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There is an increasing need for questionnaires to assess the health-related quality of life of Turkish and Moroccan cancer patients in the Netherlands (chapter 1). The first generation of Turkish and Moroccan immigrants was relatively young at the time of migration, but is now reaching the age at which the incidence of chronic diseases, including cancer, rises sharply. However, Turkish and Moroccan immigrants are often excluded or underrepresented in health-related quality of life studies because they do not have adequate command of Dutch, and the available questionnaires are not available or validated in their mother tongues.

This thesis aims to contribute to the participation of Turkish and Moroccan ethnic minority cancer patients in health-related quality of life research in oncology. The primary objectives are to: 1) translate two cancer specific and two generic health-related quality of life questionnaires for use among Turkish and Moroccan cancer patients; 2) assess the psychometric properties of these questionnaires when employed among the Turkish and Moroccan cancer population; 3) determine the viability of employing Dutch speaking proxies, e.g. relatives, of Turkish and Moroccan patients as a proxy source of information on the patients’ health-related quality of life; and 4) determine and attempt to resolve the methodological and practical barriers involved in conducting health-related quality of life studies among these two groups.

Two generic questionnaires, the SF-36 and COOP/WONCA charts, and two cancer specific questionnaires, the EORTC QLQ-C30 and Rotterdam Symptom Checklist, have been translated. The validation of only the first three questionnaires is presented.

The first and second objectives are addressed in chapters two to five, the third objective in chapter five, and the fourth objective in chapter six. In chapter seven the results are discussed.

A summary of the chapters is given below.

In chapter 2 the psychometric properties of the cancer specific EORTC QLQ-C30 (version 3.0) questionnaire are presented. The questionnaire was translated into two Moroccan oral languages: Moroccan-Arabic and Tarifit. The Turkish version - from Turkey - was linguistically and culturally adapted for use in the Netherlands. Ninety Turkish and 79 Moroccan cancer patients completed the questionnaire. The following psychometric properties were assessed: feasibility, internal consistency reliability, validity and responsiveness. Feasibility was analyzed by descriptive statistics; internal consistency was analyzed by calculating Cronbach’s $\alpha$; validity was assessed by multitrait scaling analysis, interscale correlations and known groups comparisons; and responsiveness was analyzed by comparing the QLQ-C30 change scores with changes in the scores of the Karnofsky Performance Status Scale.

Feasibility of the QLQ-C30 proved good, with normal administration time, low levels of missing questionnaires and missing items. The feasibility appeared to be better in the Turkish group than in the Moroccan group.
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Internal consistency was satisfactory for all scales except the Cognitive Functioning scale in the Turkish sample and Moroccan-Arabic language subgroup, and the Nausea/Vomiting scale in the Moroccan-Arabic language subgroup.

Validity: The hypothesized scale structure, using multitrait scaling analysis, was largely confirmed. The convergent validity was strong for the multi-item scales. Interscale correlations were generally satisfactory; although the Cognitive Functioning with Emotional Functioning and Physical Functioning with Fatigue scales seemed to be related. In the known groups analysis, the questionnaire was able to distinguish clearly between subgroups formed on the basis of performance status, and in the Moroccan group also for comorbidity, but it could not distinguish between stages of disease and status of treatment in this study.

The QLQ-C30 showed moderate responsiveness to change over time in performance status.

In conclusion, these data support the use of the QLQ-C30 among Turkish and Moroccan cancer patients residing in the Netherlands. Additional studies are needed using larger samples of patients in active treatment in order to confirm the known groups validity and responsiveness.

In chapter 3 the psychometric properties of the generic SF-36 questionnaire (version 1.0) for use among cancer patients are presented. The questionnaire was translated into two Moroccan oral languages: Moroccan-Arabic and Tarifit. The Turkish version from Turkey was linguistically and culturally adapted for use in the Netherlands. Ninety Turkish and 79 Moroccan cancer patients completed the questionnaire.

The following psychometric properties were assessed: feasibility, internal consistency reliability, validity and responsiveness. Feasibility was analyzed by descriptive statistics; internal consistency was analyzed by calculating Cronbach’s α; validity was assessed by multitrait scaling analysis, interscale correlations, known groups comparisons, and differential item functioning in relation to indigenous Dutch cancer patients; and responsiveness was analyzed by comparing the SF-36 change scores with changes in the scores of the Karnofsky Performance Status Scale.

