Adaptation of a Runyankore version of Skindex-16 for oral administration in Mbarara, Uganda

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Abstract

Background—Health-related quality of life instruments are typically developed and validated for use in developed countries by patients who can read and write. Little is known about the feasibility of using adaptations of validated instruments in situations where literacy rates are low.

Objective—We aimed to translate, culturally adapt, and test an oral version of Skindex-16 in Runyankore, the predominant language in Mbarara, Uganda, for use in dermatologic research.

Methods—Skindex-16 was forward- and back-translated to Runyankore. The Runyankore version was administered orally to 47 dermatology patients and 47 random hospital visitors. Additional questions regarding duration, dyspigmentation, concealment status of the skin problem, and overall quality of life effect were also asked.

Results—Oral delivery was feasible; ≤10 minutes per subject. High Cronbach α values (0.86, 0.88, and 0.85 for symptoms, emotions, and functioning subscales, respectively) demonstrated internal consistency reliability. As hypothesized, subjects with reported skin problems, dyspigmentation, and difficulty in concealment had higher mean Skindex scores. A total of 72.4% of responses to the open-ended question were addressed in Skindex-16, indicating content validity.

Conclusion—The orally delivered Runyankore version of Skindex-16 is reliable, with construct and content validity, and feasible for use in dermatology research in Mbarara, Uganda. Orally administered quality of life instruments have potential for use in low literacy groups worldwide.

Introduction

Health-related quality of life instruments are increasingly used to measure patient-centered outcomes. Most of these instruments are developed and validated in English in countries with high literacy rates.

We adapted Skindex-16, a 16-item one-page dermatologic specific quality-of-life instrument for the purposes of dermatologic research in Mbarara, western Uganda. Skindex has been

widely translated and validated in different languages across the world.[1–8] However, validation of oral delivery of Skindex in any language has not been reported to our knowledge. Oral delivery of research instruments is important in populations with low literacy rates.

The estimated adult literacy rate in Uganda in 2007 is 73.6%[9], but the figure is lower in women and in rural areas, where the vast majority of Uganda's population live. The predominant language in this region is Runyankore. Various written versions of languages in western Uganda were developed by Christian missionaries in the first half of the 20th century with standardize spelling for Runyankore established in the 1950s.[10]

Our goal was not merely to translate Skindex-16 literally but to achieve semantic and idiomatic equivalence, and adapt it to the local cultural context. We also aimed to demonstrate the feasibility, reliability, and validity of oral delivery of our translated instrument.

Methods

Guillemin et al.'s[11] proposed guidelines for translation and cross-cultural adaptation of health-related quality of life measures were used as a general guide for this study. More specific guidance was obtained from Jones-Caballero et al.'s[1] methods for the translation and adaptation of Skindex-29 from English to Spanish.

Translation

Skindex-16 was translated and back-translated by two independent translators. The back-translated version was compared with the original Skindex-16 in English by the authors. Equivalence of translation was graded as satisfactory, almost satisfactory, or doubtful. Items for which equivalence was judged as doubtful or almost satisfactory were reviewed and revised until satisfactory equivalence was achieved.

Pre-test interviews

To assure that Skindex-16 comprehensively inquires about ways in which skin conditions affect the quality of life of typical patients who speak Runyankore, clinical staff in the dermatology clinic and the research team (four dermatologists, one nurse, and two research assistants) were asked an open question "In what way(s) do the skin conditions of patients bother them?" There was consensus that patients were bothered most by itching and by effects on appearance, especially if the skin condition involved dyspigmentation and was difficult to conceal. Based on this information, we composed additional questions regarding the duration, presence of skin color change, and concealment status of the skin conditions. We also included an open-ended question "In what way(s) does your skin condition(s) bother you?"

Data collection

The instrument was orally administered by trained bilingual (Runyankore and English) research assistants to 47 consecutive patients attending a teaching hospital's dermatology clinic, as well as 47 randomly selected non-patient visitors to the hospital. The non-patient participants included persons with self-reported skin conditions ($n = 32$) and those who did not report skin conditions ($n = 15$). Research assistants were asked to adhere to the translated version of Skindex-16 and not self translate from the English version. Basic demographic information was also collected from patients, and medical records were reviewed for clinical data.

