

Goals, beliefs, knowledge, and barriers for diabetes self-care in a multi-ethnic population in Malaysia: A qualitative study

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ABSTRACT

Introduction: Ethnic differences may influence diabetes self-care practices and glycaemic control among people with type 2 diabetes mellitus. This qualitative study explored goals, beliefs about treatment effectiveness, knowledge, and barriers to and facilitators for diabetes self-care among the three main ethnic groups in Malaysia.

Methods: Patient focus group discussions were conducted in three different ethnic groups: Malays, Chinese, and Indians. Participants were recruited from the primary-care clinic of a university medical centre located in an urban area. Focus group discussions were audio-recorded, transcribed, and analysed using a thematic approach.

Results: A total of 31 patients participated in the study: Malays (n=12), Indians (n=10), and Chinese (n=9). There were three sessions for each ethnic group. Reported goals primarily related to quality of life and glycaemic control. Participants expressed the belief that the combination of diet, exercise, and medications is effective for controlling diabetes. Groups described their obtaining information external to a healthcare system and reported a need for more specific, practical counselling from health professionals on diet, exercise, and medications. Barriers to and facilitators for diabetes self-care practices were categorised into three major themes: having discipline, social habits, and “other” themes.

Conclusion: Emerging themes were similar across the ethnic groups and included quality-of-life goals, confidence in combination treatment, common use of complementary and alternative medicine, need for further counselling, and the challenge regarding self-discipline.

KEY WORDS:

Type 2 diabetes mellitus, qualitative study, multi-ethnic, self-care, Malaysia

INTRODUCTION

Malaysia is a nation with diverse ethnic groups. Of Malaysian citizens, the three main ethnic groups are Malays

(54.6%), Chinese (24.6%), and Indians (7.3%).¹ The overall prevalence of diabetes in Malaysia is high and has increased from 11.6% among adults ≥ 18 years old in 2006 to 17.5% in 2015.² The prevalence is highest among Indians (22.1%) followed by Malays (14.6%) and Chinese (12.0%).² It has been reported that ethnic differences impact type 2 diabetes mellitus (T2DM) self-care practices and glycaemic control.³⁻⁵

Self-care is essential for effective diabetes control and management. Seven self-care behaviours described by the American Association of Diabetes Educators include healthy eating, being active, monitoring, taking medication, problem solving, healthy coping, and reducing risks.⁶ Issues influencing diabetes self-care are numerous. Some of these are adherence, attitudes, beliefs, knowledge, empowerment, health literacy, culture, ethnicity, language, religious beliefs, motivation, self-efficacy, coping and problem-solving skills, locus of control, depression, fear of hypoglycaemia, comorbidities, financial resources, social support, and provider factors.^{7,8}

The conceptual background of the study is derived from social cognitive theory and personal models theory. Social cognitive theory, which includes self-efficacy⁹ and self-regulation¹⁰ among other concepts, has been used to explain and improve chronic disease self-management behaviours.⁹ Knowledge is presupposed for health behaviour change.⁹ Goal setting,^{9,11,12} barriers,^{9,13} and (from personal models theory) beliefs about treatment effectiveness^{13,14} are important factors in regulating diabetes self-care behaviours. These last four categories of self-care-related factors are the focus of the current study.

In Malaysia, medical nutrition therapy and structured educational interventions have been shown to reduce glycated haemoglobin (HbA1c) modestly in prospective studies.^{3,15} Differences in ethnic groups in adherence to recommended medical nutrition therapy³ and in glycaemic control⁴ have been observed. For instance, a study noted that Chinese and Indian patients were more receptive to medical nutrition therapy than Malay patients.³ Another study reported that Malay patients had higher mean HbA1c values compared to non-Malay patients, 8.7% versus 7.7% (72 vs.

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61mmol/mol).⁴ There seems to be a significant association between Malay ethnicity and higher HbA1c.^{4,5} However, there is little published research that explores reasons for these ethnic differences.