The feasibility was acceptable. The average time required to complete the SF-36 was almost 20 minutes. This is about twice as high as reported in other studies of this questionnaire. Normal levels of missing questionnaires (4%) and missing items were found: on average 3.2% items in the Turkish and 4.4% items in the Moroccan sample. In the Moroccan group more missing items and words that required explanation were observed.

Internal consistency was satisfactory for all scales, with the exception of the Vitality scale in the Moroccan sample and Tarifit language group, the Social Functioning scale in the Turkish sample, and the General Health scale in the Turkish and Moroccan samples and Moroccan-Arabic language group.

Validity: The multitrait scaling analysis showed overall good results, although the General Health, Mental
Health and Vitality scales exhibited some problems. Interscale correlations were good. In the known groups analysis, the questionnaire was able to distinguish clearly between subgroups formed on the basis of performance status, and in the Moroccan group also for comorbidity, but it could not distinguish between stages of disease and status of treatment in this study. Some evidence of differential item function was found in both ethnic groups. Clear differential item functioning was found for the Physical Functioning item ‘vigorous activities’ in both ethnic groups. The SF-36 demonstrated reasonable good responsiveness to change over time in the Turkish group, but moderate to poor responsiveness in the Moroccan group.

In conclusion, these results support the use of the SF-36 among Turkish and Moroccan cancer patients in the Netherlands. We recommend additional studies with larger samples of patients in active treatment to examine the responsiveness in the Moroccan patient population.

In chapter 4 the psychometric properties of the SF-36 for use among a general ‘healthy’ Turkish and Moroccan population, compared to the general indigenous Dutch population, are presented. Data were derived from the Second Dutch National Survey of General Practice. In total, SF-36 data were available for 409 Turkish, 377 Moroccan and 9,628 Dutch respondents. The analyses were conducted on two levels: first, for the total Turkish and total Moroccan sample, regardless of the Moroccan language versions of the SF-36 that were used; and second, for subgroups of the Turkish (n=162) and Moroccan-Arabic (n=52) language versions of the SF-36.

The following psychometric properties were assessed: feasibility, internal consistency reliability and validity. Feasibility was analyzed by descriptive statistics; internal consistency was analyzed by calculating Cronbach’s $\alpha$; validity was assessed by factor analysis, known groups comparisons, and differential item functioning in relation to indigenous Dutch cancer patients. The SF-36 proved to be feasible, with very low levels of missing items and no missing questionnaires observed in both ethnic groups. Internal consistency was satisfactory for all scales, except for the Vitality scale in the Moroccan group and Vitality and Social Functioning scale in the Moroccan-Arabic language subgroups. Confirmatory factor analysis supported the hypothesized SF-36 scale structure for the Dutch and Turkish groups, but high correlations between the mental health and vitality factors were observed for the Moroccan group. The only item that did not fit well was Vitality-item ‘full of pep’ in the Moroccan group. Known groups validity was found to be satisfactory across samples using age, sex, education and comorbidity as grouping variables, but not using marital status. Some evidence of differential item functioning was found in both ethnic groups.

In conclusion, these results support the use of the SF-36 for general population research among Turkish
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and Moroccan ethnic minorities in the Netherlands. Additional studies are recommended to confirm the psychometrics of the questionnaire when used among these populations in other Western European countries.

In chapter 5 the psychometric properties of the COOP/WONCA charts, and the patient-proxy agreements of the charts, are presented. The charts were translated into Turkish and two Moroccan oral languages: Moroccan-Arabic and Tarifit, and were administered to patients. The Dutch version of the COOP/WONCA charts were administered to the proxies. Ninety Turkish patients with 36 proxies and 79 Moroccan patients with 21 proxies participated in the study.

The following psychometric properties were assessed for the patient group: feasibility, validity and responsiveness. Feasibility was analyzed by descriptive statistics; validity was assessed by correlations to conceptually similar scales of the SF-36 and known groups comparisons; responsiveness was analyzed by comparing the COOP/WONCA change scores with changes in the scores of the Karofsky Performance Status Scale and Subjective Significance Questionnaire outcome. Patient-proxy agreement was analyzed at group level with the paired Student’s t-test and at individual level with proportions of agreement.

