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General Discussion

Bustanul Arifin, Maarten J. Postma

GENERAL DISCUSSION

In 2011, Indonesia's population was about 246 million people with around 7.3 million living with DM [1,2]. Currently, Indonesia's total population is 261 million with around 10.3 million DM patients [2,3]. In 2011, Indonesia had the 10th highest number of DM patients in the world and it was predicted that this would rise to 9th by 2030 [1]. But in only five years (2017), Indonesia had risen to 6th position [3]. Worldwide, 90% of DM patients are Type 2 diabetes mellitus (T2DM) patients [4].

Since 2010, the Indonesian government has launched Prolanis, a chronic diseases management program managed by the BPJS (the social security administrative agency) [5]. To date, the program continues to run with a larger number of members and wider coverage of the regions [5]. Since the last few years, besides focusing on T2DM, Prolanis has also been expanding its scope on hypertension. Prolanis aims to control health costs and optimize the health-related quality of life (HRQoL) in T2DM outpatients [6]. Through Prolanis knowledge about T2DM can be shared from physicians to patients. Also, Prolanis can serve as a forum for sharing experiences among T2DM patients. Finally, Prolanis assists the government in monitoring T2DM and can be core in decision-making for the improvement of T2DM patient services.

In the introduction, we reviewed 14 HRQoL studies in Indonesian T2DM and 13 of these studies are concentrated on Java and one in Sumatra and we have not found any studies reporting index values in T2DM outpatients. This index value is crucial in pharmacoeconomic analysis and health economic evaluation modelling. In this thesis, we performed five studies on Indonesian T2DM outpatients. Our participants came from Java, while some of them

were from the island of Sulawesi. We added Sulawesi as our study site because in the last few years, the incidence of T2DM has increasingly occurred in Sulawesi and the numbers have even almost doubled by comparing the 2007 and 2013 data [7]. In particular one study also describes the EQ-5D index values in Indonesian T2DM outpatients. Below we present the main findings in this thesis.

Main findings from this thesis

Firstly, we created an Indonesian version of the DDS (DDS17 Bahasa Indonesia) [8]. In *chapter 3*, we elaborated on the original DDS study that divides diabetes distress into four domains, namely physician distress, emotional burden, regimen distress, and interpersonal distress [9]. Based on the qualitative analysis in our study, we found that further barriers cause diabetes distress (DD) concern healthcare services and the lack of knowledge. Distress concerning healthcare services appeared most related to hospital bureaucracy faced by Indonesian T2DM outpatients. Furthermore, Indonesian T2DM outpatients stated that they felt more comfortable when T2DM therapy was given directly by the consulting resident medicine rather than the general practitioner (GP). Second, the lack of knowledge of the changing regulations concerning health insurance caused DD. The result of this study also reveals that spirituality, positive attitude, and acceptance are the most common coping mechanisms for reducing DD. A subsequent modeling study on DDS analyzed the effect of sociodemographic characteristics and clinical conditions on DD. Our results are unique and interesting because there are several contradictory results compared to previous studies. A study in a Dutch population showed that the level of DD in T2DM patients in primary care settings was lower compared

to those in secondary care settings [10] exactly opposite to our findings in Indonesia. These results need to be interpreted with caution as data collection was obtained when the Indonesian government initiated a transformation in health insurance system with various switches from primary to secondary care and vice versa. *Chapter 5* compares the measurement properties between EQ-5D-3L (3L) and EQ-5D-5L (5L). The 5L was shown to have better measurement properties than the 3L in terms of scoring and ceiling, redistribution from 3L to 5L, discriminative power, and test-retest reliability. Our research also indicated that participants stated that pain/discomfort was the dimension mostly affected by T2DM. In the final study in this thesis, we presented the EuroQoL-5D (EQ-5D) index values based on socio-demographic characteristics and clinical conditions in Indonesian T2DM outpatients. Our study found that the EQ-5D index value was 0.77 (0.75 – 0.79). Furthermore, the five factors mainly associated with lower EQ5D index value were: (i) treatment in secondary care, (ii) lower educational level, (iii) dependency on caregivers, (iv) not undergoing T2DM therapy, and (v) being a housewife for females.

Challenges, opportunities, and lessons learned in diabetes research in Indonesia

The following challenges are based on our experiences during the research conducted in Indonesia for the purpose of this thesis:

- Quite some level of *research permit bureaucracy* was encountered during the project. Notably and in addition to ethical clearance, another document that must be furnished by Indonesian researchers with university affiliations abroad concerns a research recommendation from the Ministry of Internal Affairs. Moreover, if the research team

has one or more foreigners, they must obtain a research permit from the Ministry of Research, Technology & Higher Education (Kemenristekdikti). Furthermore, after the recommendations are obtained, the researcher must apply for the research permit again to several related offices at provincial and district levels. In addition, the researcher must obtain permission from the director of the hospital or the head of other health facilities. Based on my experience, the process of gaining the necessary research permits in Indonesia takes about 6-12 months.