This study explores four categories of factors influencing self-care behaviours among people with T2DM who are of Malaysia's three main ethnic groups. Thus, the research centred on four aims: first, to understand patients' goals for diabetes self-care; secondly, to describe beliefs of participants about the effectiveness of different components of treatment; thirdly, to explore their knowledge about diabetes; finally, to elucidate barriers to and facilitators for diabetes self-care activities.

MATERIALS AND METHODS

Research design

This qualitative study consisted of focus group discussions (FGD) stratified by ethnic groups: Malays, Chinese, or Indians. The study received ethical approval from the University of Malaya Medical Centre (UMMC) Medical Ethics Committee (reference number 1024.11, approval date October 24, 2013) and the University of Kansas School of Medicine-Wichita (KUSM-W) Human Subjects Committee (reference number 376, approval date December 13, 2013).

Participant selection criteria

Malaysian patients from UMMC primary-care clinic served as the study population. Inclusion criteria were patients aged 18 to 89 years, having ongoing care for T2DM from a doctor at UMMC primary-care clinic, and belonging to one of the three ethnic groups: Malays, Indians, or Chinese. The following criteria excluded patients from the study: enrolment in the Joint Asia Diabetes Evaluation (JADE) study, whereby patients received more intensive care compared to usual¹⁶; uncomfortable speaking either English or the Malay language; concurrent pregnancy; mental disability preventing communication (e.g., aphasia, dementia, schizophrenia); or other disability limiting participation in group discussion (unless overcome by bringing one's own assistant).

Recruitment

Patients were recruited from the waiting areas of the primary-care clinic and UMMC venepuncture station between January 8 and 24, 2014. The investigator conveyed oral and written information (in either Malay or English) about the study's purpose, procedures, benefits, risks, and assessed eligibility. Volunteers agreed to participate in a FGD session (according to the ethnicity that they designated via an eligibility questionnaire) to be held later in January. Additionally, investigators attempted same-day recruiting when the turnout from prior recruiting was limited to one or two participants.

Measurement tools

A focus group topic guide was used for the FGD.^{13,17-19} Participants completed a self-administered demographic questionnaire.^{15,20-22} Based on the first two FGD sessions, adjustments for clarity and to explore perspectives on medications finalised the topic guide.

Focus group discussion procedures

Each FGD was conducted in a private room near the primary-care clinic reception area. Before each session, the investigator provided details of the study and obtained written informed consent from each participant. The research team maintained the anonymity of participants by safely storing sign-up and consent forms in a confidential folder, by using numbers rather than personal identifiers in the FGD transcripts, and by conducting the analysis and reporting only in aggregate. At the conclusion of the FGD, participants completed a 12-item demographic profile. Each participant received RM50 (about USD15 at time of study) in cash as compensation for time and travel.

A total of eight FGD sessions and one in-depth interview session were conducted. Each FGD session had between two and five participants. The in-depth interview session was conducted with an Indian participant, as there was no other participant on that day. Each session lasted between one hour and 1½ hours. All sessions were audio-recorded. Most groups spoke a combination of English and Malay. Investigators conducted three sessions for each ethnic group, heard consistent themes, and so ended the data collection phase.

The FGD sessions and in-depth interview were conducted by the first author (RSN) with the assistance of an English-Malay interpreter and a note taker. RSN was a doctor studying Master in Public Health at the time of the study. He was not involved in patient care and had no prior relationship with participants. He had been trained in qualitative methods by KUSM-W.

Analysis

Investigators analysed the FGD content for themes derived from the data. Participants did not review transcripts or the study findings. The first author (RSN) conducted primary coding and application to translated transcripts using Dedoose software, 4.12.4. Another investigator (NA) independently performed secondary coding and secondary application of the primary codes, with no divergence in emerging themes.

