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Diabetes literacy and knowledge among patients with type 2 diabetes mellitus attending a primary care clinic in Seremban, Malaysia

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ABSTRACT

Introduction: Good health literacy and knowledge are associated with improved outcomes in diabetes. The purpose of this study was to determine diabetes-specific literacy and knowledge levels, and its associated socio-demographic factors, among adults with type 2 diabetes mellitus (T2DM). **Methods:** This cross-sectional study was conducted among 196 adults from the Indian, Chinese, and Malay ethnic groups with T2DM who attended a primary care clinic in Seremban, Malaysia. The Literacy Assessment for Diabetes and Diabetes Knowledge Test 2 were used to assess diabetes-specific literacy and knowledge, respectively. **Results:** The majority of participants (75.0%) had literacy scores that corresponded to Ninth Grade Level but only 3.6% of participants had a good knowledge of diabetes. Literacy scores explained up to 19.8% of the variance in knowledge scores (r=0.445, p<0.01). Indian participants had the lowest literacy and knowledge scores when compared to Chinese and Malays (p<0.05). Participants with higher education had better literacy and knowledge scores (p<0.05). Educational level was more likely than ethnicity to predict both literacy and knowledge scores (p<0.001), while gender and age did not significantly predict either score. The majority of participants could answer general questions about physical activity, diabetes-related complications and healthy eating. Knowledge of diabetes and its relation to specific foods and the effect of diet on glucose control were limited among the participants. **Conclusion:** Education and ethnicity were associated with literacy and knowledge on diabetes. There existed a deficit of diabetes-related nutrition knowledge among the participants. These findings may help healthcare providers tailor individualised patient educational interventions.

Keywords: Diabetes literacy, diabetes knowledge, type 2 diabetes

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INTRODUCTION

Malaysia has the highest prevalence of diabetes mellitus (DM) among the 13 countries in the Western-Pacific region (Whiting *et al.*, 2011). Over a period of 10 years, the prevalence of type 2 diabetes mellitus (T2DM) among Malaysian adults increased from 11.6% to 17.5% of the population but only <15% of these patients met their glycaemic targets of glycated haemoglobin (HbA1c) of <6.5% (IPH, 2015; Letchuman *et al.*, 2010; Mafauzy *et al.*, 2016).

Factors that contribute to poor glycaemic control in patients with diabetes include poor self-care management and medication, and a failure to adhere to dietary and lifestyle prescriptions. This behavioural inertia can be attributed to low health literacy. Health literacy is defined as the patient's capacity to obtain, understand and act upon health information (Nielsen-Bohlman, Panzer & Kindig, 2004). Health literacy affects people's ability to navigate the healthcare system, engage in self-care and chronic-disease management, and may, in turn, also affect the way knowledge about diabetes is understood and remembered for application at a later time (Powell, Hill & Clancy, 2007; Bains & Egede, 2011). Patients with diabetes who lack adequate health literacy and knowledge have a higher risk of poor glycaemic control and microvascular complications (Phillips, Rahman & Mattfeldt-Beman, 2018; Saeed *et al.*, 2018).

The current knowledge of health literacy in Malaysia may not be sufficient as previous studies were limited to the use of non-diabetes specific health literacy tools and mostly involve healthy individuals (Rajah, Hassali & Murugiah, 2019). The purpose of this study was to address this gap and to determine diabetes-specific literacy and knowledge levels, and its associated socio-demographic factors, among adults with T2DM.

MATERIALS AND METHODS

Participants

This cross-sectional study was conducted among adult patients with a confirmed diagnosis of T2DM attending a government primary care clinic in Seremban, Malaysia. The patients who were eligible for inclusion into the study were those aged 30-65 years and who could communicate in English, Malay or Mandarin. This study excluded patients who were pregnant, lactating, or who had severe diabetic complications that limited the testing of literacy and knowledge. Patients were approached in the clinic for participation based on convenience sampling from the diabetes registry of the clinic. They were then screened for eligibility and were asked to provide written informed consent before entering the study. The Medical Research and Ethics Committee of the Ministry of Health, Malaysia, provided ethical approval (NMRR-15-2231-27958) for the study.

