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The Rheumatoid Arthritis Quality of Life (RAQoL) for Indonesia: Translation and Pilot Test

Khoirunnisa, S.M.[1], Perwitasari, D.A[2]

***Abstract*—** The primary objective of this research were to produce and evaluate the official Indonesian language version of the Rheumatoid Arthritis Quality of Life instrument (RAQoL). The UK RAQoL was translated into Indonesian by a forward-backward translation. A separate lay panel was conducted to consider the appropriateness and comprehensibility of the items in Indonesian. The translated version of the RAQoL was pilot tested to determine whether the questionnaire RAQoL could be well understood and well accepted. Pilot test was conducted by interviews with 20 subjects, which 10 healthy Indonesia people and 10 rheumatoid arthritis patients who were recruited from X hospital in Yogyakarta, Indonesia. Items on the two response format questionnaire used in pilot study were scored one for a 'yes' response and zero for a 'no' response. The individual total item scores with a high score indicating poor QoL. Few difficulties arose in the translation process and the new language version was well received by the lay panel and field-test participants. Statistical analysis was conducted to determine the difference of completion time between healthy subjects and RA patients, and the total score of the questionnaire answers between healthy subjects and patients. The average total score of responses to questionnaire on the healthy subject and patients by T test was significantly different ($p < 0.05$). The official Indonesian RAQoL was well received by RA patients. The psychometric quality of the translated questionnaire means that it is suitable for validity and reliability of the questionnaire towards patients with RA.

***Keywords*—**Rheumatoid Arthritis, questionnaire, RAQoL, translation, pilot test

I. INTRODUCTION

Rheumatoid arthritis is an inflammatory disease of unknown origin that affects 1% of the adult population. The disease is characterized by inflammation of the synovium, progressive bone erosions, joint destruction, and weakness in the surrounding area and muscle tissue. Data in 2007 showed that in Indonesia, the prevalence of RA was 32.2% with the highest prevalence simultaneously there were in the province of West Java, West Papua and East Nusa Tenggara with rheumatic largest proportion distribution contained in the province of West Java, Central Java and Java East. RA usually occurs at age 30-55 years , and mostly experienced by women. The disease attacks people of all ethnics, with the incidence in people aged over 18 years ranges from 0.1 percent to 0.3 percent, whereas in children and adolescents less than 18 years of as much as 1/100,000. It is estimated that the prevalence of RA suffered at the age of 18 years and ranges from 0.1% to 0.3% of the total population of Indonesia [1-3].

This disease has an impact on the patient's functionality with different ways. Pain dominates in the early stage, with functional limitations and tiredness, which are associated to the inflammatory processes. In more advanced stages, persistent inflammation lead to joint destruction, deformity and dysfunction. The goal of therapeutic interventions in rheumatoid arthritis "is not only to improve symptoms and functional status, but also to improve quality of life of patients. To assess quality of life in patients with RA properly, required an instrument that is intended for patients with RA, disease-specific, reliable, valid, and responsive to changes in quality of life following the intervention and practical for use in clinical trials [4]. Quality of life according to the World Health Organization (WHO) is the perception of a person in the context of the culture and norms that correspond to a person's life as well as related to the goals, expectations, standards and concerns during his lifetime [5].

In the beginning, quality of life measurements for patients with RA were carried out with instruments designed with a focus on other diseases and subsequently adapted. Eventually the need to have specific instruments became more evident. In 1997 Whalley et al performed an analysis with indexes used up until then, including the Arthritis Impact Measurement Scales (AIMS and AIMS2), the MOS 36-Item Short Form Health Survey (SF-36), the EuroQoL, the Sickness Impact Profile (SIP) and the SEIQoL. Unsuitable methodological aspects were observed these scales, prompting the development of a new instrument called "Rheumatoid Arthritis Quality of Life Scale (RAQoL)". The RAQoL was brought about through direct free-form interviews with RA patients. This application was simultaneously conducted in 2 countries (United Kingdom and Holland) to reduce cultural bias, and has a good validity and realibility, and well accepted by RA patients. The RAQoL is a questionnaire consisting of 30 elements that assess different aspects of the quality of life in people suffering from RA [4, 6].

Research on quality of life in patients suffering from chronic diseases in Indonesia is still very limited, especially in patients with RA. This is due to the unavailability of quality of life questionnaire that has been validated in the Indonesian version.