- Indonesia has *no integrated T2DM database* connecting health facilities. The BPJS has begun integrating T2DM patient data into all healthcare services, however, the process is still ongoing. Since January 1st, 2014, the financial pattern of T2DM in Indonesia has changed from a “pay for service” system to the Ina-CBGs system (where the BPJS pays a hospital based on a package per illness). This is a challenge to pharmacoeconomics researchers because the identification of unit costs becomes more difficult. As an illustration, the system of payment of medical services is determined by many factors such as a physician’s experience, specialist education, doctor’s tenure, as well as the availability of physicians in a region. Ergo, this is an interesting area for further study in future research.
- The *quality of human resources* is unevenly distributed between areas. Most health workers, especially consulting residents medicine, work in a number of large cities in Indonesia. In fact, the Indonesian government has been attempting to distribute the health workers more evenly throughout Indonesia. One of the efforts is through an

internship program for freshly graduated general practitioners (GPs). They are sent to one hospital and primary health care settings throughout Indonesia for one year. For the new specialist graduate program, known as WKDS/Wajib Kerja Dokter Spesialis (obligatory work of a specialist), new residents of internal medicine, pediatricians, surgeons, obstetricians & gynecologists, and anesthesiologists are obligated to work, for at least one year, in areas that have been determined by the government. The challenge is that the availability of doctors does not match the number of areas in Indonesia that require their labor. Availability of GPs and specialists in a health facility is also very important because it is closely related to the health facility's accreditation status.

- *Data on HbA1c examinations* are increasingly difficult to obtain due to a lack of diagnostic equipment. It is important to note that therefore not all T2DM outpatients have HbA1c data. In general, the examinations performed are fasting blood glucose, postprandial blood glucose, and random blood glucose. Ergo, in our study, we could not perform analyses of the relationships between HbA1c levels and DD or EQ-5D index values.
- The *number of international publications* on HRQoL in T2DM in Indonesia is very limited. This provides a challenge to researchers in Indonesia. My guess would be that there is actually a lot of research on HRQoL in Indonesian T2DM outpatients, but this has not yet been publicly published in peer-reviewed international journals.
- In some health facilities in eastern Indonesia, the *medical record reporting process* of T2DM outpatients is still

carried out manually. Researchers who want to use this data have to invest extra time to check T2DM medical record documents that are sometimes illegible. There are two reasons why these documents are illegible: (i) the documents are too old and (ii) the researchers are unable to read the handwriting of the physician or the nurse who wrote the document.

- Indonesia is a unique country with a *diverse population*. HRQoL assessment in Indonesian T2DM outpatients requires a special approach. Besides the instruments used needing to be easily understood by the participants, the methods used to collect data must be suitable to be adapted to the local cultures. In my experience, during data collection, it is crucial to involve several research assistants who can speak the local language. The use of local languages as the language of instruction can make participants feel more comfortable and questions better understandable
- The need for *cooperation with the research assistant* is an important factor to highlight. The principal investigator must have the same perception as the research assistant that helps the data collection process. The initial step that can be applied is to provide training to the research assistants. In addition, to minimize information bias, another thing that can be done is to conduct meetings regularly until it can be concluded that the principle investigator and the research assistants have the same perception of the purpose of the research and the use of instruments.

T2DM Screening in Indonesia

One interesting point to be reviewed is the T2DM screening program. This screening program has been introduced since 2010

along with Prolanis [11]. The BPJS health screening program is divided into two groups: (i) screening for primary prevention of diseases that require the greatest financing, i.e. T2DM and hypertension and (ii) selective secondary preventive screening aimed at detecting cervical cancer in married women and breast cancer in general. Currently, T2DM, hypertension, and cancer screening programs are commonly recommended to BPJS participants over the age of 30 years [11].

Since 2016, the BPJS has launched a mobile health screening feature. This feature is an additional feature in the “Mobile Health BPJS” app. Its use is simple: after downloading the “mobile JKN” application, the member will be asked to enter their BPJS and ID numbers and some other data. Screening begins after BPJS participants confirm consent by digital informed consent. In total, there are 44 questions to be completed, including questions on lifestyle, diet and physical activity [12]. Throughout 2016, 739,870 BPJS participants have undergone T2DM screening. As a result, 702,994 were considered low risk, 36,225 moderate risks and 651 to be at high risk of developing T2DM [12]. On 5 January 2018, I tried to do a health screening through this app, and my result was considered as low risk. This T2DM screening feature is a very good first step in chronic diseases’ prevention. This will also greatly help BPJS and T2DM researchers in the process of collecting data. I recommend carrying out psychometric measurement studies on the scaling of answers for each item so that the results obtained are more optimal.

Recommendation

At present, the DDS17 Bahasa Indonesia is increasingly used as a diabetes distress screening instrument in Indonesia as it has been recommended by the American Diabetes Federation as a standard of medical

care and by the International Diabetes Federation in their global guidelines for T2DM patients [13,14]. Furthermore, empowerment/strengthening of the T2DM community/club and increasing the awareness of the context may be beneficial to reduce DD, by educating T2DM outpatients on the reforms in the health insurance system and healthcare provision as well as engaging the family members in T2DM education. I also recommend gender-specific approaches such psychological consultations to female T2DM, especially for the housewife.

