

Translation and cultural adaptation to portuguese of a quality of life questionnaire for patients with melasma

Tradução e adequação cultural para o português de questionário sobre qualidades de vida em pacientes com melasma

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Summary

Dermatoses, mainly those with important esthetic involvement, can produce a significant impact in the social, familiar and professional life of patients. Among these diseases, melasma is distinguished by its relapsing hyperchromic macules, with disappointing therapeutic results. Considering all these features, besides the objective evaluation of the therapeutic results, the dimension of the disease influence on the quality of life is considered of similar relevance. This influence is measured by validated questionnaires, most of them written in English. Its translation and cultural adaptation are necessary steps before being applied to people whom speak other languages. This study describes the translation and adaptation to Portuguese of the quality of life questionnaires developed for patients with Melasma (MELASQoL), according to the rules established by the World Health Organization. In summary: two independent literal translations to Portuguese; review by a health professionals bilingual group; application of the first version to 10 volunteer patients that agreed to report their opinion; discussion of items and administration procedures; back-translation to English; evaluation by the original author; review by the bilingual group and formatting of the final Portuguese questionnaire. The version and routine application of the MELASQoL instrument will allow a significant improvement on the individual evaluations as well as the participation on multi center studies, producing consistent and comparable results.

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Key words: quality of life, scales, melasma, hyperpigmentation.

Resumo

As dermatoses, especialmente aquelas com envolvimento estético importante, podem ter um significativo impacto na vida social, familiar e profissional dos pacientes. Entre essas doenças está o melasma, caracterizado por manchas hipercrômicas, recidivantes e de tratamento nem sempre satisfatório. Considerando estas características, além da avaliação objetiva dos resultados das intervenções terapêuticas, a medida da influência das doenças na qualidade de vida tem relevância similar. A influência destes aspectos é usualmente mensurada por questionários validados para tal, a maioria deles elaborados na língua inglesa. Por isto, sua tradução e adaptação cultural são necessárias antes de aplicá-los a pacientes de outro idioma. Este estudo descreve a tradução e adaptação para o Português do questionário para qualidade de vida em pacientes com melasma (MELASQoL), de acordo com as regras estabelecidas pela Organização Mundial da Saúde. São elas: duas versões independentes de tradução literal; revisão por grupo bilingüe; aplicação das questões adaptadas a 10 pacientes voluntários que apresentam suas opiniões; discussão dos itens e procedimentos de administração; retro- tradução para o Inglês; avaliação pelo autor do questionário original; revisão por grupo bilingüe e elaboração do instrumento final em Português. A versão e aplicação rotineira do MELASQoL-Port possibilitarão tanto a melhora das avaliações individuais como a participação em estudos multicêntricos, produzindo resultados consistentes e comparáveis.

Palavras chave: qualidade de vida, escalas, melasma, hiperpigmentação.

The impact of diseases on the physical health, in the work performance and its implications on the familiar and personal life increase the treatment context. Thus, improvements in the quality of life become as important as the clinical-laboratorial responses to interventions, enlarging the scope of therapeutic results. Quality of life (QoL) is a term which involves many issues, including social well-being, health, family and psychosocial relationships[1, 2]. Most dermatoses are not life-threatening, but may cause a great impact in the emotional condition, social relationships and in the daily activities of patients[3]. Besides, it is common for patients and physicians to express different opinions about this influence, interfering directly in the acceptance of the treatment[4].

Most questionnaires used to evaluate the QoL were developed for English speaking populations. In consequence, they are rarely adequate in terms of correct translation or correspondence to the reality of other countries[5, 6]. So, these questionnaires have to be validated in order to be applied to the reality of each specific population. Some dermatological diseases for which QoL instruments were produced are: atopic dermatitis, psoriasis, acne, contact dermatitis, and melasma[7-14].