Demographic variables and medical history data

A self-reported questionnaire was used to collect data on age, gender, ethnicity, level of education and the duration from the first diagnosis of diabetes. The most recent HbA1c values of the participants, within the previous 6 months, were obtained from the medical records.

Diabetes specific literacy

Diabetes specific literacy was assessed using the Literacy Assessment for Diabetes (LAD), which is an instrument that is used to assess the ability to read 60 nutritional and medical terms, including terms specific to diabetes that are arranged in the order of increasing

complexity (Nath *et al.*, 2001). Two independent Malaysian translators back-translated the LAD from English to both Malay and Mandarin, to complement the native language used by the patients attending the clinic. A score was given for each correct pronunciation, and the raw score was then converted into one of three reading grade levels: Fourth Grade or Malaysian Primary Standard Four and below (0–20 points); Fifth to Ninth Grade or Malaysian Primary Standard Five to Secondary Form Two (21–40 points); and Ninth Grade or Secondary Form Three and above (41–60 points).

Diabetes specific knowledge

Specific knowledge of diabetes was assessed using the Diabetes Knowledge Test 2 (DKT2), which is a 14-item test of the knowledge of diabetes for people who do not use insulin (Fitzgerald *et al.*, 2016). This instrument assesses diabetes-related knowledge of physical activity, diabetes-related complications, nutritional management and glucose monitoring. The DKT2 was back-translated from English to Malay and Mandarin in a similar fashion as the LAD. A score was given for each question answered correctly, and the raw score was then converted into one of three categories: low (0-7 points); acceptable (7–10 points); and good (11–14 points) (Al-Qazaz *et al.*, 2010).

Statistical analysis

Statistical analysis was performed using the SPSS version 22 software (IBM Corp., Armonk, NY, US). Descriptive statistics (mean, standard deviation [*SD*], median, interquartile range [*IQR*], frequency and percentage participants) were used to describe the characteristics of the participants, literacy scores and knowledge scores. The independent t-test was used to compare literacy and knowledge scores between genders. The analysis of variance (ANOVA) with post-hoc Tukey's honestly significant difference (HSD) test was used to compare literacy and knowledge scores between age groups, ethnicity and educational attainment levels. A stepwise multiple regression was performed to sequentially identify the socio-demographic characteristics including gender, age, ethnicity and educational attainment levels that were most closely associated with literacy and knowledge scores, respectively. All *p*-values were two-tailed. A *p*-value of <0.05 was considered statistically significant.

RESULTS

A total of 723 patients were assessed for eligibility. Of these, a total of 515 were excluded as 417 were deemed ineligible and 98 declined to participate. Of the 208 patients who participated in the study, 196 participants provided complete data and were included in the analysis (Figure 1). The participants had a mean±*SD* age of 55.6±7.7 years. They were predominantly women (56.1%), with secondary school education (61.2%) and were of Chinese or Indian ethnicity (Malay 19.1%; Chinese 31.1%; Indian 49.0%). The median (*IQR*) duration of diagnosis with diabetes was 8.0 (9.0) years with a median (*IQR*) HbA1c of 8.1 (2.7) %.

