Exploring the Feasibility of Implementing Self-Management and Patient Empowerment through a Structured Diabetes Education Programme in Yogyakarta City Indonesia: A Pilot Cluster Randomised Controlled Trial

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Thesis Summary

BACKGROUND

Diabetes is a global public health problem which can cause serious disabling complications. Indonesia is among the top four countries with the highest numbers of diabetes. Diabetes self-management education (DSME) is widely recognized as an essential element of diabetes care. Patient empowerment has long served as the philosophical foundation for DSME. However, self-management and patient empowerment are largely unknown in diabetes education and care in Indonesia. The current traditional diabetes education found in hospitals and publicly funded community health centres (CHCs) does not incorporate these two concepts. Therefore, there is a particular need for research on DSME and patient empowerment for people with type 2 diabetes (T2D) in Indonesia.

AIMS

The main aims of this research project were to develop a pilot model of a structured diabetes education programme promoting diabetes self-management and patient empowerment for people with T2D in the primary care setting in Indonesia, and to evaluate its effectiveness on clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy. The research project also aimed to cross-culturally adapt the 24-item Diabetes Knowledge Questionnaire (DKQ-24), the Diabetes Health Belief Measure (DHBM), the Summary of Diabetes Self-Care Activities revised scale (SDSCA), and the Diabetes Empowerment Scale - Short Form (DES-SF); and to identify the perceptions of people with T2D and their family members, and health care providers (HCPs) towards the current diabetes education and/ or diabetes education intervention administered.

METHODS

This research project was undertaken in two studies. A convenience sample survey (n = 83) was used to test the internal consistency reliability of the final Indonesian versions of the DKQ-24, the DHBM, the SDSCA, and the DES-SF in an Indonesian population (Study 1). The internal consistency reliability of the adapted instruments were then reassessed among the participants of the main study (n = 101). A pilot cluster randomised controlled trial comparing a four-weekly structured diabetes education programme (intervention group = 51) and a three-hour diabetes seminar trial (control group = 50) in improving clinical outcomes and diabetes related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy for patients with T2D was conducted at four community health centres (CHCs) in Yogyakarta City, Indonesia (Study 2, the main study). Both groups received a set of

comprehensive diabetes leaflets. Outcome assessment was performed at baseline and 3 months after the research interventions were completed. Six scoping discussions were also conducted with four groups of patients with T2D and their family members (*n*=43), and two groups of health care providers working at the participating CHCs (*n*=18).

Quantitative data were double-entered for verification, analysed and digitally stored using SPSS statistical software version 18. Descriptive statistics were used to examine sociodemographic characteristics and medical history outcome variables. Cronbach's alpha coefficients were performed to assess the internal consistency reliability of the Indonesian version of the DKQ-24, the DHBM, the SDSCA, and the DES-SF. *T*-tests were used to analyse differences on continuous data between mean scores for the intervention and control groups. Categorical data were analysed using Chi-square statistics to test the significance of different proportions. Repeated measures ANOVA were used to assess the group differences on clinical outcomes and diabetes-related scores of diabetes knowledge, health beliefs, self-care behaviours and self-efficacy.

Scoping discussions were audiotaped and notes of important issues were taken during the discussions. Loose transcription of discussions and interview notes were combined to generate a summary of key findings.

RESULTS

Study 1

Using the main study population, the Indonesian versions of DKQ-24 (α = 0.723) and the DHBM (α = 0.718) demonstrated satisfactory internal consistency reliabilities. The Indonesian versions of 10-item SDSCA (α = 0.605) and the DES-SF (α = 0.595) showed adequate internal consistency reliabilities to be used as research instruments for a preliminary study.

Study 2 (the main study)

Participation in the structured diabetes education programme led to significant improvements only in diabetes knowledge (95% CI = 1.43 to 14.75; p = 0.004); 2-hour postprandial plasma glucose level (95% CI = -2.82 to 1.58; p = 0.02) and waist circumference (95% CI = -6.15 to 5.14; p = 0.04) at 3-month follow-up. The intervention group demonstrated improvements in HbA1c (primary outcome), fasting blood glucose, systolic and diastolic blood pressure, body weight, BMI, the SDSCA scores on general diet, specific diet, exercise, blood sugar testing and foot care, and the DES-SF score. However, these changes did not significantly differ to the changes in the control group. Findings from soping discussions suggested that there was inadequate provision of traditional diabetes education due to constrained resources and the characteristics of patients attending CHCs.

Patients with T2D attending CHCs were ready and enthusiastic to engage with diabetes self-management and patient empowerment concepts. In contrast, the scoping discussions raised questions about the readiness of HCPs working at CHCs to embrace diabetes self-management education, particularly when they were reluctant to engage adequately in traditional diabetes education, let alone accommodate the patient empowerment concept.

