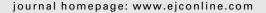


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Translation and validation of the EORTC QLQ-C30 for use among Turkish and Moroccan ethnic minority cancer patients in the Netherlands

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ABSTRACT

The purpose of this study was to validate the core EORTC quality of life questionnaire, the QLQ-C30 (version 3.0), for use among Turkish and Moroccan cancer patients in the Netherlands. The questionnaire was translated into two oral Moroccan languages , and the existing Turkish version was culturally adapted for use in the Netherlands. Ninety Turkish and 79 Moroccan patients completed the questionnaire. Administration of the questionnaire proved feasible, with low levels of missing questionnaires (4%) and missing items (on average, 1.5–2.4%). With one minor exception, the evidence of convergent validity was strong for all multi-item scales. Internal consistency reliability was above 0.70 for all scales except the cognitive functioning scale in the Turkish sample. The questionnaire was able to distinguish clearly between subgroups formed on the basis of performance status and comorbidity, and was moderately responsive to change over time in performance status. These data support the use of the QLQ-C30 among Turkish and Moroccan cancer patients residing in the Netherlands. Additional studies are needed to confirm the psychometrics of the questionnaire when used among these ethnic minority groups residing in other Western European countries.

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1. Introduction

There are currently approximately 2.8 million Turkish and 1.2 million Moroccan immigrants living in West-Europe. Turkish and Moroccan migrants came in large numbers in the 1960s and 1970s, and were later followed by their family members. The original cohort of immigrants was relatively young at the time of migration. However, it is now reaching the age at which the incidence of chronic diseases, including cancer, rises sharply. Although, in general, interest in assessing the

perceived health status and health-related quality of life (HRQL) of patients with cancer has increased dramatically in recent years, this has lagged behind in the case of Turkish and Moroccan patients. This can be attributed primarily to the fact that the majority of first generation Turkish and Moroccan immigrants do not speak the language of their host countries, and thus they are not able to complete HRQL questionnaires in the available Western European translations. Additionally, high levels of illiteracy among these immigrant populations necessitates careful consideration of the

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feasibility of collecting HRQL data, both with regard to the content of the questions being posed, and the mode of administration of questionnaires (oral versus written).

The European Organization for Research and Treatment of Cancer (EORTC) has been at the forefront in developing HRQL questionnaires for use in cross-cultural oncology. The core EORTC HRQL questionnaire, the QLQ-C30, has been internationally validated, ^{2,3} and is currently available in more than 48 languages (www.eortc.be). However, the QLQ-C30 has not been translated into Moroccan languages, and the Turkish version ⁴ has not been investigated among Turkish immigrants living in Western Europe. This is important in that the majority of Turkish immigrants came from rural areas of Turkey where educational and literacy levels are lower than those in the country as a whole.

The aims of the current study were: (1) to translate the English language version of the QLQ-C30 (version 3.0)³ into two oral Moroccan languages (Moroccan-Arabic and Tarifit) for use among Moroccan cancer patients living in the Netherlands; (2) to culturally adapt the Turkish language version of the QLQ-C30 for use among Turkish cancer patients living in the Netherlands; and (3) to assess the psychometric properties of these translations, specifically in terms of the replicability of the original scale structure, internal consistency reliability, known groups validity, and responsiveness to change over time.

2. Patients and methods

Translation and cultural adaptation of the EORTC QLQ-C30

The EORTC QLQ-C30 is a 30-item questionnaire composed of nine multi-item scales and six single items that reflect the multidimensionality of the quality-of-life construct.^{2,3} We followed the EORTC guidelines for the forward-backward translation of the English language version of the QLQ-C30 into two Moroccan languages. 5 As only well-educated Moroccans have a good command of the official language in Morocco, Standard-Arabic, we translated the questionnaire into two oral languages commonly spoken among Moroccans in the Netherlands: Moroccan-Arabic and Tarifit. The Moroccan-Arabic translation was generated in phonetic Arabic script. As the Tarifit language (spoken by Rifberbers in northern Morocco) has an original ancient script that is not well known and rarely used, we generated the translation in the more commonly used Latin script. The Moroccan language versions were developed for oral administration. For both Moroccan versions we produced a male and a female version, as the grammar in these languages depends on the sex of the respondent. Finally, audiotaped versions of the two Moroccan translations were produced for purposes of interviewer training.

Due to the high level of illiteracy among the first generation of Moroccans in the Netherlands⁶ it was necessary to modify several of the questions slightly. Item 20, which queries about 'difficulty in concentrating on things like reading a newspaper or watching television' was changed to '...listening to the radio or watching television'. Some words could not be translated literally into the Moroccan languages; nor could

they be replaced with a proxy equivalent or a short description. For example, there are no Moroccan-Arabic equivalents for the words 'hobby' or 'quality' (as in 'quality of life'). In these cases, a Standard-Arabic word was used.

The EORTC procedure for cultural adaptation⁵ was applied to adapt the Turkish language version of the QLQ-C30 for use in the Netherlands. This involved using slightly different wording, where appropriate. For example, the description of vomiting in the Turkish version of the questionnaire 'kustunuz mu?' or 'Did you throw up?' was changed to 'istifra ettiniz mi?' "Did you vomit".

2.2. Patient recruitment

Between May 2000 and September 2002 Turkish and Moroccan cancer patients were recruited from seven outpatient oncology clinics in four cities in the Netherlands. Consecutive patients were eligible if they were at least 18 years old, had a life expectancy greater than 6 months, were diagnosed with cancer after 1985, and were still under medical supervision. Patients or one of their parents had to have been born in Turkey or Morocco. Finally, they had to be proficient in Moroccan-Arabic, Tarifit or Turkish, irrespective of their proficiency level in Dutch.

Eligible patients were invited to participate by a bilingual letter followed by a personal invitation (by phone or in the waiting room) by one of the bilingual, female research assistants. The study was approved by the local ethical committees of the seven participating hospitals.

2.3. Instruments and procedures

Patients completed the QLQ-C30 questionnaire together with three other HRQOL questionnaires (the SF-36, the COOP/WON-CA Charts, and the Rotterdam Symptom Checklist) in random order. For Turkish patients the questionnaires were either self-administered or administered in the form of an interview, depending on the preference of the patient. For Moroccan patients the questionnaires were administered orally. The research assistants made notes when patients had any comments or clarification of an item was needed. The QLQ-C30 was assessed twice with an interval of 3 months.

Data on diagnosis, stage of disease, and treatment were retrieved from the hospital medical records. Demographic data and information on comorbidity, literacy, experience with surveys, and patient's judgement of their proficiency in Dutch was obtained from the patients. Performance status was assessed by the research assistant using the Karnofsky performance status scale (KPS).⁷⁻⁹

2.4. Statistical analysis

Scores on the items and scales were linearly transformed to a scale from 0 to 100. A higher score on the functional scales (PF, RF, CF, EF, SF, GQL) corresponds to a higher level of functioning, while a higher score on the symptom scales or items (FA, NV, PA, DY, SL, AP, CO, DI, FI) correspond to more symptoms.

Descriptive statistics were generated to evaluate missing data, items for which explanations were provided, score

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