Diabetes literacy and knowledge scores

The mean diabetes literacy score of the participants as measured by the LAD was 43.8±19.6 (mean±*SD*) points out of a possible maximum of 60 points. The majority had scores corresponding to the Ninth Grade Level (Year 9) or Malaysian secondary education of Form Three (< Fourth Grade Level or Malaysian Primary Standard Four, 16.8%; Fifth to Ninth Grade Level or Malaysian Primary

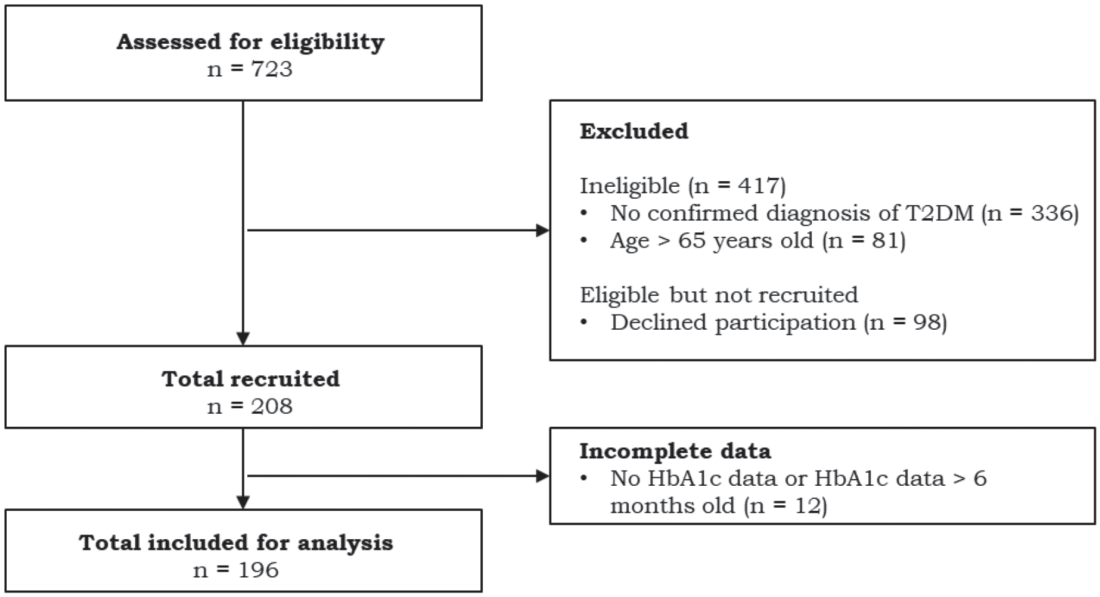

Figure 1. Flow diagram for the selection of participants of the study

Standard Five to Secondary Form Two, 8.2%; ≥Ninth Grade Level or Malaysian Secondary Form Three, 75.0%). Knowledge of diabetes as measured by the DKT2 was 6.8±2.6 (mean±*SD*) points out of a possible maximum of 14 points, and only 3.6% of participants were classified as having a good knowledge of diabetes (poor 42.9%; average 53.6%; good 3.6%). LAD scores and DKT2 scores were significantly correlated, with the former explaining up to 19.8% of the variance in the latter (r =0.445, r^2=0.198, p<0.01).

Table 1 displays the diabetes literacy and knowledge scores by participant characteristics. There was a statistically significant difference in literacy and knowledge scores between ethnicities as determined by ANOVA (p<0.01). A Tukey post-hoc test revealed that Indians had significantly lower literacy and knowledge scores compared to Malays and Chinese (p<0.05) and that there was no significant difference between Malays and Chinese (literacy: p=0.630; knowledge: p=0.919). In addition, there was a statistically significant difference in literacy and knowledge scores between participants of different educational levels as determined by ANOVA (p<0.001). For literacy scores, the Tukey post-hoc test showed that this difference was significant between all educational levels (p<0.05) except for between no formal and primary education (p=0.931), and secondary and tertiary education (p=0.285). For knowledge scores, the Tukey post-hoc test showed that this difference was significant between all educational levels (p<0.05) except for between no formal and primary education (p=1.000), and no formal and secondary education (p=0.471).