[1]Department of Pharmacy, Faculty of Science, Institut Teknologi Sumatera, Jalan Terusan Ryacudu, Way Huwi, Jati Agung, Way Huwi, Lampung Selatan, Kabupaten Lampung Selatan, Lampung 35365, Indonesia.
[2]Departement of Pharmacy, Faculty of Pharmacy, Jl. Prof. Dr. Soepomo, S.H., Janturan, Warungboto, Umbulharjo, Yogyakarta 55164, Indonesia
[*]Correspondence, email: sudewi.mukaromah@itera.ac.id Tel.:+62-8137-9082833

RAQoL instruments have been used and adapted in the RA population in Turkey, Canada, Estonia, Autralia, and Sweden [7]. Although RAQoL has been used in various countries, in Indonesia is not available yet. This article describes the process of translation RAQoL for use in the Indonesian population and includes results produced by the translation panel and pilot test. Therefore, the purpose of this research is to translate RAQoL into Indonesian version in RA patients that after a pilot test, the questionnaire can be followed on validity and reliability test of the instrument.

II. Subject and Methods

This study was an observational study with survey method, which uses questionnaire as the main instrument to collect data. RAQoL questionnaire translated into Indonesian by the forward-backward translation method

A. Translation Procedures (Step 1)

RAQoL questionnaire in English version was translated into Indonesian to produce a good translation, appropriate and acceptable to the people of Indonesia. The forward translation of RAQoL questionnaire in English version into Indonesian did by two experts in the English Department separately and coordinator of the study comparing the two translations and check for any differences between the results of two translations. The differences were discussed with the translators until we agreed on the single provisional forward translation. Modifications were made in this draft to diminish discrepancies and it was adjusted with a view to the habits of Indonesian people. The result for the forward translation was then back translated by two native speakers of English independently. The questionnaire has been translated into English and then compared with the original questionnaire to ensure no different meanings of the questions in the questionnaire. The differences were discussed and resolved until agreement within the translation group.

B. Pilot Test (Step 2)

Pilot test was performed to determine whether the questionnaire RAQoL can be well understood and well accepted by rheumatoid arthritis patients. The translated version of the RAQoL was pilot tested in 20 patients, who were recruited from X hospital in Yogyakarta, Indonesia. Inclusion criteria for the pilot test were: rheumatoid arthritis patients and healthy people; aged 18 years or older; ability to read and write standard Indonesian; and willing to participate in the study. The Indonesian version of RAQoL was distributed to the rheumatoid arthritis patients and to the healthy people. Any difficulties that the patients had experienced with the questionnaire were recorded by the researcher during the time the patients completed the questionnaire. The patients' obstacles in understanding and completing the questionnaires were reviewed and used to modify the questionnaires by the translation group.

C. Statistical analysis (Step 3)

Items on the two response format questionnaire used in pilot study were scored one for a 'yes' response and zero for a 'no' response. The overall score was the sum of the individual item scores with a high score indicating poor QoL. The version RAQoL instrument produced ordinal level scores and consequently, non-parametric statistics were applied. The data were analysed using the Statistical Package for the Social Sciences

III. Result

Step 1: Translation and Back-Translation

Translation stage RAQoL questionnaire was translate the questionnaire with the objective that the questionnaire was easy to understand and can be used to Indonesian's habits and occupations. In this research, translation RAQoL questionnaire was translated from English to Indonesian. RAQoL questionnaire was conducted by Forward and Backward Translation. In the forward translation, the questionnaire was translated from English to Indonesian by 2 expert English separately until generated two questionnaires RAQoL Indonesian version. The next two questionnaires RAQoL Indonesian versions are combined and views for compliance by the coordinator of research into one questionnaire RAQoL Indonesian version. One version of the questionnaire is then carried backward translation by 2 native speakers separately and obtained two versions of the questionnaire backward translation.

Two versions of the questionnaire were subsequently consulted with one of the experts in English to their compatibility translation results then obtained one version of the backward translation questionnaire. The result of backward questionnaire then compared with a original questionnaire to be seen whether there are words whose meaning is different between the two versions of the questionnaire. In this study, there were several different words as "tired" in the original version of the questionnaire, whereas in the backward version of the questionnaire translation becomes "exhausted". There were some differences in the back-translations of the questionnaire but the translators had the opinion that the differences would not change the meaning of word, because the Indonesian language has less vocabulary than the English language.

Step 2: Pilot Test

Twenty people (10 healthy people and 10 rheumathoid arthritis patients) were enrolled in the pilot test. The age range for the healthy people varied from 19 to 45 years with a mean of 32.88 years (SD = 7.77), the age range of rheumathoid arthritis patients varied from 34 to 47 years with a mean of 41.44 years (SD = 4.53). The average completion time of translated version of the RAQoL were 3.9 minutes (SD = 1.66) for healthy people and 4.9 minutes (SD = 0.74) for rheumathoid arthritis patients. Most patients were able to fill out the questionnaires by themselves, except for items 16 and 29, where the patients needed an explanation about the meaning of the QoL in the less formal language style. Generally, the subjects asked about the meaning of QoL or asked to the researcher to give a short description about QoL.