Scoring

The instrument was scored in the conventional manner. A continuous bipolar scale with seven boxes anchored by the words "Never Bothered" and "Always Bothered" at each end, were presented for each item.[12] All responses were transformed to a linear scale of 0–100, where 0 refers to no effect and 100 refers to maximum effect on quality of life. Questions in Skindex-16 inquire about the effect of skin disease on three domains: symptoms (questions 1–4), emotions (questions 5–11), and functioning (questions 12–16). The average of scores for questions in each scale, known as the scale score, was calculated.

Measurement of psychometric properties

Reliability—Internal consistency reliability was determined using Cronbach's α coefficient.[13]

Construct validity—The following hypotheses were tested to determine construct validity.

1. Participants with skin conditions would have higher Skindex scores (hence poorer quality of life) than those without skin conditions.

2. Participants who reported difficulty in concealing their skin conditions would have higher Skindex scores than those who did not report difficulty with concealment.

3. Participants who reported skin color change as a result of their skin conditions would have higher Skindex scores than those who did not report skin color change.

Statistical Analysis System (SAS® 9.0; SAS Institute Inc., Cary, NC, USA) was used for all statistical analyses. Multivariate linear regression was used to test the above hypotheses with adjustments made for age, sex, and tribal membership.

Content validity—The answers to the open-ended question "In what way(s) does your skin problem(s) bother you?" were compared with the instrument to determine to what extent it addressed the participants' concerns. This combination of qualitative and quantitative approaches has been described by Stange *et al.*[14] and used in the evaluation of the revised 29-item Skindex.[15]

Institutional review board approval from all participating institutions has been received for this study. Bilingual research assistants obtained informed consent from all participants.

Results

Translation

There were challenges with directly equivalent translations of four items in Skindex-16. These four items were revised by consensus between the translators and authors; despite this, it was not possible to achieve completely satisfactory equivalence for two items (see Table 1). There is no equivalent Runyankore word for "frustration", hence an explanation of the concept was attempted in Runyankore. Both "embarrassed" and "ashamed" translated into the same word in Runyankore. The final Runyankore version of Skindex-16 is in Table 2.

Feasibility

In total, oral delivery of the Runyankore-version of Skindex-16 took under 10 minutes, which included an explanation of how to respond to items in the instrument. None of the

participants withdrew from the study or failed to respond to items in the instrument due to lack of understanding.

Participant characteristics

Seventy-two of the 94 participants (77%) were women, and their median age was 30 years. Half were dermatology patients, and the other half were randomly selected hospital visitors (classified as non-patient participants). A significantly greater proportion of non-patient participants were women compared with patients (94% vs. 60% respectively, $P < 0.001$). The median age of non-patients was 30 years compared with 25 years in patients ($P = 0.03$). Thirty-two of 47 (68%) non-patients reported current skin conditions, and none had sought medical care. Clinical dermatological diagnoses of the patient participants are listed in Table 3. Seventeen of 47 (36%) patients had more than one diagnosis recorded.

Measurement properties

Reliability—High Cronbach α values were obtained for all three sub-scales (α = 0.86, 0.88, and 0.85 for symptoms, emotions, and functioning subscales respectively).

Construct validity—Patients had the highest mean Skindex scores in all three subscales, followed by non-patient participants with reported skin conditions and then non-patients without reported skin conditions (Table 4). The proportion of participants reporting the presence and absence of dyspigmentation was almost equal (47.9% vs. 52.1%). Participants who reported dyspigmentation had significantly higher mean Skindex scores in all three subscales than those who did not report dyspigmentation (Table 5). One in three participants reported difficulty in concealing their skin conditions. Mean Skindex scores were higher in all three subscales in participants who reported concealment difficulty, but this was statistically significant ($P \leq 0.05$) only in the symptoms subscale (Table 6).

The duration of skin conditions ranged from 0.01 to 23 years. Median duration of skin conditions in both patients and non-patients with reported skin conditions was one year (interquartile range was 2.83 and 5.65 years, respectively). There was no significant correlation between duration of skin conditions and Skindex scores in symptom, emotion, and functioning subscales ($P = 0.33$, 0.49, and 0.43 respectively). Adjustments were made for age, sex, and tribe in all the above analyses.

Content validity—Sixty-eight of 94 (72.3%) participants responded to the open-ended question "In what way(s) does your skin condition(s) bother you?" There were a total of 58 skin-related responses. Of these, 42 (72.4%) were contained in Skindex-16. Sixteen responses were not addressed in Skindex-16. Three non-Skindex responses (sores or wounds, malodor, and swelling) were mentioned by more than one participant. The other non-Skindex responses were bleeding, weeping, scarring, dry skin, change in skin texture, and discomfort exacerbated by footwear and cold weather.

