Distress and health-related quality of life in Indonesian type 2 diabetes mellitus outpatients

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SUMMARY

Type 2 diabetes mellitus (T2DM) has become a worldwide phenomenon that needs special attention, not only because of the increasing number of patients but also because of the widened age range of T2DM patients. In the past, T2DM was only found among the elderly, but today T2DM is also found in the younger generation. In the 34 provinces of Indonesia, based on the report by the Ministry of Health of Republic of Indonesia, prevalence of T2DM grows in almost every province. The increasing numbers of T2DM patients need to be anticipated and needs to involve all healthcare sectors. Starting 1 January 2014, the government of Indonesia has planned a universal health coverage and targeted that, in the year 2019, all Indonesian communities will be covered by health insurance.

Health insurance in Indonesia is managed by BPJS/Badan Penyelenggara Jaminan Sosial (social security administrative agency). Related to T2DM, BPJS has one program known as Prolanis that concenrs the chronic diseases management program. This program aims to optimise health costs, as well as to improve the health-related quality of life (HRQoL) for the T2DM patients. In Indonesia, research on HRQoL is urgently needed to provide adequate insights into the psychological conditions of the T2DM patients as well as to provide utility values that can be used in pharmacoeconomic/health economic studies.

Overall, in this thesis, we used two types of HRQoL measurement tools, the diabetes distress scale (DDS) and the EuroQoL five-Dimensional (EQ-5D instrument). We divided the diabetes distress (DD) studies into three chapters: translations, revisions, and validations (*Chapter* 2), a qualitative study (*Chapter* 3) and a modelling study (chapter 4). Furthermore, the study with the EQ-5D instrument consists of two chapters: first, we performed a comparison study between EQ-5D 3 level (3 L) and 5 level (5L) versions (*Chapter* 5). Secondly, we conducted a study of EQ-5D utility values in Indonesian T2DM outpatients (*Chapter* 6).

Chapter 2 concerns the performing of a translation, revision and a validation study of the DDS questionnaire for Indonesian T2DM outpatients with various types of complications. The final result of this study is a DD measurement tool for T2DM outpatients which we labeled "DDS17 Bahasa Indonesia". Furthermore, still related to DD, to have a deeper understanding of DD in Indonesian T2DM outpatients, we performed a qualitative study (*Chapter* 3). This qualitative study used the 17 questions from the DDS17 Bahasa Indonesia. Participants involved in this qualitative study were divided into two groups; i.e., groups concerning focus group discussions and in-depth interviews. The result of this qualitative study provides a description that spirituality, positive attitude, and acceptance are the most commonly used coping mechanism by the participants. Besides, this study recommends that housewives living with T2DM are a community group that needs special attention. Then, there is a DD modelling study (*Chapter* 4), in which we compared the level of DD for the participants treated in primary care to those who are treated in secondary care. For this study we developed five models. All five models provide the result that the level of DD in participants treated in primary care is higher than in those participants treated in secondary care. This requires furthere investigation, also as the time of data collecting was 2014. At that time, Indonesia had just started the new health care system in which all the T2DM services must be executed in primary care.

In the EQ-5D instrument study, we found that EQ-5D 5L achieves better than

3L in terms of scoring and ceiling, redistribution from 3L to 5L, discriminative power, and test-retest reliability. Notably, the result of this study recommends that during the whole process of data collecting it is better to have a professional, for example, visiting the patients, especially to help the elderly and the group participants with a lower education level to understand the questions (*Chapter* 5). Furthermore, in the EQ-5D utility study, one of our final results was a reference set of EQ-5D utility values which is very useful for pharmacoeconomic analysis (cost-utility analysis and modelling for health economic evaluation). Moreover, another important finding concerned factors influencing the EQ-5D utility in Indonesian T2DM outpatients. Notably, the following are some socio-economic factors that can negatively influence the EQ-5D utility value in Indonesian T2DM outpatients: being treated in secondary care, having a lower level of education, not currently undergoing T2DM therapy, and being a housewife. It should be highlighted that the participants that were accompanied by a caregiver during their visit to a health facility reported that their EQ-5D utility was more decreased. This was logical because participants who required a caregiver were those with worse clinical conditions compared to those who were still able to come alone (*Chapter* 6).

In conclusion, our study emphasizes that T2DM outpatients do not only need attention on getting the adequate medicines. The Indonesian T2DM outpatients also need attention to psychological aspects, like knowledge of T2DM and the changing system of services for T2DM outpatients, such as the changing context of health insurance in Indonesia. Our study also recommends special care to lower educated T2DM outpatients and housewives with T2DM, like special programs assigned to these two groups. Knowledge of T2DM is not just necessary for T2DM patients, but also for the family members, because they are the ones who know most about the health conditions of the T2DM patients.