The stepwise multiple regression showed that educational level was more likely than ethnicity to predict both literacy and knowledge scores, while gender and age did not predict either literacy or knowledge scores (Table 2). There was no interaction among the characteristics of age, gender, ethnicity,

Table 1. Diabetes literacy and knowledge scores by participant characteristics (*N*=196)

Characteristics	*Literacy scores (Mean±SD)*	*p-value*	*Knowledge scores (Mean±SD)*	*p-value*
Gender				
Women (n=110)	43.3±19.9	0.713	6.7±2.6	0.347
Men (n=86)	44.4±19.4		7.0±2.5	
Age group				
30–39 years (n=8)	42.8±19.7		6.1±2.2	
40–49 years (n=30)	39.6±22.2	0.313	6.8±2.4	0.877
50–59 years (n=83)	42.6±20.4		6.9±2.5	
60–65 years (n=75)	46.9±17.5		6.8±2.8	
Ethnic background				
Malay (n=39)	50.7±10.4[b]	0.002	7.5±2.4[a]	0.005
Chinese (n=61)	47.1±19.0[a]		7.3±2.3[a]	
Indian (n=96)	38.9±21.7[a,b]		6.2±2.7[a]	
Level of education				
No formal (n=5)	26.6±24.9[a,b]		5.6±2.9[a]	
Primary (n=57)	31.6±24.0[c]	<0.001	5.6±2.3[c]	<0.001
Secondary (n=120)	48.7±14.4[a,c]		7.2±2.5[a,c]	
Tertiary (n=14)	57.6±3.9[b,c]		9.2±1.6[a,c]	

The same alphabets denote significant difference: a = p<0.05; b = p<0.01; c = p<0.001

and educational level. In the analysis for literacy scores, level of education and ethnicity were significantly related to literacy scores F (2,193)=33.417, p<0.001. The multiple correlation coefficient was 0.507 and 25% of the variance of literacy scores was accounted for by the level of education and ethnicity. The regression equation for predicting literacy scores was: predicted literacy scores = 8.220 + 0.469(educational level) + 0.250(ethnicity). In the analysis for knowledge scores, the level of education and ethnicity were significantly related to knowledge scores F (2,193)=23.417, p<0.001. The multiple correlation coefficient was 0.442 and 18.7% of the variance of knowledge scores was accounted for by the level of education and ethnicity. The regression equation for predicting knowledge scores was: predicted knowledge scores = 2.729 + 0.397(educational level) + 0.242(ethnicity).

Table 2. Socio-demographic variables most closely associated with literacy and knowledge scores (*N*=196)

Sociodemographic variables	*Literacy scores*				*Knowledge scores*			
	β	*SE*	*t*	*p-value*	*β*	*SE*	*t*	*p-value*
Education†	14.68	1.95	7.51	<0.001	1.62	0.27	6.11	<0.001
Ethnicity†	5.58	1.39	4.00	<0.001	0.70	0.19	3.72	<0.001
Gender	0.11		1.76	0.080	-0.05		0.74	0.460
Age	0.09		1.44	0.151	-0.01		-0.20	0.843

†Variables included in reduced models
Reduced model, literacy scores: F (2,193) = 33.417, p<0.001 adjusted R^2 =0.250
Reduced model, knowledge scores: F (2,193) = 23.417, p<0.001 adjusted R^2 =0.187

Table 3. Item analysis of the diabetes knowledge test of participants (*N*=196)

Items	*Diabetes knowledge tested*	*% Correct*
Physical activity		
9	Effect of exercise on blood glucose	62.2
Diabetes-related complications		
14	Identification of complications – eye, kidney, nerve	66.8
11	Diabetes self-care practice – foot care	65.3
12	Prevention of macrovascular complications – heart disease	63.3
13	Detection of microvascular complications – nerve disease	56.6
10	Effect of infection on blood glucose levels	10.7
Nutritional management		
1	Description of diabetes diet and healthy eating	61.7
2	Identification of carbohydrate-rich foods	49.0
3	Identification of high-fat foods	33.7
8	Dietary management of hypoglycaemia	28.1
7	Effect of unsweetened fruit juice on blood glucose	24.5
4	Identification of "free food"	23.0
Glucose monitoring		
6	Self-monitoring of blood glucose	54.6
5	Glucose testing – HbA1c	36.2