RESULTS

Of the patients who were eligible (n=101), 64% (n=65) agreed to participate in the FGD. Forty-two per cent (n=27) of these arrived for their scheduled FGD session. Two more participants for each of two sessions were recruited on the same day as the FGD. A total of 31 participants participated in the FGD and in-depth interview; this total consisted of 12 Malays (39%), 10 Indians (32%) and nine Chinese (29%).

Demographic questionnaire

Chinese participants were all 60 years or older, whereas Malay and Indian participants included those younger than 60 years (Table I). Several Chinese and Malay participants reported having college or tertiary education, compared to one Indian participant with college education. All participants reported taking medication for diabetes. Two Malay and five Indian participants, but none of the Chinese participants, reported being prescribed insulin.

For more than half of Chinese participants, the self-reported main sources of advice for both diet and exercise were external to a healthcare team (Table II). Indian participants did not indicate using reading or media as a source of exercise or diet information. Instead, they reported sourcing information from health professionals, friends, family, and self.

Focus group discussions

There were four major domains: patients' goals for diabetes self-care, patients' beliefs about treatment effectiveness, patients' perceived knowledge of diabetes, and barriers to and facilitators for diabetes self-care activities.

Patients' goals for diabetes self-care

Participants' goals across ethnic groups are summarised in Table III. Participants reported having quality-of-life goals such as enjoying life, avoiding worsening health, and minimising the need for medications. Better glucose control was a major theme. In a few instances, participants stated that goals seemed unattainable or differed from what the doctor advised.

Patients' beliefs about treatment effectiveness

Across ethnic groups, two main themes emerged. One was the combination of treatments, and the other was complementary and alternative medicine (CAM).

Participants stated that the combination of treatments was effective when followed. An Indian man said, *"We are diabetic, the doctor told us that cannot be cured at all but can bring under control. If you go on all the, the method like the exercise, medication, the diet, everything, you can bring under control or just minimise."* Also all of the ethnic groups emphasised lifestyle practices, such as regular exercise, dietary modification, and rest. One Chinese woman stated, *"Half of the medicine is myself. Care food, care your sleep ... and your heart, very important ... So ... medicine you have to take, but rest, exercise and diet ... at the same time."*

Two Malay groups and one Indian participant questioned their ability to sustain effective exercise and diet regimens. One Malay man described, *"[With strict diet and exercise] ... the blood level reduce, you know, but after that, you go back to your old, normal routine. So, it's a, so it is not, not sustainable, you know."*

Besides effectiveness of conventional combination treatment, the other theme that emerged was the use of CAM. One Chinese woman who reported using CAM contrasted conventional Western medication and CAM, *"The consensus around is drugs are harmful. Herbs are not so harmful you see, when you ask around ah, they always said, 'Oh! You can try it. If you can get with the herbs, better not take medication because medication will affect your liver, will affect your kidney.'"*

Participants from all ethnic groups reported using CAM. Most self-reported CAM users' anecdotes endorsed such therapy. Compared to Malay groups, the Chinese had more heterogeneity, with reported non-users and users. Indian groups discussed CAM less than Chinese and Malay groups.

Although several participants described CAM benefiting general health, kidneys, or cholesterol, more often CAM reports related to blood glucose control.

Examples of CAM products included bitter melon (*Momordica charantia*), Misai Kuching, and black seed (*Habbatus sauda* or *Nigella sativa*). Several Malay male participants mentioned taking black seed. One Malay man stated, *"My blood sample, it was the lowest in the last eight years, eight years and I just took over two months, you know ... The lowest ever, you know. So, it's a now, so, I'm not sure now whether it was, you know, because of the exercise, because of the food or because of this, as I said, Habbatus sauda and then, and the bitter honey, you know ... But, but according to her, as I said; the people who have taken this one and didn't have to take any more, any medicine after that ... So, I am in the process, I am still trying."*

Several Chinese and Indian participants reportedly did not favour using CAM. One Chinese man said, *"I dare not try ... Yeah, yeah, I still stay put what the doctor prescribe, that's what I do. I don't want to go try this, try that, no."* Overall, although there was a spectrum, a common view was seeing traditional treatments as a potentially beneficial supplement to one's regimen of lifestyle practices and prescription medication.

