

questionnaire. Patients diagnosed with dementia ($n = 97$) had lower Amsterdam IADL scores than patients without dementia ($n = 99$), $t(194) = 5.1, p < .001$. The AUC for the Amsterdam IADL Questionnaire® (.70, 95 % CI: .63–.78) was higher than for the DAD questionnaire (.63, 95 % CI: .54–.73).; **CONCLUSIONS** Results suggest that the Amsterdam IADL questionnaire® is helpful in diagnosing dementia and performs better than an existing IADL questionnaire.

(2019) Basic genetics: what the QOL researcher needs to know

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AIMS Exploring the genetic underpinnings of QOL domains is an emerging scientific endeavour. The aim of this presentation is to provide QOL researchers with basic information about genetics in order to understand how they might incorporate genetic variables into their QOL research.; **METHODS** We will review findings of recent publications of the GENEQOL consortium, focusing on interpretation of results for the non-geneticist. We will provide a glossary of genetic terms and a “roadmap” for how to incorporate genetic variables into QOL research studies. **RESULTS** Recent research has indicated relationships between cytokines, folate genes, the glutathione metabolic pathway and fatigue/QOL domains. Results have been replicated across separate studies and different disease populations. **CONCLUSIONS** QOL researchers need basic knowledge of genetic terms and recent results to be able to incorporate genetic variables into their research.

(2020) Emotional well-being and lifestyle factors among community-dwelling older adults

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AIMS Well-being is one of the important factors for achieving successful ageing, and it is useful to examine the factors that are relevant to a status of well-being. The purpose of this study was to clarify the cross-sectional and longitudinal relationship between emotional well-being and lifestyle factors among community-dwelling older adults in Japan.; **METHODS** The participants were 475 individuals (196 men and 279 women) aged 73 years and older who participated in a baseline survey in August 2009 and were subsequently followed annually for 2 years. The baseline survey had gathered data on basic demographic factors (sex, age, activities of daily living (ADL) and living arrangement) and lifestyle factors (drinking habit, smoking habit, frequency of going out every week, physical activity, sleep duration, engaging in a hobby, and dietary habits (dietary variety score consisting of 10 food category items)). Emotional well-being was assessed using the five-item Japanese version of the World Health Organization Well-Being Index (WHO-5). Multiple linear regression analysis, adjusted for age, sex, ADL, living arrangement and the WHO-5 (only in longitudinal analysis) was used to examine the association between emotional well-being and lifestyle factors.; **RESULTS** The mean age of the study participants was 78.3 ± 4.3 years (range 73–96 years). Among the participants, 86.7 % were physically independent, 9.1 % lived alone, 30.7 % drank alcohol, 6.4 % smoked, 81.4 % went out every day of the week, 37.4 % were physically active, 33.1 % slept 7–8 h per night, 49.3 % engaged in a hobby, and the mean number of food items consumed daily was 4.4 ± 2.6 . Multiple regression analysis showed that the frequency of going out, engaging in a hobby, and dietary variety score were

positively associated with emotional well-being in cross-sectional analysis. In contrast, only engaging in a hobby was associated with emotional well-being in longitudinal analysis.; **CONCLUSIONS** These results indicate that older adults who have favorable lifestyle (i.e. frequently go out, engage in a hobby, and good dietary habit), are more likely to be high in emotional well-being. In addition, engaging in a hobby predicted maintenance of emotional well-being in longitudinal analysis, suggesting that engaging in a hobby is particularly important for emotional well-being community-dwelling older adults.

