Regular Quality-of-life assessment in routine HIV care

MarieJosé Kleene, Narda van der Meche, Daoud Ait Moha, Martje Dermer, Irene Schouten, Kamilla Lettinga, Chantal den Daas, Kees Brinkman, Guido van den Berk, on behalf of the OLVG-HIV team

Internal Medicine, OLVG, Amsterdam, the Netherlands, 1Department of Interdisciplinary Social Science, Faculty of Social and Behavioural Sciences, Utrecht University, Utrecht, The Netherlands

Background
To improve the quality of HIV care in our hospital, we developed a program of Value Based Health Care for HIV (VBHiC) in outpatient care. Since patient related outcome measures (PROMs) are an important value for the patient, we extended a set of 8 clinical and laboratory parameters with the regular evaluation of the quality of life (QoL). Here we report the first preliminary results of this extension.

Methods
In our newly designed ‘care protocol’ patients receive an email 2 weeks before the yearly main consultation (and 3 times in the first year after diagnosis), linking to an on-line questionnaire (program: Questmanager®). The questionnaire is a compilation of short versions of different well-known validated scales and some scales we adapted for our purpose, including the Short Form Health Survey (SF-12), the Hospital Anxiety & Depression Score (HADS), the short Stigma scale, the Social Support List, a scale measuring Sexual Difficulties, a single item measuring Self Esteem, Sleep Difficulties (out of the SCL-90) and an item assessing experienced side effects. The care-path was launched on November 24th 2016, we analysed the responses until August 1st 2017. If a patient completed several questionnaires, only the last one was included in the analysis.

Results
From 1089 questionnaires send out, 643 questionnaires were completed (response rate 55%): not every patient received a questionnaire before his consultation due to logistical issues. In total 600 individuals participated: 94% of respondents were male, the mean age was 50.0 yrs (range 20-81). Scores above a predefined threshold were observed for anxiety/depression (HADS>15) in 25% of the participants, for stigma in 50%, for sleep difficulties in 77%, for moderate to high social support in 62%, for low self esteem in 35% and for sexual difficulties in 47.5%.

Conclusion
Structural assessment of the different domains of physical and mental health is a valuable part of HIV care. It enables clinicians to tailor care to the individual needs and at the same time to enhance communication with patients. Although a response rate of 55% is promising, this rate needs optimisation to make our VBHiC program more successful. For the moment, the questionnaires revealed for the individual care several QoL related issues, prompting to discuss interventions for improvement. Future questionnaires will be used to evaluate the success of these interventions.