CONCLUSION

A structured diabetes education programme for patients with T2D resulted in significant improvements in diabetes knowledge, 2-hour postprandial plasma glucose level and waist circumference at 3-month follow-up, but no significant difference in the primary outcome (HbA1c). The findings of this preliminary study can contribute to the development of DSME programmes based on patient empowerment approach in the primary care settings with limited resources, and will provide building blocks for an improved programme of diabetes education and care in Indonesia.

Key Words:

Type 2 diabetes, cluster randomised controlled trial, structured diabetes education programme, diabetes self-management education, and patient empowerment

Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide.

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Date: _____

Conference Presentations Resulting from This Thesis

1. Hilman-Agrimon O, Beilby J, Street J. Patient Empowerment Programme Promoting Self-Management for Adult Patients with Type 2 Diabetes in Primary Care Setting in Indonesia. *2009 State Population Health Conference,* Adelaide, Australia, 31 October 2009,

2. Hilman-Agrimon O, Beilby J, Street J, Prabandari YS. Cross Cultural Adaptation Of Diabetes-Related Health Belief Instrument For Patients With Type 2 Diabetes in Indonesia. *The 18th WONCA Asia Pacific Regional Conference 2011,* Cebu, Philippines, 21-24 February 2011.

3. Hilman-Agrimon O, Beilby J, Street J, Prabandari YS. Patient Empowerment Program Promoting Diabetes Self-Management in Community Health Centres (*Puskesmas*) in Yogyakarta City, Indonesia. *The 2nd ASEAN Regional Primary Care Conference 2011,* Jakarta, Indonesia, 24-26 November 2011.

4. Hilman-Agrimon O, Beilby J, Street J, Prabandari YS. Patient Empowerment Programme Promoting Diabetes Self-Management in Primary Care Setting in Yogyakarta City, Indonesia. *The 19th WONCA Asia Pacific Regional Conference 2012,* Jeju, Korea, 24-27 May 2012.

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List of Terms

AADE	American Association of Diabetes Educators
ADA	American Diabetes Association
ASEAN	Association of South East Asian Nations
Askes	*Asuransi Kesehatan* (Government mandatory health insurance for civil servants)
Askeskin	*Asuransi Kesehatan Keluarga Miskin* (Government subsidised social health insurance programme for poor families)
BMI	Body Mass Index
CBIA-DM	Community-Based Interactive Approach - Diabetes Mellitus
CDSME	Chronic Disease Self-Management Education
CDSMP	Chronic Disease Self-Management Programme
CHCs	Community Health Centres (*Puskesmas*)
CVI	Content Validity Index
DAWN	The Diabetes Attitudes Wishes and Needs study
DCCT	Diabetes Control and Complications Trial
DES-SF	The Diabetes Empowerment Scale – Short Form
DHBM	The Diabetes Health Belief Measure
DKQ-24	The 24-item Diabetes Knowledge Questionnaire
DSME	Diabetes Self-Management Education
DSMS	Diabetes Self-Management Support
DSMT	Diabetes Self-Management Training
FBG	Fasting Blood Glucose
FPG	Fasting Plasma Glucose
GDM	Gestational Diabetes Mellitus
GLP-1	Glucagon-Like Peptide
GMS	General Medical Services

GNI	Gross National Income
GPs	General Practitioners
GSM	Grams per Square Metre
HCPs	Health Care Providers
HDI	Human Development Index
IDI	*Ikatan Dokter Indonesia* (Indonesian Medical Association)
IDF	International Diabetes Federation
IDR	Indonesian Rupiah (AUD 1 = IDR 9,600-10,600)
IMR	Infant Mortality Rate
Jamkesmas	*Jaminan Kesehatan Masyarakat* (Government subsidised public health security programme for poor people)
Jamkesos	*Jaminan Kesehatan Sosial* (Government social security programme)
Jamsostek	*Jaminan Sosial Tenaga Kerja* (Social security insurance for work forces)
LM	The Lifelong Management programme
MKDT	Michigan Diabetes Knowledge Test
MMR	Maternal Mortality Rate
NCDs	Non-Communicable Diseases
NCI	National Cancer Institute
NDPs	National Diabetes Programmes
NGSP	National Glycohemoglobin Standardization Program
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NSF	National Service Framework
OGTT	Oral Glucose Tolerance Test
PCO	Primary Care Organisation
PEDI	*Perhimpunan Diabetes Edukator Indonesia* (Indonesian Diabetes Educator Association)
PERKENI	*Perhimpunan Endokrinologi Indonesia* (Indonesian Society of Endocrinology)