(2021) Busting the top myths about quality of life assessment in clinical practice

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AIMS Despite advances in quality of life (QOL) research and the potential for QOL data to inform clinical care, QOL tools remain underutilized in clinical care. This presentation will identify and dispel leading myths that may limit utilization.; **METHODS** During the author’s multi-decade experience working in this field, she has heard many contentions from clinicians about why they don’t incorporate systematic QOL assessment in their practice. Each of these contentions is a myth, countered by research data. This presentation will identify leading myths and provide data from the literature that argue against each myth.; **RESULTS** The seven myths are: (1) Patients don’t want to fill out questionnaires; (2) If my patients had QOL concerns, they would raise them with me; (3) QOL is a philosophical construct that can’t be measured; (4) It takes a long time because you have to ask so many questions; (5) I don’t have a nurse who can give out these questionnaires; (6) These questions will trigger lengthy discussion and will increase the length of the clinic visit; (7) QOL data haven’t informed clinical practice so there’s no need to ask about it. Data from QOL research will be summarized in response to each point.; **CONCLUSIONS** QOL assessment may be under-utilized because of unfounded beliefs about how to do it and the impact of such assessment on clinical practice. Data are available to counter these misconceptions. This presentation will provide useful pointers to “bust the myths” and facilitate clinical use of QOL assessment.

(2022) Symptoms and quality of life indicators of persons with lower limb loss

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AIMS The purpose of the study was to examine the pattern of symptoms and quality of life (QoL) indicators in a large sample of amputees and to compare their levels of pain interference, fatigue, physical function, sleep disturbance, depression, and satisfaction with participation in social roles to the PROMIS US general population norms.; **METHODS** The Patient Reported Outcomes Measurement Information System (PROMIS)-29 was administered to lower limb prosthetic users as a part of a cross-sectional study of mobility. PROMIS-29 assesses respondents on seven health domains: physical function, anxiety, depression, fatigue, sleep disturbance, participation in social roles and pain interference. PROMIS T-scores of 50 represent the US general population mean in each domain. Respondents were recruited via prosthetic clinics, magazine advertisements, listservs, websites, and social networks. Inclusion criteria were 18 + years of age, ability to read English, unilateral lower limb amputation

with traumatic or dysvascular etiology, and use of prosthesis to ambulate. Items describing demographic and disease characteristics were also included.; **RESULTS** The PROMIS-29 was administered to 650 persons with limb loss (mean age = 53 years, SD = 14 years; 69 % male; 36 % transfemoral amputation, 66 % traumatic amputation). Respondents reported lower physical function ($M = 42.69$, $SD = 8.6$; $p < 0.01$) and fatigue ($M = 48.10$, $SD = 9.8$; $p < 0.01$), and higher pain interference ($M = 54.48$, $SD = 9.2$; $p < 0.01$) than the general US population. Mean anxiety ($M = 49.32$, $SD = 9.8$; $p < .08$), depression ($M = 49.11$, $SD = 9.5$; $p < 0.02$), satisfaction with participation in social roles ($M = 48.70$, $SD = 10.3$; $p < 0.01$) and sleep disturbance ($M = 49.30$, $SD = 9.0$; $p < 0.05$) levels were similar to general population norms even though some differences reached statistical significance.; **CONCLUSIONS** Worse physical function and more pain would be expected in a population of users of lower limb prosthetics. That persons with limb loss report lower fatigue than the general population was not anticipated and has not been previously described. We hypothesize that reduced capacity for physical activity and pain associated with limb loss lead to limited physical activity and, by extension, lower fatigue. PROMIS-29 is an efficient and informative way to describe the pattern of symptoms and QoL indicators in amputees. The comparisons with general US population norms provide valuable information about functioning of individuals with limb loss.

(2023) Translation and linguistic validation of two COPD symptom diaries for use in global clinical trials