Atopic dermatitis has a specific validated instrument, the Quality of Life Index for Atopic Dermatitis (QoLIAD), which contains 25 items, is self-explanatory and fast to be filled[7]. In relation to psoriasis, many questionnaires were developed, such as the Psoriasis Disability Index (PDI) and the Psoriasis Life Stress Inventory (PLSI), depending on the objectives of the study, patient's characteristics and psychometric measures[8]. The newest one is the Psoriasis Index of Quality of Life (PSORIQoL), still in the stage of responsivity demonstration in clinical studies[9]. For acne, a few specific instruments were developed: the Acne Disability Index (ADI), the Cardiff Acne Disability Index (CADI)[10] and the Acne-QoL[11]. Vitiligo and contact dermatitis do not have particular questionnaires, but the interference of these diseases in the QoL have already been evaluated through the application of tests developed for other dermatoses[12-14]. This observations show the importance of the issue for dermatologists and the need to broaden the number of diseases in good analysis conditions.

Melasma or cloasma is an acquired alternation of the skin pigmentation characterized by irregular hyperchromic spots, mainly in the face[15-17]. It affects women with greater incidence in their 40s[18]. The treatment of melasma is not always satisfactory; sometimes it is incomplete and the disease is characterized by frequent recurrences[19]. Like other dermatoses, the presence of melasma lesions can produce great impact in the patient's well-being, apart from their objective extension or severity as measured by specific scales (like the Melasma Area and Severity Index-MASI). This difference,

Table 1. Reproduction of the MELASQoL scale in the original language*

<i>On a Likert scale of 1 (not bothered at all) to 7 (bothered all the time), the subject rates how she feels about:</i>
1. The appearance of your skin condition
2. Frustration about your skin condition
3. Embarrassment about your skin condition
4. Feeling depressed about your skin condition
5. The effects of your skin condition on your interactions with other people (e.g. interactions with family, friends, close relationship, etc.)
6. The effects of your skin condition on your desire to be with people
7. Your skin condition making it hard to show affection
8. Skin discoloration making you feel unattractive to others
9. Skin discoloration making you feel less vital or productive
10. Skin discoloration affecting your sense of freedom
* reproduced from reference[20].

between the clinical severity and the socio-psychological impact of the disease, clearly illustrates the need to broaden the evaluation of therapeutic results and even the whole process of conducting an individual medical consult.

The instruments of the MELASQoL (Melasma Quality of Life scale) were formulated and validated in English[20]. It allows gathering valuable information on the life impact of the pigment alteration, through a systematized form and the use of the Likert's scale of attitude measurement. From the SKINDEX-16 scale 21 and a questionnaire about skin depigmentation formulated by specialists in melasma, ten items were selected to create the MELASQoL. All the development stages of this instrument are described with more details in the original study[20]. Its population was composed by 102 female patients between 18 and 65-years. Most of the sample components had a complete high school degree (87%), 97% of them were between 31 and 65 and 64% of them did not have any other disease.

The final version of the MELASQoL has 10 questions and is reproduced in the Table 1. The score obtained in the answers varies from 7 to 70 with the higher indexes indicating the worst quality of life related to the disease. The questions proposed in this instrument have showed a high internal consistency (0,95), validity and good discriminatory power when compared with other questionnaires (DLQI, SKINDEX-16) besides separating patients in different groups. Moreover, the MELASQoL, as well as the other quality of life scales used in the study, correlated only moderately with the MASI emphasizing the idea that patients use other criteria, besides the disease severity, to evaluate its impact on their quality of life[20].

Table 2. Portuguese Version of MELASQoL***QUESTIONÁRIO DE QUALIDADE DE VIDA PARA PACIENTES COM MELASMA (MELASQOL-PORT)**

Considerando a sua doença, melasma, e na última semana antes desta consulta como você se sente em relação a:

	Nem um pouco incomodado	Não incomodado na maioria das vezes	Não incomodado algumas vezes	Neutro	Incomodado algumas vezes	Incomodado na maioria das vezes	Incomodado todo o tempo
1. A aparência da sua pele.	1	2	3	4	5	6	7
2. Frustração pela condição da sua pele.	1	2	3	4	5	6	7
3. Constrangimento pela condição de sua pele.	1	2	3	4	5	6	7
4. Sentindo-se depressivo pela condição da sua pele.	1	2	3	4	5	6	7
5. Os efeitos da condição da sua pele no relacionamento com outras pessoas (por ex: interações com a família, amigos, relacionamentos íntimos, etc.).	1	2	3	4	5	6	7
6. Os efeitos da condição da sua pele sobre o seu desejo de estar com as pessoas.	1	2	3	4	5	6	7
7. A condição da sua pele dificulta a demonstração de afeto.	1	2	3	4	5	6	7
8. As manchas da pele fazem você não se sentir atraente para os outros.	1	2	3	4	5	6	7
9. As manchas da pele fazem você se sentir menos importante ou produtivo.	1	2	3	4	5	6	7
10. As manchas da pele afetam o seu senso de liberdade.	1	2	3	4	5	6	7

* With the agreement of the original author -Rajesh Balkrishnan[20].

The objectives of this study were to translate and to adapt to Portuguese the MELASQoL questionnaire, refining its terms and adapting it to our culture.

Methods

The Portuguese version of the MELASQOL followed the stages established by the World Health Organization[5]. Initially, two translators prepared independent literal transla-

tions of the instrument. These versions were reviewed by a bilingual group (BG) composed by dermatologists, a psychiatrist, a nurse and Medicine students, in order to select the most adequate terms and to elaborate only one questionnaire from the two initial translations. The resulting version of this stage (Version 1) was applied to volunteer melasma patients that agreed to participate and to present their opinion about the text; two researchers had to register the comments, doubts and suggestion. After, the BG discus-

sed the items and procedures of application and finished the Version 2 in Portuguese. This was back-translated to English by a translator different from the two first ones and submitted to the author of the original questionnaire (Balkrisnann R) for his review and comments. In the last stage, the alterations requested by the author of the instrument were inserted, and the items with at least 70% of agreement were considered adequate and composed the Final Version.

Results and Comment

As the questionnaires must be self-applicable, the contribution of volunteer-patients was very important to clarify their meaning. Most of the patients have suggested a few changes to enhance the text understanding. The most important were related to the table format and the answers presentation. Besides, the lack of an introductory phrase for the questions was cited as a confusion factor by all the interviewees. So, these suggestions were inserted in the instrument final version.

Patients under treatment reported difficulties in discriminating if they should answer the questions based on the real moment or on the one previous to the beginning of medication. They also asked for space to add personal comments, showing the need to express their opinions.

Concerning to the questions, the comprehension of number 10 was affected probably because the expression "sense of freedom" has a greater and defined meaning for the original study population. This was taken into consideration in the translation, but there was some difficulty in modifying the question without changing the sense proposed by the authors of the original instrument.

In relation to the answers, most interviewees defined them as "too similar" or of difficult distinction, and that "it is

necessary to pay much attention". But, after a detailed reading, everybody answered the whole instrument in approximately 6 minutes with no doubts. Maybe the small number of questions eases the quick application of the questionnaire, even with the need of giving more attention to the answers.

Considering the analyses of the original and back-translated versions, small differences in relation to the terms and to the grammar construction were observed, not interfering in the meaning of questions or answers. The final version in Portuguese, considered adequate for the routine use, is found in Table 2.

The systematic development of a Portuguese version for the MELASQOL will provide an expressive help and an increase in the accuracy of measurements for clinical studies. The possibility of applying it to the population of Portuguese speaking countries, where the incidence and prevalence of melasma are probably very high, will allow our participation in global evaluations, preserving our own cultural identity.

Conclusions

The translation of a questionnaire must be faithful to the original instrument, but its cultural adaptation allows the authors to formulate small alterations without interfering in the primary meaning. The evaluation of the quality of life in melasma patients, by means of a dermatosis specific instrument, could bring a new comprehension of the results of different treatments. However, validating the MELASQOL among Portuguese speaking people is still required. For this, large populations of different regions have to participate. The experience of the individual application of this version by different observers will allow the necessary adaptations and will contribute for its refinement.

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