PERSADIA	*Persatuan Diabetes Indonesia* (Indonesian Diabetes Association)
Prolanis	*Program Pengelolaan Penyakit Kronis* (Integrated chronic disease management programme based on self-management initiatives developed by *Askes Inc.*)
QOF	Quality and Outcome Framework
RCT	Randomised Controlled Trial
SDSCA	The Summary of Diabetes Self-Care Activities
SEEIP	The Self-Efficacy Enhancing Intervention Programme
SMART	Specific – Measurable – Achievable – Realistic – Time line
SMBG	Self-Monitoring of Blood Glucose
STR	*Surat Tanda Registrasi* (Certificate of registration for new medical doctors, one of prerequisites to practice)
TPB	The Theory of Planned Behaviour
T2ARDIS	The Type 2 Diabetes Accounting for a Major Resource Demand in Society study
2-h PBG	Two-hour Postprandial Blood Glucose
2-h PPG	Two-hour Postprandial Plasma Glucose
T1D	Type 1 Diabetes
T2D	Type 2 Diabetes
UKDI	*Uji Kompetensi Dokter Indonesia* (National competency examination for newly graduated medical doctors)
UKPDS	The United Kingdom Prospective Diabetes Study
WHO SEARO	World Health Organisation South-East Asia Regional Office

The PhD Project Context

Researcher's background, training and experience working in the area

The researcher obtained a medical doctor degree in 1997 from University of Gadjah Mada Faculty of Medicine, in Yogyakarta, Indonesia. The university is one of the oldest and leading state universities in Indonesia. After graduating, she worked as a general practitioner in several private clinics in Jakarta (the capital city of Indonesia) prior to embarking on three-years of government service in a community health centre in Gondomanan Subdistrict, Yogyakarta City in 1998. While conducting the government service, she also opened her private practice as a general practitioner at her home in Sleman Regency serving the local communities; and worked as an attending physician at an emergency unit in a private hospital in Yogyakarta City.

Approaching the end of her government service in Yogyakarta City, she was involved in a joint voluntary team of medical graduates from Gadja Mada University and Universitas Muhammadiyah Yogyakarta to serve East Timorese refugees in Belu Subdistrict, at the border of Indonesia and East Timor. She joined the voluntary work for three months from November 1999 to January 2000. She was appointed as the coordinator of the team and assigned at Belu Community Health Centre providing health care services to thousands of refugees.

After completing the government service, she worked as a lecturer at Universitas Muhammadiyah Yogyakarta Faculty of Medicine, a private medical school. She was assigned to the Department of Public Health to direct the teaching Family Medicine – a newly introduced subject in Indonesian medical schools at the time – for medical students and clerks. She was also involved in the development of problem based curriculum commenced in 2004 at the medical school. During this period, she maintaied her private practice at home and her work at the private hospital. She was then sent to take a master's study programme in Family Medicine at the University of the Philippines Manila, Philippines, funded by the Universitas Muhammadiyah Yogyakarta Faculty of Medicine. Two of the important core competencies taught were communication and counseling skills for family doctors. The topic of her master's research project was the development of Family Medicine Practice in Indonesia. She obtained the Master of Science in Clinical Medicine – Family Medicine in 2007.

After returning to her home university, she continued teaching Family Medicine and began to teach communication and counseling skills at the medical school. She was also involved in the national initiatives for the development of Family Medicine/ Primary Care in

Indonesia. Additionally, she was involved in the Joint Committee for Competence Exam of Indonesian Doctors (KBUKDI) to set up a national competence exam for medical doctors which has been administered in Indonesia since February 2007. In August 2008, she obtained a scholarship from the Republic of Indonesia Ministry of Education and Culture Directorate of Higher Education to undertake a doctoral study at the University of Adelaide, Australia. She commenced the doctoral study in the Discipline of General Practice and Public Health in mid October of 2008. While conducting the PhD research project in Yogyakarta City in 2009-2011, she continued to be involved in national meetings for developing Family Medicine/ Primary Care in Indonesia.

Selection of the PhD Research Project Topic

The researcher chose this topic for her PhD research project based on several factors. This research project was initiated out of the researcher's concern for the alarming increasing prevalence of chronic diseases in Indonesia, particularly in type 2 diabetes. During her practice at the private clinics, community health centres, at home and at the hospital, she observed that many patients with chronic diseases were not well-informed about their chronic conditions. This might be related to the approach of many Indonesian health care providers who offer prescriptions during patient-provider encounters without providing adequate information to the patients about their health problems. The situation where patients were being instructed to take the medicines prescribed without being informed about their underlying condition was very common. This observation was supported in discussions with the researcher's colleagues. In particular, it was clear that the idea of self-management and patient empowerment in the area of chronic disease management was very poorly understood in Indonesia.

The lack of sufficient provision of education and empowerment in health care delivery to patients with chonic diseases became the researcher's main concern. Additionally, both the researcher's parents also suffered from chronic diseases with her father suffering from type 2 diabetes and chronic heart disease, and mother from hypertension and chronic heart disease. Both parents were hospitalised several times while the researcher was conducting field work in Yogyakarta City. Both parents then died during the time the researcher was waiting for the outcome of the thesis examination. These circumstances inspired the researcher to provide solutions for addressing the needs of patient self-management and empowerment in Indonesian health care delivery management by conducting a research topic in the area.