Step 3: Statistical Analysis

Statistical analysis to determine whether there are differences in the time to fill out questionnaire and the total score of the questionnaire answers between healthy subjects and patients. From the analysis has founded that the average of questionnaires completion time by healthy subjects was 3.9

minutes, while the completion time by the patients was 4.9 minutes. The results T test showed that the difference in the average of RAQoL questionnaire completion time between healthy and patients was significantly difference ($p < 0.05$) . The average total score of responses to questionnaires on the healthy subject and patients by T test was significantly different ($p < 0.05$) . The post test results was shown in Table 1.

Table 1. The Post Test Result of RAQoL Questionnaire by t Test

	The Average of Completion time (minutes)	*p*	*The Average of Total Score*	*p*
Healthy Subjects	3,9	0,00	7	0,00
Patients	4,9		7	

Post test results indicated that the questionnaire RAQoL Indonesian version can be used by the Rheumathoid Arthritis patients and sufferers to do the validation test.

IV. Discussion

Clinicians and policy makers are growing increasingly aware of the importance of measuring QoL. In the past decade, patient completed questionnaires have been introduced to clinical trials in RA. The most frequently used instruments are the Arthritis Impact Measurement Scales (AIMS), NHP, EuroQoL, and MOS 36-Item Short Form Health Survey (SF-36) and the limitations of these have been reviewed elsewhere. Although such instruments were developed for different purposes, they are all commonly referred to as measures of QoL. However they actually assess health status (or health state preferences in the EuroQoL) as they cover impairments, disabilities and to a limited extent handicap, as defined by the World Health Organization. Tennant and McKenna and Heinemann and Whiteneck have recently shown that QoL measurement goes beyond such constructs by assessing the impact of health status on the individuals, and the interactions between health status and other influences on their lives. In the development of the RAQoL, Hunt and McKenna's model was adopted in which QoL is defined as the extent to which RA interferes with the patient's ability to fulfill his or her needs [4].

A disadvantage of some of the currently used health status measures is that they are comprised of subscalesor sections that cannot validly be combined into an index. A profile makes the assessment of change following an intervention more difficult to interpret. Furthermore, an index is essential for incorporation into certain types of economic analyses [4].

The commonly used generic health status measures were designed for use in population studies. In the absence of an RA-specific QoL instrument, these generic measures have been employed as outcome measures in clinical trials. However, as such instruments were intended to be applicable to a wide range of diseases, they include irrelevant items and omit important areas for RA patients, reducing their responsiveness. This, together with their relatively poor reliability, limits their value in clinical trials [4].

The only arthritis-specific health status instrument commonly used in clinical trials is the AIMS. Its content was derived from existing measures and represents the opinion of experts rather than patients. The instrument is limited in terms of its sensitivity to change and its practicality for clinical practice. The AIMS is arthritis specific rather than RA specific and, consequently, omits certain issues of importance to RA patients.

The RAQoL is the first patient-completed instrument specifically developed for use with RA patients. It consists of 30 items derived directly from relevant patients, using, as far as possible, their own words. Respondents are required to indicate whether or not each of the items applies to them. Scores can range from 0 to 30, with a high score representing poor QoL. It was developed simultaneously in The Netherlands and the UK with items that could only be expressed in one of the languages or that were not applicable to both cultures omitted from the questionnaire. Consequently, adaptation of the RAQoL into additional languages will be facilitated [6].

The development of the RAQoL brought to light some aspects patients, indicated as relevant in the impact of RA, such as mobility limitation, loss of dexterity, frustration, depression and anger, and feelings of humiliation or embarrassment at having to ask for outside help for some tasks. Patients referred to difficulty in concentrating, tiredness and severe interference from the illness in social and family activities. All these aspects are assessed by RAQoL. The syntax and relevance of the questions was well received by the patients and gives it suitable validity regarding aspect and contents. The methodology used in the translation of the British English RAQoL to Indonesian utilized a pre-established methodology comparable to previous translation of RAQoL to other English versions (Canadian, Australian) [8,9] or other languages (Estonian, Swedish, Turkish, Dutch) [10-13]. The user acceptance parameters are very similar.

The RAQoL is a practical instrument, taking only 4 to 5 min to complete. It is easy to administer and score, with the total score being the number of items affirmed. As such, the instrument is suitable for use in Indonesian. Post test results indicate that the RAQoL Indonesian version can be used by the Rheumathoid Arthritis patients and sufferers to do the validation test.

V. Conclusion

RAQoL questionnaire in Indonesian version is suitable and suggested to do validation and reliability test.

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