The feasibility was good. A few missing items were observed. Evidence of construct validity based on comparisons with the SF-36 was relatively strong, especially in the Turkish group. The known groups validity of the COOP/WONCA Charts was moderate. The charts showed a clear distinction between subgroups formed on basis of performance status and in the Moroccan group also on comorbidity, but not between stages of disease and status of treatment.

The COOP/WONCA charts showed moderate responsiveness to change over time in the Turkish group and poor responsiveness in the Moroccan group. The charts Overall Health and Social Activities showed best responsiveness, which is in line with previous studies. Patient-proxy agreement at the group level was relatively high for all domains, except pain. Fifty-four percent of the proxies systematically underestimated patients’ pain. On average, proxies underestimated patient pain by 17 points on a scale from 0 to 100. This is in contrast to other studies where proxies tend to overestimate patients' pain. Agreement at the individual level was poor. A relatively high percentage of large discrepancies was found: on average the proxy and patient deviated by more than two response categories. Therefore proxy ratings may be appropriate at the group level, but not at the individual level.

In conclusion, the results provide relatively strong support for the use of the translated COOP/WONCA charts. However, additional research is required to examine the responsiveness in the Moroccan patient population. Proxy COOP/WONCA chart ratings may be appropriate at group level, but not at individual level. Chapter 6 presents the methodological challenges and practical barriers that were encountered in this quality
of life study among Turkish and Moroccan ethnic minority cancer patients, in relation to the translation of the questionnaires, recruitment of patients and ethical issues surrounding the interviewing of cancer patients. The main problem encountered in the translation process was achieving semantic equivalences in the Moroccan spoken languages, for which loanwords from related languages were imputed. For evaluating the quality of the translation work it is essential to have native speakers of the target languages available to the research team. Problems encountered during the administration of the questionnaires involved the use of these loanwords. Additional problems were the use of numerical rating scales, use of distances, lengthy questions and response scales, and culturally sensitive and inappropriate questions. For using these questionnaires, the researcher should invest in selective recruitment of research assistants, as the quality of the questionnaire assessment in an interview setting for oral languages depends highly on the eligibility and training of research assistants.

The identification of patients was hampered by privacy laws that prohibit hospitals from registering the ethnicity of patients. Therefore Turkish and Moroccan patients were identified by surnames. Recruiting patients to the study was often difficult due to low literacy levels, lack of familiarity with and distrust of research, not keeping appointments, and inaccurate or missing contact information. This led to lower response rates than is the case with the population of indigenous Dutch cancer patients. In future research, the researcher should anticipate the necessity of extra effort, time and budget for studies of this nature.

Ethical issues that arose, concern patients’ problems with communicating with their health care providers, their lack of understanding of their diagnoses, treatment and prognosis, and the potential role conflict experienced by bilingual research assistants who may wish or be asked to intervene on the patients’ behalf. Throughout the research the word ‘cancer’ was avoided in order not to upset the patients with their diagnoses. Research assistants should be provided with extra support and ethics committees should be involved in the research process.

In conclusion, research among Turkish and Moroccan cancer patients in the Netherlands is feasible, but requires special effort, planning, budget and support. We believe that such additional effort is justified to ensure that ethnic minority populations are included in health-related quality of life research.

In Chapter 7, the general discussion, the main findings of the studies in this thesis are summarized and discussed. The psychometric evaluation showed good results with regard to feasibility, internal consistency reliability and validity of the items and scales. The SF-36, EORTC QLQ-C30 and COOP/WONCA Charts can therefore be used in cross-sectional studies. More evidence should be acquired for responsiveness of the health-related quality of life questionnaires before we can
recommend the use of these translated questionnaires in longitudinal studies.
A limitation of our study is that we did not assess the content validity of the construct ‘health-related quality of life’ for Turks and Moroccans living in the Netherlands. Furthermore, we focused primarily on the quantitative psychometric evaluation and less on the qualitative evaluation of the health-related quality of life questionnaires. In addition, the sample sizes were rather small for some analyses, in particular for measuring known groups validity and responsiveness. Further research is needed to evaluate the test-retest reliability and responsiveness of the translated questionnaires. In addition, we recommend that the psychometric properties of the translated questionnaires be evaluated in other European countries and in other patient groups.
A future challenge is the introduction and validation of a talking touch screen for the oral languages and illiterate Turkish and Moroccan respondents.