Diabetes knowledge – item analysis

Table 3 shows the number of correct responses to each question of the DKT2. More than 60% of the participants were able to correctly answer the question regarding physical activity (Item 9). On the subject of diabetes-related complications, >60% of the participants correctly answered questions regarding identification of complications (Item 14), diabetes self-care practice (Item 11), prevention of macrovascular complications (Item 12), and detection of microvascular complications (Item 13). However, only 10.7% of the participants correctly identified that an infection will most likely raise blood glucose (Item 10).

Responses to questions on the nutritional management of diabetes indicated that the majority of participants (61.7%) correctly answered the question on diabetes diet and healthy eating (Item 1). However, they had limited knowledge about food groups and the effect of food on blood glucose. While 49.0% of the participants could correctly identify carbohydrate-rich foods (Item 2), only 33.7% of the participants could correctly identify low-fat milk as being highest in fat among carbohydrate-rich food such as orange juice, corn, and honey (Item 3). The participants also had poor knowledge of hypoglycaemia management as only 28.1% correctly identified food or beverage portions containing 15 grams of simple carbohydrates (Item 8). About a quarter of participants (24.5%) correctly indicated that unsweetened fruit juices increase blood glucose (Item 7) and only 23.0% of the participants correctly identified that 'free food' (food items on the diabetes exchange list that are very low in calories and contain a very small amount of carbohydrates) contains <20 calories per serving (Item 4).

On the subject of diabetes monitoring, 54.6% of the participants correctly indicated that blood glucose as opposed to urine checking was the better method for checking glucose at home (Item 6). However, only 36.2% of the participants correctly knew that HbA1C was a measure of average blood glucose levels for the past 6-12 weeks (Item 5).

DISCUSSION

The socio-demographic characteristics of the participants from this study mirrored that which was seen in the registry data of the study site. However, the ethnic composition of participants in this study differed from the patient demographics in hospital-based outpatient centres across Malaysia. The participants in this study were predominantly of Indian or Chinese ethnicity. In contrast, the DiabCare 2013 study showed that patients with diabetes in Malaysia were mainly from the Malay ethnic group, followed by Chinese and Indian in similar proportions (Mafauzy *et al.*, 2016). Ethnicity can influence health literacy and knowledge outcomes when language and cultural differences exist between the patient and healthcare system (Nelson, Stith & Smedley, 2002). Thus care should be taken when generalising the results of this study to the Malaysian populace.

Consistent with other findings, >2/3 of the participants from this study presented with health literacy equivalent to secondary school education (Osborn, Bains & Egede, 2010; Bohanny *et al.*, 2013). This study also found that health literacy was positively associated with diabetes knowledge, echoing results from a meta-analysis on these variables (Marciano, Camerini & Schulz, 2019). This finding indicates the need to tailor diabetes education to the level of health literacy of the patient, as knowledge is associated with appropriate self-care and health outcomes (Kueh, Morris & Ismail, 2016). In this study, participants who had a lower level of education and those of Indian ethnicity had lower literacy and poorer knowledge scores when compared to patients of other ethnic groups. In Malaysia, the prevalence of diabetes is highest among Indians when compared to other ethnic groups (Rampal *et al.*, 2010). The low levels of literacy and knowledge among Indians shown in this study are of concern, as this may be a hindrance to the better management of diabetes among these patients.