In *Chapter 5*, we provided the results of measurement properties of the EQ-5D-3L and 5L versions in Indonesian T2DM outpatients. It is important to bear in mind that our study suggests that the 3L version could be given to those with lower educational levels, the elderly, as well as housewives with a maximum education level of senior high school. For other groups, the 5L version might be optimal. Thus, researchers need to consider which version to be used in their investigations in T2DM outpatients. We argue that the result of this research (*Chapter 6*) will be very useful for the Indonesian government and the BPJS to assist in formulating any policies related to the financing of T2DM in Indonesia. Better knowledge of the BPJS, in general, is needed.

I also have several recommendations for BPJS. First, research partner collaboration in some studies, for example, in screening T2DM and hypertension is beneficial. This could, for example, be implemented in EU Horizon2020 project proposals. Second, the use of human resources capacity especially IT, in BPJS personnel related to the health data is to be enhanced. This personnel would be given health training so that they become familiar with the health terminology to assist the communication process between the researcher and the BPJS personnel. Third, BPJS should write more

international publications so that the health insurance system in Indonesia can be recognized by the world's researchers. In October 2017, I typed in "BPJS" in PubMed, but I could not find any article explaining BPJS.

Further work

Currently, we are doing a meta-analysis and systematic literature review study on EQ-5D in T2DM patients. Besides this, we also perform a study to investigate the association between DD and EQ-5D-3L index values and we analyse the influence of DD specific domains on the five dimensions of EQ-5D-3L. Presently, we also have data to investigate the comparative performance of the EQ-5D-5L and WHOQoL in Indonesian T2DM outpatients. Furthermore, to enrich the utility data in Indonesian T2DM patients, I would like to perform HRQoL analyses in Indonesian T2DM inpatients. Another interesting research is mapping the use of medicine pattern for T2DM. The mapping can be started by comparing the therapy pattern before and after implementation of BPJS. I intend to continue these studies back in Indonesia, together with Dutch partners.

Limitations

A major limitation of this study concerns the general difficulty of collecting clinical data in Indonesia. Data from records of blood sugar checks as well as information on the duration of T2DM are just two examples of categories of data that are scarce and difficult to access. We tried to overcome this by using various types of self-reported data. Yet, this may be considered as prone for improvement. Also, this study could only address specific aspects of the clinical and humanistic impacts of T2DM. For example, the role of the broader environment of the patient could only be touched upon. There remains vast space for follow-up research in this area.

REFERENCES

1. IDF. IDF diabetes atlas, Fifth edition [Internet]. 2011. Available from: www.diabetesatlas.org
2. World-Bank. Indonesia [Internet]. World Bank. 2017 [cited 2017 Jan 8]. Available from: <https://data.worldbank.org/country/indonesia>
3. IDF. IDF diabetes atlas, Eighth edition [Internet]. Brussels, Belgium: International Diabetes Federation; 2017. p. 1-150. Available from: www.diabetesatlas.org
4. WHO. Diabetes mellitus. World Heal. Organ. 2018.
5. Idris F. Pengintegrasian Program Preventif Penyakit Diabetes Melitus Tipe 2 PT Askes (Persero) ke Badan Penyelenggara Jaminan Sosial Kesehatan (BPJS Kesehatan). J Indon Med Assoc [Internet]. 2014;64:115-21. Available from: http://eprints.unsri.ac.id/5313/1/Pengintegrasian_Program_Preventif.pdf
6. BPJS Kesehatan. Pedoman Prolanis. Jakarta: Badan Penyelenggara Jaminan Sosial (BPJS Kesehatan); 2012.
7. PUSDATIN. Situasi dan analisis diabetes [Internet]. Jakarta; 2014. Available from: <http://www.depkes.go.id/resources/download/pusdatin/infodatin/infodatin-diabetes.pdf>
8. Arifin B, Perwitasari DA, Cao Q, Atthobari J, Krabbe PF, Postma MJ. Translation, revision and validation of the diabetes distress scale for Indonesian type 2 diabetic outpatients with various types of complications. Value Heal. Reg. Issues. 2017;12C:63-73.
9. Polonsky, W.H., Fisher, L., Earles, J. E Al. Assessing Psychosocial Distress in Diabetes. Diabetes Care. 2005;28:626-31.
10. Stoop CH, Nefs G, Pop VJ, Wijnands-van Gent CJM, Tack CJ, Geelhoed-Duijvestijn PHLM, et al. Diabetes-specific emotional distress in people with Type 2 diabetes: A comparison between primary and secondary care. Diabet. Med. 2014;31:1252-9.
11. BPJS Kesehatan. Skrining kesehatan. Jakarta: Badan Penyelenggara Jaminan Sosial (BPJS Kesehatan); 2010.
12. BPJS Kesehatan. BPJS Kesehatan Luncurkan Fitur Mobile Screening pada Aplikasi BPJS Kesehatan

- Mobile. Badan Penyelenggara Jaminan Sos. 2017.
13. International_Diabetes_Federation. Global Guidelines for Type 2 Diabetes. *Diabetes Res. Clin. Pract.* 2014;104:1-52.
 14. ADA. Standards of medical care in diabetes. American Diabetes Association; 2017.