Patients' knowledge of diabetes

Participants generally demonstrated basic diabetes self-care knowledge by describing healthy dietary and exercise practices for diabetes. For instance, an Indian woman said, *"The drinks, especially, the drinks. You drink more plain water is better instead of all the carbonated and all the juices and all that."* Nonetheless, participants posed questions to the moderator. One Chinese man asked, *"... When is the best time for us to take medicine? ... Very, very important, because the effect may not be good after food or maybe the effect is better before food, we don't know."* One Indian woman said, *"Sometimes people say that you, if you take too much medications, it can cause kidney problems or stroke; that's what scares me."*

Discussion about knowledge included sources of information, knowledge level, and the challenge of putting knowledge into practice. All three ethnic groups mentioned people, such as health professionals, as a source of information. Except for Indian groups, participants also reported getting information from reading or other media.

Across all ethnic groups, participants' opinions differed as to whether they wanted more diabetes information. When asked whether participants know enough to manage diabetes, one Malay woman responded, *"Really, no. It's not 'enough knowledge,' it's nothing at all."* In contrast one Chinese woman reported, *"We don't need more info ... We need more determination."*

Although many participants emphasised that information is readily available through media, several wanted more personalised, detailed counselling. One Malay man said, *"I think the doctor needs to explain further on food, the types of food, ... on the ways to exercise. They just provide medicine but they don't explain further ... how the medicine will work and how to exercise."*

Table I: Focus Group Participant Demographics and Characteristics, n (%)

	Chinese, n=9	Indian, n=10	Malay, n=12	Total, N=31
Age, years				
40-49	0	0	2 (16)	2 (7)
50-59	0	4 (40)	5 (42)	9 (29)
60-69	7 (78)	3 (30)	5 (42)	15 (48)
70-79	2 (22)	3 (30)	0	5 (16)
Gender				
Female	7 (78)	5 (50)	4 (33)	16 (52)
Male	2 (22)	5 (50)	8 (67)	15 (48)
Education				
Never	0	0	0	0
Primary	1 (11)	4 (40)	1 (8)	6 (19)
Secondary	3 (33)	4 (40)	3 (25)	10 (32)
College	3 (33)	1 (10)	3 (25)	7 (23)
Tertiary	2 (23)	0	4 (34)	6 (19)
Missing	0	1 (10)	1 (8)	2 (7)
Primary Meal Preparer				
Self	6 (67)	4 (40)	3 (25)	13 (42)
Family member	0	6 (60)	7 (59)	13 (42)
Domestic helper	0	0	1 (8)	1 (3)
Restaurant	0	0	1 (8)	1 (3)
Other ^a	3 (33)	0	0	3 (10)
Diabetes Duration, years				
2-4	1 (11)	3 (30)	2 (17)	6 (19)
5-9	2 (22)	1 (10)	4 (33)	7 (23)
10-14	0	1 (10)	3 (25)	4 (12)
15-24	4 (45)	2 (20)	1 (8)	7 (23)
25-41	2 (22)	3 (30)	2 (17)	7 (23)
Last HbA1c, % (mmol/mol)				
≤6.5 (48)	1 (11)	2 (20)	4 (33)	7 (22)
6.6-7.5 (49-58)	5 (56)	0	4 (33)	9 (29)
7.6-8.9 (60-74)	1 (11)	1 (10)	1 (9)	3 (10)
9.0-10.9 (75-96)	1 (11)	2 (20)	0	3 (10)
≥11.0 (97)	0	0	2 (16)	2 (7)
Don't know	1 (11)	5 (50)	1 (9)	7 (22)
Diabetes Medication Prescribed				
Only pills	9 (100)	5 (50)	10 (84)	24 (77)
Only insulin	0	1 (10)	1 (8)	2 (7)
Pills and insulin	0	4 (40)	1 (8)	5 (16)

^aParticipant-specified; reflected a combination of restaurant plus either self or family member.

