses other drugs, not antiretrovirals?:** (1) No (2) Yes (3) not in the record (s).
1.3.8.1) If so, what? _____

2. HEALTH BEHAVIORS

2.1. HABITS

2.1.1) Do you smoke? (1) no (2) yes

2.1.1.1) How long have you smoked? _____

2.1.1.2) How many cigarettes do you smoke per day? _____

2.1.2) **Do you use alcohol?** (1) no (2) yes

2.1.2.1) How long have you used it? _____

2.1.2.2) How much do you drink per day? _____

2.1.3) **Do you use drugs?** (1) no (2) yes

2.1.3.1) How long have you used them? _____

2.1.3.2) What kind of drugs do you use? _____

2.1.3.3) How often do you use them per day? _____

2.1.3.4) Do you use needles and syringes? (1) no (2) yes

2.1.3.4.1) Do you share needles and syringes? (1) no (2) yes

2.1.3.4.2) Where do you get the syringes and needles for use? _____

2.2. SEXUALITY

2.2.1) Do you still have sexual relationships? (1) no (2) yes

The questions numbered 2.2.2 to 2.2.5.2.1 shall be asked of respondents who are still having sexual relationships

2.2.2) **Who is your sexual partner?**
(1) person(s) of the same gender as you (2) person(s) of different gender than you (3) person(s) of both genders

2.2.3) Do you have a stable partner? (1) no (2) yes
2.2.3.1) How long? _____
2.2.3.2) Do you live under the same roof? (1) no (2) yes

2.2.4) Do you have sexual relationships with more than one person today? (1) no (2) yes

2.2.5) Do you use any kind of protection in sexual relations today? (1) no (2) yes
2.2.5.1) What? _____
2.2.5.2) Do you have any trouble using it? (1) no (2) yes
2.2.5.2.1) What?_____

2.2.6) Before discovering you carried HIV/Aids, did you have sex with more than one person? (1) no (2) yes

2.2.7) Before discovering you carried HIV/Aids, did you use some kind of protection during sexual relationships? (1) no (2) yes
2.2.7.1) What?_____
2.2.7.2) Did you have trouble using it? (1) no (2) yes
2.2.7.2.1) What?_____

If the respondent does/did not use/wear protection in his/her sexual relationships:
2.2.8) **Why do/did you not use protection in your sexual relationships?** _____
_____

2.2.9) **Do you use some medication to help your sexual performance?** (1) no (2) yes
2.2.9.1) Which one (s)? _____
2.2.9.2) How long have you used it? _____

If the respondent uses medication to help sexual performance:
2.2.10) **Has the drug led to improvement in your sexual performance?** (1) no (2) yes
2.2.10.1) In relation to what? _____

3. BELIEFS AND ATTITUDES ABOUT THE DISEASE AND TREATMENT

3.1) How long ago did you learn that you have HIV/Aids?
(A) less than 1 year (2) 1-3 years (3) 4-6 years (4) 7-9 years (5) over 9 years (6) does not remember

3.2) How did you learn that you had HIV/Aids?
(1) during the medical consultation / collection of routine tests (2) during a hospital stay (3) during pregnancy
(4) upon request of serology tests for having had relations with a person infected with HIV/Aids
(5) What other way?_____

3.3) How do you believe you acquired HIV/Aids?
(1) sex (2) blood transfusion (3) using injection drugs
(4) other. What? _____ (5) does not know

3.4) **Have you had any complications in your health related to HIV/Aids?** (1) no (2) yes
3.4.1) What? (1) pneumonia (2) eye infection (3) diarrhea (4) problem / infection in the head (5) thrush
(6) lymphoma / cancer (7) other. What? _____

3.5) Do you currently have any health complications related to HIV/Aids? (1) no (2) yes
3.5.1) What? (1) pneumonia (2) eye infection (3) diarrhea (4) problem / infection in the head (5) thrush
(6) lymphoma / cancer (7) other. What? _____

3.6) **How long ago did you start treatment for HIV/Aids?**
(A) less than 1 year (2) 1-3 years (3) 4-6 years (4) 7-9 years (5) over 9 years (6) does not remember

3.7) With the treatment you are receiving for HIV/Aids, do you feel:
(1) better (2) neither better nor worse (3) worse

3.8) **Have you ever left treatment?** (1) no (2) yes
3.8.1) Why?_____

If the respondent has ever abandoned treatment, ask the next three questions:
3.9) How many times have you left treatment? _____
3.9.1) For how long? _____

3.10) When you stopped treatment, was there a change in your disease? (1) no (2) yes
3.10.1) What?_____

3.11) What made you return to the treatment? _____
_____