Discussion

We adapted and tested a version of Skindex-16 that was suitable for oral administration to patients who speak Runyankore in Uganda. We found the instrument to be feasible to use, reliable, and to have considerable evidence of construct and content validity.

Measuring skin-related quality of life in Uganda with conventional written instruments developed in Western countries raises many challenges, including the cultural and socioeconomic context, relatively low literacy rates, and the predominance of the oral rather than written communication. Our study addresses this gap in available measurement tools,

and results provide a practical way to determine skin-related quality of life in patients for whom a written instrument developed in a Western country would not be suitable. Moreover, these findings provide a basis for further studies of both the common and unique effects of skin diseases on the quality of life of Ugandan patients.

It is essential to do pre-test interviews of clinicians and staff to understand social issues surrounding skin disease such as stigma. From experienced clinicians, we learned that issues such as skin color change and concealment likely affect quality of life, possibly because they suggest syphilis and/or HIV. These interviews helped generate hypotheses that were used to test for construct validity of the adapted instrument.

Fidelity of translation is essential for the meaningful use of instruments in new populations. Direct translation of four of 16 items in the instrument from English to Runyankore was not possible. Interestingly, there were similar problems with the translation of "frustration" and "embarrassed" into both Turkish[8] and Spanish.[1] This problem was addressed by paraphrasing and then translating the items, achieving largely satisfactory semantic equivalence. No participant failed to answer questions in the instrument due to lack of understanding.

Oral delivery of measures of patient reports must be standardized and consistent to avoid bias. To achieve this, our research assistants were asked to adhere to the translated version of Skindex-16 with every study participant. We found that with trained research assistants, oral delivery of the Runyankore versions of Skindex-16 was feasible in busy clinic settings.

Measurement properties of the adapted instrument are acceptable. Cronbach α values of 0.7–0.8 are considered satisfactory for scales used as research tools to compare between groups.[16] All three subscales of this instrument have had α values of 0.85–0.88, reflecting good internal consistency reliability. Construct validity was demonstrated by the fact that subjects responded in the way we had expected based on our prior hypotheses. Content validity was shown by the fact that the majority of responses to the open-ended question "In what way(s) does your skin condition(s) bother you?" were contained in Skindex-16.

The three most frequent responses to the open-ended question were sores, malodor, and swelling. These signs are likely associated with infections, which may account for a larger proportion of skin conditions in Uganda compared with the USA, where Skindex-16 was developed and validated. Our goal was to adapt a widely-used generic tool for dermatologic research in Mbarara, Uganda. In the future, to provide a comprehensive understanding of overall quality-of-life effects of skin diseases in Uganda, items addressing these signs and others could be appended as a supplemental module to the parent Skindex.

Interestingly, 68% of non-patient participants had skin conditions for which they had not sought medical care. Their Skindex scores were lower than those of the patient group but higher than non-patient participants who did not report any skin conditions. Seeking health care may in itself be an indicator that a skin condition affects quality of life.

The sample size was relatively small and drawn from patients and visitors of a teaching hospital and so may not be completely typical of the average Ugandan person. The study participants were relatively young adults (median age of 25 and 30 years for patient and non-patient groups, respectively). This reflects World Health Organization statistics of life expectancy of 49 and 51 years for men and women, respectively, in Uganda.[17] Also, there was a greater proportion of women in the non-patient group. The non-patient group was randomly sampled from hospital visitors, many of whom were there to care for their relatives. Women are probably more likely to be caregivers, hence the greater proportion of women in this group. Men may respond differently to quality-of-life issues as a result of

their skin conditions, and their relative lack of representation in the non-patient group may have affected the overall response profile of the group.

In conclusion, the culturally adapted and orally delivered Runyankore version of Skindex-16 is reliable and has construct and content validity. It is feasible for use in dermatology research in Mbarara, Uganda. The oral administration of Skindex-16 or any other quality of life instrument has potential to be very useful for conducting research in groups of people with low literacy levels across the world. The reliability and validity of orally administered instruments could first be evaluated in the original language of the instrument, avoiding translation difficulties. In the case of Skindex-16, further studies evaluating its oral administration in English would be valuable in assessing the effects of skin disease on quality of life in communities with low literacy rates in the USA and UK whose healthcare needs may be chronically underserved.