Table II: Participants' Sources of Dietary and Exercise Advice, n (%)

	Chinese, n=9	Indian, n=10	Malay, n=12	Total, N=31
Main Source of Dietary Advice:				
Doctor	4 (44)	5 (50)	5 (42)	14 (45)
Nurse	0	0	1 (8)	1 (3)
Dietician	0	2 (20)	1 (8)	3 (10)
Diabetes educator	0	1 (10)	3 (25)	4 (13)
Other ^a	5 (56)	2 (20)	2 (17)	9 (29)
Main Source of Exercise Advice				
Doctor	2 (22)	7 (70)	5 (42)	14 (45)
Nurse	1 (11)	1 (10)	0	2 (7)
Dietician	0	0	1 (8)	1 (3)
Diabetes educator	1 (11)	0	1 (8)	2 (7)
Other ^b	5 (56)	2 (20)	5 (42)	12 (38)

^aParticipant-specified, included: other people (n=3); other people plus either reading or media (n=2); self, reading, and internet (n=1); reading (n=1); "own source" (n=1); "don't have" (n=1).

^bParticipant-specified, included: self (n=7); reading or media (n=2); self, reading, and internet (n=1); "exercise group" (n=1); and "own source" (n=1).

Table III: Participants' Goals for Diabetes Self-Care

Area	Theme	Quotes
Overarching values	Enjoy life	<i>You don't know how long you have, so life is for enjoying, but do not go overboard. (Chinese woman)</i> <i>Well, my, my ultimate aim as I said, to reduce sugar level ... And then, live normally without taking any more medicine. (Malay man)</i>
	Avoid symptoms or Complications	<i>Like to be healthy. Reduce my diabetic and the, so that I don't have any, you know, in the future, don't have any, heart problems or ... kidneys. (Indian woman)</i>
	Reduce need for medication	<i>It's the lesser of the two evils, yeah? If you don't take, your problem will not be solved, and it will affect your internal organs, you see. So of course if you can avoid, you try to avoid. But if your other, if your sugar or whatever cannot be controlled without the medication, you just have to take. (Chinese woman)</i>
General areas of goals	Better glucose control	<i>Well, obviously, it's trying to re-, you know ... reduce that, the sugar level, you know and that is the first thing. (Malay man)</i>
	Diet and exercise improvement	<i>And ... so I hope, I hope I have to be more diligent with the food, with my intake, the volume. So that's, that's what, that's my target. (Chinese woman)</i> <i>I definitely ... zero in exercise, zero activity for that. I think I should start doing that part of it la. (Chinese woman)</i>
	Current intention to lose weight ^a	<i>Of course, we want it to go down, reduce weight but the weight doesn't go down, only increasing, only. (Indian woman)</i>
Specifics of goals	Target glucose level ^b	<i>Yeah, for him it's five, for the lady is seven, for me is six. (Malay man)</i>
	Patient-doctor goal divergence	<i>He asked me some sort like 15 kilo, from current weight ... It's too drastic if I ... in a three month time I can reduce to 15 kilo, it's very drastic ... I believe it cannot be done ... Three to four kilo, I think it can be done ... (Malay man)</i>
	Attainability ^c	<i>Can. Like if I tell myself, I need and have to do it and if I say I can, then sure I can. (Indian woman)</i> <i>Confident, we are confident to achieve ... But we cannot reach. ... Cannot. The tongue, our, our mouth cannot control. (Indian woman)</i>

^aAppeared in two Malay and three Indian group sessions, whereas two Chinese groups mentioned past weight loss achievement.