Despite having adequate literacy to acquire and use health information, the participants from this study had lower diabetes knowledge scores when compared to those of other studies (Al-Qazaz *et al.*, 2010; Fitzgerald *et al.*, 2016). The participants from this study could answer general questions about physical activity, diabetes-related complications and healthy eating. However, diabetes-related knowledge of specific food groups and the effect of diet on glucose control was limited among participants of this study. These findings reflect the current diabetes education situation in Malaysia. In most hospitals, diabetes nurse-educators deliver information on the general management of diabetes and self-care practices via established Diabetes Resource Centers (Zanariah *et al.*, 2015). The provision of education on nutrition is nonetheless limited to general nutrition and healthy eating. In this study, majority of the participants could not identify food sources of carbohydrate and fat. Instead, they had misconceptions about food that could be incorporated *ad-libitum* into their diet.

Local studies on the knowledge of diabetes-related nutrition among Malaysian diabetics are scarce. However, the findings of local studies suggest that Malaysians with diabetes tend to consume a diet that is high in carbohydrate and fat (Norimah & Abu Bakar, 1993; Moy & Rahman, 2002; Chin

et al., 2013), hinting at a poor knowledge of diabetes-related nutrition. The lack of diabetes-related nutrition knowledge among patients is not isolated and has also been shown in other patients, for example, those from China. The study by Zijian *et al.* (2017) showed that Chinese patients with diabetes generally had a poor understanding of practices related to medical nutrition therapy. The Chinese patients who had better knowledge, attitude, and practice scores, exhibited better control of blood glucose (Zijian *et al.*, 2017). Nutrition education strategies that provide instructions beyond general healthy eating, such as carbohydrate calorie counting, have been shown to improve glycaemic control in both patients with type 1 DM and T2DM (Kitajima *et al.*, 2016; Brake, 2017). Among Malaysian adult patients with T2DM, specific nutritional education led to significant weight loss and improved HbA1C (Arasu *et al.*, 2016).

This study had several limitations. While the instruments that were used to assess literacy and knowledge levels had been validated in English-speaking populations (Nath *et al.*, 2001; Fitzgerald *et al.*, 2016), the translated Malay and Mandarin versions were not validated for use among Malaysians. As such, the results of this study may be subject to errors of measurement. Secondly, this study did not look at the access to healthcare provision, the attendance at educational classes on diabetes or consultations with diabetes nurse-educators or dietitians. Access to healthcare amenities and contact with a healthcare provider are associated with literacy and knowledge status of patients with diabetes (Fenwick *et al.*, 2013; Bailey *et al.*, 2014).

Trained interviewers administered the LAD and DKT2 tools by using face-to-face interviews in order to reduce the cognitive demand on the participants. The development of self-administered electronic tools that take into consideration literacy requirements can help reduce the resource burden of future studies in this area. Knowledge may not directly predict patient behavior but it is a prerequisite for appropriate self-care. This study, however, did not look at the association between diabetes-related literacy and knowledge, and actual self-care behaviour. Further research is needed to identify gaps between knowledge and practice that may exist among Malaysian patients with diabetes. The current burden of diabetes and its future implications warrant the need for educational programmes in diabetes that are tailored to the literacy and cultural environment of high-risk subjects as main target groups (Rampal *et al.*, 2010). In addition, the gaps in the knowledge of diabetes-related nutrition that exists among the participants of this study present an opportunity for appropriate interventions.

CONCLUSION

The participants of this study had fairly good diabetes-specific literacy to process health information. The study results also indicated that educational level and ethnicity were key factors for poor diabetes literacy and knowledge. There also existed nutrition-related knowledge deficits among the study participants. These findings should help healthcare providers tailor individualised patient education interventions.

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Authors' contributions

LCL, the principal investigator, conceptualised and designed the study, led the data collection, data

analysis and interpretation, prepared the draft of the manuscript and reviewed the manuscript; WCSS, designed the study, supervised the data collection, advised on the data analysis and interpretation and reviewed the manuscript; KA, designed the study, supervised the data collection, conducted data analysis and interpretation and reviewed the manuscript; KSK, designed the study, supervised the data collection, advised on the data analysis and interpretation and reviewed the manuscript; SZA, designed the study, supervised the data collection and reviewed the manuscript.

Conflict of interest

The authors have no conflict of interest to declare.

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