Acknowledgments

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Table 1

Original and back-translated versions of four items in Skindex-16 and classification of equivalence of translation

Original version	Back-translated version	Equivalence
4. Your skin being irritated	Your skin failing to get peace	Satisfactory
8. Frustration about your skin condition	Hating yourself and everything around you because of your skin condition	Almost satisfactory
9. Embarrassment about your skin condition	Feeling ashamed of your skin condition	Almost satisfactory
14. Your skin condition making it hard to show affection	Your skin condition making it hard to show your love for others	Satisfactory

Table 2

Final Runyankore version of Skindex-16 administered

Omubiri gwawe kukurya

Omubiri gwawe kukwotsya nings kukutonera

Omubiri kukushasha

Omubiri kuburwa obusingye

Okugumizamu ninga kugarukwamu oburwire bwomubiri

Okwerarikirira ahabwe embera yomubiri. *Ekyokureberaho*:

okujanjara, okweyongera kubakubi, enkojo, obutatebereza embera nebinidi

Endebuka yomubiri gwawe

Okweyanga ahabwomubiri gwawe

Okushwara ahabwomubiri gwawe

Okunyiga ahabwomubiri gwawe

Okugira enaku ahabwomubiri gwawe

Omubiri gwawe kuteganisa okukwatanisa nabandi, *Ekyokureberaho*:

Okukwatanisa nabeka yawe, banywani bawe, nabandi abanyabuzare abakuhikire, nabandi

Ekyomubiri gwawe giresire obutenda kuba nabantu

Omubiri gwewe kukuremesa kworeka okukunda

Ahabwomubiri gwawe gukozire aha mirimo yaburijo

Omubiri gwawe kukugumiza okukora ninga kukoraekyorikukunda

Table 3

Dermatologic diagnoses of patient participants

Diagnosis	Frequency
Dermatitis (including atopic, seborrheic irritant	18
Fungal infection (of skin, scalp, hair & nails)	11
Folliculitis	5
Other inflammatory skin conditions	
Acne	3
Urticaria	2
Anogenital lichen sclerosus	1
Cutaneous adverse drug reactions	1
Cutaneous lupus erythematosus	1
Cutaneous sarcoidosis	1
Viral exanthem	1
Prurigo nodularis	1
Panniculitis	1
Pityriasis rosea	1
Pityriasis versicolor	1
Psoriasis	1
Isolated lesions	
Hypertrophic scars or keloids	4
Kaposi's sarcoma	2
Pyogenic granuloma	1
Other skin infections or infestations	
Impetigo	2
Condylomata acuminata	1
Scabies infestation	1
Other skin conditions	
Acrodermatitis verruciformis	1
Cushing's syndrome due to oral corticosteroids	1
Hyperhidrosis	1
Psychogenic or senile pruritus	1

Table 4

Mean Skindex scores in patients and non-patient participants, with and without reported skin conditions

Mean (±SD) Skindex scale scores	Patients ($n = 47$)	Non-patients with reported skin conditions ($n = 32$)	Non-patients without reported skin conditions ($n = 15$)	Adjusted P values
Symptom	68.4 ± 26.0	60.1 ± 27.1	9.7 ± 13.9	<0.001
Emotion	55.0 ± 27.0	39.4 ± 26.8	6.5 ± 17.1	<0.001
Functioning	36.1 ± 30.4	31.2 ± 27.8	3.1 ± 6.5	<0.001

Table 5

Mean Skindex scores in participants who did and did not report dyspigmentation as a result of their skin condition

Mean (± SD)	Dyspigmentation (*n* = 45)	No dyspigmentation (*n* = 49)	Adjusted *P* values
Symptom scale score	72.9 ± 26.9	41.0 ± 29.1	0.034
Emotion scale score	57.2 ± 26.6	28.0 ± 27.4	<0.001
Functioning scale score	39.1 ± 29.0	20.1 ± 26.6	0.0034

Table 6

Mean Skindex scores in participants who did and did not report concealment difficulty of their skin condition

Mean (±SD)	Concealment difficulty ($n = 31$)	No concealment difficulty ($n = 62$)	Adjusted P values
Symptom scale score	68.9 ± 24.5	51.1 ± 33.5	0.023
Emotion scale score	48.9 ± 26.5	39.4 ± 31.9	0.28
Functioning scale score	35.3 ± 29.4	26.7 ± 29.0	0.43