^bAlthough it varied, participants were likely to aim for a fasting value of six or lower (mmol/L). According to Malaysia's clinical practice guidelines for diabetes²³ at the time of the study, glycaemic control was to be 4.4-6.1 mmol/L fasting, 4.4-8.0mmol/L non-fasting, or HbA1c less than 6.5% (48mmol/mol).

^cComments about goal attainability were few and ranged from attainable to uncertain or unattainable.

However, participants stated that this service would be difficult to provide. One Malay man stated, *"The problem is ... There is a lot of patients ... there's not enough time to explain in the duration of the half hour or 15 minutes. We have to take our own initiative."* A Malay woman remarked, *"I would like to meet the dietician, but it is not provided."* One Chinese woman pointed out that some people do not access information as readily: *"So a lot of people don't see the newspaper, don't see the books, some don't know how to read ... so we have to form a class to let those people, the sick ones, to attend the class, teach them how to do exercise, everything, every day how long, how to start ... and eat what, and the medicine how to eat."*

Barriers to and facilitators for diabetes self-care activities

Table IV displays the major themes grouped into three categories: having discipline or motivation, social habits or lifestyle, and "other" themes. These themes appeared across ethnic groups with some variations as follows. Compared to Malay groups, which strongly expressed all four dietary barriers, Indian groups were less vocal about the sense of taste, and Chinese and Indian groups had fewer comments about eating out.

Two barriers to exercise emerged with some variation across the three ethnic groups. Several participants (more from Chinese, fewer from Malay, and none from Indian groups) spoke about having a busy lifestyle. A few participants mentioned concerns about access to exercise facilities. Included in this category were perceptions of an unsafe environment in which to exercise, a barrier expressed by several female Indian participants.

Indian groups reported all three facilitators for exercise: convenience, companionship, and motivating health effects. Compared to the other groups, Chinese groups discussed convenience less. Relative to other facilitators for exercise, Malay groups spoke mostly about convenience.

Regarding relative difficulty to comply with self-care practices, diet seemed to be most difficult and taking medications easiest overall. One Chinese woman said, *"Because especially Malaysia, food is very tempting, ... we live for our food."* An Indian woman said, *"Because what I do is, just after breakfast; I take all my medicines, go down the line—what are the medicines—and then I take."*

Table IV: Summary of Diabetes Self-Care Barriers and Facilitators

Theme	Topic	Barrier	Facilitator
Discipline	Healthy eating	Uncontrolled desire: <i>After you see all the food also, you like to eat. We never control ourselves.</i> (Indian woman) Sense of taste: <i>So they are asking me to try to reduce eating rice. ... That is my favourite foods ... since I was born.</i> (Malay man)	Self-moderation: <i>Actually, I get used to training myself not to have sugar in my drinks you know. In the morning, I just take, at first it was difficult because I like Nescafe [coffee], so no sugar, how to drink? So I tried to supplement it with milk. It's okay; with milk I am okay.</i> (Chinese woman)
	Exercise	Low motivation: <i>In the mood we go, and then not in the mood, don't feel like going.</i> (Chinese woman)	Motivating health effects: <i>So when we walk for that one hour and when I sweat I know that it's good and my body will feel good in the long run and you can reduce weight as well.</i> (Indian woman)
Social	Healthy eating	Social habits: <i>I mean because of our culture when we go to people's house, whatever they serve you, we have to eat.</i> (Malay man) Eating out: <i>The restaurant you go, all sugar. I mean, really shock, lot of sugar.</i> (Indian woman)	Home-prepared foods: <i>Like myself, I cook for my family you know ... breakfast, lunch, dinner; yeah they will have to follow me. ... I don't add sugar; I don't add sugar to my food. And salt also, you know I don't use.</i> (Chinese woman)
	Exercise	Busy lifestyle: <i>But I never walk at all, doctor, or I do anything. I so busy ... doing my household work lah, my grandchildren lah, go office lah, coming lah. Running here and there.</i> (Chinese woman) Facilities: <i>Male is okay. Female all must have indoor only exercise. Indoor exercise. Very hard to go out. Thieves a lot.</i> (Indian woman)	Companionship: <i>And then, another thing is ... friends, you know? ... If you don't have any friend ... walk together, or jog together and then you get very bored. ... Yeah ... it more to motivated. ... While we are walking, we are talking.</i> (Malay man)
Other	Exercise	Physical limitations: <i>What I can do is just walking around the lake due to knee problems.</i> (Malay man)	Convenience: <i>That's why I said use the trampoline is really easy. Just jump for a while, then, will do.</i> (Malay woman)
	Medications	Concern for adverse effects: <i>...the medication, too much drugs all ... chemical all, you know ... stress, strain on the kidney.</i> (Chinese woman) Forgetfulness: <i>It's not difficult, it's forgetful. Because they're asking us to take one before our meal, one after our meal, that is the forget.</i> (Indian woman)	(No major themes)