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AIMS Two patient-reported outcome (PRO) measures, the Nighttime Symptoms of COPD Instrument (NiSCI) and Early Morning Symptoms of COPD Instrument (EMSCI), were developed to support treatment benefit endpoints in global clinical trials. Translations that were conceptually equivalent to the English source version and easily understood by the target country populations were needed. The purpose of this study was to translate and assess conceptual equivalence of the NiSCI and EMSCI for use in 6 countries: United States (Spanish), Canada (French), Australia (English), New Zealand (English), Hong Kong (Traditional Chinese and English) and Singapore (Simplified Chinese and English).; **METHODS** The NiSCI and EMSCI were translated following ISPOR guidelines for translation and cultural adaptation of PRO measures (Wild et al., 2005) using the universal approach discussed in the second Task Force Report (Wild et al., 2009). Translation into Spanish occurred in parallel with usability testing which resulted in minor changes to the English version. The revised English source version was reviewed by native English speakers in Australia, New Zealand, Singapore and Hong Kong to ensure suitability. For each non-English language, 2 forward translations by native translators, reconciliation of the forward translations, 1 back-translation by an English-speaker fluent in the target language, and final reconciliation by a native speaking language coordinator were conducted for both measures. Harmonization was performed to ensure conceptual equivalence across languages. Interviews were conducted among 60 native-speaking COPD patients in 6 countries. Interview data were analyzed to assess linguistic and cultural validity of the diaries in each language and confirm conceptual equivalence.; **RESULTS** Mean age of the sample ($N = 60$) was 60.91 years, (range, 40–86) and 68 % were male. The translations were well understood and considered relevant, with patients raising only minor issues during interviews. Challenges arose in finding patient-friendly language to

describe rescue medication, but were resolved through consultation with linguists and pilot-testing with patients. Only the Spanish translation required post-testing revision following changes in the English source version.; **CONCLUSIONS** The universal English, Spanish, French, Simplified and Traditional Chinese versions of the NiSCI and EMSCI were found to be conceptually equivalent and acceptable for use in the 6 countries evaluated.

(2024) Implementation of quality of life evaluation in oncology daily practice: breast cancer in focus

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AIMS Quality of life evaluation as a routine clinic practise is still not a common procedure. However, considering breast cancer, recent studies suggest that Quality of Life is an increasingly prominent health marker. The present study aims to validate the EORTC-QLQ C30 and the specific module BR23 Portuguese PC-software versions, in order to implement Quality of Life routine assessment at the Breast Cancer Clinic of the Portuguese Oncology Institute-Porto, Portugal.; **METHODS** Ninety-nine women from the Breast Clinic of the Portuguese Oncology Institute participated in this study after given their informed consent. Patients answered the questionnaires made in both formats (paper and computer), with an interval of 30 (thirty) minutes between the two evaluations. The computer assessment was made using the Quality of Life Informatics Platform (QoLIP) used at this institution. The Wilcoxon test (95 % confidence interval) and percentiles calculus were used to evaluate sample similarity. In order to understand if QoLIP had any influence in the patient's responses, we admitted two statistical hypotheses to realize a bilateral test: hypothesis $H_0:F(\times 0) = F(\times 1)$ or hypothesis $H_1:F(\times 0) - F(\times 1)$.; **RESULTS** The usability of the platform was high, considering that 76,8 % of the patients preferred the electronic format of the questionnaires. The null hypothesis (H_0) was accepted for all questions and so QoLIP revealed to had any influence in the patient's responses.; **CONCLUSIONS** The Quality of Life Informatics Platform revealed to be a powerful and effective tool for routine Quality of Life assessment in breast cancer patients. This patient reported outcome may contribute to support clinical decisions, identify unmet needs and can be used in routine care appointments. The electronic Quality of Life assessment revealed to be technically feasible in breast cancer patients at the Breast Clinic of the Portuguese Oncology Institute-Porto.

(2025) Unidimensionality, validity and responsiveness of the ANMS Gastroparesis Cardinal Symptom Index-Daily Diary

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AIMS Patient-reported symptom scales are necessary for evaluating treatments for gastroparesis. The ANMS Gastroparesis Cardinal Symptom Index-Daily Diary (GCSI-DD) was developed to assess daily symptoms in patients with gastroparesis. To evaluate the dimensionality, reliability, validity and responsiveness of the GCSI-DD in patients with gastroparesis.; **METHODS** A 4-week observational study was