

Identification of Domains of Health-Related Quality of Life Important and Relevant to Multiethnic Asian Patients with Systemic Lupus Erythematosus (SLE)

Wee Hwee Lin



Systemic lupus erythematosus (SLE) is an autoimmune disease with variable clinical manifestations and multi-organ involvement which exerts a negative impact on the physical, social and psychological aspects of life of the patients (i.e. their Health-related Quality of Life, HRQoL). The Asian patients' perspective on the impact of SLE on their HRQoL is not well understood. Although similar input from SLE patients residing in Western countries has been obtained through qualitative research studies, these perspectives may not be representative of Asian SLE patients due to culture-specific differences in HRQoL.

In a study performed by the Singapore Pharmacoeconomics and Outcomes Research Group (led by Dr Wee Hwee Lin, funded by the National Medical Research Council New Investigator Grant) among 27 women participating in six focus group and two men participating in individual interviews, 21 domains of HRQoL were identified to be relevant and important. Interestingly, four of these domains are not currently addressed by any of the existing SLE-specific HRQoL questionnaires available locally and overseas. These domains are: family, relationships, freedom, and stigma/ discrimination. Of these, family and stigma/ discrimination are possibly accentuated in the Asian sociocultural context. Thus, we have identified gaps that need to be filled in the design of future SLE-specific HRQoL instruments, especially when used among Asian patients. This study has been accepted for publication in *Arthritis Care and Research*, official journal of the American College of Rheumatology.

Building upon this work, our team is also in collaboration with Professor David Cella, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine to evaluate the cross cultural feasibility, validity and reliability of item banks developed under the Patient-Reported Outcomes Measurement Information System (PROMIS) network. In addition, we aimed to evaluate if the PROMIS item banks may serve as a useful core set of items for the assessment of outcomes among SLE patients in Singapore and overseas. The PROMIS network is a National Institutes of Health (NIH) initiative to construct item banks that measure key symptoms and health concepts applicable to a range of chronic conditions. These item banks enable the use of new measurement approaches involving item response theory and computerized adaptive testing, offering advantages for outcome assessment, including increased precision and reduced respondent burden. Our study found that 14 of all domains identified by SLE patients were addressed by PROMIS Version 1.0 banks. Within each domain, each sub-theme was also generally well-addressed by items from the PROMIS banks. Hence, these findings demonstrate the tremendous potential of PROMIS items to be used as a core set of items for the assessment of outcomes among SLE patients. The next step in our collaboration is to establish the measurement properties of the items in Singapore in a calibration exercise involving 120 SLE patients and to compare these with the item measurement properties in other countries. The findings would have relevance for multinational clinical trials using the PROMIS item banks.