However, Chinese and Indian groups presented varied opinions about relative difficulty, whereas Malay participants mostly reported dietary adherence to be difficult and exercise and medication to be relatively easy. One Malay man said, "With the dietician, they have advised me, told me what I should reduce, rice and all, don't take oil, but ... for me that is the main problem lah ... Yeah, but the rest like exercise, taking medications, I do it every day."

DISCUSSION

Goals

Clear differences in diabetes self-care goals among the three ethnic groups were not apparent; a quantitative study could be helpful in assessing further for ethnic differences in this and the other domains. Participants discussed goals related to quality of life as well as glucose control. Reported blood glucose values were confusing at times because participants often did not specify HbA1c versus fasting or non-fasting blood glucose (mmol/L), and many seemed unfamiliar with the term "HbA1c." Nonetheless, blood glucose targets mostly

approached the upper end of the clinical practice guideline targets²³ at the time of the study: fasting value of 6.1mmol/L or HbA1c of 6.5% (48mmol/mol).

Based on these focus group discussions, it was unclear whether there are ethnic differences in goal-setting behaviour. Several participants described certain management goals as unattainable or unacceptable to them. Goals ideally should be challenging but realistic or accepted.^{12,24,25} Doctors need to understand patients' own goals, and collaborative or self-selected goals are options for action planning besides physician-assigned goals.^{11,26}

Beliefs about treatment effectiveness

Across the three ethnic groups, participants appeared to believe in the effectiveness of diet and exercise plus prescription medication to control diabetes. This is important because perceived effectiveness of treatment is a predictor of diet and exercise adherence.¹⁴

Many expressed concerns about side effects of medication, and two participants actually described reducing their use of conventional medications as a result. In other studies, worries about side effects of medication predict non-adherence to diabetes medications.²⁷⁻²⁹ Although concerns for side effects can vary by ethnicity,²⁷ no ethnic differences in perceptions of adverse effects were evident in this study.

Reported use of CAM was common to all three ethnic groups. This study did not set out to ask specifically about CAM, but once this theme emerged, it became an area in which to look for ethnic differences. Many reported CAM use, although Chinese and Indian groups may have reported less use than Malay groups.

A study in Malaysia indicated that self-reported CAM prevalence among 240 clinic patients with diabetes was 62.5% overall.³⁰ This study found no significant difference in CAM use by ethnicity but did report a significant association between CAM use and Islam, which is primarily associated with the Malay group.³⁰

It is uncertain whether ethnic (or religious) differences in CAM use, if present, would be clinically important—that is, whether they affect glycaemic control either directly or indirectly through altered adherence to conventional therapy. Regarding a direct effect, there is limited literature to suggest reductions in blood glucose from CAM use, such as black seed or bitter gourd.^{31,32} As far as potential influence on conventional medication adherence, a common sentiment in all focus group discussions was that it would be used as complement to conventional treatment, not as replacement.

