DEVELOPMENT OF A NEW HEALTH-RELATED QUALITY OF LIFE QUESTIONNAIRE SPECIFIC TO HIV/AIDS: AN INTERNATIONAL AND CROSS CULTURAL INITIATIVE

Duracinsky M\(^1\), Herrmann S\(^2\), Acquadro C\(^3\), Berzins B\(^4\), Lecoeur S\(^5\), Hyland N\(^6\), Fournier I\(^7\), E. McKinnon\(^8\), Nolan D\(^3,8\), Mallal S\(^2,8\), Chassany O\(^3,8\).

Service de Médecine Intérieure et de Maladies Infectieuses, Hôpital Universitaire de Bicêtre, Paris, France\(^1\), Centre for Clinical Immunology & Biomedical Statistics, Royal Perth Hospital & Murdoch University, Perth Western Australia\(^2\), Département de la Recherche Clinique, Hôpital Saint-Louis, Paris, France\(^3\), Division of Infectious Diseases, Northwestern University, Chicago, USA\(^4\), Programs for HIV Prevention and Treatment (PHPT), Chiang Mai, Thailand\(^5\), Sexual Health Services Royal Perth Hospital, Perth Western Australia\(^6\), Institut Pasteur du Cambodge, Phnom Penh, Cambodia\(^7\), PathWest Laboratory Medicine WA\(^8\).

Health-Related Quality of Life (HRQL) questionnaires (Q’s) specific to HIV/AIDS were developed before the advent of antiretroviral therapy (ART) and/or before current co-formulations which have, purportedly, a lower toxicity profile. Arguably, these Q’s have diminished sensitivity to measure the current impact of HIV disease and treatment on People Living With HIV/AIDS (PLWHA). Relevant domains important for PLWHA such as sleep, perception of treatment and impact of current common side effects, including lipodystrophy are missing and the assessment of psycho-social impact could be improved.

The objective is to develop a new Patient-Reported Outcomes (PRO) questionnaire to measure the HRQL of PLWHA in different countries and cultures, using an item bank developed from semi-directive interviews which explored the multidimensionality of PLWHA’s HRQL with participants. To capture cultural differences in perceptions, interviews were held in: Senegal, Brazil, USA, Australia, Thailand, China, Cambodia, India and France and recorded, transcribed and translated into English and French.

Globally 148 (47% female) individuals consented to the interviews from which the domains representing PRO’s were identified. Using participants’ verbatim, 300 items were generated in French and English and organized into a 24-domain item bank. An endpoint model was designed to explain the relationship between PRO's, health status, symptoms, side effects and the different domains of HRQL. Cultural differences were identified in domains such as daily activities, stigma, and relations with family and/or friends. Cognitive debriefing was carried out at each centre on 5 participants not part of the original interview group, using a 70 item questionnaire that had been developed—this was subsequently reduced to 60 items after harmonization.

At the next stage the questionnaire will be administered to 100 participants at each centre. In WA the results will be correlated with appropriate clinical information from the WA HIV Cohort database. It is anticipated that following psychometric validation and translation into the target languages this questionnaire will be a contemporaneous tool to use with WA patients and migrants from high prevalence countries. Globally, the new HRQL instrument will be used by those who seek to measure the impact of HIV and treatment on PLWHA accurately.