Knowledge or information about diabetes

In all ethnic groups, participants asked for additional specific, practical counselling from physicians, dietitians, or diabetes educators. Many participants reported doctors' limited time and having lack of access to dietitians. Few participants cited dietitians as the main source of advice for diet or exercise. Instead, doctors and "other" sources were commonly identified for information needs.

Many participants reportedly relied on information sources external to a healthcare system. However, one participant noted that some patients, due to literacy or other access issues, are not able to obtain needed information. A study in Malaysia described how patients are informed and influenced by a number of sources: family members, friends and peers, health care providers, books and electronic materials.³³ Studies have indicated that lower education is associated with poorer diabetes knowledge.^{20,34,35} Lower education levels may have influenced Indian participants' reporting (in FGD sessions and in the demographic questionnaire) health professionals and other people, but not reading and media, as information sources.

Other studies of people with diabetes in Malaysia have suggested that patients have inadequate knowledge of diabetes and that there is a shortage of professional educators such as dietitians or diabetes educators.^{15,20,34,36} One study reported a number of challenges that diabetes educators face in effectively helping patients with their self-care.³⁷ Given limited resources, creative approaches such as brief, structured education may help to address knowledge gaps and improve diabetes self-care.¹⁵

Barriers to and facilitators for diabetes self-care

Barriers and facilitators of diabetes self-care emerged similarly across all ethnic groups and were grouped in theme areas of having discipline, social habits, and "other." Although emphasis placed upon individual barriers or facilitators in the focus group discussions may have varied, clear theme differences among ethnic groups were not apparent.

Other studies in Malaysia have reported some similar barriers and facilitators. In a study that interviewed health care professionals and Malay patients, barriers to diabetes control similarly included social and educational themes.³⁸ A qualitative interview study of patients (who were clinic employees) also reported forgetfulness as a barrier to medication adherence, but concern for adverse effects was not a barrier (perhaps related to the different study populations).³⁹ Another study similarly identified motivation (in that study, fear of complications) and social support as self-care facilitators, and as barriers it reported dietary cultural expectations and time limitations affecting exercise.³⁷ Comparing this study to a study of type 2 diabetes patients using insulin, similar barriers were difficulty controlling cravings for food, lack of motivation, and physical limitations affecting exercise.⁴⁰

LIMITATIONS

The results of this study cannot be generalised to all people with diabetes in Malaysia. Although the number of participants in each of the ethnic groups was small, the volume of data and the consistency of emerging themes suggested that the numbers of participants and sessions were reasonable. An important limitation was that the selection process excluded Chinese and Indian patients who could not speak Malay or English. Therefore, the study may have had a more educated group of participants. Also the scheduling of sessions on another date was biased toward individuals

available to return during daytime working hours—thus favouring retirees, the unemployed, or those with flexible schedules. Self-reported HbA1c values need to be interpreted with caution given recall bias and some participants' uncertainty about the meaning of HbA1c.

CONCLUSION

The findings of this study seem reliable given its strengths such as the consistency of themes expressed by FGD participants, use of a structured topic guide, and data analysis by primary and secondary coders. This qualitative study is exploratory in nature with limited generalisability, and quantitative research could help to assess further for ethnic differences in the emerging themes. Nonetheless, this study suggests implications for practitioners to bear in mind. Healthcare professionals can assist patients in setting diabetes-related health goals that are clinically appropriate and acceptable to the patient. Doctors are to take note of the individual patient's use not only of prescription medications but also of complementary and alternative medicine. Taking into account the desire for more knowledge, health professionals are to provide patients with specific, practical counselling on diet, exercise, and medications. Existing resource limitations within the healthcare system, such as inadequate access to dietitians, necessitate creative solutions. While keeping in mind common diabetes self-care barriers and facilitators, health professionals also are to recognise that these may vary across and within ethnic groups. Healthcare providers can seek to understand the barriers and facilitators most relevant to a specific patient.

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